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The ‘information spectrum’: a qualitative study of how breast cancer surgeons give information and of how their patients experience it

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The ‘information spectrum’

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Ethical approval

Liverpool NHS Ethics Committee approved this research (ref:07/H1005/66). All patients and surgeons gave informed written consent.

Abstract

Objective: Cancer clinicians are routinely criticised for communicating information poorly to patients, but expert guidance is sometimes contradictory or impractical. We wanted to understand how, and how well, breast cancer surgeons in their normal practice balanced the competing tasks of informing patients while keeping them hopeful.

Method: In a post-operative surgical outpatient clinic in a UK breast unit, we recruited 20 breast cancer patients and the nine surgeons with whom they consulted. We audiorecorded their consultations, and interviewed both patients and surgeons about these consultations, then analysed data qualitatively within and across cases taking a constant comparative approach.

Results: Every consultation contained biomedically factually explicit information, but the information that was most significant for patients was factually less explicit. Progressively less explicit forms, along a 'spectrum' of information, included: judgments about treatment implications; judgments about prognosis; evaluative comments; and clues about what information signified. Surgeons used the less explicit types of information to communicate hope. Where prognosis was poor, communication was confined to more explicit information. Surgeons' practice was closely aligned with what patients sought.

Conclusion: Common criticisms of cancer clinicians for giving 'too little' information belie the complexity of their task in simultaneously managing information needs and hope. The 'information spectrum' could help educators and clinicians to understand this task.

Introduction

Over 30 years, research has confirmed that patients with cancer want information about disease and treatment[1, 2]. Information can help them take ownership of treatment decisions, feel confident in clinicians' expertise, and make sense of what is happening[3-6]. Providing information is therefore a key clinical responsibility[7-9], and cancer clinicians are often criticised for providing insufficient or being over-optimistic[10-17]. However, in parallel with showing that patients want information, research emphasises that they and their families want to be protected from information that might destroy hope[18-22]. In one survey, 100% of patients wanted honesty from clinicians, but 91% also wanted optimism[23]. Clinicians' task in giving information is therefore more complex than criticism of them implies.

Whereas the need to reconcile information-giving with maintaining hope is widely recognised[24-26], clinicians find that practical guidance is unhelpful[27]. Guidance currently takes two broad approaches: give 'full information' or 'the information that patients want'[17]. The former is impractical, because information is effectively infinite and can be presented in different ways. The latter is problematic because patients cannot know in advance what information exists[17]. This illustrates the limitation of approaches to bioethics that emphasise application of general principles[28-30]. These principles are often based on views of human nature that are contested or culturally specific and, in regarding ethics as individuals' choices, they neglect social processes of moral life. There is therefore a tension between social science, which describes what 'is' in specific cultural contexts, and bioethics, which seeks to describe what 'ought to be'[31]. However, Kleinman argued that social scientific study should be the starting point for ethical reflection[29]. That is, exposing the values actualised in the contests and compromises of everyday life should underpin debate that might inform practice.

In the present study we examined how surgeons reconciled giving patients with breast cancer information with supporting patients' hope. Rather than rely on the researchers' evaluations of how they gave information, an approach which limits much previous research, we integrated observations of consultations with information from surgeons' and patients' perspectives. Our initial aim was to identify convergence

and divergence between information that surgeons provided and information that patients wanted. However, what surgeons and patients told us in interviews indicated that several types of information were being given simultaneously. Therefore, we refined the aim to (i) delineate the types of information that surgeons provided, and (ii) understand their functions in the tension between hope and information.

Method

Sampling and participants

Women aged 16 years or more who underwent mastectomy or wide local excision for breast cancer were recruited from a breast unit serving a socioeconomically diverse urban population. Sampling was purposive to include diversity in ages, prognoses and socioeconomic backgrounds of patients attending the unit. A breast care nurse (BCN) told patients about the study pre-operatively. Women were then recruited on attendance for post-operative consultations in which surgeons reported on histological analysis of the tumour and planned treatment based on prior review by the multidisciplinary team (MDT). When patients arrived at the clinic, a practitioner invited them to see the researcher who provided study information and sought written consent. Recruitment of patients continued in parallel with analysis, ending when further data did not change analysis (i.e. 'data saturation' was reached). Surgeons who saw patients in the study clinic received written study information and were asked for written consent.

Data collection

The researcher (a female medical undergraduate intercalating a research degree) audio-recorded consultations and then interviewed surgeons and patients separately within seven days. Before each interview she reviewed consultation recordings to identify sections relevant to information-giving in order to inform the interview questions. Patients were interviewed at home or hospital, as each preferred. Surgeons were interviewed on several occasions linked to different consultations.

