Patient experience of infertility management in primary care: an in-depth interview study

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\textbf{Background.} GPs do not have a full range of diagnostic resources to help manage infertile couples. Little is known about the patient experience of infertility management in primary care.

\textbf{Objective.} To explore the patient experience of infertility management from a primary care perspective.

\textbf{Methods.} This was a nested qualitative study with infertile couples in North-East England. In-depth interviews of infertile couples identified in the course of an observational study describing the incidence, prevalence, referral patterns and pregnancy outcomes for infertile couples. A grounded approach was used, with the interviews and analysis proceeding together using the method of constant comparison. Emergent themes and their links gave an overall explanation to the interview data.

\textbf{Results.} We interviewed 22 patients in 13 interviews. Factors that influenced a couple’s experience of infertility management were personal and professional relationships, patient autonomy in decision making and access to services.

\textbf{Conclusions.} This study provides insights into the experiences of infertile couples seeking assisted reproduction from their GP. A good experience was linked to a strong personal relationship, a patient-centred professional relationship fostering informed decision making by the couple, GPs using diagnostic resources, interpreting restrictive clinical and social criteria and referring appropriately.

\textbf{Keywords.} Family medicine, fertility, qualitative research.

\section*{Introduction}

One in seven couples (14\%) in the UK experience difficulty in conceiving during their lifetime.\textsuperscript{1–3} Approximately, half of couples trying to conceive do not seek help for their subfertility\textsuperscript{4} and of those that do seek help the overwhelming majority are satisfied with the service they received.\textsuperscript{5,6} However, couples in one study have shown general dissatisfaction with written and verbal information routinely provided by a fertility clinic because it suggested lifestyle changes they had already attempted to adopt.\textsuperscript{7} Poor referral patterns have also been cited as a cause for concern for infertile couples.\textsuperscript{8} Couples value technical competence\textsuperscript{9} and a patient-centred psychosocial approach to infertility care.\textsuperscript{10} Predictors of a good experience of infertility services include support from their spouse and a compassionate caring health professional,\textsuperscript{9} but little is known of patient attitudes to GP involvement in infertility management.

The aim of this study was to explore the reasons underpinning the attitudes and perceptions of the primary care patient experience of infertility management in Northumberland and Tyne and Wear in North-East England.

\section*{Methods}

\textbf{Design}

A qualitative in-depth interview study to explore the experiences, attitudes and perceptions of infertile couples. This study was nested within a stratified cluster randomized controlled trial, with 58 participating...
practices, evaluating the use of open access hysterosalpingography (HSG) in the initial management of infertility in primary care. A grounded approach allowed the exploration and development of the emerging themes.

Setting
Couples were recruited to the study from the 58 participating practices in Northumberland, Tyne and Wear. Couples were interviewed at their GP’s practice or in their own home.

Participants and sampling
Interview confidentiality was assured and the process of the interview explained. SW interviewed 22 patients in 13 interviews. Four women attended for interview without their partner and nine women with their partner (F1 to F13 with males denoted by M). We purposively sampled infertile couples from rural, urban, small and large practices initially. We also sampled couples whose GPs did and did not have access to tertiary fertility services and GPs who did and did not initiate fertility investigations. Patient characteristics were identified via the open access tubal assessment trial and are summarized in Table 1. The study was limited to heterosexual couples. Theoretical sampling was used to test emerging themes. Sampling and analysis for the in-depth interviews proceeded together within this study and continued until no further categories or new information was emerging from the interviews. The interviews were audi-taped and fully transcribed and quotes from the transcripts were anonymized.

Analysis
Data from the in-depth interviews were categorized and formed into emerging themes, using the method of constant comparison, which fed into the development of a concept diagram (Fig. 1). Data were analysed and coded, firstly with open coding (labelling), axial coding (categorization) and finally selective coding (core categories/themes) independently by three researchers, SW AC and NH. Emerging themes were negotiated, explored and tested in further interviews until we reached data saturation and an overall explanation of the data.

Results
The factors that influenced a couple’s experience of infertility management were categorized into personal and professional relationships, patient autonomy in decision making and access to services (Fig. 1).

Personal relationships
The couple. When couples had a strong supportive relationship and shared ownership of the problem, they felt they could face most stressful situations in life together and did not require professional support.

