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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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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. 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.

Introduction

Over half a century, expert formulations of decision-making in health care have portrayed a spectrum from doctor responsibility through shared decision-making to patient responsibility (Elwyn, Edwards, Mowle, Wensing, Wilkinson, Kinnersley 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 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 safe-guard against the potential excesses of medical power (Manson & O'Neill, 2007; Tauber, 2003; Tauber, 2005). Recommendations for decision-making and patient consent therefore emphasize 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, Watt, Gilhooly, Bugge, Haites, & Walker, 2004; Saba, Wong, Schillinger, Fernandez, Somkin, Wilson 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, Roter, Johnson, Ford, Steinwachs, & Powe, 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, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000; Clayton, Hancock, Butow, Tattersall, Currow, Adler 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 (Eggly, Penner, Albrecht, Cline, Foster, Naughton 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 in a unit that provided a breast cancer service to a socioeconomically diverse urban population. 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 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 nine surgeons who were asked to take part agreed to do so, of whom eight were included in the study; five were female, four (including two 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 its coherence and theoretical validity, whereby conclusions should connect with theoretical ideas beyond the present study, and catalytic validity – that is, its potential to influence practice and research (Kincheloe & McLaren, 2000).

We present data from consultation dialogue, then surgeon and patient interviews. We provide the identification number of the person speaking followed by that of the corresponding party to the consultation which contained the dialogue or which prompted the interview from which the dialogue was drawn; e.g. S1/P1 signifies that Surgeon 1 is speaking in consultation with Patient 1 or in the interview associated with that consultation. ‘B’ indicates speech by the breast care nurse. The ellipsis (...) signifies omitted speech. Square brackets mark concurrent speech. ‘<>’ during dialogue marks explanatory text.

Findings

Most consultations involved several decisions. We distinguished two types of decision, according to whether surgeons provided patients with decisions that they had already made (present in every consultation) or asked patients to decide aspects of treatment (present in nine). The former included decisions where the MDT had agreed a treatment as ‘best practice’; for example radiotherapy when a WLE had been performed or chemotherapy when the benefits were significant. Decisions were generally presented to patients if best practice was unclear or the decision would not

significantly affect outcome; for example chemotherapy when its benefits were low, or participation in clinical trials (N=8).

Patients' and surgeons' perspectives showed, however, that these decisions could not simply be distinguished according to who had responsibility for them.

Decisions made for the patient

Consultation

Surgeons presented most decisions as ones that they had already made. They described these in relatively authoritarian ways as statements about what will happen ('we will give you some anti-hormone tablets'^{S7/P16}), had to happen ('in that situation you always, always have to have radiotherapy'^{S9/P14}) or was 'needed' ('you will need some anti-hormone tablets'^{S7/P13}). Surgeons presented justifying reasons alongside almost all decision statements. For example, in describing why she was referring a patient to the oncologist, a surgeon explained:

'We also say to ourselves "Well we've removed all the breast, we've removed all the lymph glands, but we want to make sure there's no other cells just sitting there waiting to try and find a home for itself", so we're going to give you, we're probably, we're certainly going to ask the radiotherapist to do radiotherapy'^{S8/P19}

Surgeons rarely took individual responsibility for the decision. They generally said 'we' rather than 'I', and referred to the multidisciplinary team in ways that made explicit its responsibility for decision-making.

Surgeons' perspective: responsibility

In their interviews, surgeons were explicit that they offered the treatment that they thought clinically most appropriate; that is, that maximised survival, and avoided unpleasant treatments with no survival benefit. S6 described his general approach:

'If there's really no choice, then you can say "Well this is what we recommend" ...For very good prognosis tumours you never give them the choice of chemo and very poor tumours you would push them quite heavily in one direction' S6/P1.

Which treatment was appropriate depended on MDT policy. For example, at the start of the study, when the MDT had no policy for patients with micrometastases in lymph nodes, surgeons presented treatment options to patients. Once the MDT decided that such patients should be considered 'node negative', no treatment was offered.

