

INTRODUCTION

Sylvia: 'We always said, all that hassle, we *thought* – we always emphasized that – we would not do it [in vitro fertilization, IVF]. We *thought* so, that is what we always stressed. Because we had understood from our environment, from people around us who were confronted with the same problem, that it is not so easy to say "It does not matter; we will see what will come". We thought, let us first go to the Canisius [regional clinic, not offering IVF], maybe it is just simple... But it was not so obvious for us to go there. And then later we went to the Radboud Clinic [the academic clinic where the study presented in this book was carried out, offering IVF]. In fact, it always goes like that, you simply go...'

Bob, Sylvia's husband, nods his head and says: 'You shift your boundaries. Yes, that is it, you shift your boundaries. And that is what we always heard. Now you look at it like this, but you do not know how you look at it when you are in the midst of it yourself. I can easily say "I do this and this and this". But that is not reality. Because once you've taken the first step, then maybe you make different decisions'. (A couple with fertility problems about to start their first IVF treatment)¹

Medicalization and Persistence

Having once entered the field of reproductive medicine, many people with fertility problems find it hard to stop treatments such as IVF before all medical options have been exploited. The

dominant picture in empirical studies is that people are drawn into a kind of ‘medical treadmill’, and many shift their initial borders regarding how far they would be prepared to go in their pursuit of a child (Franklin 1997; Verdurmen 1997; Pasveer and Heesterbeek 2001). Expressions such as sitting ‘in a never halting express train’ (Pasveer and Heesterbeek 2001: 114) or ‘roller coaster’ (Becker 2000: 165), being ‘taken over’ (Franklin 1997: 131) or feeling ‘compelled to try’ (Sandelowski 1991: 29), are frequently heard when people talk about their experiences with fertility treatments, indicating – as Bob and Sylvia express in the above interview excerpt – that once the first step into treatment has been taken, initial boundaries shift, and many feel overwhelmed by dynamics that they feel they cannot fully control.

People with fertility problems are often characterized as very persistent in their ‘quest for conception’ (Inhorn 1994), sometimes even being depicted as ‘addicted’ to treatment (Sandelowski 1991: 30–31). Only a small number discontinue treatment or do not start any treatment at all, even when these treatments would be paid for by health insurance.² The situation of those undergoing fertility treatment has also been depicted as ambiguous: they simultaneously want to continue and yet also to discontinue treatment (Pasveer and Heesterbeek 2001). Clearly, a tension exists between the eagerness of many infertile people to make use of assisted reproductive technologies (ARTs) – as they seem the only way to achieve their desired goal, a child of their own – and the demanding and controversial characteristics and dynamics of ARTs that they get involved with once they enter the medical field.

What makes it so difficult for many people with fertility problems to say no to (further) treatment, to jump off the roller coaster? What makes them go from one treatment to another? What makes them so inclined to continue treatment, so ‘eager for medicalization’ (Becker and Nachtingall 1991: 456)? The simple answer, of course, is that these couples dearly wish to have a child. If not, they would not have gone to the clinic. And this wish for a child certainly in part explains their determination. Several (ethnographic) studies have illustrated the importance of childbearing for many people worldwide, and the resulting suffering and social consequences when people do not succeed in this; this makes them eager to search for a solution (see for example Inhorn and Van Balen 2002; Greil et al. 2010). But there is more, and that is what this book is about.

Critiques of ARTs

Since the advent of ARTs at the end of the 1970s, many scholars from different perspectives have addressed the above questions and examined and critiqued the continuing medicalization of infertility and childlessness and couples' (persistent) use of ARTs.³ Criticism has been directed at the limited success rates;⁴ the physical and emotional burdens of treatment;⁵ ethical issues; the high costs; and the medical risks involved. These risks, in particular for the women and/or the children to be conceived, and the effectiveness of (newly introduced) treatments have been said to be insufficiently known (Buitendijk 2000; Heesterbeek and Ten Have 2001), prompting alarms about women's bodies becoming sites of medical experimentation (Klein and Rowland 1989). In this context, female risk taking has been perceived as particularly problematic when male infertility is treated by intracytoplasmic sperm injection (ICSI), whereby the healthy woman becomes the 'patient' who has to bear the risks of medical reproduction (Kirejczyk 1996).⁶

