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The ambiguity of patient-centred practices: the case of a Dutch fertility clinic

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When in-vitro fertilization (IVF) was introduced in the 1970s, doctors were criticized for not properly informing prospective users about its possible risks and limited success rates as well as for medicalizing fertility problems. Nowadays, many fertility clinics are seeking to improve their accountability to stakeholders through patient-centred practices. Based on an ethnographic study of a Dutch fertility clinic, outspoken in its aims to provide patient-centred medicine and to empower clients, this paper addresses how patient-centred medicine affects couples’ decision-making to use IVF and related reproductive technologies. The author contends that while patient-centred practices facilitate informed decision-making and support couples emotionally, they may also have unintended disciplining and normalizing effects. The information and support provided, the trust couples have in clinic staff, the ongoing visualization of conception mediated by medical technology – all can be seen as practices that strengthen lay people’s ‘medical gaze’ in how they come to view their bodies, fertility problems and possible solutions. These unintended effects are labelled ‘the ambiguity of patient-centeredness’ as they (may) interfere with processes of autonomous decision-making.

Keywords: infertility; IVF; reproductive technologies; patient-centred practices; bio-power; patient empowerment; Netherlands; hospital ethnography

Introduction

Since the advent of in-vitro fertilization (IVF) in the 1970s, IVF as well as other assisted reproductive technologies (ARTs) have been shrouded by criticism and concern. Criticisms have focused on limited success rates, the risks involved, the physical and emotional burdens of treatment, ethical issues, high costs and issues of unequal access. In the early days, criticisms also focused on how ARTs were offered and the involvement of potential users in decision-making. In particular, doctors and clinics were criticized for being paternalistic, for their reluctance to inform patients about the possible adverse effects of hormonal drugs used in IVF treatments, and for their tendency to present biased, incomplete and sometimes manipulated information on IVF success rates, which raised unrealistic expectations and distorted informed decision-making (Gupta 1996; Sandelowski 1993; Thompson 2005). Overall, (radical) feminist and other critical scholars took exception to the role played by doctors in the medicalization of fertility problems (see Inhorn and Van Balen 2002, 14).

The past three decades have witnessed significant changes in the provision of assisted reproductive technologies, both at the level of policy and within clinics. Many fertility
clinics, particularly in western countries, have introduced patient-centred practices to reduce the paternalism that previously infused medical encounters and to guarantee patient autonomy and informed decision-making. The field of infertility care has even come to be known for its efforts to increase accountability to stakeholders (e.g. Thompson 2005, 25). But scholars, most often working from a Foucauldian perspective, have also pointed to the possible adverse effects of patient-centred practices, which introduce new doctor—patient power relations that in effect mould patients to think and act in particular ways (Mayes 2009).

This paper examines the manifold effects of patient-centred practices on women and men undergoing IVF treatment. Based on an ethnographic study of a Dutch fertility clinic — one that is particularly outspoken in its aims to provide quality, empowering, patient-centred care — the paper asks: what do all the supporting and empowering practices and expressions of concern, empathy and commitment do to the women and men visiting the clinic? How do these patient-centred practices affect the way people experience treatment and make decisions about using ARTs? What intended and unintended effects do, or might, they have? The author contends that while patient-centred practices — as intended — facilitate informed decision-making and support couples emotionally, they can also have unintended disciplining and normalizing effects.

Two bodies of literature

The possible effects of patient-centred practices have been addressed in two bodies of literature. The first emphasizes the importance of patient-centred medicine, in particular when dealing with infertility. While the different views that exist about patient-centred medicine (see Mead and Bower 2000 for an overview) belie uniform definitions, patient-centred medicine can be seen to be comprised of those medical practices that give due attention to the interpersonal aspects of care and the need to fully inform patients and involve them in decision-making. These aspects of care have been recognized as key determinants of patient satisfaction in healthcare more generally (Mead and Bower 2000) and have been found to be particularly important in how people experience infertility treatment (see, for example, Becker and Nachtigall 1991; Greil 1991; Halman, Abbey and Andrews 1993; Hojgaard, Ingerslev, and Dinesen 2001; Inhorn 2003).