Whitney et al (Whitney, Holmes-Rovner, Brody, Schneider, McCullough, Volk et al., 2008) observed that when there is only one course of optimal treatment, it is inappropriate to present information as if choice exists. Surgeons echoed this view in describing it as unfair to present different treatments as options to patients when they had evidence that one was superior in maximising survival. Indeed, surgeons thought that presenting treatment options in such circumstances meant abnegating their professional responsibilities.

Patients' perspectives: trust and ownership

Trust in surgeons' expertise

When recounting their treatment plans, patients described questioning of surgeons as unnecessary and cited their surgeon's expertise as evidence that the recommended treatment was, by definition, the best. Indeed, being told what will

happen inspired confidence, as P18 illustrated in recounting how S3 told her his treatment plan:

‘that I didn’t have to go for more surgery, that they’d got it all away, and there was no chemotherapy. It was just as he’d said in the first place. Er three weeks of radiotherapy and tablets for five years ...and regular mammogram every 12 months ... I thought it was excellent. He went through everything ... There was nothing really that I needed to ask him really, because he was thorough, he’d gone through everything’ P18/S3.

Moreover, patients felt reassured that recommendations depended on the MDT: *‘It’s kind of like getting a second opinion because you’ve got a bunch of people who are all experts in their particular field’* P15/S4.

Kukla (2005) has argued that, in assessing ethics of healthcare practice, conceptions of autonomy are needed which avoid obliging patients to make decisions that they feel ill-equipped to make and which avoid equating self-determination with autonomy. For Kukla, it is rational for patients to defer to practitioner expertise when they judge that practitioners are better placed to decide on a treatment. We therefore drew on Kukla’s account in interpreting patients’ sense of involvement with decisions.

Ownership

Kukla’s concept of ‘conscientious autonomy’ centres on patients’ sense of ownership of, and commitment to, decisions rather than on their responsibility for making them. This concept helped to understand how patients could describe accepting the surgeons’ decision without presenting as passively complying. For example, P15 was typical in describing having no choice about her mastectomy:

‘I didn’t feel like I was making a decision ... I didn’t, you know, didn’t want to say “No” because obviously it was very important to do it. So there wasn’t a

discussion about whether to have a mastectomy. It was he was recommending a mastectomy and on his recommendation I would say yes' P15/S4.

Nevertheless only one patient presented her role as passive and disengaged. Others conveyed ownership of the decision in that they described feeling involved in it and committed to it. Two factors underlay their ownership. First, in reporting surgeons' decisions, patients consistently recounted the justifications that they had received and several were explicit about the importance of this information in helping them feel involved in the decision. For example, P12 described her difficulty in accepting that she was not being offered the radiotherapy that had previously been mentioned as a possible treatment. She sought more information, not to question the decision but to feel confident with it:

'If they don't think I need it <radiotherapy> now then great you know ... when <S8> talked to us she was saying it's not just down to her, it's down to the whole team of people and you're fed into a computer and this is sort of "The computer says" you know, so I know it's sort of, it's not random. It's just... but I would be interested to know why, but ... as I said, I trust her and and the people, the other people on the team really. I'm not interested in looking for a different opinion if you know what I mean?' P12/S8.

Patients' ownership also reflected their knowledge of their power of veto and they explained that they could refuse any treatment if they wished. As van Kleffens also found in patients who refused cancer treatment (van Kleffens, van Baarsen, & van Leeuwen, 2004), autonomy is not necessarily the freedom to choose between treatments; it is also the sense that, ultimately, patients are free to refuse or accept recommendations. This perhaps explains why no patient in our study described a surgeon's decision in coercive or authoritarian terms. Despite surgeons' use of authoritarian or paternalistic language, patients described hearing '*recommendations*' or '*suggestions*'.

Three patients deviated from the pattern of accepting and owning surgeons' decisions (Box 1). For one, ownership proved contingent on severity of threat: when, following histological examination of the tumour tissue which was removed during surgery, her disease proved less serious than previously feared, she wondered whether she should have sought less radical surgery. Two others negotiated to change the surgeon's decision. However, whereas one became concerned lest her uninformed preference had compromised care, the other felt ownership of her decision because she had expert knowledge.