Interviews were conversational, using prompts, reflection and open questions to facilitate talk. Each patient was prompted to describe what she sought from the consultation and her experience of it. The interviewer explored references to information about disease and treatment and prompted patients about information that they wanted to have or avoid. Surgeons were prompted to describe what they sought to accomplish, and what they thought they had accomplished, in each consultation. The interviewer explored any explicit mention of information-giving and prompted surgeons to describe their intentions and actions around information-giving. She also explored the implications, for information-giving, of other objectives that surgeons described (such as supporting patients' hope), and prompted surgeons to describe how they selected the information to give. In addition, surgeons were invited to describe their general attitudes to information-giving, and to discuss how specific consultations illustrated or diverged from their general approach. Mean (and range) duration of consultations, patient interviews and surgeon interviews were, respectively 19.92 minutes(9.9-41.8), 59.9 minutes(29.8-101.0), and 24.8 minutes(6.1-61.6).

Data analysis

We followed a constant comparative approach within a grounded theory framework[32], whereby we developed and refined broad analytic categories to describe the content and function of speech in the context of what was said across the consultation or interview as a whole. As well as considering what was said, we were concerned with topics that were not voiced. Observational and self-report data were nested within cases, requiring both cross-case and within-case analysis[33]. We initially focused on each of the three types of data (consultation, surgeon interviews and patient interviews) across cases, analysing each independently from the other two. Then, as cases accumulated, we progressively emphasised parallel within-case analysis. That is, we analysed the consultation and interviews for each case in turn, creating brief narrative accounts of each case linking the different types of data. To connect the two streams of analysis, we used analytic categories arising from the cross-case analysis to populate these accounts. This allowed us to 'test' and

develop those categories and thereby develop the cross-case analysis in parallel with the within-case analysis. Whereas analysis focused on commonalities across the data we also attended to heterogeneity and divergence in developing the analysis, consistent with use of 'deviant' data in qualitative research[34]. NM led analysis, discussing it frequently and in detail with PS and BY, who also read all transcripts. Analysis was inductive, in that we developed theory from the data and aimed to avoid examining data through existing concepts.

Quality of analysis was enhanced by continually testing alternative formulations[35, 36], reviewing the developing analysis according to its catalytic validity (potential to influence practice and research[37]), and by respondent validation whereby we discussed the emerging analysis with later participants. We present data from consultations and surgeon and patient interviews to illustrate categories of the final analysis. For extended quotations, we indicate the surgeon (S) and patient (P). 'R' denotes the researcher. The ellipsis (...) signifies omitted speech. Square brackets mark explanatory text.

Results

Sample characteristics

Two patients declined consent, the final sample numbering 20 (median age 60 years, range 39–86). Most (N=16) were employed in, or retired from, non-professional occupations. Four had ductal carcinoma in situ (DCIS); the others had invasive cancer at grade 1 (N=5), 2 (N=9) or 3 (N=2). Prognoses for those with invasive cancer, estimated from the Nottingham Prognostic Index[38] were 'very good' (N=2), 'good' (N=3), 'moderate' (N=6), 'poor' (N=2), or 'very poor' (N=3). All nine surgeons who were asked to take part agreed, of whom one saw no study patients. Five were female; four (including two females) were consultants. One patient and one surgeon declined interview because they were too busy; we retained the corresponding consultations and interviews for analysis.

The 'information spectrum'

Surgeons' and patients' interviews indicated that the most significant information was given and received in forms with little explicit factual content and that the information surgeons gave was generally closely aligned with what patients sought. We used the metaphor of a 'spectrum' to distinguish types of information with varying degrees of factual explicitness (Figure 1). These different types are summarised below, in order of decreasing explicitness. In addition, we describe three cases which illustrate key features of the findings: the limitations of biomedical information (Box 1); the importance of information in less factually explicit forms for communicating hope (Box 2); surgeons' avoidance of these types of information where prognosis was poor (Box 3).

Biomedical information

At the factually explicit end of the spectrum, surgeons had extensive biomedical information available in every consultation. While every patient received some, this was typically limited to number of nodes involved, whether the tumour was oestrogen positive and its grade or size. In interviews, surgeons explained that they were selective in giving information of this type, usually deciding before consultation, as S4 illustrated: *'I always make a plan...so we give the information that we discuss at the MDT but try not to give it in too much of a medical fashion...My aim was to have her remember key main points...Information needs to be relevant to their life. Otherwise it's going to go over their head.'* As S4 went on to explain, biomedical information was of limited value because *'you can't teach someone about breast cancer and pathology'*.