From this perspective, patient-centred care matters for fertility clinics for a number of reasons. As the experiences of infertility and treatment (which generally entails numerous procedures over an extended period) are emotionally demanding, empathic treatment and psycho-social support are considered key to making treatment more bearable, minimizing stress and (supposedly) limiting drop-out rates (Alper et al. 2002; Smeenk et al. 2004). Stress reduction has even been referred to as a ‘non-invasive way of improving infertility’ (Campagne 2006, 1656). It has further been suggested that psycho-social inter-ventions — in particular when directed at a ‘pre-treatment clinically depressed group’ — can increase pregnancy rates (Smeenk et al. 2004, 267). Second, as infertility care is personal and intimate, people value being treated in ways that respect their privacy by personally engaged clinical staff (Blonk, Kremer, and Ten Haaf 2006; Inhorn 2003). Third, the provision of adequate and repeated information is thought crucial to empower patients to be fully involved in decision-making (Kremer 2007). This is particularly so as women and men undergoing fertility examinations and treatments must make decisions about complex medical issues at many points along their treatment trajectories.

Scholars who focus on the empowering effects of patient-centred practices generally do not pay attention to the unintended effects that may interfere with informed decision-making and patient autonomy. These are the focus of a second body of literature by
medical anthropologists, science and technology scholars, and ethicists (e.g. Cussins 1998; Gastaldo 1997; Mayes 2009; Pasveer and Heesterbeek 2001; Sawicki 1991; Thompson 2005) who, inspired by Foucauldian ideas of biopower and disciplinary power, have critiqued concepts such as patient empowerment, autonomy and informed consent.

From this perspective, the ‘disciplinary power of biomedicine operates through patients’ internalizing of appropriate discourses on how they should know and experience, behave, monitor and regulate themselves’ (Jaye, Egan, and Parker 2006, 141). Practices designed to better inform lay populations so that they can wrest control from doctors — for example patient empowerment and health education (Gastaldo 1997) — may even further the ‘medicalization of people’s lives by encouraging them to acquire medical knowledge for themselves more actively’ (Lupton 1997, 107). In addition, these practices may ‘involve the imposition of “truths” about health, in which the patient loses control of her or his own body’ (Gastaldo 1997, 129–130). Finally, as Mayes (2009) argues, the literature on the patient-centred approach generally conceives of power as something that an individual or group possesses and uses as a repressive force. But from a Foucauldian perspective, power is ‘a relational and productive force that constructs each actor to act, think and expect certain responses from themselves and others’ (Mayes 2009, 484). This paper thus argues that although patient-centred medicine may liberate the medical encounter from paternalistic power, at the same time it introduces a new complex of power relations between doctors and patients.

Previous research has examined the disciplinary and normalizing practices of fertility clinics that affect how women (they rarely speak of men) come to see themselves, the treatments they undergo, and their use of reproductive technologies (Cussins 1998; Pasveer and Heesterbeek 2001; Sawicki 1991; Thompson 2005). These studies have shown how disciplinary and normalizing practices accustom people to the clinic’s bureaucratic routines, encourage them to follow medical instructions, embrace medical knowledge, and undergo painful medical examinations and treatments (Pasveer and Heesterbeek 2001, 53–70). It is precisely due to these practices that women and men undergoing infertility treatment are more inclined to look at themselves and their bodies through a ‘medical gaze’ and to see themselves as patients, which enables them to behave as such (Lupton 1997, 99). But disciplinary power, Sawicki (1991, 83–85) suggests, does not force medicalized views upon women in treatment as orthodox critiques of medicalization assert (see Lupton 1997). Rather, medicalized views result from the disciplining that takes place within clinical encounters. Sawicki further argues that clinical encounters and the reproductive technologies on offer do not merely ‘incite desires’ but address women’s real needs and provide concrete solutions, to which women willingly subject themselves (Sawicki 1991, 85). From this perspective, decision-making on the use of ARTs is not only about conscious and informed decision-making by autonomous individuals. Rather, as Pasveer and Heesterbeek (2001, 69–70) argue, women whose views have been shaped or medicalized by disciplinary practices become increasingly inclined to continue with treatment. From a Foucauldian perspective then, normalizing and disciplining work in complex ways (Lupton 1997) can have intended as well as unintended consequences. This is also the perspective the author takes in this paper.

