



The ethics of responsibility and ownership in decision-making about treatment for breast cancer: Triangulation of consultation with patient and surgeon perspectives[☆]

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ARTICLE INFO

Article history:

Available online 19 March 2010

Keywords:

UK
Clinical communication
Decision-making
Ethics
Breast cancer

ABSTRACT

Doctors are widely encouraged to share decision-making with patients. However, the assumption that responsibility for decisions is an objective quantity that can be apportioned between doctors and patients is problematic. We studied treatment decisions from three perspectives simultaneously – observing consultations and exploring patients' and doctors' perspectives on these – to understand how decision-making that we observed related to participants' subjective experience of responsibility. We audio-recorded post-operative consultations in which 20 patients who had undergone initial surgery for breast cancer discussed further treatment with one of eight surgeons in a general hospital serving a socioeconomically diverse urban population in England. We separately interviewed each patient and their surgeon within seven days of consultation to explore their perspectives on decisions that had been made. Qualitative analysis distinguished procedurally different types of decision-making and explored surgeons' and patients' perspectives on each. Surgeons made most decisions for patients, and only explicitly offered choices where treatment options were clinically equivocal. Procedurally, therefore, shared decision-making was absent and surgeons might be regarded as having neglected patients' autonomy. Nevertheless, patients generally felt ownership of decisions that surgeons made for them because surgeons provided justifying reasons and because patients knew that they could refuse. Conversely, faced with choice, patients generally lacked trust in their own decisions and usually sought surgeons' guidance. Therefore, from the perspective of ethical frameworks that conceptualise patient autonomy as relational and subjective, the surgeons were protecting patient autonomy. Studying subjective as well as procedural elements of decision-making can provide a broader perspective from which to evaluate practitioners' decision-making behaviour.

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Introduction

Over half a century, expert formulations of decision-making in healthcare have portrayed a spectrum from doctor responsibility through shared decision-making to patient responsibility (Elwyn et al., 2001; Emanuel & Emanuel, 1992; Karnieli-Miller & Eisikovits, 2009; Szasz & Hollender, 1956; Thompson, 2007). Underlying this spectrum is the assumption that responsibility for decision-making

[☆] We are grateful to the surgeons, breast care nurses and patients of the Linda McCartney Centre for their enthusiastic cooperation. Preparation of the manuscript was assisted by the award of a Distinguished Fellowship to PS from the Institute of Advanced Studies at LaTrobe University, Melbourne.

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is an objective, finite quantity, such that increasing one party's responsibility reduces the other's; that is, a 'zero-sum'. The value attached to enhancing patients' influence at the expense of doctors' has drawn moral support from individualist views of patient autonomy, whereby patients' opportunity to take responsibility for decisions concerning their clinical care is regarded as a safeguard against the potential excesses of medical power (Manson & O'Neill, 2007; Tauber, 2003, 2005). Recommendations for decision-making and patient consent therefore emphasise that patients should receive information about different options, reflect on it, and deliberate in visualising and weighing up the alternatives (Beauchamp & Childress, 2001; Charles, Gafni, & Whelan, 1997, 1999; Delany, 2008; Faden & Beauchamp, 1986) and suggest that a 'good decision' is one that shows all these elements (Elwyn & Miron-Shatz, 2009).

However, recent research suggests that decision-making can be seen very differently by patients, doctors, and expert observers

(Entwistle, Skea, & O'Donnell, 2001; Entwistle et al., 2004; Saba et al., 2006). In particular, patients can sense involvement where to an observer – or the practitioner – it was absent and *vice versa*. Therefore observed shared decision-making does not reliably translate into improved patient experience (Cooper et al., 2003; Mead, Bower, & Hann, 2002).

In cancer care, research and clinical recommendations concerning decision-making have reflected the broader field of research and ethics in focusing on the allocation of influence between doctor and patient and on the need to promote patients' influence (Baile et al., 2000; Clayton et al., 2007; Department of Health, 2007; National Institute for Clinical Excellence, 2004). Evidence that few patients are told of treatment options is therefore regarded as failure of shared decision-making (Gattellari, Voigt, Butow, & Tattersall, 2002). However, patients' subjective accounts have suggested that they see decision-making in ways that do not readily correspond to a zero-sum. Women with breast or other cancers gained a sense of involvement in treatment decisions from their relationship with their doctors and in the absence of feeling that they had any choice (Henman, Butow, Brown, Boyle, & Tattersall, 2002). Similarly, women with breast cancer gained a sense of involvement from 'having the option' (feeling that they could, in theory, say 'no') even when they saw no choice (Wright, Holcombe, & Salmon, 2004).