Choices offered to the patient

Consultation

These occurred where surgeons set out options, but without attaching their authority to any one. The following exchange is typical of discussions about the possibility of chemotherapy:

- S6 *I guess the difference that these new findings make is whether or not we should consider chemotherapy ... you're in a group where there are some benefits but a fairly small benefit... So what we would do is, if we bring you back next week to see the oncologist*
- P1 *Mmm*
- S6 *And then she will discuss with you the pros and cons of chemotherapy and what the benefit might be ...*
- P1 *And your advice would be?*
- S6 *Well, um, my advice would be to talk to the oncologist*

This extract illustrates how patients commonly sought surgeons' guidance. There were two patients to whom a surgeon presented surgical options equivocally; both sought the surgeon's direction. The following consultation extract illustrates how, even when the patient sought the surgeon's direction, she still felt involvement and ownership. P6 was unusual in that she had undergone wide local excision (WLE) to remove ductal carcinoma in situ (DCIS) but this did not leave a clear margin. She therefore needed further surgery. S3 offered P6 mastectomy but then, at the beginning

of the extract, invites her to consider breast-conserving further WLE, which might necessitate further surgery if a clear margin was again not achieved. P6 is tearful and repeatedly seeks the surgeon's guidance (bold text).

S3 *But as I say, if if you are strongly against it and you don't feel, you know, you don't want to lose the breast, if you want to do further more surgery too then we can offer, you know ... if you want, even do some reconstruction or something, you can do if you want to.*

P6 **You tell me.**

S3 *Hmm.*

B4 *So, we've got all these options now and we are not, you know, we're not expecting you to make a decision here and now ...*

P6 *I mean, I'm not, **I would I would sooner you tell me what's best for me** <patient upset> **I would sooner you did that, don't leave it** because I don't know. I don't know.*

S3 *Now what do you feel about having your, you know, breast removed. You know some people are OK with that. As I say, they kinda ask me to remove the whole thing there and there's no chance of it coming back and I would be more than happy that way rather than me keeping the breast. Some people are not OK with this and say whatever, I want to keep my breast and you do everything in your possible hands because I want to keep my breast. So, we have two different views people have. It depends upon what you feel, you know.*

P6 *No, I, **I would prefer to do what's best_for the [health] side.***

S3 *[Hmm].*

P6 *Yeah, I would, I would.*

S3 *You're not more worried about your cosmetic*

After the patient then explains that she would be happy to use a breast prosthesis, S3 recommends mastectomy, which P6 enthusiastically accepts. When invited to deliberate, she declines (bold text).

S3 *The lesion was you know what we say four and half centimetres size. When it's five centimetres we say you know definitely you need mastectomy. Four and half is not much difference there, and in your case you're already worried about anaesthetics and things.*

P6 *I mean, I hate I [hate] it with a passion...*

S3 *[Yeah] so maybe one operation, try to do the, you know, proper thing then you'll be alright. ...*

P6 *I would go for that and then I'll take it from there ...*

S3 *Do you, do you want to take your time or discuss, er your preferation is mastectomy and if you change your mind we will do something, or what do you want?*

P6 *I, I, **I would go for ... I'm looking at it strictly...from the health point of view ...***

- B4 *Well it's not written in tablets of stone, so shall I come out in the week and go through and we can go through everything [again?]*
- P6 *[yeah] but I mean ...let's just just let's get it done as quick as possible, that's it.*

Despite the evidence of her seeking and accepting the surgeon's guidance, P6 told the interviewer that she had decided.

'You've got the information and then you can make the choices, which I did this week, made the choice that I thought was right for me ...He said all along to me "It's your choice" and <BCN> also said "It's your choice" ... The choice is mine and I could change my mind if I wish to ... I was given the information to make the decision and it was my decision'.

Conversely, S3 thought, not that the patient had chosen, but that she had had the option to disagree with his decision.

'I offered her mastectomy and what the MDT felt as well. Wide local is theoretically possible but because of this thing, mastectomy is the safer option and yeah, best operation for her. So that is what I decided, that I will be going more towards this'.