The study

The current paper is based on a comprehensive ethnographic study (Gerrits 2008) the author conducted at the Radboud University Medical Centre’s Clinic for Reproductive Medicine in Nijmegen, the Netherlands (hereafter referred to as the Radboud clinic). The
study, which took place between September 2003 and August 2005, examined how daily clinical practices affect the use of ARTs. Methodologically, its two main pillars included ethnographic observation and prospectively following 23 couples visiting the clinic. Observation in the clinic provided insight into daily clinical practices and encounters, in what people — women and men visiting the clinic as well as the clinic staff — actually did, underwent, and said as they encountered each other and the reproductive technologies. By intensively following 23 couples experiencing fertility problems, insight was acquired into accounts of their thoughts, feelings and experiences, and how these changed over their treatment trajectories. The couples were followed over a period of one to two years through multiple and extended in-depth interviews in their homes, observations and conversations at the clinic, phone calls and email. Some participants also kept a diary on behalf of the study (see Gerrits 2008 for the research design). Ethical clearance for the study was given by a regional medical ethics commission (CMO Regio Arnhem-Nijmegen).

Patient-centred care in the Radboud fertility clinic

The Radboud clinic bills itself as a patient-centred practice ‘offering high quality care’ and ‘providing adequate and modern patient information’, one which aims to actively involve patients in decision-making (UMCN website). The clinic has extensive guidelines on what information has to be given, when, how and by whom; staff members indeed spend much of their time talking to the visitors and answering their questions. Educational materials such as brochures and DVDs support the information given during individual consultation hours and at the plenary education evenings organized thrice a year for couples. Aware that patients will be unable to immediately understand all the material, clinic staff encourage them to read things over at home and contact them if ‘things are not clear’.

The Radboud clinic also provides couples in IVF treatment with online access to their medical files through the Digitale Poli which — at the time of the study — was unique in the Netherlands (Tuil et al. 2006). Participating couples here receive detailed information on their individual diagnosis and prognosis, and how they ‘score’ on each and every step of their IVF treatment. They also receive a digital photo of the embryo(s) to be transferred the evening before the transfer. The Digitale Poli further allows couples to chat online with clinic staff and other couples in treatment about their experiences, questions and concerns.

The clinic’s educational materials and communication events cover many issues. Throughout the process, couples learn about the bodily processes affecting conception in general and about their own fertility problems in particular. Doctors make sincere attempts to clarify and interpret the results of examinations and/or failed treatments, and explain further possible steps in ways that they hope will be understandable, and in response to questions. Couples are explicitly informed about limited success rates (20–25% per IVF treatment cycle) and IVF’s potential risks — most notably Ovarian Hyper Stimulation Syndrome, multiple pregnancies, and the potential side-effects of hormonal treatment for women.

While these potential risks and side-effects are emphasized again and again, couples are reassured that the risks are not ‘irresponsibly high’. The clinic stresses that risks are largely kept ‘under control’, e.g. by transferring a maximum of two embryos and by intensively monitoring follicle growth. Doctors also explicitly point to the existing gaps in medical knowledge, for example on the long-term effects of hormonal treatments on mother and child. They thus underline the importance of follow-up studies on women who have had IVF treatment and children born of IVF/ICSI (intracytoplasmic sperm injection) — in which they are actively involved — to gain insight into the long-term effects on health and/or development. Doctors are also clear about the limitations of existing reproductive
technologies, and that they cannot predict if and how particular (hormonal) treatments will affect individual women. They often state that the first IVF cycle is a sort of ‘try out’, and even then admit this does not predict how the next treatment will go.