In particular, and especially in the early days of IVF, criticism focused on how ARTs were offered and the involvement of potential users in decision-making. Above all, doctors and clinics have been criticized for being paternalistic, for their reluctance to inform women (and men) about the possible adverse effects of the hormonal drugs used in IVF treatments, and for their tendency to raise success rates by selecting only promising candidates for treatment as well as manipulating the data presented to them by presenting biased, incomplete and sometimes altered information. All of which was suggested to raise unrealistic expectations and distort informed decision-making (Sandelowski 1993; Gupta 1996; Van Balen and Inhorn 2002; Thompson 2005). Overall, (radical) feminist and other critical scholars have particularly criticized the role played by doctors and the medical system in the ever increasing medicalization of fertility problems, as the summary of these critiques below shows:

[Doctors] actively participate in women's medical risk taking by encouraging their repetitive and often extreme use of the latest technologies . . . rather than by developing low-tech solutions, giving 'nature' more time, advocating adoption or fostering, suggesting that treatments be stopped altogether and childlessness accepted, or searching for ways to prevent infertility. (Van Balen and Inhorn 2002: 14)

Patient-Centred Medicine

The past two decades have witnessed significant changes in the provision of ARTs, both at the level of policy and within clinics, partially addressing these critiques. Many fertility clinics, particularly in Western countries, have introduced patient-centred practices to reduce the paternalism that previously infused medical encounters and guarantee patient autonomy and informed decision-making. The way in which ARTs are being provided has changed enormously; indeed, in Western countries, the field of ARTs has even become known for its patient-centred services and for its accountability to stakeholders (e.g., Thompson 2005).⁷ The focus of this book is on how such new forms of ART provision, which are more patient-centred and accountable, affect the use of these technologies.

Patient-centred medicine can be said to be comprised of 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.⁸ Such 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 for how people experience infertility treatment, for a number of reasons (Dancet et al. 2010).⁹ First, as both 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), and it has been suggested that psycho-social interventions – 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 by personally engaged clinical staff in ways that respect their privacy (Inhorn 2003; Blonk, Kremer and Ten Haaf 2006). Third, the provision of adequate and repeated information is thought to be crucial to empower patients to enable them to be fully involved in decision-making (Kremer et al. 2007). This is particularly so as women and men undergoing fertility examinations and treatments must make decisions about complex medical issues

at various points along their treatment trajectory.¹⁰ A recent study underlined the importance of patient-centredness in infertility care: women and men undergoing IVF were found to be willing to trade off a proportion of the pregnancy success rate per cycle in order to receive more patient-centred care (Van Empel et al. 2011). In addition, 'lack of patient-centredness' was the most often mentioned non-medical reason for changing fertility clinics.

Another View on Patient-Centredness

Scholars who focus on the empowering effects of patient-centred practices generally do not pay attention to the unintended effects that these practices may also have. These other effects have been examined by a number of medical anthropologists, science and technology scholars and ethicists who, inspired by Foucauldian ideas of biopower and disciplinary power, have critiqued concepts such as patient empowerment, autonomy and informed consent.¹¹ From this perspective, practices designed to better inform lay populations so that they can wrest control away from doctors – such as patient empowerment and health education (Gastaldo 1997) – are thought to further the medicalization of people's lives as they encourage them to acquire medical knowledge for themselves more actively (Lupton 1997). The 'disciplinary power of biomedicine' is said to operate through patients' internalizing of appropriate discourses on 'how they should know and experience, behave, monitor and regulate themselves' (Jaye et al. 2006: 141). 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 (doctors) possesses and uses as a repressive force, from which the patient has to be liberated. 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). Thus, Mayes argues, although patient-centred medicine may liberate the medical encounter from paternalistic power, it nevertheless introduces a new complexity of power relations between doctors and patients that may have other – disciplining and normalizing – consequences, which in turn may increase medicalization. Hardon and Moyer (2014: 107) point to such unexpected and complex dynamics of health care constellations when they propose that social scientists

should inquire into the ‘micro dynamics of power’ surrounding medical technologies in order to understand the full complexity of responses to (new) forms of health care or new medical technologies. This is exactly what I intend to do in this book.

