

CHAPTER 2

THE MAKING OF THE NEW PATIENTS

1. INTRODUCING: THE COUPLE AND THE FETUS

To speak of fetuses and couples as patients may seem neither particularly surprising or consequential. After all, we all know that pregnant women carry fetuses in their wombs that may have something wrong with them. In such cases, it seems hardly strange to talk of these fetuses as little patients in the womb. Likewise, couples who, despite serious efforts, are unable to have children, have a problem that may lead them to seek medical help together. But everyone knows that fetuses grow inside women's bodies, and it is women who will visit doctors, who ask for and are given advice, prescriptions and tests. Similarly, everyone knows that a couple consists of two individuals with separate bodies. They may have a problem as a couple, but the shared nature of their problem stems from their shared wish for a child and shared grief about its remaining unfulfilled. So, while it seems self-evident that fetuses and couples may have medical problems, to call them 'patients' is just a manner of speaking, not to be taken too literally. At any time it will be clear who the 'real' patients are. For all practical purposes, it would hardly seem to make any difference. However, Meerabeau, drawing on observations of 55 clinic sessions in three fertility clinics in the United Kingdom, concluded: "Doctors are not accustomed to treating more than one patient simultaneously, and the use of the concept 'couple' in subfertility treatment presupposes a commonality of aims which may not exist. ... There are attempts to construct the fertility problem as a joint endeavor, but these tend to founder on the biological imbalance in the situation."¹³¹ Moreover, This view about the innocence and inconsequentiality of language and conceptualizations relies on the idea that the relation between language and reality is one in which language refers to an independent reality. This view implies that changes in vocabulary have no consequence for the reality described, since language only passively "mirrors" this reality. In this work I rely on a theory of language that accords a much more active role to language in the constitution of the realities we inhabit.¹³²

In this chapter I will develop the argument that the notions of the couple as patient and the fetus as patient are simultaneously more 'real' *and* stranger than their current prevalence in medical-scientific discursive practices suggests. Fetuses do not just figure as patients in the fancy titles of the many recent textbooks, articles, and reports on current developments in prenatal medicine. The concept of the fetus-as-patient has gained a presence much wider than that. Similarly, the couples in infertility medicine play the role of patient in a much more literal sense than might be expected from the everyday use of the word. Within the discourses on fetal surgery and in vitro fertilization, 'fetuses' and 'couples' have come to occupy positions very similar to those of more conventional types of patients. Like patients in general, they are referred to clinics, undergo tests, and receive diagnoses and treatments. While their patient status has thus become 'real', at the same time this development constitutes a departure from the meanings 'fetuses' and 'couples' have in contexts other than reproductive medicine, as well as from more conventional meanings of what being a patient is. In as much as they have been turned into real patients, 'fetuses' and 'couples' become rather strange entities.

First, we will take a closer look at the 'couples' populating the discourse on male infertility and reproductive technology. The term 'populating' intends to underscore once more that my approach to these texts will primarily be a semiotic one, in the sense that the question what the terms and categories deployed refer to *outside* these texts is (temporarily) bracketed. As Bruno Latour, explaining the value of a semiotic approach to scientific texts in the study of science and technology, writes: "Semiotics is the ethnomethodology of texts. Like ethnomethodology, it helps to replace the analyst's prejudiced and limited vocabulary by the actor's activity at world making."¹³³ Moreover, the focus is on the world that is emerging from the texts, without reference to the presumed intentions of the author or the social context. Thus, I focus on *internal* referents and meanings generated by the texts themselves.

From this perspective, infertile couples are far less ordinary than their strong resemblance to the well known social category that denotes a combination of two individuals somehow belonging together might suggest.¹³⁴ The rapidly developing discourse on infertility treatments seems to have construed a creature that - although called a 'couple', or sometimes a 'male factor patient' or an 'infertility case' - seems more adequately described as a hermaphrodite being, rather than a combination of two recognizable individuals of different sex.

Numerically, for instance, couples are not counted as two patients, but as *one*. Papers reporting clinical research involving only a small patient sample

commonly refer to individual cases with a number. A man and a woman who make up a couple are counted, in these reports, as one, so that when there are, for example, 15 couples involved in a study, the total patient count is 15 rather than 30. Naturally, a reader will take "patient no.6" to refer to one particular human being. This patient might be said, for example, to suffer from oligospermia. The reader then will infer that patient no.6 is a man, because she knows that oligospermia is a pathological condition of the male reproductive system, in which the sperm produced contains abnormally few spermatozoa. When next, however, the reader is told that this same patient underwent an embryo transfer (ET) and became pregnant, she starts suspecting that this patient is not exactly an average male human being.

