The diagnosis of infertility: patients' classification processes and feelings

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ABSTRACT

This paper is about patients' accounts of the processes through which a medical diagnosis of infertility is made, in particular of the medico-technical procedures and practices of the definition of, and clinical intervention in, the 'fertility problem'. It uses data drawn from interviews with couples who were medically diagnosed with infertility and had achieved a non medically assisted conception after at least one IVF treatment. By examining the place of the physician's expertise in helping lay people make sense of the diagnosis of infertility, we aim to understand the heterogeneities and complexities that shape the relationships between infertility patients' agency and feelings, medical knowledge production and the design of technical practices. Linking phenomenological and constructivist approaches, we suggest that these connections often take singular and uncertain forms that challenge traditional notions of passive subjects being objectivised in order to be medically known. We explore some of the processes involved in patients' translation of the medical diagnosis of infertility and of the expert's authority, to argue that this phenomenon is constructed within existing social relations, in particular gender relations, and that fertility investigation technologies are re-invented within everyday contexts.

KEYWORDS

Infertility, Medical diagnosis, Uncertainties

Introduction

Medical diagnosis of infertility represents a fertile location for observing many of the social conflicts within the context of medicine, as the social construction of infertility begins at the time when medical professionals and other parties determine the existence and legitimacy of this condition. The social construction of a diagnosis of infertility involves a multiplicity of understandings, relationships and actions that are constantly in flux and combine to promote a reconfiguration of the category 'infertility'. By analysing how the diagnosis of infertility is socially constructed, we explore how symbolic interactionism and social forces shape patients' understandings of, and actions towards, infertility (Brown, 1995).

According to the *European Society of Human Reproduction and Embryology* classification, which is consistent with standard practice and the WHO glossary, infertility is defined in medical terms as the diminished ability, or the inability, to conceive and have offspring. Infertility is also defined in specific terms as the failure to conceive after at least one year of intercourse without contraception (Vayena et al., 2002). The medical definitions of infertility often do not adequately account for factors that may influence conception, such as the frequency or timing of intercourse. Moreover, the establishment of one year of intercourse without contraception as a clinical criterion for an infertility diagnosis might be uncertain, ambiguous and misleading (Habbema et al., 2004), because this period can clinically vary from 6 months to 5 years and there are differences in thresholds when comparing clinical and epidemiological studies:

A threshold of 1 year to fulfil the definition of 'infertility' has become the gold standard for clinical purposes. (...) A threshold of 2 years, however, is used in many epidemiological studies (ibid: 1498).

Despite these arguments, some recent work on medical definitions of infertility has shortened the period of time that should be allowed before considering the possibility of infertility to 6 months (Brosens et al., 2004) with the presence of certain factors leading to a further shortening of the period before a diagnosis of infertility is made, such as a history of amenorrhoea, total impotence, previous male or female sterilisation, ovulation disorders and the age of the woman being 39 years or older (Homburg, 2005: 318; Steeg et al., 2005). The definition of the length of time in which couples have been unsuccessful at conceiving is especially important in a context where couples consult a specialist doctor about infertility at an increasingly early stage (Olsen et al., 1996), which might result in unnecessary overtreatment due to false-positive diagnoses of infertility (Balasch, 2000).

These discourses assume that specialist physicians of reproductive medicine are the only experts that can analyse, interpret and explain the biological body in order to confirm a diagnosis of infertility. But this confirmation procedure is mediated by the technologies that allow access to body parts, render them visible and malleable, and apparently reveal the silent symptoms of infertility through the results of a set of medical tests on the uterus, fallopian tubes, ovaries and sperm, within a process described by Pickstone (2000) as 'technomedicine'. These contemporary technologies are powerful instruments in the diagnosis of infertility, but they produce forms of diagnosis that are more likely to depend on the language of probabilities and uncertainties than on the language of causality (Webster, 2002: 447). Therefore, the recent debate concerning the ambiguities and uncertainties that distinguish the medical definition of infertility highlights issues such as the tensions between the desire to produce a more 'accurate' diagnosis of infertility and the present capacities of available diagnostic tests and treatments (Gleicher and Barad, 2006). Medical and scientific recognition that the uncertain and partial nature of the diagnosis of infertility may be irresolvable (Siristatidis and Bhattacharya, 2007) may result from the acceptance of the idea that any diagnosis is, to some extent, artefactual and contingent (Mol, 1998).

