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Infertility; isolation and the Internet: A qualitative interview study

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ABSTRACT

Objectives: This study explores the roles and meanings of the Internet, which is commonly used in this age group, as a source of support for people with fertility problems.
Methods: A qualitative interview study with 27 women and 11 men who had been, or were going, through treatment for infertility. A maximum variation sample was sought. Narrative interviews were conducted and transcribed for thematic analysis.
Results: Women and men with fertility problems often feel isolated. The Internet offers anonymity, emotional support, normalisation and reassurance. It also offers the prospect of niche support from others going through treatments at the same time and in similar circumstances. Online infertility networks can play a valuable role in helping people deal with the emotional stresses and isolation they feel during and after treatment, but has the potential to reinforce isolation.
Conclusions: The Internet is changing people's experience of infertility, giving people access to other's experiences. Internet communication is highly valued by couples, especially those isolated in their real world relationships.
Practice implications: Clinicians can help by referring couples to websites while being aware that increasingly 'niche' support could compound isolation.

1. Introduction

The experience of infertility can be devastating. While individuals experience infertility differently [1], research shows that the experiences have lasting emotional effects. Unsuccessful treatment can leave women feeling sad, anxious and depressed [2], with a sense of loss and bereavement [3]. Even successful treatment can come at great emotional cost [4]. Infertile women experience levels of psychological distress similar to patients with grave medical conditions, such as cancer or those going through cardiac rehabilitation [5–7].

Health is one of the most common reasons for using the Internet: 68% of the British public use the web to search for information about health [8]. The Internet is very widely used in the age groups involved in infertility treatment and studies highlight increasing Internet use among people with infertility problems. People going through infertility treatment are turning to the Internet for a variety of reasons. Himmel et al. [9] in a study of a German fertility website found visitors seeking detailed medical advice and emotional support. In the US Kahlor and Mackert [10] found the Internet the most heavily relied on source for information and social support. Women reported feeling better informed and able to make decisions as a result of online information, which also helped communication with doctors and partners. Their Internet use also helped them realise they are not alone in facing these issues, inspired hope and even helped them to develop new friendships. Cousineau et al. [11] found that few women in the USA thought they needed to use professional psychological services during treatment but many went online in pursuit of medical information and support from other women in chat rooms.

Malik and Coulson [12] highlighted the beneficial role of the Internet for those going through fertility treatment, or coming to terms with its aftermath. In a self-completion questionnaire study of people using an infertility web forum they found involvement in online support groups was reported as reducing the respondent's sense of isolation, providing information and empowerment and reducing the burden on relationships.

However, while the Internet can help people facing infertility through education and empowerment, it can also be associated with problems. An American survey [13] studied the Internet use and psychological well-being of two groups of infertility patients; those who had only the Internet for support and those who had additional outlets of support. Epstein suggests that validation and support from others online may have encouraged them to withdraw from difficult real world situations, for example talking

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with friends who had children. A British questionnaire study [12] of users of several online infertility support groups identified negative as well as positive aspects to the online experiences of individuals. Access to other people's experiences could lead to feelings of overwhelming sadness or compound psychological distress. Some found that comments could be taken the wrong way, leading to upsetting misunderstandings, and participation online could lead individuals to becoming preoccupied, or obsessed, with their condition.

Qualitative research can illuminate meanings and understandings. This article draws on interviews collected for a wider study of people's experiences of infertility, and their information and support needs. We use qualitative methods to help explain why and how couples going through infertility are using the Internet for support, highlighting in particular the positive and negative effects of niche support online. The definition of niche support used here is support tailored to a person's (health) status, providing a place of safety or retreat. Our qualitative analysis adds to the literature by exploring how this Internet use is linked to, and potentially reinforces, the sense of isolation that couples can feel when dealing with infertility. We consider the consequences for real world interactions and clinical communication.

