"You get on a rollercoaster where you can't get off": Treatment decision-making and 'choice' in the context of infertility after breast cancer

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1. Introduction

Individual 'choice' is currently a pervasive and powerful concept in medical research and practice (Wilkinson and Kitzinger 2000, p. 801). In breast cancer research, in connection with responsibility for one's own health, it is often defined as avoiding certain 'risk factors' and having a healthy 'lifestyle' (Simpson 2000). While most of these 'risk factors' are actually inherently social, such as the number of children a woman has, her diet, or exposure to environmental pollution (Potts 2000), a discourse of 'lifestyle' and individual 'choice' shifts what should be social and political responsibilities onto the individual woman in a prime example of 'victim-blaming' (Wilkinson and Kitzinger 2000). And 'choice' is a popular term not only in the aetiology of breast cancer, but also in its management. The Department of Health (DOH) has in recent years published several documents concerned with increasing patient involvement and 'choice' in treatment decision-making (Department of Health, 2001, 2003, 2006).

However, the notion of treatment choice in breast cancer practice has been criticised for several reasons. Because of space limitations I will focus here on only one aspect: Following arguments made in other fields such as HIV/Aids (O'Manique 2004), I will problematise the utilisation of the neoliberal conceptualisation of 'choice' as the internal, psychological process of an autonomous individual making a rational decision

based on factual information by the Department of Health (DOH). Using a particular case from my current PhD research on young women's experiences of breast cancer I will argue that firstly, using this construction in medical practice denies the multi-factorial complexity of decision-making, especially the importance of emotional, social and material factors in the process. Secondly, the reliance on rationality and 'factual' information implies that there is one 'right choice' – the treatment recommended by the medical team, which denies alternative choices. That means that this construction, supposedly installed to increase autonomy, actually functions to decrease it.

2. In Theory – Department of Health Policies

In its most recent publication on patient choice the Department of Health (DOH) argues that 76% of people wish for more patient involvement in treatment decisions (Department of Health 2006). The DOH envisages an 'expert patient', who is a 'key decision-maker in the treatment process' (Department of Health 2001, p. 5). At the same time, somehow paradoxically, the DOH argues in a different publication that 'choice is already central to the relationship between doctors and patients' (Department of Health 2003, p.12). The previous model of patient compliance is discussed as outdated and said to therefore have been replaced by 'concordance' (shared decision-making) (ibid.). However, the next paragraph introduces Grace, one of the participants of my PhD research, whose story provides a stark contrast to the 'expert patient' (and the medical team embracing her and the idea of 'concordance') as described by the DOH.

3. In Practice: Presenting Grace

The focus of my PhD research is on women who have become infertile as a consequence of breast cancer treatment. Women either become biologically infertile

because the chemotherapy they receive destroys their follicles; or they are 'quasi-infertile', which means that biologically they could conceive, but they are advised to take the oestrogen-suppressing drug tamoxifen[i] for five years after diagnosis, during which time pregnancy is not recommended. For Grace, a 46 year-old single woman (at the time of diagnosis), it was so important to retain the possibility of becoming pregnant that she contemplated refusing to take tamoxifen.

G: And they wanted to put me on tamoxifen straight after the chemotherapy (E: Right) and I said 'no'. I was going to take six months out and caused all sorts of hoo-ha you know? (We laugh)

E: (In mock voice) As a patient deciding what to do? Never! (We laugh)

G: I know. And they were very good actually. They provided as much support as they could to help me make the decision. And ahem, and actually I was, ahem, I was working with this guy in the Psychological Medicine department using like ah, Cognitive Behavioural Therapy processes to help me make the decision (E: Yeah) and ahem, I reached it and then decided that ahem, it was important for me to have some kind of ritual about it, you know? So the beginning of it needed to be an important day, not just any day in the calendar (E: Yeah). So my birthday seemed to be the start of the new life. You know? […]

E: Right. Oh that's good. You know, that sounds like a, you know, how did it actually feel when you started doing it then? You know, started taking

G: It felt like a really (.) positive thing for me. Because (.) the thing, that the process, the decision-making process threw up was that (.) I couldn't be in a place of not taking it and living with the fear of it returning and then having to deal with the consequences of that. Having to face people. Having to deal with the grief of people, of my family, was too much. And that far outweighed, far outweighed the reasons why I didn't want to take tamoxifen (E: Yeah, yeah) which is about control, and about not being a patient, and

> about you know, having a full-stop on treatment. […] So I felt like I was being submissive, […] that I was polluting my body, and that, that part of how I lived was, you know, to eat cleanly, and respecting what my body needed.

Compliance or Concordance?

Grace describes that even her taking some time to make up her mind 'caused all sorts of hoo-ha', although this behaviour, according to the DOH, is exactly what the 21st century 'expert patient' should do, and the medical profession should welcome. The interaction between the medical team and Grace is superficially dressed as concordance, which in relation to medication is defined as 'an agreement reached after negotiation between a patient and a health care professional, that respects the wishes and beliefs of the patient in determining whether, when, and how medication is to be taken' (Department of Health 2001, p. 22); with Grace arguing that her medical team wanted to help her achieve that autonomy and was 'very good', providing 'all the support they could'. However, concordance only extended to being allowed to decide *when* to take her medication (an opportunity she willingly takes up with her ritual about starting tamoxifen on her birthday and starting a new life) not *whether* to take it at all. Grace's hesitation at taking tamoxifen (for reasons such as wanting to resist the medicalisation processes related to continuous medication, reclaiming control over her life, and a (healthy) body) is followed by a referral to Psychological Medicine. Grace describes 'the guy from Psychological Medicine' as part of her support. However, I want to offer a different reading, and argue that the act itself of sending Grace to the department of Psychological Medicine, to use 'Cognitive Behavioural Processes' to help her 'make a decision' could be seen as a pathologisation of her wish to make a decision as mental disturbance. This is reminiscent of prison staff in women's prisons who use subtle