Doctors at the Radboud clinic explicitly point to the clinic’s ‘expectative policy’, which refers to their position on not offering more intensive treatment than is needed. As one of the doctors told a couple:

We here [in this clinic] are very much in favour of taking a good look at what is the problem. We do not want to over-treat or offer a treatment that we know won’t help you to get pregnant. (IVF doctor, observation, consultation hour)

They also warn couples that treatments, in particular IVF, can take a heavy toll — both emotionally and physically. Couples are often encouraged to seriously consider their options rather than stepping blindly into a treatment trajectory, as can be seen in the quote below where an IVF doctor counsels a couple on potential treatment options:

You must realize that it is not an easy thing, such a treatment. You have to think hard about it, before making a decision. You [looking at the woman] have to take many medicines and emotionally it is quite demanding. You will get additional information about this. But it is important to recall that you really have to think about whether you really want this. Once you get started, you easily forget this. (IVF doctor, observation, consultation hour)

Aware of the potential psychological demands of IVF, clinic staff pay ample attention to the psycho-social needs of women and men undergoing treatment. In routine daily practice, doctors and nurses are generally empathetic towards the couples attending consultation hours and treatment sessions. In addition, a social worker, a psychologist, and a sexologist are attached to the department to provide extra psycho-social support and sexual counselling when needed.

The effects of patient-centred practices

Couples visiting the Radboud fertility clinic are provided with plenty of information, while clinic staff generally show concern and empathy for the women and men visiting the clinic. Doctors emphasize that they do not want to offer more treatment than necessary (as they do not want to overburden their patients or expose them to unnecessary risks) and warn couples that despite precautions, monitoring and support, treatment will demand much from them. Couples have online access to the outcomes of all steps in their IVF treatment and receive an enormously amplified picture of the embryo the evening before the transfer takes place. Doctors and nurses express their hopes (the ‘embryos look so good’) and their sorrow when results are disappointing. Couples and clinic staff often build long-term relationships in which couples share their concerns, emotions and hopes with clinic staff, whose judgements they (often) come to trust. How do women and men seeking treatment experience and respond to these patient-centred practices? The following section presents and discusses their multiple effects on the women and men visiting the clinic.

Intended effects: supporting, empowering and enabling informed decision-making

Overall, study participants were highly appreciative of the services offered by the clinic (see Gerrits 2008). That this applied to most couples was apparent in the patient satisfaction surveys (Blonk, Kremer, and Ten Haaf 2006) and the fact that the Radboud clinic has been recognised by Freya, the Dutch patient organisation for people with fertility
problems, as the most patient-friendly fertility clinic in the country four times. Points of criticism exist as well, including issues of privacy (the location of the waiting room and the room where semen has to be produced),3 couples being seen by different doctors during their treatment trajectories, and (occasionally) a particular doctor’s behaviour or response to patient concerns.

In particular, study participants appreciated the friendly and committed way that clinic staff generally approached them; the fact that they were seen and treated as human beings rather than as numbers; the amount of time clinic staff (often) spent with them; the abundant information they received through different means of communication; that they could communicate with staff outside clinic hours through the Digitale Poli; and the empathic way in which they felt they were (generally) dealt with. The quotes below illustrate some of these positive experiences and feelings:

It is much more personal than I expected it to be. They do I don’t know how many treatments a year! In fact it is a factory which is doing this, and still you have the feeling that you are treated very personally. (Woman, interview 2)