The Aim of this Book

In the first place, this book provides an extended ethnographic portrait and analysis of the daily practices in a Dutch fertility clinic – the Radboud Clinic – which strongly profiles itself as being patient-centred. It also presents in-depth insight into the situated accounts of the women and men visiting the clinic. The main question I address is how visiting such a patient-centred clinic – in all its different dimensions – affects people with fertility problems. What do all the empowering and supporting practices and expressions of concern, empathy and commitment do to these women and men? How do the patient-centred practices affect the way they experience treatment and make decisions about using ARTs?

Throughout the book, I will show and discuss the various – intended and unintended – effects that these practices have, and argue that at times they may (and do) actually conflict with the aims of patient-centredness. For instance, such practices may interfere with processes of autonomous decision-making, one of the cornerstones of patient-centredness. This complex dynamic I have labelled the ‘paradox of patient-centredness’, and it lies at the heart of my analysis of infertile couples’ journeys through the intricate and ambiguous process of medically achieving a child of their own. Both clinic practices and the couples’ journeys are placed in the context of ‘Dutch IVF’ – referring to ART legislation and regulations in the Netherlands – and trends in contemporary Dutch society.

Outline of the Book

In Chapter 1, I first discuss the theoretical and empirical insights within social science studies of ARTs that have informed the current book, addressing an important turn in social science scholarship: from a focus mainly on dominant discourses to a more nuanced understanding of the medicalization of fertility problems. Next, I picture some relevant features and trends of Dutch society, the Radboud Clinic and the study design (a hospital ethnography) and methods.

Chapter 2 depicts the main aspects of Dutch ART legislation, national professional guidelines and current health insurance coverage, which strongly inform the actual practice and use of ARTs in Dutch fertility clinics.

In Chapter 3, I introduce the main players in this study: the couples whom I followed intensively over the course of their treatment trajectories. I first describe their socio-demographic backgrounds, and then use case studies to picture the diversity of their situations at the moment they found themselves confronted with fertility problems. Following this, I describe the ways in which they acted from that point on, including their quest for a child, in the biomedical health system and from complementary and alternative healers, and the ways in which they approached – and predominantly refused – adoption as an option.

In the next four chapters, different aspects of the daily practices in the Radboud Clinic are described and couples are followed throughout their treatment trajectories in the clinic. Each chapter shows the fertility treatment trajectory and the couples' experiences from a different angle.

Thus in Chapter 4, I sketch out the daily patient-centred practices in the Radboud Clinic, and couples' appreciation and – occasional – discontentment with these practices. The chapter focuses particularly on four themes that stood out in couples' stories and my own observations: interpersonal aspects of care; privacy; the provision of information; and psycho-social support. Subsequently, I discuss the empowering impact of these daily practices, but also point to 'missed opportunities' in the practice of patient-centredness. In the chapter's conclusion, I assert that some of these patient practices may render couples more inclined to continue with treatment. These practices and their effects are further described and scrutinized in the following chapters.

In Chapter 5, I consider the abundant information that couples receive about the risks and success rates of fertility treatments, and the way in which they interpret and handle this information. I will show that, as expected, this information increases their capacity to make well-informed decisions, but I also reveal how many find it difficult to apply the information to their own situation. Trust in health staff appears to be of crucial importance in decision-making, which challenges one of the core principles of patient-centred medicine.

In Chapter 6, the treatment process is analysed from the angle of technology. I first describe couples' initiation into the medical world

of infertility, which increases their ‘medical gaze’ towards their fertility problem and possible solutions. In the second part of the chapter, I follow the couples through all of the distinct steps in an IVF cycle and examine how the visualization of all these steps and the ample ways in which couples are informed about their in-between results affect their insights, experiences, hopes and decision-making. An extended case study, consisting of excerpts of a diary of one of the study participants, illustrates the meaning and impact of visualizing technologies.