Similarly, when another surgeon invited P3 to decide between treating micrometastases in lymph nodes by surgery or radiotherapy, a decision only emerged after the surgeon asked her if she would like his help in making the decision and then recommended radiotherapy.

Surgeons' perspective: clinical responsibility vs patient choice

Surgeons explained to the interviewer that, even when offering choices, they retained control. They chose which options to offer and which not to offer. They

described offering choices where best practice was unclear. S5 illustrated their approach in explaining that:

'If the benefit is considerable ... we advise ... If the benefit is very minimal we will give the choice to the patient'^{S5/P17}.

Surgeons described two difficulties with offering choice. First, they emphasised the difficulties patients had in making choices and how they usually turned to surgeons to decide for them. Second, they felt that it was difficult to convey uncertainty in clinical management without alarming patients or undermining their confidence in surgeons' expertise.

Patients' perspective: challenge of choice

Most patients described the difficulty of exercising choice. For some, difficulty resided in the very fact of equipoise in relation to their main concern – survival. P3 described the impossibility of choosing treatment of a micrometastasis in lymph nodes when the options of surgery or radiotherapy were presented as equally beneficial:

'If the doctors said "Right ... I need to take those lymph nodes away" I'd just go "OK, fine". And it's out of my hands then...What I'm really struggling with is, although both the doctor and <BCN> have reassured me that ... whichever treatment, they're equal, one isn't better than the other ... but what if? What if, you know, what if I don't have them removed? And it does spread? ... But then I don't want to have them removed and end up with lymphoedema, erm and you you know down the line say, I wish now hadn't'^{P3/S2}.

For others, the difficulty lay in the additional burden, as P14 illustrated when given the choice to participate in a clinical trial:

'I wish I hadn't been asked, because I can't sort of make, you know, think about another decision' P14/S9.

Patients therefore described looking to practitioners for guidance: they consistently emphasised that they looked to surgeons to tell them the best option. Others described trying to infer what their practitioners 'really thought'. For example, after being invited to consider chemotherapy, P9 observed that:

'<Surgeon and BCN> didn't say you need it but they didn't say I didn't need it... So I think the ball's in my court a bit', but then went on to explain that *'I got the impression they were advising me to have chemo'* P9/S4.

Although models of shared decision-making do not exclude patients ceding authority to practitioners, some experts argue that, by turning to doctors for guidance or asking doctors to decide, patients abnegate a moral responsibility for themselves and place unfair demands on doctors (Goodyear-Smith & Buetow, 2001). However, like Kukla, Thompson (Thompson, 2007) argues that patients' delegation of decision-making to doctors does not mean rescinding agency. Indeed, the interview with P6 (above) indicated that accepting surgeons' recommendations was compatible with feeling ownership of the decision. Moreover, patients' ownership and commitment generally depended on believing that surgeons retained responsibility in relation to the patients' decisions. In particular, several patients felt safe in the belief that the only decisions that they would be allowed to influence would be ones that would not affect their chance of survival. For example, once she had rejected chemotherapy, P8 (Box 1) described her oncologist's reassurance that, if she had really needed chemotherapy, the oncologist would have persuaded her. P8 went on to describe how she would expect any decision that mattered not to be given her as a choice; she expected the clinician to guide her to the right treatment. Patients were therefore comfortable that their influence was constrained by the doctor. For example, P3 described her potential

influence on the decision to retain or remove lymph nodes as entirely contingent on the surgeon:

'Maybe I can do a deal with the doctor ... where he removes some more <lymph nodes> but not them all ... He might not agree to it, but it's worth asking' P3/S2.

Reflecting on the experience of an acquaintance who, having been offered choice of treatment, had selected WLE but subsequently needed mastectomy, one patient explicitly advocated patients not being given a choice where clinicians know the 'best' course of action. That is, she wanted doctors to take responsibility for her interests.