They take time for you. You can ask how and what. . . . You get all your questions answered in understandable language. Not in Latin or Greek; short and clearly. (Man, interview 2)

Then I hear something in the clinic, and when I do not fully understand it, I go to the internet and get some more information. But that is general information. When I am back in the hospital I will ask the doctor again, ‘What does that mean for me, in my case?’ (Man, interview 2)

Overall, study participants considered it important to receive ‘fair and ample’ information on all aspects of their treatment and prognosis. At the same time, they found it difficult to assess exactly what the information on, for example, risks practically entailed, particularly for their own situation. Yet, trust in the doctors seemed to reassure couples and helped them to accept the risks:

They simply would not offer this treatment if they thought it irresponsible or too risky. (Woman, interview 2)

In addition, couples felt well monitored and in good hands:

Concerning the risks, you are kept under control. Whatever happens, they intervene! . . . I don’t see that as a problem. (Woman, interview 2)

Trust in the doctors seemed to be strengthened by the doctors’ transparency about possible risks, limited success rates and the uncertainties of IVF treatment. Study participants were keenly aware that the doctors were not omnipotent and thus could not predict outcomes. When couples were asked how they felt about being confronted by all of these risks and uncertainties, most said that they preferred it this way, rather than doctors pretending that they knew everything and had everything under control. Transparency about uncertainty in effect increased patient trust:

I rather prefer that doctors do not pretend as if they are ‘half gods in white’. I think it is realistic when doctors show that they do not know and cannot accomplish everything. It makes them more human. I would not like it if they pretended that they had everything under control. (Woman, interview 2)
I think that if a doctor shows his limitations, that gives me a lot of trust. Much more than if they pretend that they know everything and that they can accomplish everything. If he is saying, 'we are not yet sure about this, or this and that is not yet quite clear' . . . Yes, if you recognize your own limitations that enhances my trust. (Woman, interview 2)

Patient-centred practices — being treated humanely, being listened to, having questions and concerns properly addressed — contributed to most study participants’ trust in the clinic staff, even in the face of uncertainty (Gerrits 2008, 2009).

In sum, patient-centred practices — as intended — decreased the burden of treatment and enhanced couples’ ability to consider the pros and cons of (further) treatment and make informed choices. Twenty-two out of 23 couples in the study felt well informed to decide about their next steps in the treatment process. It can thus be concluded that patient-centred practices in the Radboud clinic fostered conscious deliberation and decision-making. This does not mean, however, that women and men make decisions based on only purely rational assessments of information (see Gerrits 2008 for a detailed analysis of how information was handled).

Unintended effects: disciplining and normalizing practices

Can patient-centred practices have unintended effects as well? Seen through a Foucauldian lens, patient-centred practices can serve to strengthen the ‘medical gaze’ (Foucault 1977) among patients and ‘normalize’ the burdens of treatment, thus (possibly) interfering with processes of autonomous and deliberate decision-making and informed consent.

The medical gaze

Through the extensive provision of information, the women and men visiting the Radboud fertility clinic come to understand a great deal about what is going on in their (malfunctioning) bodies. But this initiation into medical thinking also fosters their ‘medical gaze’ and their inclination to think of and talk about their fertility problems and possible solutions only (or mainly) in biomedical terms. This enables them to better follow, understand and assess the outcomes at all steps of the IVF treatment cycle. The diary excerpt below, kept by a woman on behalf of the study, illustrates how she reflected on her chances on the day the follicle aspiration took place:

Immediately after the follicle aspiration (in the restroom) we are informed that twelve eggs have been found. This is the same amount as during the second treatment in October. At that time only four were fertilized. Then we were disappointed, because the average fertilization rate is sixty or seventy per cent. Why would it be that much lower with us? I so much hope that it will be better now. In the first place I hope that more eggs will be fertilized, and in the second place that they [the embryos] will divide well. The last time they transferred two embryos, both of four cells: one of moderate and one of reasonable quality [the preferred number of embryo cells at the moment of transfer is eight]. Everything has to be perfect this time; this has to be the one! (Woman, diary)