F3 It doesn’t really bother me [the lack of professional support in primary care], because I have got the support of the people around me outside. I have got the support of my family, I have got the support of Mark, and so it doesn’t really bother me.

The experience was more negative when couples looked for someone or something to blame for their infertility. Often the ‘blame’ was directed inwards to their relationship resulting in emotional isolation, poor communication and arguments.

F8 It caused a few arguments and then a couple of times we argued, and he would throw up oh it’s your fault that we can’t have babies, it’s not mine.

Couples felt that GPs and fertility specialists were poor at identifying and easing ‘communication’ difficulties between couples who were struggling to cope with the emotional aspects of infertility.

Family and friends. Couples felt ‘isolated’ when families were not supportive despite a will on the part of the couple to share their experience. The support of one set of parents was enough to make the experience of infertility management a positive one.

F8 Well I haven’t got much family around me, but his mam and dad were supportive and I had a couple of good friends and that. I did have the support, I could sit down and talk if I wanted to.

Negative experiences were more common when couples felt that it was awkward talking to their friends about their difficulties in conceiving, especially when their friends had a child. They did not want their friends to feel guilty that they had a child or to diminish their pleasure derived from talking about their child or ‘showing their baby off’. This led to avoidance behaviour and ran the risk of damaging long-term friendships. Men who had strong relationships with their partner, defined by good communication, were more able to talk to their own friends and most couples preferred not to talk with work colleagues about their difficulty in conceiving. Some of the most positive experiences came from couples with peer support from personal friends who had experienced in vitro fertilization (IVF).

F7 really the most support I have had is from a friend who has had IVF and I have been very lucky in the fact that she has been through it all before me.

Professional relationships
The GP. The couples’ relationship with the GP, their ‘trust’ in his/her ability and perceived level of
“expertise” all had a bearing upon their experience of infertility management in general practice. Some couples felt that not all GPs had the necessary level of expertise. A lot of couples described a positive experience when they were redirected within the practice to see one of the GPs who had a special ‘interest’ in infertility. In some instances, couples were able to select these GPs for themselves.

F2  I think it’s great if you have got one specialist in the practice … It depends upon how good a relationship you have with your GP, and how much trust you have got, I think that’s a big thing.

Most couples had a good relationship with their GP but tended to lose contact once they had been referred and this concerned them when they returned to their

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**TABLE 1  Participant characteristics**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (years)</th>
<th>GP practice</th>
<th>GP initiated investigations</th>
<th>Child in current relationship</th>
<th>Child from previous relationship</th>
<th>Place of initial referral</th>
<th>Cause of subfertility</th>
<th>Length of time trying to conceive (years)</th>
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Nine males accompanied their female partners in their respective interviews.

* Small practices <3 whole time equivalent (WTE) GPs, large ≥4 WTE GPs.
* Secondary care: non-HFEA licensed fertility centres; tertiary care: HFEA licensed fertility units.
* Participants with quotes shown in results section.
* Spontaneous pregnancy.
GP with either a baby or with the stress of failure to conceive. Some couples were disappointed if their GP did not make an effort to help them while others perceived being passed directly to a specialist as a positive experience.

M9 I would prefer to just go straight there, because at the end of the day, your GP doesn’t seem to do much at all really.

The fertility specialist. Couples felt confident that they were getting the treatment they required when they were seeing an expert. Technical expertise was valued more than the relationship in most instances. Many couples felt that it was the fertility specialist who would ultimately help them achieve a pregnancy and not the GP. They also felt more confident with specialist tertiary fertility units compared to secondary care.

F6 It is always nice to see the consultants, these people specialise in this particular subject, therefore would you get the tyres for your cars changed at McDonalds?

Some negative influences on the experience of specialist infertility services included long waiting times, the impersonal production line feel to the process, being rushed, a poor relationship with the fertility specialist, seeing different people each visit and a poor bedside manner.

F3 When you eventually go to the hospital, you can’t guarantee who you are going to see … sometimes we ended up just seeing an IVF nurse.