Discussion

Main findings

The critical feature of our method is that we examined decision-making from three perspectives: by observing consultation and hearing both surgeons' and patients' subjective accounts. From observing consultation, decision-making could be divided into two procedural forms, depending on whether surgeons explicitly took responsibility or asked patients to choose. However, how patients and surgeons experienced decisions was not a simple function of the roles that they and surgeons took in consultation.

When surgeons decided, patients knew that they retained autonomy in accepting these decisions. Therefore, although surgeons were typically authoritarian or paternalistic in communicating their decisions, patients described hearing 'recommendations' rather than instructions. Moreover, although patients generally accepted surgeons' decisions, flagrant compliance or passivity was rare. Mostly, with exceptions that we consider below, patients described these decisions with a sense of

personal ownership; that is, as ones that they felt involved in and committed to as the 'right' decision. Patients' ownership reflected their trust of surgeons and the multidisciplinary team to decide the course of action.

When surgeons offered choice, subjective and procedural perspectives diverged again. Both patients and surgeons appreciated that surgeons retained responsibility for deciding when to invite choice and in controlling the 'option set' from which patients could choose (O'Neill, 2002; Wirtz, Cribb, & Barber, 2006). Moreover, patients' ownership generally still depended, not on their own choice, but on trusting surgeons' expertise and responsibility. Patients described feeling ownership of decisions once they perceived that surgeons endorsed them, or in the belief that surgeons would not allow them to influence important decisions, or after inducing the surgeon to make a recommendation. Even when, on occasion, patients had rejected surgeons' own decisions, ownership was not a simple function of their exercising choice. A patient who successfully negotiated to have surgery earlier than the surgeon had proposed felt insecure because her own relatively uninformed influence had overturned the surgeon's authority and he did not explicitly endorse the change.

Ethics of surgeons' behaviour: respecting patient autonomy

If we consider just the procedural elements of decision-making, key ingredients of shared decision-making were absent (Charles et al., 1999). Little information was provided, patients rarely reviewed options or explicitly agreed decisions. On this analysis, surgeons fell short of ethical standards. This perspective gains moral authority from the self-determinist view of the ethical principle of autonomy, whereby patients need to be free to decide about treatments or to exercise the degree of influence they wish in order to protect their interests in the face of medical power. Although this view has been important in reversing excesses of medical paternalism, locating autonomy within the individual in this way is philosophically problematic. It is hard to reconcile, for example, with the view that

individuals' actions are themselves products of prior states and events and with recognising that individuals' decisions are embedded in social and institutional contexts (Cribb, 2005; Kleinman, 1999; O'Neill, 2002, 2003). It has been argued that the self-determinist view of patient autonomy persists because it serves institutional rather than patient interests (Salmon & Hall, 2003).

Alternative conceptualisations of autonomy provide a different perspective on the acceptability of surgeons' behaviour. From philosophical and empirical perspectives, several writers conceptualise patient autonomy or involvement as relational or subjective, such that patients can be involved by virtue of what they feel about their role and their relationship with clinicians (Appiah, 2005; Entwistle & Watt, 2006; Schneider, 1998; Stirrat & Gill, 2005; Tauber, 2003). Kukla (Kukla, 2005) proposed the concept of 'conscientious autonomy' to describe a stance of commitment and responsibility whereby patients take ownership of treatment decisions, not necessarily in choosing between options, but in being responsible for their judgements – which could include judging experts' recommendations as trustworthy – and being committed to the rightness of decisions.

From this perspective, surgeons were generally successful in respecting patients' autonomy. As reported previously, patients found no tension between doing what practitioners suggested and feeling involved (Entwistle, Williams, Skea, MacLennan, & Bhattacharya, 2006). Patients felt that decisions were theirs, even when there was no overt evidence in consultation that their role extended beyond acquiescence and when surgeons felt they had controlled or constrained decision-making. Indeed, having an expert take responsibility was important to 'en-courage' patients – i.e. to find courage in face of fear and doubt (McKneally, Martin, Ignagni, & D'Cruz, 2009).