The visualization of conception through all of its steps — mediated by medical technology and the Digitale Poli — makes couples feel close to being pregnant. This is particularly the case when they reach the moment of embryo transfer and receive a digital picture of the embryo (which some couples call their ‘mini-baby’) or when couples see a white spot on the uterus on the screen in the treatment room, indicating that ‘there is
really something’ that has been placed in their bodies. This awareness seems to increase hopes and expectations. In the words of one of the male participants of the study:

We knew very well that it is only a small percentage [that succeeds], but still! Look, they replace the embryos, and then you really think like ‘That has most probably not happened to us before’. So, then you have much more hope than you in fact can have... And I think we indeed had too much hope. And maybe that is not bad, but then it falls harder afterwards. (Man, interview 2)

When treatment then fails — after having been so close — it is hard to say no to one more attempt. The way in which reproductive technologies divide the process of conception into stages, how the outcomes are visualized, explained and interpreted at each step, and the meaning these outcomes come to assume for couples — all of these factors can incline couples towards another treatment, even when their experiences of IVF and/or their prognoses have been anything but encouraging (cf. Sandelowski 1991).

Normalizing the burdens of IVF
Couples at the Radboud fertility clinic are well prepared to face the possible difficulties of treatment with ARTs. Seen from a Foucauldian perspective, this has two implications. First, they learn that experiencing pain and stress is unexceptional, and to a certain extent normal in IVF treatment. Attempting to conceive through IVF is thus not expected to come without suffering. This normalization of the side-effects, pain and stress of treatment may make couples more willing to accept it when it actually occurs. Second, as they expect pain and stress, women in particular tend to compare and relativize their own experiences with what they have heard and read, often concluding that it ‘could be worse’. One woman recalled the conversation she had with two other couples when waiting for her first ova pick-up:

They both told stories that did not really make you happy. One of them had been pregnant twice, but the implantation was the problem. She miscarried twice. And after the ova pick-up she really had a lot of complaints. And the other woman had a very swollen belly. Compared to them, things are not too bad for me, though I had pain after the ova pick-up when sitting and standing up. (Woman, phone call)

Alongside feeling prepared for what they could expect, couples (generally) also felt well monitored, treated and supported, which strengthened their bonds with and faith in the clinic staff. The concern and commitment shown by staff enhanced the feeling among couples that their attempts to resolve their fertility problem were being taken seriously and had become a shared undertaking. The extended examination and treatment trajectories in fertility care — sometimes stretching over years — mean that couples and clinic staff often build close relationships (some couples even find it hard to say farewell in the end). They come to feel that their wish for a child is in the hands of skilled and knowledgeable professionals who do not take unnecessary risks and who closely monitor them. One couple, concerned about the length of time she had to take hormones, at the same time felt relief because they knew that she was being intensively monitored. The husband told the author before they started their first IVF treatment:

Yes. That is what I hold on to. Over a certain period she has to go for frequent monitoring, and I think these have to be done well. If there is any indication that things are not going well, we will have to stop, I think. That gives me confidence. That gives me more confidence
than if they would say ‘do it on your own, and come back for a check-up once a week’. But that is not how it goes. (Man, interview 1)

At the same time, this feeling of ‘being in good hands’ may increase patients’ dependence on the views and judgements of doctors (‘as they know best’) and their trust in medical professionals (‘as they want the best for us’). The couple’s trust in the doctor plays a vital role in how they assess the risks and consider the pros and cons of (further) treatment, which may thus interfere with the process of autonomous decision-making. The normalization of the pain and difficulties of IVF, the relativizing notion that it can always be worse, and the bonds with and faith in clinic staff may make women and men more prepared to go on and bear the burdens of treatment, even when these are substantial.