During the process of diagnosing infertility, female bodies are subjected to a set of processes at the disposal of the medical profession, such as pelvic exams, several ultrasounds, laparoscopy and hysteroscopy (Cussins, 1996). In fact, fertility tests are part of a long history of medical procedures designed to be used almost exclusively on women's bodies (Douglas, 1991; Ploeg, 2001). These medical examinations aim at identifying the biological mechanisms that cause infertility, in order to act on them through a medical and technical intervention (Habbema et al., 2004; Homburg, 2005). Fertility treatment is thus constructed as preferable to other options, such as adopting a child or remaining childless, hence privileging the traditional, heterosexual, preferably married, concept of family and biological kinship (Stanworth, 1987; Edwards et al., 1999) and reinforcing the assumption of motherhood as a biological destiny and fatherhood as a way of proving men's capacity for genetic continuity.

The words used to describe the specific causes of infertility are expressed very personally (Cussins, 1996: 591) and reinforce the idea that infertility is not a neutral term (Bowker, 2001). The use of medical jargon, such as 'hostile mucus', 'blocked fallopian tubes', 'incompetent cervix' and 'failure to conceive', reflects the ways in which women's infertility has been constructed as a physical impairment. In comparison, male causes of infertility are described in less conclusive terms, using concepts such as 'subnormal' or 'low sperm mobility' (Ulrich and Weatherall, 2000: 324).

This qualitative study was undertaken to explore patients' accounts of the processes through which a medical diagnosis of infertility is made, in particular the medico-technical procedures and practices and clinical intervention that construct the 'fertility problem'. We reflect on the place for physician expertise, by exploring the way patients make sense of what is happening to them during the waiting time before commencing fertility investigations. We go on to analyse the processes involved in translating and reinventing the expert's authority and in understanding the technical practices encountered within the context of the uncertainty that precedes a diagnosis of infertility. In sum, we aim at mapping out some of the relational contours between the physician's expertise and lay perspectives in the context of an infertility diagnosis.

As Ian Shaw argues, in actively searching for meaning, patients can adopt basic stances and fundamental concepts of the expert/physician's explanations and interpretations of their 'medical' condition as a means of orientating themselves in their everyday life and can come to accept such rationality, but they also utilise these experiences as a way of negotiating and critiquing the medical knowledge (Shaw, 2002). In short, the way people understand health experiences and make sense of these implicate complex negotiations and mutual reconfigurations (Hamlin, 1992; Mackay et al., 2000; Shaw, 2002; Webster, 2002), including how they relate to institutional structures, where interaction takes place, and how they play out their social roles (Brown, 1995). An understanding of medical knowledge and practices, and of diagnostic procedures, associated with having a 'fertility problem' demands an examination of the main modalities of codification and interpretation undertaken both by medical experts and the infertile couples. Our analysis of the institutional strategies developed by the medical system to define infertility leads us to argue that these processes are uncertain and aim at reinforcing existing behavioural norms and social beliefs about motherhood and fatherhood, justifying medical intervention for *abnormal* couples in this domain, that is, couples unable to conceive a biological child.

Method

We intended to identify lay accounts that have been filtered through medical rationality and then 'owned' by patients. Based on the assumption that to question the power base of the diagnosis of infertility is particularly relevant in the cases of couples who were medically diagnosed with infertility and had achieved a non-medically-assisted conception after at least one IVF treatment, this qualitative study was undertaken to explore, in depth, these couples' scrutiny of the medical diagnosis of infertility. A qualitative phenomenological methodolody was selected because this method is useful when little is known about a phenomenon, as it can be used to explore the patients' processes of classification and feelings within a diagnosis of infertility and, in particular, to analyse their detailed descriptions of the complexities and uncertainties in a diagnosis of infertility (Alderson, 2001). We attempt to follow Strauss and Corbin's "grounded theory" approach: an interpretative and qualitative research methodology, which is characterised by a hypothetic-inductive perspective (Strauss and Corbin, 1990).