All surgeons explained in interview that they were cautious with biomedical information because it did not, alone, help patients feel confident about care and hopeful for the future. For example, in explaining her own caution, above, S4 emphasised the need to combine *'hope with honesty'*. Surgeons described explicitly managing information to keep patients positive and hopeful, as S2 and S3 illustrate (Boxes 1,2) and as S5 emphasised in describing the need for information to ensure treatment adherence (Box 3).

Patient interviews showed no evidence that they wanted more biomedical information than they received. Indeed, several described not wanting *'too much'*. P7 described receiving *'too much'* (Box 1) from a junior surgeon. Although this surgeon emphasised the importance of supporting patients' positivity, he gave much more biomedical information than others. P7's account of being overwhelmed belied a literal interpretation of her earlier statement that she wanted *'to know everything'* (Box 1).

Judgments about treatment

In consultations, surgeons usually linked factually biomedical information to its treatment implications, as Boxes 1-3 illustrate. Typically they made the link explicit, giving histology results followed by *'so'* (14 consultations) or *'that means'* (seven consultations). In interviews, surgeons all said that patients mainly wanted information about treatment and all described prioritising this (see Box 2), some withholding information that had no treatment implications, as S8 illustrated:

R *'One of the things that was said in the MDT meeting was that it [tumour] came up to the posterior margin. Now that was something that you didn't bring up [in consultation].'*

S8 *'No, I didn't bring that up [Explains that radiotherapy or further surgery are not clinically appropriate]. It is possible that it could be seen as a lie, an omission, you know, but I don't see any point in saying that to a patient with a pretty good prognosis tumour.'*

When we asked patients what information they wanted and remembered, they overwhelmingly emphasised treatment (see Box 3). Some were explicit about only remembering treatment implications, as P17 illustrated when asked what S5 had told her: *'I can't even remember half the things she said...I know she said about the radiotherapy, and she said [BCN] will take you through to see [oncologist] and that, but apart from everything else, I don't know.'*

Judgments about prognosis

Prognostic information was relatively non-explicit in consultations. Surgeons gave no statistical estimates of prognosis. They presented comparisons with other (unspecified) patients, such as by telling a patient that she had '*a better prognosis than most other people*', or describing treatment in ways that implied improved prognosis. For example, they referred to surgery as having '*cleared*' cancer, and described radiotherapy or chemotherapy as '*reducing the risk*' of recurrence, '*increasing the insurance of it not coming back*' or '*mopping up escaped cells*'. Prognostic information arose in consultations asymmetrically. Box 2 illustrates how surgeons highlighted evidence of relatively good prognosis. By contrast, Box 3 shows that, when prognosis was relatively poor, information was limited to factually explicit forms: i.e. biomedical information and treatment implications.

In interviews, surgeons were explicit that this asymmetry was intentional, as S5 illustrates in Box 3, explaining that, in the context of curative treatment, they would give information implying relatively poor prognosis only '*if patients ask*'.

Although a few patients told the interviewer that they wanted to know their '*chances*', none had asked for this information in consultation. Like surgeons, their approach to prognostic information was asymmetric: they wanted to avoid it when prognosis was poor:

R '*If your doctor did have a crystal ball and could tell you what was going to happen in the future, would you want to know?*

P12 '*Oh God, it's a "Yes" and "No" isn't it you know? "Yes" if it was no recurrence and "No" if it was a recurrence.*'

Evaluative comments

In most consultations, surgeons also gave information that was factually even less explicit. They routinely labelled results as '*good*' or even '*excellent*', or '*fantastic*', doing so in all but three consultations. Surgeons' positive comments extended to other aspects of patients' presentation, for example that the surgical wound was healing '*nicely*' or '*beautifully*'. Non-specific messages that the patient was '*doing well*' or was a '*good patient*' were also common, as S2 (Box 2) illustrated. As with prognostic implications, this type of information was deployed asymmetrically. Whereas Box 2 illustrates extensive use of evaluative comments in the context of

good prognosis, Box 3 shows that, where prognosis was poor, evaluations were absent, surgeons presenting results factually.

