6 Discourses of Health and Illness in Accounts of IVF Failure

KAREN THROSBY

When *in vitro* fertilisation (IVF) fails, there are few socially and culturally intelligible resources available with which to make sense of those experiences other than tragic stories of despair and interminable lack. This paper argues that those for whom treatment fails occupy an ambiguous liminal location between dominant stories, and that they have to draw strategically from often contradictory discursive resources in order to make sense of those experiences in a way which minimises the significance of their reproductive difference and produces belonging. Based on a series of interviews with women and couples who had IVF unsuccessfully and ended treatment, this paper explores the ways in which the participants mobilised discourses of health and illness in order to make sense of those experiences both to themselves and others. The analysis illustrates the extent to which reproductive normativity produces a burden of justificatory discursive labour for those for whom treatment fails, and highlights the seemingly intractable association of healthy femininity with motherhood. However, this discursive work also exposes the dynamic and provisional nature of the apparently static categories of health and illness, opening up possibilities for transformation in power relations.

Introduction

The dominant narratives of *in vitro* fertilisation (IVF) are of treatment success, and its mainstream history is populated with miracle babies, grateful couples and the pristine trappings of medical science. However, of the 25,273 cycles of treatment started between April 2000 and March 2001, only 21.8% resulted in live births (5513 births) (HFEA, 2002) meaning that the dominant experience of IVF is of treatment failure, not success. One consequence of the dissonance between the dominant narrative and the high failure rates for those whose treatment fails is a paucity of socially and culturally intelligible discursive and narrative resources with which to make sense of the experience of treatment failure as anything other than insurmountable despair and interminable lack. However, those for whom treatment fails and who have subsequently ended treatment are not so much located **outside** of the dominant narratives, but **between** them - what Elspeth Probyn describes as a state of "outside belonging" (Probyn, 1996). From this perspective, they can be seen as

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occupying an ambiguous liminal space between conformity to, and transgression of, normative reproductive values: they have tried to conceive but have been unable to; they desire children but are no longer actively pursuing that desire; they have brought technology into the normatively "natural" process of reproduction without the counterbalancing outcome of a reassuringly "natural" baby. The socially exclusionary potential of this liminal location means that those whose treatment fails have to move strategically between those categories in order to locate themselves as belonging. The categories of health and illness are central to the discursive work of accounting for IVF failure in ways that resist the exclusion and isolation which IVF failure can produce, and in this paper, I will explore some of the ways in which those whose treatment fails construct themselves as both healthy and ill in order to minimise the significance of their own reproductive difference and to establish themselves and their experiences as fundamentally "normal" and unremarkable.

Methodology

The interviews upon which this paper is based were conducted as part of my PhD research project (Throsby, 2002), which explored the experiences of 15 women (whose male partners did not participate in the interviews), and 13 couples, all of whom had had unsuccessful IVF, with their most recent cycle having taken place at least two years prior to the interviews. The research aimed to explore the factors informing the end of treatment, and the impact of treatment failure on perceptions of the technology and on the experience of involuntary childlessness. The study begins from a feminist perspective which recognises not only some of the pernicious effects of the technology, but also the demand for it from women. Therefore, rather than seeing women as being duped or coerced into harmful practices, as some feminists have argued (see for example: Corea, Klein et al., 1987; Spallone and Steinberg, 1987; Corea, 1988; Rowland, 1992; Raymond, 1993), I begin from the assumption that women are active agents in the IVF process. My key question, then, was always to think about what function particular discourses were performing in their accounts and what that might tell us about the power relations within which the engagement with IVF takes place.