Participants were recruited through newsletters; the first author sent a newsletter via email to colleagues at work and friends and asked them to pass the message to other people, in a snow-ball strategy. Semi-structured tape-recorded interviews, lasting about one hour, were conducted at the house or work place of the women and men who volunteered to take part in this study. The tapes were transcribed verbatim. The interviews were completed between June 2005 and February 2006. We used a purposive sample, which means that we added new data to the analysis when it was of theoretical interest, and its size relied on the concept of 'saturation', that is, recruitment continued until no new themes emerged from the interview data. According to Guest et al., basic elements for metathemes were present as early as six interviews (Guest et al., 2006). Our degree of data saturation over the course of thematic analysis was ascribed in the first seven interviews. Data were systematically coded and synthesised by four main themes: how patients' make sense of the waiting time before starting a fertility investigation; how knowledge of the body and the conjugal organisation of sexual intercourse are reconfigured in a context of a 'fertility problem'; what are the main factors involved in the decision of looking for medical help; how patients appraise medical practices and, in particular, fertility tests. The processes for arriving at conclusions conformed to standard conventions of qualitative analysis (Becker and Bryman, 2004).

In a total of seven interviews, two couples (woman and man), four women and one man participated in this study. The nine participants in this study were all Portuguese, heterosexual, married and white. The age of the participants ranged from thirty to thirty-eight. Five interviewees held a university degree, one a master's degree, one a PhD, one had nine years of education and one had twelve years of education. Four of the seven family units had a family income of between 2500 and 3000 Euros a month and two less than 2500 Euros. The occupations of the female interviewees were the following: nurse, bank clerk, civil engineer, financial manager, chief technician in a biotechnical company and commercial employee. In the case of men, one was a university teacher, one a manager in a biotechnical company and one was a commercial employee.

Ethical approval for this study was obtained from the Foundation for Science and Technology (Portuguese Ministry of Science, Technology and Higher Education). We followed the Code of Ethics of the International Sociological Association.

Infertility patients' narratives around the diagnosis of infertility

We conclude that patients develop a set of criteria to judge the medical knowledge and technical expertise that surrounds diagnosis and decision-making in the area of infertility, creating an awareness of the uncertain and partial nature of medical diagnostic knowledge and the armamentarium that accompanies it.

Lay making sense of the waiting time before starting a fertility investigation

The period spent trying to conceive before the interviewees approached a specialist doctor in reproductive medicine varied between six months and two years. The decisions about when to start a fertility investigation are usually taken under the authority and expertise of physicians, mainly gynaecologists. Medical knowledge tends to dominate interviewees' making sense of the 'adequate' waiting time before starting an infertility evaluation, but lay perspectives and aims can be mobilised in order to shorten (or to extend) this period. Hence, time might be a resource to manipulate, either by the medical experts or the infertile couples, with the intention of maximising the possibility of reaching their goal (pregnancy). For instance, one couple who initiated fertility investigations before one year of trying to achieve a pregnancy did so because the male partner intended to work abroad and the female partner wanted to get pregnant before he left the country:

We were trying for less than a year (...) but we were conditioned because he was going to Europe and I wanted to get pregnant. (33-year-old woman, university degree, bank clerk)

The possibility that the woman might not be able to get pregnant if and when a couple wants to might be one element that leads women to take responsibility for the 'failure' of the project of getting pregnant. The female interviewees stated that they were the first ones to think that there was a possibility of having a problem in conceiving, forming hypotheses based on their personal health history and hunches about what might be going wrong in their own case:

It was easy to convince myself that there might be a problem. Not because I am pessimistic but because of my personal health history. (33- year-old woman, university degree, financial manager)

Unlike the women, the male interviewees seemed to be 'thoughtless', because they did not think there could be a 'problem' with the couple's fertility. Consistent with common cultural assumptions regarding fertility and pregnancy being a woman's issue, men report that they comfort their wives through reassuring them that 'these things' take time (Webb and Daniluck, 1999). This adoption of the protective role on the part of the male interviewees may well reflect differences in the ways in which men and women have been socialised to cope with a negative affect, associated with the assumption that the male body is naturally fertile and that the female body has more need of medical help and intervention, and is, therefore, more vulnerable to screening processes. The creation of socially constructed notions of proper bodies, that implies a female fertile body that should achieve pregnancy if and when the couple wants it, seems to delay the start of a fertility investigation. At the same time, it reinforces the social image of the women as being responsible for the 'failure' of the project of getting pregnant. In this sense, women who are concerned about infertility could occupy what Webster (2002: 445) called the 'therapeutic limbo', since they perceived themselves as patients, even without symptoms and a diagnosis of infertility. The female interviewees worried about the possibility of having a problem in conceiving, even when there was no 'fertility problem'.

