EDITOR'S CHOICE

Are patients receiving enough information about healthcare rationing? A qualitative study

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ABSTRACT

Background There is broad international agreement from clinicians and academics that healthcare rationing should be undertaken as explicitly as possible, and the BMA have publicly supported the call for more accountable priority setting for some time. However, studies in the UK and elsewhere suggest that clinicians experience a number of barriers to rationing openly, and the information needs of patients at the point of provision are largely unknown.

Methodology In-depth interviews were undertaken with NHS professionals working at the community level of provision, and with patients and professionals receiving or providing treatment for morbid obesity and breast cancer (n=52).

Results Nearly all patients wanted to know about healthcare rationing and had high expectations of their clinical professionals to provide all relevant information about treatment options. However, professionals did not always understand these information requirements, and cases of implicit rationing were common. The existence of relevant national guidance was not always known about, meaning that patients were often reliant on other sources of information about treatment options, which included the popular media, the internet, patient advocacy groups and informal networks of support.

Discussion Clinical professionals need to understand patients' need for detailed information when it comes to rationing, and to understand that they are the main gateway for this to be provided. However, disclosure could be distressing for both patients and professionals, and thus the most sensitive and acceptable ways to make this information available requires further investigation.

BACKGROUND

Rationing is ubiquitous in healthcare systems around the world.[1–3] However, it is agreed that there is currently no 'gold standard' for managing priority setting in healthcare,[4] and it has been characterised as one of the most important policy issues to be addressed in the 21st century.[5] There is broad agreement from clinicians and academics alike that healthcare rationing should be undertaken as accountably and explicitly as possible,[6 7 8] and policymakers around the world have responded to this by introducing policies to set priorities more explicitly.[9] The UK has taken a leading role in this area, most obviously through the establishment of the National Institute for Health and Clinical Excellence (NICE). Moves to make decision-making as open as possible were also endorsed within the recent 'NHS Constitution,' which has been billed as a handbook for patients and healthcare professionals to detail their rights and responsibilities when it comes to NHS provision.[10]

NICE has been lauded as an international leader when it comes to more accountable priority setting in healthcare,[11 12] and its methodology and organisational structure are being closely observed by policymakers around the world.[13] However, NICE guidance only covers the treatment of particular health conditions, and its mandatory guidance generally only relates to the assessment of selected new healthcare technologies. Other potential sources of information about rationing for patients are the popular media, patient support groups, family and friends, and the clinical professionals involved in their care. Professional bodies representing clinicians have supported more explicit healthcare rationing for some time, and have repeatedly called for Ministers to set priorities more openly to relieve some of the responsibility on clinicians to allocate scarce NHS resources.[1 14] Despite this commitment to openness as a professional body, empirical research shows that rationing openly on the 'front line' of healthcare provision can be very difficult, and doctors are concerned about the distress such disclosures may cause, and their implications for sustaining ongoing relationships with patients.[15–18]

Research over the past 30–40 years has shown consistently that patients require a great deal of information when it comes to their healthcare,[19 20] and most want to be involved in clinical decision-making.[21–23] Indeed, research shows that patients' requirements for information consistently outstrip the expectations of clinicians.[24 25] There have been three studies that have researched the views of the public when it comes to knowing about rationing,[26–28] but, prior to this study, none relating to the views of patients.[29] The three studies with citizens consistently showed that the majority of the public wanted to know as much information as possible about how healthcare priorities are set, and would want to know if financial factors were affecting their own access to treatments. However, the one qualitative study with citizens showed that informants struggled to know how much information they would want if they were actually in the role of patients themselves.[26]

This research set out to understand patients' experiences of implicit and explicit rationing, whether they wanted to know when financial factors affected their access to healthcare, and whether they received enough information from the sources available to them.

RESEARCH DESIGN AND METHODOLOGY

The study took a qualitative approach, and commenced with an exploratory study with

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professionals working at the community level, which was used to select two clinical case studies (morbid obesity and breast cancer) to structure the remainder of the fieldwork. Sampling commenced using a snowballing approach and became more purposeful as the research was ongoing to ensure that representatives from a number of different professional groups working in the clinical areas selected had an opportunity to participate. Clinical professionals facilitated access to patients and worked with the researcher to ensure that patients with a range of views and experiences were recruited to the research, including those who had experienced implicit and explicit decision-making, and those who had accepted rationing decisions, contested them or paid for private care. Patients were recruited either by letter or in outpatient clinics. Approval from NHS ethics committees was obtained prior to any fieldwork being carried out.