Current theory and guidance in decision-making has been grounded in analysis by expert observers inspired by ethical principles of individual autonomy, and it is not clear what should be the implications of recognising that observer and subjective perspectives can diverge. One inference is that patients might be recognised as being involved in decisions by virtue of what they feel and their relationship with the practitioner rather than just what they say or do to participate (Entwistle & Watt, 2006; Saba et al., 2006). This divergence between procedural and subjective perspectives on involvement has parallel in philosophical debate about whether to conceptualise patient autonomy – the ethical principle that underlies concern with patient involvement – as individualistic and as expressing patients' self-determination in the face of practitioners' power, or as relational and subjective (Kukla, 2005; Manson & O'Neill, 2007; Schneider, 1998; Tauber, 2003).

Analysing the local solutions that practitioners and patients find to dilemmas in clinical practice is potentially informative about how ethical principles can be translated into practice (Eggle et al., 2006; Kleinman, 1999). Therefore, in the present study, we examine the implications of examining both subjective and observer perspectives for theoretical and ethical understanding of decision-making in breast cancer care. Our first aim was to differentiate, from an observer perspective, the ways in which treatment decision-making occurred in routine consultations and to understand, from both patients' and surgeons' perspectives, how these different solutions influenced each party's experience of decisions. Our second aim was to consider the theoretical and ethical implications of any divergence between these perspectives.

Method

The study was conducted from October 2007–May 2008 in a National Health Service (NHS) unit that provided a breast cancer service to a socioeconomically diverse urban population in England. Patients were women aged 16 years or more with primary breast cancer which had been treated by mastectomy or wide local excision (WLE). After approval by the local NHS Research Ethics Committee (ref 07/H1005/66), we studied post-operative consultations during which surgeons reported on histological analysis of the tumour and agreed further treatment based on prior review of the results during multidisciplinary team (MDT) meetings attended by various practitioners including surgeons, oncologists and

specialist breast cancer nurses (BCN). A BCN was present during the consultation and was available to patients for further discussion after the surgeon's consultation ended.

Patients were first told of the study by a BCN pre-operatively, then those attending the results clinic on study days were invited to see the researcher. Those who agreed received written and verbal information about the study and were asked for written consent. Sampling was purposive to ensure representation from the ranges of age, diagnosis, mode of presentation (screen-detected vs symptomatic), prognosis and educational background seen in the unit. Therefore we monitored recruitment regularly in respect of these variables, targeting patients as necessary to ensure a range that matched that seen in the clinic. Recruitment continued in parallel with analysis and ended when additional data did not appreciably change the analysis. Two patients declined consent, the final sample size being 20. The median age of participating patients was 60 years (range: 39–86). Every surgeon who conducted these clinics received written and verbal information about the study and was asked for written consent. All 9 surgeons who were asked to take part agreed to do so, of whom 8 were included in the study; 5 were female, 4 (including 2 females) were consultants.

The researcher was a non-participant observer in consultations with consenting patients. She audio-recorded them (using a digital audio-recorder) and took field notes. She reviewed recordings of each consultation, identifying features relevant to the emerging analysis, to inform interviews with the surgeon and patient as soon as possible within seven days. Patients were interviewed in their homes (17 patients) or at the breast unit or by telephone (one patient each), as they preferred. Surgeons were interviewed on several occasions linked to different consultations. One patient and one surgeon declined an interview.

Interviews were semi-structured and conversational, using prompts, reflection and open questions to facilitate participants' talk. Pace and sequencing of topics depended on the participant, but an interview guide ensured that patients were prompted to talk about their views of the consultation in general and, specifically: what they wanted to learn from it; what (and how) they were told about their condition and further treatments; and what this information meant for them. Similarly, surgeons were prompted to talk about their views of the consultation, what they wanted patients to learn or decide about their condition and further treatments and how they approached patients. In their first interview, each surgeon was prompted also for attitudes to discussing clinical information and management with patients.

Consultations and interviews were pseudo-anonymised and transcribed verbatim. Analysis was inductive, following a constant comparative approach led by NM who read transcripts several times to develop analytic categories both descriptively, in relation to the content of specific speech turns or exchanges, and theoretically in addressing the meaning or functions of speech locally and across the consultation or interview as a whole. Other authors (PS, BY) also read all transcripts and all authors contributed to testing and developing the analysis by periodic discussion. Initially, we developed narrative summaries combining all data sources for each case. This case-by-case analysis was supported by developing a cross-case framework. In focusing here on treatment decisions, we use consultation data to distinguish different types of decisions and we draw on surgeon and patient interviews to understand how they experienced these.

Procedural measures to ensure quality of analysis included documenting a reflexive audit trail which identified key conceptual turns and areas of tension, respondent validation by discussing the emerging analysis with later participants, attending to deviant cases, and continually testing alternative formulations of the data. We scrutinised the quality of the developing analysis according to

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