2. Methods

A qualitative design was used comprising narrative and semi-structured audio recorded interviews with 38 people. We aimed for a diverse, maximum variation sample [14] of participants who were going through treatment or had finished treatment. Variation was sought across causes, treatment received, successful and unsuccessful treatment, those living with, and those living without, children, geography and NHS or private care. With approval from UK Anglia and Oxford multi-centre research ethics committee (MREC), participants were recruited through GP surgeries, specialist consultants, support groups, online newsletters and word of mouth.

Participants were visited at home by a social scientist, trained in qualitative methods (LH). Interviews were conducted individually even if both partners were contributing to the study. A narrative interview was audio recorded, with informed consent. Respondents were asked to tell their own story, with as little interruption as possible, to capture their own accounts of their experience of infertility and highlight the aspects that were important to them. The interviewer then used a series of prompts to explore particular issues further in the semi-structured part of the interview. This section of the interview included questions about how and why information and support had been accessed, although this was frequently raised in the initial narrative. Questions were added during the course of the study as new issues emerged.

2.1. Sample characteristics

Forty interviews were conducted with 38 individuals. One couple was interviewed twice, seven months apart, to capture their experience of the IVF cycle they had been waiting for during the first interview (LH took the opportunity to conduct the follow-up interviews when she returned to the city for other fieldwork). The sample included 27 women and eleven men. Some were still receiving treatment, but the majority had completed treatment. Of the 30 who had completed treatment, 21 had had a successful pregnancy, 5 had gone on to adopt and 4 were living without children.

The age range was 28–63 years; nine people went through their fertility treatment before the Internet was widely used. Twenty-nine people were recruited using support groups email lists. While not all described actively using the Internet for support, the sample was Internet literate, and those who were still going through treatment were active Internet users. Interviews were conducted from 2007 to 2009 in England and Scotland (Table 1). Ten of those interviewed had treatment only through the NHS, twenty had only private treatment, including a couple who participated in an egg sharing scheme for their first attempt. The remaining eight pursued a combination of private and NHS treatment.

Table 1
Infertility, isolation and the Internet: a qualitative interview study.

	Men (11)	Women (27)
Stage of treatment		
In treatment	3	5
Finished treatment	8	22
Children (or pregnant)	6	15
Adoption	2	3
No children	0	4
Causes		
Female factor	2	5
Male factor	3	4
Both partners	3	4
Unexplained	2	12
Sterilisation	1	2
Treatments		
No treatment	0	3
Only IUI	1	2
IUI with sperm donation	2	2
IVF	5	12
IVF with egg donation		1
IVF with sperm donation		3
ICSI	1	2
ICSI with egg donor	1	1
IVF with donor egg and sperm	1	1
Age range[a]	34–63	28–61

IUI, intrauterine insemination; IVF, in vitro fertilisation; ICSI, intracytoplasmic sperm injection.
[a] Two interviewed 20+ years after treatment.

2.2. Analysis

The interviews were transcribed verbatim for analysis. After checking by LH, the transcripts were sent to each of the participants to review and approve. Interviews were read, re-read and systematically coded [15]. A qualitative interpretative approach was taken, combining thematic analysis with constant comparison [16,17] so that data were explored for themes already known from the literature as well as emergent themes. The data and themes were developed by LH and SZ and discussed by all authors. NVIVO 7 software was used to help sort and retrieve the data for analysis, compare themes across the data set and highlight cases which did not fit with the emerging analytic pattern (known as 'deviant cases' or outliers) [18]. Anticipated and emergent themes were identified, deviant cases were explored and themes discussed and further refined by the authors. Pseudonyms are used when presenting the data.

3. Results

While many respondents used the Internet to find health *information*, we focus here on the ways the Internet is changing their experiences of support and isolation. We report on the support needs that people described and where and how they tried to fill those needs.

3.1. Isolation and the infertility experience

While interviewees often talked about unpleasant physical aspects of treatment it is the emotional and social consequences of their infertility that stand out in their descriptions. Isolation, as an