techniques to coerce women into taking part in cognitive behavioural programmes, which Kendall argues, can be 'conceptualised as a type of governmental technology or way of regulating people's conduct that is in keeping with the current political climate' (Kendall 2002, p. 183). This is not to say that the consequences of non-compliance might not be very different in a forensic setting from a medical setting, but I would argue that 'cognitive behaviouralism' in a hospital setting fulfils similar functions in that it aims to ensure compliance with hegemonic practices; this is expressed by Grace when she says 'I felt like I was being submissive'. Incidentally, it has been argued that Foucault's concept of the 'panopticon' and the continuous surveillance of the prisoner (Foucault 1979) has been transferred to modern welfare states which govern the health and well-being of their citizens by a kind of 'scientific panopticism' (Terry 1989).

Cognitive Behavioural Therapy

CBT is a form of 'therapy' which is based on the premise that thoughts, rather than people or events, cause negative feelings (Hazlett-Stevens and Craske 2002), which means that the 'problem' as well as the 'solution' are supposedly located in the individual. Grace's CBT process seems to have induced a shift from thinking about her own positioning and a refusal of the role of patient, compliance and lack of control, to feelings of guilt and an emphasis on her responsibility for other people's feelings – 'having to deal with the grief of people'. This maps onto a very stereotypical image of 'femininity' and 'woman' as ultimate carer and nurturer, who never belongs to herself but always already to others (Leopold 1999). While Grace does not discuss the CBT processes explicitly as having induced these feelings, her choice of language implies as much. She does not take a very active speaker position, but instead defines those

feelings of guilt and responsibility as something that 'the decision process threw up' – the 'decision process' is the agent and she the passive recipient of these feelings.

CBT largely ignores the 'importance of negative environments as depressing realities rather than misinterpretations' (Hurst and Genest 1995, p. 237). In so doing, it is diametrically opposite to feminisms, which recognise the importance of social and political factors in shaping women's lives, decisions and thoughts (Wilkinson 1997; Jackson 2001). For instance, in Grace's case, the choice constructed as 'right' by the medical profession would be to comply with treatment and maximise her chance of survival according to scientific medical evidence (here, 'right' equals 'rational' and 'evidence-based'). But, this does not take into account her wishes and desires for her own (biological) child, which are bound up with societal expectations and constructions of womanhood and femininity, and her pain and anger in having to make this decision. It does not acknowledge that the 'right' choice for Grace in her particular life situation might be an entirely different one.

4. Concluding Comments

Feminists can work in both theory and practice against practices which, under the cover of objectivity and equality continue to disadvantage women. This paper is hopefully a contribution to the theoretical aspects of the struggle. I have problematised the notion of 'choice' within the NHS because this construction on the one hand does not *acknowledge* that other aspects (e.g. fears and desires) than factual knowledge also play a part in decision-making processes; but on the other hand, it *uses* those emotional aspects to convince women of the 'right' choice. Women who hesitate to accept treatment recommendations, which are often medical opinions dressed up as 'facts', are

sometimes mentally pathologised. Women should be enabled to make choices with access to all information available and in the time they need to make them (even though the issue of 'choice' in itself remains problematic). In this, they should be supported by their medical team, even if their doctors consider their decisions either personally or professionally wrong. We, as feminists, need to work towards a breast cancer theory and practice which acknowledges the complexities of each individual woman's situation, and the social, political, and material factors that shape it. Only then can we provide a feminist alternative to a paternalistic, patriarchal and heterosexist health system[ii].

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[i] In addition, the medical evidence on tamoxifen is not as clear cut as it might appear, and tied up with larger issues around the power of pharmaceutical companies. For instance, in an ironic twist, tamoxifen (the most widely prescribed drug for breast cancer) is produced by Zeneca, sponsor of breast cancer awareness month and fourth largest producer of pesticides in the US, some of which have been linked to increased breast cancer incidence Potts, L. K. (2000) 'Introduction: Why Ideologies of Breast Cancer? Why Feminist Perspectives?' pp. 1-11. In L. K. Potts (Ed.), *Ideologies of Breast Cancer: Feminist Perspectives*. Hampshire: Macmillan Press Ltd

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[ii] With this conclusion I would like to acknowledge the book chapter which inspired me to do feminist breast cancer research, "Towards a Feminist Approach to Breast Cancer" Wilkinson, S. and C. Kitzinger (1994) 'Towards a Feminist Approach to Breast Cancer'. In S. Wilkinson and C. Kitzinger (Eds.) *Women and Health*. London: Taylor & Francis

, which concludes "A feminist analysis of health and illness begins by acknowledging that we ARE victims – victims of a patriarchal world and a heterosexist health system, which, as feminists, we struggle against. It continues with campaigns and community action: to change current medical, social and political approaches to cancer, and to provide information and support for all who need it. […] That is what we mean by a feminist approach to breast cancer" (ibid.: 138). While the notion of 'victim' could be problematised, I fully agree that this should be the direction of (feminist) breast cancer research.

Short biography:

Eike Adams is a third year PhD student at the University of East London. She researches women's experiences of breast cancer-related infertility, using a Foucauldian inspired discourse analytic approach combined with feminist post-structuralism. She is supervised by Dr Pippa Dell, Dr Kenneth Gannon and Dr Mark McDermott. Amongst other things, she is also interested in qualitative methodologies and issues of women's health more generally. The research presented in this paper was funded by a PhD scholarship from the University of East London. Address for correspondence: University of East London, School of Psychology, Romford Road, London E15 4LZ. Email: e.adams@uel.ac.uk or eike.adams@gmail.com