Reconfiguration of knowledge of the body and the conjugal organisation of sexual intercourse

Becoming aware of the importance of when sexual intercourse occurs during the menstrual cycle (Brosens et al., 2004) appears to be the first element which launches an 'anticipatory socio-naturalisation' of women, in the sense that they are much more aware of the phases of the menstrual cycle and the need for timing intercourse (Cussins, 1996: 581-2). According to one of the female interviewees, the first step in the process of a fertility evaluation is usually a therapy involving ovulation induction and ovarian stimulation, that is, the use of hormone therapy to stimulate oocyte development and ovulation (release of the ripened egg in midcycle). This therapy also involves learning to determine the fertile phase of the menstrual cycle, in order to promote fertility-oriented intercourse:

At the time what he [gynaecologist] did was to prescribe some medication (...) that stimulated ovulation. Then he got my temperature and made graphics of temperatures. When it was ovulation time a raise of temperature was supposed to occur. In those days I should have sex. (32-year-old woman, university degree, chief technician in a biotechnical company)

The assumption related to this medical suggestion is that difficulties in achieving pregnancy are caused by possible irregularities in ovulation or because the particular couple doesn't have sexual intercourse during the fertile period. In the context of having to schedule sexual intercourse, in order to assure that it takes place during the fertile period, one of the female interviewees talks about the difficulties that she and her partner experienced in having to 'function' [to have sexual desire] (38-year-old woman, university degree, nurse). One of the male interviewees also admits that the regulation of sexual intercourse in order to accomplish medical objectives was problematic:

It meant measuring exactly when ovulation took place and having sex around that period, sometimes in days when it would not be normal because, I don't know, I was more tired or something else? (36- year-old man, manager in a biotechnical company).

These narratives highlight the intersection of biogenetic, mental, social and emotional factors involved in sexual intercourse and show how men might also be implicated in the absence of pregnancy, through, for instance, possible alterations in sperm quality that might occur during periods of increased anxiety or tiredness (Pook et al., 1999). They also show how modern bodies are technological artefacts that are made and remade through medicine and technology. The specialists in reproductive medicine seem to develop new forms that allow an increasing access to bodies. Whether fertile or infertile, bodies are viewed as empirical objects that should be regulated through reproductive medicine and self-discipline (i.e. control of desire, passion and need) in order to ensure a fertility-oriented intercourse and a successful reproduction.

Deciding to procure medical help and the change from hope to disappointment

It is clear from the interviews that decisions to seek medical help in conceiving are frequently made by women. In the opinion of one of the female interviewees, this has to do with the fact that usually women have more initiative than men in relation to fertility and that men are afraid of finding something wrong with them:

She has more initiative to do something than he has! That's my impression. I know one couple who is going to start the fertility consultations and I suppose he also fears to go to the consultations. He fears, he is afraid of finding something wrong with them. (38-year-old woman, university degree, nurse)

The fact that it is usually women who take the initiative to start fertility investigations reflects the traditional gender relations that operate in relation to emotional work and may reflect women's longstanding involvement with medicine during their lives (Webb and Daniluck, 1999: 20). The assumption that women are more emotionally fragile than men and that they experience greater overt distress in response to infertility also supports the belief that women have greater need of medical advice and treatment. In sum, both women and men have gender identities which structure their experiences and this influences decision-making and feelings in the context of the diagnosis of infertility.

The interviewees describe their first encounter with a specialist doctor in reproductive medicine using terms such as 'normality' and 'optimism'. These experts are symbolically elected as the ones who can resolve their 'problem'. But there are some situations that reconfigure this 'hope' into a disappointment: when the commercial issue comes out in the first consultation (contrasting with the couples' 'non-profitable' motives for having a child); when couples who have had a negative response from one doctor seek the opinion of a second doctor, only to have to answer the same questions and be forced to retell their clinical histories; or when the doctor doesn't recommend an immediate therapeutic procedure when the couple has already spent a long time waiting to have a child. Most of the interviewees say that their main recollection of the first encounter with an expert in assisted reproductive medicine concerns the quantity of medical tests required, and they underline the fact that most of the tests were aimed at the women. The interviewees tend to 'normalise' and 'naturalise' the experience of undergoing these tests, perceiving them as everyday clinical practices.

Clinical intervention in the human body can be seen as being legitimised through the anatomic-pathological examinations that aim at identifying the probable causes of the 'problem' and arriving at a suitable technical intervention that is its solution. So, the relationship between a specialist doctor in reproductive medicine and patients in the context of the first encounter due to a diagnosis of infertility is described by the female and male interviewees as being based on technical knowledge. Ethical, moral and social issues are redefined as technical and, thus, doctors are becoming 'technologists of the body' (Webster, 2002: 451).