One might think that such phrases are just one author's occasional slip of the pen, resulting in an accidental omission of words like "the wife of", in the sentence about ET and pregnancy. The same phenomenon, however, turns up again and again throughout the literature. Consider the following examples, taken from scientific publications on the use of IVF in cases of male infertility:

Ooplasmic injection (single sperm heads) was done in 38 oocytes from three patients with extremely severe oligozoospermia; only four pronuclear zygotes were obtained and replaced into two patients, without any resulting pregnancy.¹³⁵

In severely teratozoospermic patients, significantly fewer partially zona-dissected than subzonally inserted embryo's implanted.¹³⁶

Fig.3 Ongoing pregnancy rate per cycle in different groups of men with the corresponding lower limit of sperm concentration.¹³⁷

In the first two quotes, we find the same patients being oligozoospermic or teratozoospermic, as well as producing oocytes and having embryo's replaced into their bodies. The third quote shows how far this discourse is removed from most other discursive practices. Without a trace of irony the authors claim the achievement of pregnancies not just in couples, but literally in men. However, instead of ascribing to the authors a rather incredible ignorance about the facts of life, quotes as these are perhaps better interpreted as showing the degree to which couples indeed have come to be considered as one functional organism in this practice. They have become true hermaphrodites: one patient, with both male and female physical characteristics.

The conceptualization of a fetus as a patient is a departure from long standing conventions as well, but some other nuances are involved here. While the conception of the fetus as a patient in itself might have allowed for

the woman to retain her conventional status as the patient in prenatal care (thus yielding a "double patient"), this is very rarely the case. Each 'case' yields one patient only, and though it can remain ambiguous for some time in the course of a particular text, whether this 'patient' refers to a woman or a fetus, this ambiguity is usually resolved at some point, as in the following example:

In their review of 74 fetuses with bilateral hydronephrosis, they reported results on 16 patients who were defined as having good prognosis. Nine of 16 patients had intervention, and 7 of 16 did not have intervention. Of the 9 patients with intervention, 8 were delivered with normal renal function. Of the 7 patients with no intervention, 2 died, and 2 of the 5 who survived have chronic renal failure.¹³⁸

To have a good prognosis, an intervention, and to be delivered are things that could be said of a woman as well as a fetus. Yet the last two sentences resolve the ambiguity, for the renal function, death, and survival of 'the patients' clearly apply exclusively to the fetuses. In another case, the patient "was referred at 23 weeks with anhydramnios, bilateral moderate hydronephrosis/hydroureter, and an enlarged bladder and proximal urethra."¹³⁹ Again, the referral and diagnosis of anhydramnios (lack of amniotic fluid) could still indicate a woman patient, but the rest of the diagnosis undercuts this interpretation for it refers unequivocally to the state of the kidneys and the urinary tract of the fetus. Usually, however, there is less ambiguity. In the following examples it is the fetus who is undergoing diagnostic procedures and interventions:

Ten fetuses had undergone diagnostic catheter placement and in utero renal function testing. This led to placement of a therapeutic indwelling catheter-shunt in seven fetuses (three required multiple shunts) and a suprapubic vesicostomy in another.¹⁴⁰

Twenty-two fetuses with bilateral CH [congenital hydronephrosis] underwent either a diagnostic procedure, a therapeutic procedure, or both.¹⁴¹

An additional potential problem, therefore, is that those patients with a large volume of liver in the chest may not respond to antenatal therapy, as the lungs may be primarily hypoplastic and incapable of growth when the viscera are removed.

Nevertheless, because of their expected high mortality, these are the very patients on whom it is most easy to justify antenatal intervention.¹⁴²

...a second fetus with immunodeficiency disease was treated prenatally in 1989. This second patient was a younger fetus with a

complete form of severe combined immunodeficiency disease. He was treated with FLT in June 1989, at the age of 26 fertilization weeks,

....¹⁴³

In a similar vein, the results of the procedures and the concomitant complications are described as pertaining to the fetus exclusively. For instance, the report from the International Fetal Surgery Registry¹⁴⁴, purporting to give an overview of the results of all the registered cases of in utero therapy for obstructive uropathy, hydrocephalus, and diaphragmatic hernia up to 1985, relates these results exclusively in terms of 'fetal outcome'. All "cases" reported are of "treated fetuses", and all evaluative categories (including numbers of stillbirths, neonatal deaths, survivals with or without handicap, procedure related deaths etc.) refer to the fates of fetuses and children. Not once are 'women' mentioned throughout the report, not even in the category of 'complications'.

While a 'couple' can be understood as two patients becoming one, resulting in a hermaphrodite being, it is less clear how to describe what happens in the case of fetuses. Although it would create a nice symmetry to understand this see as a process of one patient becoming two (the double patient model), the examples given above show that this is not exactly the case. There still is only one patient. One possible interpretation is to view this as an instance of "pars pro toto": 'the fetus' as a figure of speech that names a part to stand for the whole, a pregnant woman. Though perhaps somewhat impolite, this would render the fetus-as-patient an innocent figure of speech, leaving the woman's position unaltered.

However, many feminist critics of developments in prenatal medicine and technology have taken a less sympathetic view on the phenomenon of fetal patients.¹⁴⁵ They worry that putting the fetus central stage may negatively affect the position of the woman as the primary focus of medical concern. Their analyses have focused mostly on prenatal diagnostic technologies, such as ultrasound and fetoscopy. These techniques produce visual representations of the fetus that literally remove the woman from the picture. Her receding into the background, or reduction to 'fetal environment', is taken as a possible sign of a diminishing relative weight of her interests in medical considerations. My examples above do seem to support this conclusion: where the fetus becomes the patient, the woman no longer appears to be.

But the fact that women are not represented as *the patient* leaves open the question how they *do* figure in this textual practice. Despite instances like the Registry's report, it is hardly conceivable that they are not in some way or other acknowledged to be present. The significance of the semiotic

Prosthetic Bodies

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