Patient autonomy in decision making
Patients were very resourceful searching for ‘information’ on the Internet, television, friends as well as professionals. Couples generally had a better experience of infertility management when they retained ‘control’ over their treatment ‘decisions’. Information allowed couples to rationalize what was happening to them, realize that other couples were in a similar situation and helped them to make informed decisions. Most couples preferred to be involved in fully ‘informed’ shared ‘decision’ making with the professional concerned (patient-centred consulting). The quote that follows comes from a couple with a diagnosis of unexplained infertility who made a decision to continue trying for a further period of time.

F5 I came back after the HSG on the Tuesday, I saw my doctor and she said that we had 2 options … we had already decided that we were going to give it another six months.

Conversely, couples had a negative experience when they felt they lacked control describing their journey as a roller coaster ride of emotions, with lives on hold, unable to arrange social events, go on holiday or leave the house and becoming sensitized to their environment. Couples who chose to delay starting their families were disappointed to discover that they needed to resort to assisted reproduction. Those couples with an understanding of the management process sometimes found it difficult to challenge the GP’s ‘decision making’. In one case, an inappropriate referral left the couple feeling out of control. A common theme was referral to secondary care then on to tertiary care and was perceived as a lot of procrastination and wasted time.

F2 I think that if we had been going to go with the IVF, then possibly the time it took to see the consultant at [secondary care], and then he did a couple more things, and then I think I had to wait … if we had been sent straight to [tertiary care], I think it would have got rid of a lot of wasted time really.

Access to services
Inconsistency. There was a perceived ‘inconsistency’ in all aspects of fertility management. Consistency in the application of both clinical and social exclusion criteria was one way to achieve fairness and should extend countrywide.

F13 It should be fair right across the country with all the same criteria because it is unfair if one part of the country is using some criteria and some other is completely different.

Couples in this study felt that most GPs were unaware of the qualifying criteria applied by Primary Care Trusts (PCTs) for fertility treatments and felt that it was reflected in the GP’s referrals. Couples were frustrated when the different parts of the National Health Service (NHS) did not link up and move the results and management process through seamlessly. Specifically, investigations performed by GPs or secondary care providers appeared not to have an influence upon management in specialist tertiary care fertility units. There were also ‘inconsistencies’ in specialist management, which created confusion.

F1 Mr X gave me a course of clomifene, but then Mr Y wanted to check my fallopian tubes.

Rationing and NHS provision. Couples articulated that ‘rationing’ was necessary in an NHS which has finite resources but felt that infertility was low on the rationing agenda because it is not perceived as a disease or illness. Rationing should be uniform throughout the country particularly in respect of ‘social rationing’. Couples who already had one child together within their relationship were more likely to accept the fact that they were ineligible for fertility...
treatment in the NHS but felt where one or other partner had a child in a previous relationship and they had no biological children in the current union, this posed significant stresses in that relationship. This was the most frequently cited example of unfairness.

F1 If he married somebody else and then he would get the money to have his baby and that would hurt because just because she hasn’t got a child that could put quite a strain on someone’s marriage.

Patients felt aggrieved that private fertility treatments were often immune from NHS ‘clinical rationing’ criteria such as age, body mass index and diagnosis. One such example was a couple with unexplained infertility as a diagnosis, for whom treatment was delayed for 3 years, based on the likelihood of spontaneous pregnancy in that time.

F6 It is really horrible. You sit there at night, thinking and hoping and praying that something is wrong so that you don’t have to have this three year wait.

Investigations in primary care. All interviewees perceived that GPs should perform the initial investigations in primary care. It was seen as ‘getting the ball rolling’ immediately and not having to wait for hospital appointments. GPs being more involved with couples may help reduce stress being in a familiar, less threatening environment, with the flexibility of accessing a GP at a time that suits the couple. The main concern was whether the GPs were competent to arrange and interpret the investigations and whether it should be done by one GP in the practice who had an interest and more expertise in that area.

F10 I thought it was much better. You didn’t think you would have to be referred to a hospital and go on a waiting list and it was potentially going to take much longer. It felt to me that it was going to be a much quicker option just to go through the GP.

Fertility specialists as well as couples found that a fuller assessment in primary care, including use of open access HSG, was beneficial and speeded up the diagnostic process within tertiary care, allowing a prognosis and management plan to be given at the first consultation.

F2 I think we got really good treatment, the consultant actually said all the groundwork is done really there was nothing really for him left to do, other than if we wanted to have IVF.

M4 She was really really impressed with what the GP had done, she said all the tests were already done, and all the results were there and that saved her about 6 weeks worth of work, so she was really impressed.