Appraisement of the tests of fertility

The discourse of the male interviewees relating to having to produce and submit sperm samples for laboratory analysis is characterised by the reconstruction of pressure. This event is translated into an anecdotic episode in order to make sense of it in the context of their everyday world (Webster, 2002). There seems to be a need to develop a positive reconstruction regarding the 'threat' of infertility which relates to the socially constructed belief about masculinity that men should struggle against adversity (Machado and Remoaldo, 2007). For example, one of the male interviewees describes the collection of sperm as 'horrible' and the necessity to deliver it was understood as an 'awkward' situation. The conception of the spermogram as a medical exam is, in this case, reconfigured comically and, mostly, through the transformation of the 'medical' act of semen collection into a private and intimate act performed at home and not in a laboratory or fertility clinic.

[The collection of semen] was horrible. (...) We didn't do it in a clinic; we did it at home, so it wouldn't be such a medical act, and a little bit more personal. (...) It was all to do with the necessity to deliver my semen. It was a little more embarrassing. At a point, we were just laughing. (36-year-old man, PhD, manager in a biotechnical company)

Another male interviewee describes the process of the collection and delivery of sperm as very 'stressful', emphasising the troublesome transportation of the sample of semen, between the location of sperm gathering (his own home) and the analysing laboratory, particularly the ways used to keep the 'adequate' temperature and the possibility of being caught for exceeding the speed limit during its transportation in order to deliver the sample on time (within one hour after ejaculation):

At the time it was very stressing, because I had to get there [private clinic] from home in a hurry. (...) My thoughts were 'I'm going to get caught for speeding'. The sample bottle was in my pocket, next to my chest, so it wouldn't get cooler. All I could think was: they [the police] were going to stop me and all I could say was: 'Look! You see this in my pocket? I have to hurry. Do you know what it is?' That was all I could think about. (36-year-old man, 12 years of education, commercial employee)

The importance of the material conditions in which the collection of sperm is completed, such as the appearance of the toilet, the degree of privacy allowed and the lack of access to magazines and erotic movies is illustrated by one of the female interviewees, who reveals the difficulties that her husband experienced in producing a sperm sample:

When he [the husband] went to do it [produce the semen sample] (...) he said, it was in a toilet, a very small one. It had two doors; he and another went inside at the same time; one to one side, the other to the other side. He said: 'It was horrible; it was an old toilet cubicle; there was nothing there: there was no...The cup was there in front of me!' Then he said he was getting desperate, because someone had gone into the next cubicle, gone out, another had gone in and gone out, again. All he was saying was: 'Ah! I won't be able to do this!' (32-year-old woman, university degree, chief technician in a biotechnical company)

The dominant view of masculinity perpetuates the idea that men can control their anxieties and emotional states by controlling the external environment. In the context of the diagnosis of infertility, this brings some particular consequences for men: they are alienated from meaningful intimacy and restricted in the ways that they can experience and/or express emotions. So men tend to prize the external world rather than their internal feelings in these discourses; moreover, they tend to minimise the impact that these medical tests have on them in comparison with the tests their wives have to undergo. The ways these narratives emphasise control of the adverse elements (both emotional and material) surrounding the act of sperm collection can be understood as being associated with the 'deleting' of men's suffering, allowing them to maintain identity processes socially attached to masculinity, namely those based on values such as competence and strength (Webb and Daniluck, 1999). There seems to be a need to develop a positive reconstruction following the 'failure' of infertility, in accord with the principle that men should be 'strong' (Machado and Remoaldo, 2007).

By contrast, the female interviewees frequently refer to the suffering and pain, in physical terms as well as in affective and emotional terms, and the changes of form and function in their own bodies (and the perception they have of them) as part of the process of being subjected to the diagnostic tests. However, these processes of dissection, interference and transformation of the woman's body are minimised by the female interviewees and can be understood in terms of providing them with the opportunity to prove their love for their potential future children (Lupton, 2003).

The different gendered constructions of the fertility tests and the interpretation of them by the individuals who underwent such tests are highly relevant – they reveal the male discomfort with, and the female acceptance of, the procedures. The fertility tests are largely focussed on women and are often highly invasive and frequently painful or uncomfortable. Yet it is the men who submit sperm samples (which are non-invasive and manually collected by the individual men via masturbation – albeit sometimes, but not always, in a clinical context), that describe the tests as 'horrible' and 'awkward'.