Chapter 7 first provides a detailed account of the way in which women and men experience the unequal burdens of IVF in the different treatment stages, reflecting gender dynamics in current-day Dutch conjugal relationships. I also describe cases of loss and grief as a result of a late miscarriage and the death of a prematurely born child following IVF. The chapter also portrays the intensive support that the clinic offers women and men, intended to decrease the treatment burden, which may also have the ambiguous effect of keeping most couples on the treatment track.

Chapter 8 discusses the requests for medical assisted conception that Radboud Clinic staff perceive as ethically sensitive and thus bring for discussion at their multidisciplinary ethics meetings, and the practices they employ to address and resolve their concerns. It places staff concerns, practices and decisions in the context of ‘Dutch IVF’ and the clinic’s Catholic roots.

Finally, in Chapter 9, I wrap up the key insights and arguments of the book and present some after-thoughts and reflections about the future of IVF services in the Netherlands and internationally.

Notes

1. Aspects to do with permission for doing the study and anonymity of study respondents are dealt with in Appendix 1.
2. For research in the Netherlands, see Koomen (1997), Verdurmen (1997) and Smeenk et al. (2004). Smeenk et al. (2004) found that about one-tenth of couples undergoing IVF treatments decided on their own to refrain from further treatments after a failed first IVF treatment, even though their prognosis was still good, and about one-fifth did so after a second failed treatment. In the same period, two other studies (in Australia and Sweden) found ‘high dropout rates’ among people undergoing fertility treatments, showing that several couples

- voluntarily discontinued subsidized IVF treatments (Hammarberg et al. 2001; Olivius et al. 2004).
3. See, e.g., Corea (1985); Tijmstra (1987); Klein (1989); Greil (1991); Sandelowski (1991, 1993); Franklin (1997); Cussins (1998); Becker (2000); Kahn (2000); Inhorn (2003); Thompson (2005); Franklin and Roberts (2006); Birenbaum-Carmeli and Dirnfeld (2008).
 4. Average success rates per IVF treatment cycle in Dutch fertility clinics are currently around 25 per cent. Success rates of fertility clinics in the Netherlands are published per clinic on a yearly basis (<http://www.lirinfo.nl>).
 5. See, e.g., Franklin (1997); Koomen (1997); Pasveer and Heesterbeek (2001); Verhaak et al. (2001, 2002, 2005).
 6. Throughout the book, I consciously avoid the use of the word 'patients' to refer to women and men with fertility problems, as I do not consider them as such. Only occasionally, when presenting the views of other authors, do I use the term patients.
 7. In the introduction to her book 'Making Parents', Charis Thompson explains her personal stance towards ARTs, in the midst of 'feminist, academic, and lay criticisms of these technologies', in the following way: 'I argue that these [assisted reproductive] technologies began as anything but a model for other areas of practice (there were few clinics, which had astonishing low success rates, imposed gruelling treatment regimens, and excluded most would-be patients because they were unable to pay or were judged to be suitable (sic) as parents) but have become unusually accountable to various stakeholders and have been established as a site of activism within medicine' (Thompson 2005: 25).
 8. Different views and definitions of patient-centred medicine exist (see Mead and Bower 2000 for an overview).
 9. Dancet et al. (2010) provide a systematic overview of studies on patients' perspectives on infertility care, in which they describe the dimensions of patient-centred practices to which patients attach importance. Overall, they found that people with fertility problems 'want to be treated like human beings with a need for: medical skills, respect, coordination, accessibility, information, comfort, support, partner involvement and a good attitude of, and relationship with, fertility clinic staff' (*ibid*: 467). See also Becker and Nachtigall (1991); Greil (1991); Halman, Abbey and Andrews (1993); Hojgaard, Ingerslev and Dinesen (2001); Inhorn (2003).
 10. In addition, Schmidt et al. (2003) have pointed out that private clinics, especially, need to cater to the multiple needs of patients in order to attract and retain 'consumers'.
 11. See e.g. Cussins (1998); Gastaldo (1997); Mayes (2009); Pasveer and Heesterbeek (2001); Sawicki (1991); Thompson (2005).

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