An additional benefit identified by couples having had a full GP work up was the cost savings for those ultimately referred privately. However, GPs and couples in more rural areas had problems when accessing semen analysis and getting falsely abnormal results from laboratories not associated with the Human Fertilization and Embryology Authority (HFEA) licensed fertility unit.

Treatment in primary care. Many couples liked the convenient access to their GP and were keen on their GPs doing as much as they possibly could. The main treatment strategies focused upon by couples were the prescribing of clomifene and to a lesser extent weight management of obese women. Couples for whom the GP had prescribed clomifene felt that it was a relatively simple form of fertility treatment, appropriate for general practice and within the GPs’ level of expertise.

M12 I think he [GP] has done a good job in giving her the tablets because he is trying to help isn’t he? They should take it at least to the level of clomifene.

Couples who had an interested GP were disappointed when he/she did not take their management to the next tier and prescribe clomifene, when it was indicated. Many couples perceived that prescribing clomifene in general practice would save time in hospital and fertility specialists could get on with more advanced parts of fertility management.

M4 It seems more sense and frees up the specialists to deal with those other things like IUI and IVF, they don’t have to spend time interviewing us just to give us tablets for 3 months.

Couples were keen to be reassured that GPs were ‘accredited’ and ‘competent’ to prescribe clomifene and argued that it did not matter whether a GP or fertility specialist prescribed clomifene because the risks remain the same for the patient. What did matter was that the person prescribing the drug did so appropriately and with the relevant knowledge and expertise. Some couples had a poor experience of general practice infertility management from investigation through to treatment and were sceptical about the motivation of GPs to become involved in many aspects of treatment.

M7 It almost seems to me that general practice in general, GPs don’t seem to initiate anything anymore. It has got to be an issue for concern.
Discussion

Summary of main findings
Couples had a good experience of infertility management when their personal relationships and communication with each other and with the GP was strong. Communication difficulties between couples were highlighted by some couples who were struggling to cope with the emotional aspects of infertility. Many couples were left isolated and unable to speak with their family and friends about their infertility. They were keen to see GPs do all they could, providing they had the necessary expertise and referred promptly when necessary. Some couples preferred to access specialist services directly, but others were frustrated when GPs were not aware of the qualifying clinical or social criteria of the centres to which they were referred or when they were referred to a secondary care fertility unit that could not deliver the treatment necessary. The most frequently cited negative experience was the application of restrictive social criteria by PCTs, which was perceived as unfair particularly for couples that have a child in that or a previous relationship. The patients’ experience of infertility management was dependent upon the strength of the couples’ relationship including shared responsibility, a patient-centred professional relationship fostering informed decision making by the couple and GPs having access to a range of diagnostic resources coupled with an ability to interpret restrictive clinical and social criteria enabling appropriate referral.

Strengths and weaknesses
This is a small in-depth interview study allowing for the exploration of complex issues associated with infertility management within the NHS. All interviews were conducted by one interviewer; however, data analysis by three researchers\(^\text{16}\) helped with the credibility of our findings.\(^\text{17}\) The study used a grounded approach which allowed for issues of concern to the interviewees to emerge and we believe these issues are transferable to other populations.\(^\text{15}\) Most of the literature describing patients’ experience of infertility management relates to their experience with fertility specialists. This paper adds a wider perspective from first consultation with the GP through to definitive treatment with the fertility specialist.

Comparison with existing literature
The majority of couples in this study wanted their GPs to be involved with their management. Two studies describing the involvement of GPs found that only 3% of couples did not want their GPs to be involved\(^\text{8}\) and one-third of patients felt that their GP had given sufficient information about infertility, the investigations and treatment options.\(^\text{18}\)

Predictors of a good experience include a supportive spouse and a compassionate caring health professional\(^\text{9}\) who is polite, appears interested and competent, listens and explains, is sympathetic and enabled questioning and shared decision making.\(^\text{5}\) Conversely, a poor experience results from poor communication between partners, a poor medical attitude, involvement of non-specialists, exclusion of one partner and poor psychological support.\(^\text{8,9,19}\) This is reflected in the weight given to personal and professional relationships in this study.