Uncertainties and the lack of 'objectivity' of medical practices

The transmission of test results and the corresponding diagnosis of infertility are a fundamental moment in the course of the interviewees' trajectories. The interviewees' sensations are contradictory: the test results provide an explanation for the absence of a pregnancy and therefore give some 'relief' for the interviewees if followed by a proposed 'solution'; at the same time, this particular period is accompanied by feelings such as 'disappointment', 'grief', 'confusion', 'resentment' and 'isolation'. The interviewees emphasise in particular the fact that the medical classification of the causes of infertility ('female' or 'male' causes) reinforces the localisation of the 'problem' not in the couple, but in the woman or/and the man, endorsing feelings of individual culpability.

The issue of individual culpability resonates through the experiences of many people undergoing infertility investigations. While the clinics treat 'the couple', often it is related to issues with the individual – and thus, tensions arise. The resolutions of these challenges by the individuals also influence their experiences and feelings related to seeking infertility treatment. The way the interviewees talk about the simultaneous existence of 'female' and 'male' causes illustrates strategies of rationalisation that intersect with emotional and physiological factors that follow from the diagnosis of infertility. A simultaneous female and male infertility makes the search for a 'solution' (the possibility to have a biological child) more difficult, but facilitates the sharing of feelings within the couple, which might be perceived as positively reinforcing the conjugal relationship:

She: We didn't have that kind of reaction, maybe more rational way of thinking: this [conjugation of female and male causes of infertility] could be worse than the cause being from only one side, isn't it? He: But we had that more rational side, which was to consider that this situation makes it easier, makes it easier ... eases communication, understanding, accepting, eases a lot of things. (33-year-old woman, university degree, financial manager; 36-year-old man, 12 years of education, commercial employee)

However, tests do not always identify the cause of infertility and, consequently, the couple are left with the result of 'unexplained infertility'. This situation of uncertainty is described as 'much more confusing', 'more distressing' and 'more complicated'. One of the female interviewees admits that she prefers to have a problem instead of not knowing the reason for not getting pregnant:

I would prefer that the doctor could have discovered a problem; it might have been solved and then overcome. (33-year-old woman, university degree, bank clerk)

The interviewees' assessment of the lack of objectivity, exactness and assurance regarding the criteria used in the diagnosis of infertility is also expressed in relation to different situations: when two or more experts interpret differently the results of tests and thus propose different therapeutic approaches; and when a pregnancy is achieved without the support of medicine or any assisted reproductive technology after a diagnosis of infertility.

Paradoxically, the uncertainties surrounding both the medical assessment of the tests and the processes of categorisation of a couple as 'infertile' have encouraged the search for more objective and accurate technical and medical information as a way of judging the merits of specific medical procedures (Webster, 2002). Hence, in a context of uncertainty, the female and male interviewees are likely to develop practices that help to establish trust and confidence in medicine and technology. The interviewees report practices they have developed for judging expert authorities, like looking for an expert considered to be more competent; simultaneously attending private and public fertility services; repeating the medical tests in laboratories considered to be 'reliable' and to have a guarantee of 'quality' according to the recommendations of the doctor seen by the couple. Another common practice is to search and access health information and treatment in diverse sources at a global level, in particular in the media and on the Internet. The female interviewees emphasise the importance of other women who have undergone fertility treatments by the dissemination of personal experiences, preferably successful ones.

I knew a colleague who had fertility treatment and I have asked her where she had it. She has told me about all the places [where fertility treatment could be accessed]. (38-year-old woman, university degree, nurse)

A person in my family had difficulties in getting pregnant because she had a problem (...) she suggested that we went to the same doctor who had seen her for a long time. (33-year-old woman, university degree, bank clerk)

In sum, patients' understandings of and actions toward a diagnosis of infertility can be reformulated as new experience and information is fed in. Assessing the merits and capabilities of expert authorities and searching for information emerge as socially accepted practices perceived as rational and morally acceptable that can be mobilised in order to negotiate and critique medical practices and knowledge (Shaw, 2002). What is important here is the role played by lay people as autonomous, active agents in helping to reduce the uncertainties that surround the diagnosis and management of infertility.