These formulations of autonomy provide a perspective from which to evaluate also surgeons' limited information-giving. As reported previously (Henman et al., 2002; Wright et al., 2004), patients did not generally value information to help make decisions. Instead, receiving reasons to justify decisions that surgeons had made enhanced their feeling of ownership. Offering reasons to justify an action that affects

another person is a fundamental aspect of ‘politeness’ in ordinary life, whereby interactional conventions mitigate threats to autonomy (Brown & Levinson, 1987), and has been advocated as ethically desirable in maintaining autonomy when patients have no realistic alternative to practitioners’ decisions (Kukla, 2005). By deploying such information, surgeons therefore promoted patient autonomy in a context defined by expert professional responsibility.

Ethics of surgeons’ behaviour: respecting patients’ interests and values

The view of autonomy as self-determination explicitly conflates respect for patients’ autonomy with protection for their interests and values. That is, by giving patients information and opportunity to deliberate and participate, it is assumed that they are equipped to safeguard their interests and values in the face of doctors’ power. Therefore, if this view of autonomy is invalid, then these procedures cannot be relied upon to protect patients’ interests (Manson & O’Neill, 2007). It follows that practitioners retain responsibility to ensure their recommendations are in patients’ interests and they cannot delegate this responsibility to patients by offering choice. They therefore need to be equipped with knowledge of patients’ perspectives that would allow them to be effective ‘agents’ for patients’ interests (Charles et al., 1997).

In choosing treatments, surgeons were, indeed, generally guided by evidence on effects on survival, which converges with patients’ overwhelming priority in breast cancer (Duric, Butow, Sharpe, Heritier, Boyle, Beith et al., 2008; Simes & Coates, 2001). Surgeons also felt that they needed to take responsibility, which converged with patients’ concern to feel looked after (McKneally et al., 2009). There were, however, casualties of surgeons’ approach, where patients became uncomfortable or distressed, which point to possible improvements in practice. Patients for whom surgeons’ decisions did not reflect their own preferences could probably have been helped simply by surgeons providing recommendations as they did, but then asking patients whether they were happy with these and identifying and exploring signs of concern. Conversely, the distress and lack of ownership that patients felt when faced

with choice (either where it was explicitly offered or where a patient sought to change a surgeon's decision) indicate the need for surgeons' explicit endorsement of patients' choices, once made.

Our reasoning therefore leads to recommendations that, while taking practitioners' expertise and patients' trust as the starting point, explicitly distinguish two ethical responsibilities that practitioners have: to ensure that their actions are in patients' interests; and to respect patients' autonomy. In this, they converge with recent proposals for managing patients' autonomy in the context of professional responsibility for decisions about health screening (Entwistle, Carter, Trevena, Flitcroft, Irwig, McCaffery et al., 2008).

Transferability

As a qualitative study which investigated decision-making in the early stages of curative treatment for breast cancer in a single unit, the findings cannot simply be generalised. Patients varied socio-demographically and clinically, but they were all from a single region of the UK and attitudes may well differ with those in other countries. Nevertheless, their accounts overlap with those of other patients internationally (Henman et al., 2002), as do surgeons' accounts (McKneally et al., 2009). Our findings converge with other evidence that patients' autonomy lies in clinical relationships rather than isolated instances of decision-making. Nevertheless, the dependence of ownership on experts taking responsibility might depend on the severity of threat (Salmon & Young, 2009). The stark prospect of death focused both patients' and surgeons' attitudes. The one patient who lost her sense of ownership of a surgeon's decision did so only after she learned that her disease was less severe than thought when she had accepted his recommendation for radical surgery. Decision-making where the threat is less pronounced and the outcomes less stark might escape the paradox in the present findings: that surgeons offer choice where they have no evidence that it matters to survival, whereas most patients want to choose to maximise survival. Montori(Montori, Gafni, & Charles, 2006) have argued that different clinical

situations might need different approaches to decision making, and sharing decision making may work best for decisions which do not influence clinical outcomes and for patients who feel free to negotiate (Price, 2009).