Assessment of the treatment experience relates less to the outcome or the type of treatment\(^\text{19}\) but the control a couple have in the process.\(^\text{7}\) This is facilitated by the availability of written information,\(^\text{7,8}\) frequency of appointments, availability of counselling, accessibility of staff and continuity of care.\(^\text{5}\) In this study, patients demonstrated their desire to be involved in the decision over when and where to be referred.

A significant theme was equity of access to fertility treatments with interviewees believing that couples who have a child in that or a previous relationship should be eligible for treatment. One study of access to fertility services compared the attitudes of infertile couples to those of parous couples.\(^\text{20}\) Infertile couples felt that social rationing was unfair believing fertility services should be available for same sex couples. Parous couples felt that rationing was necessary and the number of treatment cycles offered should be limited. Many PCTs in the UK use social criteria to deny treatment.\(^\text{21}\) A recent NHS survey has found that social criteria restricting access to advanced reproductive treatments remain variable throughout the UK with many PCTs continuing to exclude couples who have had a child in a previous relationship.\(^\text{22}\) The challenge to unify access nationwide still remains.

Conclusions
Responses from patients in this study reflect the primary care NHS gatekeeper heath care system which is also prevalent in many countries throughout Europe. A gate keeping health care system will use clinical and social criteria, demonstrated in this study, to ration access to further levels of the service, which can also be inequitable between regions throughout the same country. The challenge for such a system is to work out which couples can be managed within a primary, secondary or tertiary care setting. For primary care, this may include watchful waiting for unexplained infertility or ovulation induction with clomifene for a suitable cohort. A less specialized general gynaecology service (described in the UK as a non-HFEA licensed secondary care fertility unit) has a role predominantly in diagnosis and management of ovulatory disorders. A tertiary level service
(HFEA licensed fertility unit) is required to deliver IVF or intra-cytoplasmic sperm injection to couples with tubal or semen problems. The referral pathways remain unclear in the UK and driven by outdated commissioning arrangements in many instances.

This study provides insights into the experiences of infertile couples seeking assisted reproduction from their GP in UK general practice. Because infertility is a ‘couple’ problem and not an ‘individual’ problem, GPs have an opportunity to insist upon dual consultation and aid with information sharing and couple communication. GPs can also help couples mitigate against their feeling of isolation from family and friends by directing them to support groups (e.g. http://www.infertilitynetworkuk.com/). Infertile couples value their personal relationships, patient-centred professional relationships, confident and competent GPs and fairness of access to fertility treatments. Embedding clinical and social criteria into diagnostic and referral pathways may improve the patient journey for infertile couples. The 18-week infertility pathway gives information on initial GP assessment including open access HSG\(^23\) which allows GPs to direct couples with damaged tubes more appropriately to IVF centres.

Our findings also support the position of the British Fertility Society, which has recommended that NHS treatment be made available to couples where one partner has a child in a previous relationship.\(^24\) Further evaluation of the potential for and acceptability of infertility management in primary care is required. This includes simple management strategies such as weight loss for obese infertile women, ovulation induction with clomifene and tubal assessment using HSG.

Acknowledgements

We would like to acknowledge Sunderland University for hosting this work. Academics within the university contributed to the study design; collection, analysis and interpretation of data; production of the paper and the decision to submit the article for publication. Contributors: SW, GR and AM designed and implemented the study. SW carried out the data collection and wrote the paper. AC advised on qualitative methods. SW, DC, NH and AC contributed to the data analysis. AM and GR contributed to the editing of the paper. SW and GR act as guarantors of the study and accept full responsibility for the conduct of the study, data access and controlled the decision to publish.

Declaration

Funding: We would like to acknowledge the NHS National Coordinating Centre for Research Capacity Development who funded this work through a National Institute for Health Research award held by Dr Scott Wilkes; Primary Care Researcher Development Award, National Coordinating Centre for Research Capacity Development, Leeds Innovation Centre, 103 Clarendon Road, Leeds LS2 9DF, UK. All researchers involved in the production of this paper are independent from the funder; Sunderland University.

Ethical approval: Ethical approval was granted from Newcastle and North Tyneside as the main research ethics committee with site specific assessment approval from Northumberland, Gateshead and South Tyneside Local Research Ethics Committees. Approval was also granted from Sunderland University research ethics committee.

Conflicts of interest: None declared.

References