Conclusion

The complexity of the processes through which a diagnosis of infertility is made leads us to conclude that infertility is not a neutral phenomenon but is rather produced in different ways in different diagnostic sites. Both women and men have gender identities which structure their experiences of the medical diagnosis of infertility, the medical construction of the 'fertility problem' and the design of clinical interventions. Of particular importance seems to be the fact that the diagnosis of infertility is supported by techniques that are almost exclusively applied to women's bodies, in the context of a medical approach to women's bodies that understands them as the 'natural' and 'given' subject of medical investigation and intervention (Ploeg, 2001). In the case of the diagnosis of infertility the modalities of translation and lay reinvention are mediated by the social relations and cultural expectations related to gendered relations regarding reproductive matters and the essentialism of biological parenthood. The medico-technical procedures and practices involved in diagnosing a 'fertility problem' and the associated clinical interventions reveal exercises of kinship 'construction' which serve to reinforce the privileging of biological kinship as a social norm (Thompson, 2001). This is largely justified by cultural assumptions related to the roles of women and men in society, such as the discourses and beliefs about motherhood as a biological destiny and an inevitable outcome of a woman's biology or, in the case of men, as a way of proving strength, virility, a sense of responsibility and the capacity for genetic continuity (Webb and Daniluck, 1999). Prevailing gender relations and the normalisation of the desire to have children combine with the belief in the miraculous nature of medicine and technology, in spite of the frequent experience of disappointment resulting from the uncertainties and lack of 'objectivity' that attend the diagnosis of infertility.

In the context of the 'socialisation of clinical diagnosis' (Webster, 2002: 448) new forms of engagement between the medical profession and lay people emerge in the domain of the diagnosis of infertility. The symbolic meanings attached to the physician's authority and to the technical practices associated with it are continually being negotiated and reinvented in order for the infertile couple to make sense of their everyday world and their relationship. Lay people are increasingly presenting a challenge to the epistemological and professional authority of medical and technical practices, through the translation of the diagnosis of infertility into lay language, the demand for more precise forms of diagnosis, the willingness to assess the merits of experts and the search for medical advice and information in diverse sources. But this challenge seems to occur in the context of an ongoing search for the miraculous solution to the 'fertility problem' alongside the wish for greater patient involvement in defining, diagnosing and managing infertility, rather than in the context of a demand to develop 'counter-discourses' in reproductive medicine. Our findings suggest that it

is important to make the diagnosis of infertility more 'accurate' and gender-sensitive, which could be linked to the development of an embodied ethics within reproductive medicine.

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References

- Alderson, P. (2001) On doing qualitative research linked to ethical healthcare. London, The Wellcome Trust, <u>http://www.wellcome.ac.uk/assets/WTD003270.pdf</u>
- Balasch, J. (2000) Investigation of the infertile couple in the era of assisted reproductive technology: a time for reappraisal. *Human Reproduction*, 15(11): 2251-2257, http://humrep.oxfordjournals.org/cgi/content/full/15/11/2251
- Becker, S., Bryman, A. (eds.) (2004) Understanding Research for Social Policy and Practice: Themes, Methods and Approaches. Bristol: Policy Press
- Bowker, L. (2001) Terminology and gender sensitivity: a corpus-based study of language for special purposes of infertility. *Language in Society*, 30(4): 589-610
- Brosens, I., Gordts, Sylvie, Valkenburg, M., Puttemans, P., Campo, R. and Gordts, Stephen (2004) Investigation of the infertile couple: when is the appropriate time to explore female infertility? *Human Reproduction*, 19(8): 1689-1692, <u>http://humrep.oxfordjournals.org/cgi/content/full/19/8/1689</u>
- Brown, P. (1995) Naming and framing: the social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 35 (extra issue): 34-52
- Cussins, C. (1996) Ontological choreography: agency through objectification in infertility clinics. *Social Studies of Science*, 26(3): 575-610
- Douglas, G. (1991), Law, Fertility and Reproduction. London: Sweet and Maxwell
- Edwards, J., Franklin, S., Hirsch, E., Price, F. and Strathern, M. (1999) *Technologies of Procreation: Kinship in the Age of Assisted Conception*. London: Routledge
- Gleicher, N. and Barad, D. (2006) Unexplained infertility: does it really exist? *Human Reproduction*, 21(8): 1951-1955,