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Analysis

There is considerable anxiety in the public domain about the use of technology for reproduction, and fears of "meddling with nature" and the commodification of life fuel a steady trickle of media hype about "designer babies", cloning and genetic engineering. One of the key strategies that emerged in the accounts for countering these concerns in relation to their own engagement with IVF is the identification of infertility as a disease warranting treatment. Technological intervention into the body for medical reasons is a common feature of western society, and medical intervention into involuntary childlessness has a lengthy precedent (Pfeffer, 1993). Therefore, claiming infertility as just another disease, and IVF as just another treatment, works to normalise IVF:

> Karen: What's your general view of the technology itself? I mean, do you see it as a positive thing?
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> Courtney: [nodding] I wouldn't have said that 10 years ago, because of having children of my own [from earlier in her marriage], I'd see it, you know, as abnormal and … but to help people, I think, when people can't have kids, it's not just that … it's a disease and people should help it, not just, "Oh, go away!" You know … It's … it can't kill you, you know, like cancer and everything else, but it's still a disease …
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> Beth: […] And this is just another medical treatment to help people overcome a physical problem that they've got and I don't see why it should be different any other treatment.

The positioning of IVF within the medical system validates this interpretation, and on entry into the medical system, the IVF candidate is quickly identified as a ***patient***. The tests, scans, surgical interventions, and daily hormone injections all point to the experience of IVF as a fundamentally medical one, and of infertility as an involuntary disease which produces a valid claim to treatment. The reservations that Courtney imagines she would have felt about IVF prior to her own experience - that the treatment was abnormal - are put aside with the understanding of IVF as "to help people" who are ill. This strategy also works to legitimise claims on scarce public resources at a time when NHS provision of fertility services is erratic and constantly under threat. However, Courtney is also careful to place the claiming of infertility as a disease in perspective - it's not cancer; it can't kill you. This is important because one of the most common stereotypes of the IVF patient is of completely self-absorbed desperation (Franklin, 1990), and Courtney is therefore careful to demonstrate her own sense of perspective in her construction of infertility as an illness in order to distance herself from this suggestion.

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While the pathologising of infertility can be seen here as an effective justificatory strategy for the engagement with IVF, one of the effects of this is to synecdochically pathologise the whole woman. Importantly, it is infertility *per se*, rather than fertility-reducing conditions, that is designated as pathological, and consequently, it is the absence of genetic parenthood that becomes the marker of pathology - a rhetorical move that inevitably reproduces the socially and culturally dominant discourse of non-motherhood as a signifier of disorder in women. It is also significant that as the IVF patient, even where male factor infertility is implicated, it is the female partner who comes to embody this pathology, and not her male partner.

One strategy for managing this pathologising of the female body was to lay claim to the conventionally male prerogative of the Cartesian mind-body distinction, adopting a medicalised focus on particular malfunctioning body parts as separate from the self - what Rosi Braidotti describes as "organs without bodies" (Braidotti, 1994):

> Alice: It's sort … none of my bits are useful for what they're supposed to be used for, for whatever reason.

The confining of the disorder of infertility to her "bits" enables Alice to assert her desire to reproduce, and therefore, to assert her conformity to normative standards, at least in intention, which assume women to be mothers. Another of the participants, Claire, adopted a similar strategy when she described her inability to conceive - caused by blocked fallopian tubes - as "a transport problem". The conceptualisation of the body in mechanical terms enables the participants to bracket of malfunctioning parts in order to prevent the self from being marked as diseased, although it is important to note that this is not a strategy which was available to all the participants, since not all had been able to receive a definite diagnosis as to the cause. Furthermore, this was not a strategy that proved useful where male factor infertility was implicated, and I have explored some of the reasons for this elsewhere (Throsby and Gill, forthcoming).

A further problem created by the pathologising of the female body is that while contemporary culture accepts the use of medical technology to treat disease, there is also a potent social imperative to remain healthy, and this is combined with an assumption that an individual's health is determined largely by the extent to which they are prepared to take responsibility for it (Sontag, 1978; Coward, 1989; Stacey, 1997). Therefore, while identifying themselves as suffering from a disease - infertility - which warrants treatment, the participants also needed to demonstrate themselves fundamentally healthy, both physically and mentally. Alice is an interesting case here. At 47 when I interviewed her, she had just entered the menopause, and was still seeking out treatment options, in spite of considerable resistance from her husband and a history of

significant gynaecological problems. However, in her account of the three cycles she had undergone unsuccessfully, it became clear that she had taken significant steps to maximise her own health by losing weight, and carefully policing her diet to avoid in-taking anything that might possibly imperil a pregnancy. She reinforced her commitment with a commonly employed strategy of comparing herself in relation to a less-deserving Other - in this case, a pregnant woman she had seen in the street, who had three small children with her and who was smoking:

> Alice: […] it would be nice to think that women that tried to look after themselves were perhaps given a bit better treatment … well, not better treatment, but given more of a chance, and I mean, for all I know, that woman could get married again. There she is with three kids by three men, but couldn't have one with the next one, probably smoked all her life, and gets funding just because she happens to be 33 or whatever.

Health here is not simply a matter of luck, but emerges as a moral category which is achieved rather than bestowed. The woman she saw in the street is mobilised discursively in Alice's account as the undeserving Other against which the legitimacy of her own treatment is to be judged, and by constructing the woman as promiscuous ("three kids by three men") and a bad mother (smoking while pregnant), she posits herself as falling within the boundaries of normative femininity. "Looking after yourself", then, emerges as far more than simply eating well, and from this perspective, IVF can be understood as a disciplinary technology, producing bodily docility through surveillance by the self and others.

Mental health is an important aspect to the construction of the self as healthy, and a key area cited as evidence of mental stability and a sense of proportion was that of the number of cycles of treatment. When IVF succeeds, the cycle that results in the baby marks the point at which "just enough" treatment has been undergone; when treatment fails, this end point is more arbitrarily and discursively determined. Therefore, while it was important for the participants to show that they tried to conceive by engaging with **enough** treatment, they also have to demonstrate that they didn't try **too hard**, thereby distancing themselves from the suggestion of immoderate desperation:

> Susan: I didn't want to be one of those women that you saw on television that are sort of in their 50s, that have had sort of like hundreds and hundreds of it [cycles of IVF]. And it does take over your life. I didn't want to be … I mean, we did get obsessive, but I didn't want to be one of these complete obsessive people that that's all they live for. And we had to have some sort of reality. You know, we had to have some sort of life. Although it did take over, that … sort of … three seemed … I don't know. Three just seemed a good control number, a good sort of, you know, that's your shot.

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In this extract, Susan is juggling between desperation as a rhetorical device for demonstrating the natural, and therefore, healthy, desire for child, and desperation as indicative of poor mental health and a lack of control. Surrogacy, adoption, the use of donor eggs or sperm, alternative therapies, counselling or high financial expenditure all emerged variously as indicative of desperation, although these markers varied enormously between participants. The unifying figure is the "desperate infertile woman" who functions here as the unhealthy Other against which their own normality and healthy engagement with treatment is defined.

Conclusion

This paper has explored briefly some of the ways in which those for whom IVF has failed construct themselves as both healthy and ill in order to establish the normality and legitimacy of their engagement with IVF, even in the absence of a baby. Both health and illness emerge here as malleable and tentative categories, whose shifting boundaries are provisionally drawn and redrawn in relation to dominant normative reproductive discourse. What these interviews show is the extent to which those whose treatment fails find themselves caught between discourses, simultaneously but provisionally located in both, but never fully in either. From a feminist perspective, the burden of discursive and justificatory work that this ambiguous location produces is highly troubling, and it highlights the ongoing and seemingly intractable association of female normality with motherhood. However, the movement within and between these categories also serves to expose the categories themselves as not inevitable, but as normative discourses which reflect social and cultural ideas about technology, gender, reproduction and the female body. Therefore, while the accounts undoubtedly strive towards conformity to social and cultural norms, the very act of doing so from a location of "outside belonging" in relation to those categories constitutes a softly stated act of resistance to them. Therefore, I would argue that if we are looking for a transformation in power relations - and as a feminist, I clearly am - then it is in these small acts of resistance in what Rosi Braidotti describes as the "spaces between the stories" (Braidotti, 1994) that the potential for (although not inevitability of) transformation lies.

Acknowledgements

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