Conclusion

Studying subjective as well as procedural aspects of decision-making is important for two reasons. First, concepts in current models of decision-making are inherently subjective. For instance, clinical guidelines urge practitioners to give patients the level of control that they seek (Baile et al., 2000; Clayton et al., 2007; Department of Health, 2007; National Institute for Clinical Excellence, 2004), and what patients seek is necessarily subjective as well as contextually and relationally bound. Secondly, several writers warn that clinical reality of professional-patient relationships does not necessarily fit abstract models (Edwards & Elwyn, 2006; Karnieli-Miller & Eisikovits, 2009; Wirtz et al., 2006). By considering subjective and procedural elements of decision-making simultaneously, and by drawing on ethical approaches that encompass subjectivity, we have shown that surgeons' behaviour that appears deviant from current guidelines can be seen as maintaining patient autonomy in a context defined by practitioner expertise and patient vulnerability. However, respecting patients' autonomy does not safeguard their interests, and future research will need to address whether the relatively modest changes in practice that we have suggested would allow surgeons to be better agents for patients' interests, while not compromising patients' sense of autonomy.

Box 1 Deviant cases demonstrate complexities of ownership

These patients illustrated how ownership was not a simple function of making or accepting a decision.

P16: Ownership contingent on severity of the threat

P16 tearfully told the interviewer how she accepted S10's recommendation of mastectomy when her cancer was thought relatively serious (grade 2): '*<S10> sort of said that we recommend a mastectomy, and I knew it was coming, the way he was sort of talking round it. ...I just accepted it. I never thought to say "Well what would happen if I just had a lumpectomy?"*'. After histology showed less serious cancer (grade 1), she no longer felt committed to the decision: '*Maybe my decision would've still been to have one, but I think that that's something that I've thought about since I've come back <describes friend who underwent WLE> She was happy with that and I suppose I've thought about that ... So I think I've done the right thing but it's still going to take me a while to get to grips with it.*

P8: Ownership after influencing a decision

P8 explained that she declined S1's recommended axillary node clearance in a previous consultation: '*I said "I don't want a total clearance" ...I said "So long as you leave some <lymph nodes>, I don't care"*'. P8 then explained that her confidence in her decision was based on experience of caring for women with lymphoedema: '*I know about this lymphoedemic arms ... if I hadn't I might have said "Oh yes fine. Take them all away! I don't need them."* Well I'm afraid, I did. And I wouldn't. Indeed, when later faced with a decision about chemotherapy, P8 wanted the surgeon's recommendation: '*You sort of say to them "Well, what would you do? What do you consider the best?" ...Patients always want what's best, except if you've got a real fear of something like, they wanted to take all me nodes. Because I've seen the other side, no I wouldn't*'.

P15: Lack of ownership after influencing a decision

During consultation P15 negotiated to bring the date of further surgery forward by being operated on by a different surgeon. She described fearing that delay would worsen prognosis:

- P15 I'm just concerned that erm that's a long time between diagnosis and [chemotherapy if I do]*
- S4 [It is. The sorts of] treatment that we're looking at is very likely to be chemotherapy and that would be started first OK*
- P15 Mmm*
- S4 Now we don't start chemotherapy until everything's healed and when we know we can advise you on the best chemotherapy treatment to give you, so we've got to have those results to give you the best treatment ...*
- P15 It's just that...I just have this thing echoing in my mind of this statistic I came across ...that if it's three months between diagnosis and treatment then your prognosis changes and I just sort of think because I was a bit erm, you know, the lump was clearly...it's so large and that will be three months*
- S4 Mmm*
- P15 and I'm just getting a bit concerned that [that's a long time isn't it?]*
- S4 [I will look again] and I'll go over it and I'll see if anybody else can do your operation as well*

In her interview P15 wondered whether the originally proposed timing was to ensure that results of tests were available to establish if chemotherapy would be required before her surgery: '*Because I am a lay person and I didn't know that at the time... In my sort of panic*

of bringing it forward I just wondered if I'd slightly scuppered their plan of, we'd like to know if it's elsewhere before we have the surgery I don't want to decide my own treatment. I want them to decide it because they're very knowledgeable ... I don't know anything about cancer ... I'm worried that they, err, by pandering to my need for urgency that they've slightly changed a plan to get all the information before surgery.'

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