Conclusion

This paper has shown that patient-centred medicine at the Radboud clinic may have both intended and unintended effects on patient decision-making. On the one hand, patient-centred practices make couples feel supported and empowered: as intended, they augment the ability of women and men to carefully consider the pros and cons of (further) treatment and make informed choices. Yet the paper has also shown and argued that patient-centred practices have unintended effects. The amount of information and support provided, the ongoing visualization of the process of conception mediated by medical technology and the Digitale Poli, the bonds created between doctors and couples, and the trust couples have in clinic staff all strengthen lay people’s ‘medical gaze’ and normalize the burdens of IVF. This may then render couples more inclined to continue with treatment, even in the face of uncertain prognoses and/or the significant physical and emotional toll of continued treatment. Patient-centred practices — which aim to, and succeed in, fostering informed decision-making — may thus also bias patient decision-making towards (further) medical treatment, thereby pointing to the ambiguity of patient-centred practices.

Patient-centred medicine can thus empower and disempower at the same time. While patient-centred practices can be seen as a significant improvement over previous clinical encounters infused with paternalism, the argument here is that women and men visiting the clinic are ‘still held in a matrix of power relations that form and mould’ (Mayes 2009, 492) them to think and act in particular ways.

The finding that couples’ decisions to pursue fertility treatment are, at least partly, based on feelings of trust in the health professionals providing the treatment, even when abundant information is provided, points to a dilemma in the application — or rather the meaning — of the notion of ‘informed consent’ within contemporary biomedicine. The more complex biomedicine and biomedical technologies become, the more dependent lay people become on professionals who can interpret and translate the insights and findings (cf. De Joode and Fauser 2001). It is therefore suggested that ‘informed consent’ should not be seen as the result of a purely rational and autonomous process of decision-making, based on a profound understanding and assessment of the information professionals provide to their patients. In fact, it may be more realistic to speak about consent based on information and trust in the medical professional. Considering informed consent in this way underlines its relational and interactional aspects, and at the same time points to its potential peril, namely the possibility of abuse of this trust.

In this paper and elsewhere (Gerrits 2009), the author has shown that patient trust in doctors is strengthened by doctors’ transparency about the possible risks, limited success rates, and uncertainties involved in reproductive technologies. Franklin and Roberts
(2006) found a similar pattern in their ethnographic study of Preimplantation Genetic Diagnosis (PGD): openness about the many uncertainties of PGD technology among medical staff strengthened the feeling among potential patients that they were in good hands. This is not to say that being open about uncertainty is always valued in contemporary medicine. The positive assessment of the clinic’s openness by couples using ARTs may have much to do with their long-term relationships with the clinic’s doctors, under which circumstance it is easier to discuss uncertainty (as suggested by Gordon, Joos, and Byrne 2000). In addition, being open about uncertainty may be more positively valued in contexts where patients are generally satisfied with other aspects of patient—staff interaction, as was the case in the Radboud clinic (see Gerrits 2008). Furthermore, as has been suggested by Franklin and Roberts (2006), the fact that doctors and couples felt they were co-involved in a ground-breaking endeavour created a strong feeling of togetherness. One may thus question the context-specific and cultural circumstances under which the disclosure of uncertainty is appreciated. Finally, one may question how much uncertainty patients can endure: at what point does promoting realistic patient expectations (Quill and Suchman 1993) start undermining trust in medical staff?

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Notes
1. Although this is a different sort of argument, Schmidt et al. (2003) have pointed out that especially private clinics need to cater to the multiple needs of patients to attract and retain consumers. But this is not relevant for the Dutch situation.
2. Lupton (1997, 97) argues that the orthodox critique of medicalization paints a too black-and-white picture of ‘doctors as intent on increasing their power over patients rather than seeking to help them, and of patients as largely helpless, passive and disempowered, their agency crushed beneath the might of the medical professional.’
3. Both privacy concerns have been taken into account in the newly built clinic.

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