Every surgeon told the interviewer that, to protect patients' and families' morale, they wanted to give positive messages so that the consultation should '*feel good*', as S7 explained: '*You just tell them the truth but in a positive format...trying to encourage them by saying how well they've done with the operation, how well they've done with, with the treatment, how well they're coping...the patient and also the relative to make both of them feel really good walking out...even if I've told them some awful news basically. That's my aim, a good feeling.*'

Patients, too, told the interviewer the importance of surgeons being positive (Box 1). Moreover, most recounted surgeons as having been '*positive*' or '*really pleased*', and many recounted specific positive evaluations such that their cancer was '*caught early*' or the '*best one to get*'. Patients' positivity was clearly fed by surgeons' positivity (Boxes 1,2). P13 illustrated how even positive remarks about wound healing helped her keep positive generally: '*They were saying "It really is healing well", so that put me in good spirits right away, thinking...it's going well so everything will be OK...I just take my cue from them really.*'

Clues

At the least factually explicit end of the spectrum, most surgeons and patients described important information in the form of clues to patients' condition. Invisible in consultation transcripts, evidence of clues emerged in interviews. Surgeons particularly emphasised affiliative nonverbal cues. Their significance was complex, one surgeon commenting that '*If I smile or try and not meet their eyes, I know they're expecting worse news*'(S8).

Similarly, patients described reading practitioners' verbal and non-verbal behaviour for clues (see Box 1) and seeing clues in routine aspects of clinic procedure. They (correctly) interpreted being '*brought into the nice room with the nice sofas*' as foretelling bad news. They misinterpreted negatively other variations in practice, such as seeing a new doctor, where reasons were procedural rather than clinical. In general, clues were more liable to misinterpretation than more explicit

forms of information, as patients appreciated: *'Sometimes you pick up the wrong clues. 'You're listening, you're looking for things and your mind runs riot'* (P16).

Discussion

Overview of findings

Factual biomedical information was only a small part of the information that surgeons gave in post-operative consultations. By interpreting consultation dialogue in light of what surgeons and patients told us about it, we found that information was also given in much less factually explicit forms, and these were the key to surgeons' ability to reconcile informing patients with preserving hope. That is, surgeons did not manage hope just by constraining the facts they gave, but by deploying additional forms of communication. Using the metaphor of a 'spectrum of information', facts that surgeons recounted from histology reports corresponded to only a small, albeit highly visible, part of the spectrum. Much more information, in terms of quantity of speech and significance to patients, was transmitted in less factually explicit forms. Every surgeon strategically used these to communicate the hope that patients sought.

Relationship to previous literature

Surgeons' communication was much more complex than envisaged in current guidance about giving 'full information' or 'all the information that the patient wants'. Therefore surgeons' intentions and behaviour were not products of such guidance, and presumably reflected what they had learned from their clinical practice. Surgeons knew that patients most wanted to hear about treatment, consistent with evidence that this supports hope[39]. In every consultation they used histology results as the starting-point for information about treatment. In most consultations, less explicit forms of information were also present. Surgeons told patients how their condition or prognosis was better than it could have been, and provided positive evaluations of the factual information or of other aspects of the patient's condition – even where these were peripheral to prognosis, such as healing of the surgical wound. By

contrast, they provided no negative evaluations, confining information to the more factual types where prognosis was poor. Patients all emphasised the importance of surgeons' positivity, none asking surgeons for details of prognosis, even when they told the interviewer they wanted to be – or had been – 'told everything'. The findings reinforce evidence that managing hope is a priority for both patients and clinicians across cancer care[19-23, 40], and that constraining and framing biomedical information is central in this[41, 42]. They add to this evidence by delineating the different forms of information that surgeons deploy to reconcile sustaining hope with information-giving.

By linking our observation of consultations with interviews about what surgeons intended and what patients sought and heard, we found that surgeons' strategy was closely aligned with what patients said they wanted. The extent of alignment is hard to reconcile with criticisms that cancer clinicians give too little information[10, 11, 14, 15, 43]. However, that criticism is based on research that examines the part of the 'information spectrum' that is most visible in consultations – factually explicit biomedical information. By obtaining patients' and clinicians' perspectives, we found that much more influential information is given and heard in less explicit ways. Whereas clinicians are criticised for constraining bad news to protect themselves[43], they necessarily select what to tell patients from the copious biomedical information usually available. Surgeons in this study primarily selected information relevant to treatment, and patients relied on them to do so. Indeed, where a junior surgeon gave unusually detailed biomedical information the patient felt overwhelmed.

As well as being aligned with what patients sought, surgeons were aligned with current theoretical formulations of clinical relationships, particularly in cancer care, which emphasise relationships' asymmetry and patients' or families' vulnerability[44]. Surgeons were aligned also with recent conceptualisations of clinical relationships in life-threatening illness as having properties of attachment relationships[45, 46], whereby clinicians need to manage or constrain information to support patients' need to 'disavow' aspects of their predicament[18, 20, 47].