http://humrep.oxfordjournals.org/cgi/content/full/21/8/1951

- Guest, G., Bunce, A. and Johnson, L. (2006) How many interviews are enough?: an experiment with data saturation and variability. *Field Methods*, 18(1): 59-82
- Habbema, J., Collins, J., Leridan, H., Lunefield, B. and te Velde, E.R. (2004) Towards less confusing terminology in reproductive medicine: a proposal. *Human Reproduction*, 19(7): 1497-1501, <u>http://humrep.oxfordjournals.org/cgi/content/full/19/7/1497</u>
- Hamlin, C. (1992) Reflexivity in technology studies: toward a technology of Technology (and Science)? *Social Studies of Science*, 22(3): 511-544
- Homburg, R. (2005) Towards less confusing terminology in reproductive medicine. A counter proposal. *Human Reproduction*, 20(2): 316-319, <u>http://humrep.oxfordjournals.org/cgi/content/full/20/2/316</u>

Lupton, D. (2003) Risk, London, Routledge.

- Machado, H. and Remoaldo, P. (2008) *Incomplete* women and *strong* men accounts of infertility as a gendered construction of well-being. In B. Harris, L. Gálvez and H. Machado (eds.) *Gender and Well-being: Historical and Contemporary Perspectives*, Aldershot: Ashgate (forthcoming)
- Mackay, H., Carne, C., Beynon-Davies, P. and Tudhope, D. (2000) Reconfiguring the user: using rapid application development. *Social Studies of Science*, 30(5): 737-757

- Mol, A. (1998) Missing links, making links: the performance of some atheroscleroses. In M.
 Berg and A. Mol (eds.) *Differences in Medicine: Unraveling Practices, Techniques and Bodies*. Durham: Duke University Press
- Olsen, J., Küppers-Chinnow, M. and Spinelli, A. (1996) Seeking medical help for subfecundity: a study based upon surveys in five European countries. *Fertility & Sterility*, 66: 95-100
- Pickstone, J. (2000) *Ways of Knowing: A New Science, Technology and Medicine.* Manchester: Manchester University Press
- Ploeg, I. (2001) *Prosthetic Bodies: The Construction of the Fetus and the Couple as Patients in Reproductive Technologies.* Dordrecht: Kluwer Academic Publishers.
- Pook, M., Krause, W. and Röhrle, B. (1999) Coping with infertility: distress and changes in sperm quality. *Human Reproduction*, 14(6): 1487-1492 http://humrep.oxfordjournals.org/cgi/content/full/14/6/1487.
- Shaw, I. (2002) How lay are lay beliefs? *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(3): 287-299
- Siristatidis, C. and Bhattacharya, S. (2007) Unexplained infertility: does it really exist? Does it matter? *Human Reproduction*, 22(8): 2084-2087, <u>http://humrep.oxfordjournals.org/cgi/content/full/22/8/2084</u>
- Stanworth, M. (1987) Reproductive technologies and the deconstruction of motherhood, in M. Stanworth (ed.) *Reproductive Technologies: Gender, Motherhood and Medicine*, Oxford: Polity Press
- Steeg, J., Steures, P., Hompes, P., Eijkemans, M., van der Veen, F. and Mol, B. (2005) Investigation of the infertile couple: a basic fertility work-up performed within 12 months of trying to conceive generates costs and complications for no particular benefit. *Human Reproduction*, 20(10): 2672-2674,

http://humrep.oxfordjournals.org/cgi/content/full/20/10/2672

- Strauss, A. and Corbin, J. (1990) Basics of Qualitative Research: Grounded Theory Procedures and Techniques, Newbury Park: Sage Publications
- Thompson, C. (2001) Strategic Naturalizing: Kinship in an Infertility Clinic. In S. Franklin and S. McKinnon (eds.) *Relative Values: Reconfiguring Kinship Studies*, Durham: Duke University Press
- Ulrich, M. and Weatherall, A. (2000) Motherhood and infertility: viewing motherhood through the lens of infertility. *Feminism and Psychology*, 10(3): 323-336
- Vayena, E., Rowe, P. and Griffin, D. (eds.) (2002) Current practices and controversies in assisted reproduction, Geneva: World Health Organisation, http://www.who.int/reproductive-health/infertility/report_content.htm
- Webb, R. and Daniluk, J. (1999) The end of the line: infertile men's experiences of being unable to produce a child. *Men and Masculinities*, 2(1): 6-25
- Webster, A. (2002) Innovative health technologies and the social: redefining health, medicine and the body. *Current Sociology*, 50(3): 443-457

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