Strengths and limitations

Self-report in interviews, particularly by practitioners, can be biased by cultural norms around self-presentation[48]. Conversely, observations of dialogue can be misleading about how communication is experienced[49]. Crucially, however, our findings arise from synthesis of participant interviews with observations of consultations, thereby minimising the risk that they reflect limitations of either approach used alone. As qualitative work, our findings cannot be generalised. Patients were being treated curatively, and almost all had relatively good prognosis. Most were middle-aged adults. Management of hope may differ in important respects in a palliative context or with poorer-prognosis cancers[50] or where patients are children or young adults or elderly. As a qualitative study, we were unable to examine heterogeneity according to patients' socioeconomic characteristics. However, because they arise from detailed study of real-life compromises that actualise surgeons' and patients' values, our findings are potentially transferable in the context of broader debate about how practitioners can act ethically in situations that defy the simplicity of current ethical principles[28-30].

Implications for practice, education and research

Surgeons' behaviour contrasts strikingly with current advocacy of the importance of giving detailed information. That view has been predicated on empirical evidence and ethical theory. Empirically, patients overwhelmingly endorse survey questions indicating that they want to be 'told everything'[51]. However, qualitative evidence in the present and previous studies warns that such endorsement can mislead if taken literally[26]. Ethically, autonomy is often equated with self-determination and, therefore, patients' need for informed decision-making. Self-determination is not, however, the only conceptualisation of autonomy, particularly where, as in cancer care, choice of treatment options is often very limited[52]. Relational approaches locate patients' autonomy, instead, in their ability to trust clinicians[53-55].

Empirical observations such as ours cannot, however, simply be translated into new normative recommendations – local cultures of healthcare behaviour can actualise values that would be widely deplored. Instead, Kleinman located ethics in processes: the empirical process of working with multiple perspectives in

understanding moral behaviour in specific instances; and the dialectic amongst stakeholders that empirical work can inform[29]. Ultimately, ethical communication depends, not on codification of abstract principles, but on practitioners' judgments in moments of communication in routine practice[28]. We therefore offer the solutions that surgeons found in the present study as a contribution to debate which will need to be informed by additional data from multiple perspectives in other settings. The ethical quality of clinicians' judgments will then lie in their use of elements of this debate to inform and reflect on their moment-to-moment practice. The implication for educators is therefore that the solutions that the surgeons and patients in the present study found in practice are a potential educational resource. For example, many cancer clinicians find it difficult to combine hope with honesty[56] and the junior surgeon in this study focused more on factual information than one patient wanted. The concept of an 'information spectrum' could help communication educators by providing a framework to help clinicians reconcile hope with honesty.

The implication for research is that what is communicated in clinical consultations cannot be examined just by observing consultations[33, 49]. Detailed understanding of clinicians' and patients' perspectives is essential for a full account of what information has been given and of how it addresses patients' informational and emotional needs. Moreover, researchers and educators have much to learn by studying what experienced clinicians actually do, and how it aligns with what they intend to do and with what patients need and experience.

Figure 1. The 'spectrum of information'

Types of information	Information content	Example
<i>Biomedical information</i>	Factual information from the histology report	' <i>This is ER positive</i> ' (S, Consultation)
<i>Judgments about treatment</i>	Surgeons' judgments of the treatment implications that follow from the results	' <i>That also gives us some kind of idea of what further treatments we might use, hormonal tablets</i> ' (S, Consultation)
<i>Judgments about prognosis</i>	Surgeons' judgments of prognostic implications of the results.	' <i>ER positive is better than ER negative.</i> ' (S, Consultation)
<i>Evaluative comments</i>	How 'good' the results are for the patient	' <i>This is ER positive which is also good</i> ' (S, Consultation)
<i>Clues</i>	Features of the interaction which, although not having primarily a communicative function, are perceived to indicate how the surgeon views the patient's condition	' <i>He seemed pleased ... he looked pleased and he was smiling...I think he genuinely looked pleased to give me the information</i> ' (P, Interview)

Descending the list of types of information, factual specificity declines. Examples of each type are taken from the consultation of S1, a consultant, with P2, who was in her 60s and had undergone mastectomy and sentinel node biopsy following symptomatic presentation of recurrence. Three of nine lymph nodes removed were positive, and prognosis was relatively poor. Extracts are from part of the consultation where S1 discussed endocrine receptor status. In his interview, S1 explained that he wanted '*to tell the truth kindly*'.

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