Data were collected through in-depth individual interviews with 31 patients and 21 professionals. Interviews were focused by the use of a brief topic guide, although this was applied flexibly so that informants could raise issues that were important to them and provide their own narratives of providing or receiving care. Data collection and analysis were carried out iteratively to ensure that arising themes of interest could be followed up, and the techniques of constant comparison were used to elicit emerging themes, which were then examined by repeatedly revisiting data to build up conceptual links and test emerging hypotheses.[30] A more detailed reporting of recruitment processes, and a full description of the data collection and analysis techniques used, can be found elsewhere.[31]

All informants were asked about their general views of the appropriateness of rationing explicitly, and patients were asked to relate their personal experiences of accessing healthcare. In addition, professionals were asked about particular points on the care pathway where financial factors typically impacted on decision-making, and the extent to which this information was made available to patients. Data reported below relate to those parts of interviews where patients were reflecting on whether they wanted to be told about the impact of financial factors on their care and whether they were able to obtain sufficient information, and where professionals were reflecting on the extent of disclosure routinely employed during consultations.

RESULTS

Twenty-one professionals and 31 patients were recruited to the research, including 13 patients with morbid obesity and 18 with breast cancer. Not all patients were aware their care had been subject to financial limitations, although 15 knew they had had particular treatments withheld for financial reasons, and a further six were aware that cost had impacted on their care through waiting times or receiving a reduced quality of care. However, all were able to reflect on what information they needed about how healthcare rationing affected their access to treatments, and commented on whether they had received sufficient information.

Information needed by patients

Nearly all patients said they wanted to know how financial factors affected their access to healthcare, and this was normally because they wanted to be granted the autonomy to decide whether to contest decision-making or to access care in the private sector.

> It was my decision that I didn't want to write letters to my MP and letters to the local paper to say how disgusting it is they won't pay for it … but I would have needed to have known it existed to be able to do that. … Information is power really. (Pa3)

However, nearly all also acknowledged that it would be very distressing to know about rationing if you were unable to access care through another route, and one patient in this situation regretted having been told. Half of informants felt that explicitness was not the right approach for all patients, and four identified situations where they would not want to know (such as if the treatment was likely to be life-saving, or they were unable to afford treatment in the private sector).

> Knowing what it's like when you're at that point, to be told there is this treatment and be told that we won't get funding for it … I think that would probably have made me suicidal. (Pa9)

> If it's 20 or 30 thousand a year, no one could keep that up for very long … and I think myself I'd rather not know that. (Pa20)

Patients also needed to know that healthcare professionals—and particularly their clinicians—were being honest with them and providing them with all the necessary information to be involved in decision-making about their treatment.

> I: Do you think there's ever a case when a doctor should be holding back information that they could give to a patient?

> Pa7: No, because I don't think they should play God really should they?

For some, this included being told whether care was available in the private sector, or how to contest decision-making.

> It should be [said] … 'there's this option, it's not available on the NHS, but … you can get it through this, or paying 5 pound a week' or whatever. (Pa1)

Important sources of information about rationing

Informants talked about a number of sources of information that were open to them, and from which they had—or would expect to have had—received information about how financial factors affected their access to healthcare.

Healthcare professionals

Patients had high expectations of professionals (particularly their clinicians) to act as their advocates in terms of both informing them about potentially useful treatments, and helping them to gain access to them where possible.

> I think GPs should be giving them the option, because that's where most people go for their information—medical information—is their GP. (Pa1)

> As a patient, because we have the illness, I think we should be afforded the respect to be told everything. (Pa25)

However, interviews with clinical professionals showed that they were not always aware of patients' need for detailed information when it came to rationing, and relied on a number of cues when deciding how much information to disclose, such as waiting for patients to ask particular questions, or for them to reveal that they had been carrying out their own research.

> I won't do it [disclose rationing] every time … but where it seems that there's something about the patient that requires it—questions they're asking or concerns that they're raising—that means it's a good conversation to have, then I'll have it. (GP)

Patients were dissatisfied when they suspected, or knew, that clinical professionals had not provided them with full information, and disliked the notion that professionals used discriminatory patterns of disclosure.

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> I'm sure there are thousands and thousands of people who slip through the net because they don't know what questions to ask. (Pa28)

However, it is notable that most were forgiving of professionals when they uncovered instances of implicit rationing, and the desire to maintain good relationships with clinicians (and their ongoing need to view them as their advocates) usually led patients to excuse omissions in information giving.

> About the time I was having my chemo, [prominent Herceptin campaigner's] case kept on coming on … and I didn't really know what drug it was. I rather naively thought 'well maybe they would have said something,' and then as time went on I thought 'well I think I'm going to ask them'. … I was a little bit surprised they hadn't said anything before, but I think I can understand that they were in a bit of a difficult position. (Pa26)

There were two notable exceptions to this. One patient experienced a breakdown in the relationship with her clinician when she was not told about rationing despite feeling she had made it clear that she would want such information, and another lost confidence in her clinician when he tried to control how she reacted to rationing by discouraging her from contesting the decision.

> He [oncologist] saw me break down in tears when I was told that [hair loss] was going to happen, and he still didn't tell me about it [scalp cooling]. … I've obviously lost trust with him now … he may have had very good reasons for keeping it from me, but I can't think what they would be. (Pa22)

Clinical professionals were also the main source of information for patients when they wanted to assess other means to access care, and in some cases were co-opted into contesting the decision by professionals (although in others they were not told that formal contest routes were available).

National guidance

Of less importance to patients was the use of national guidance on what treatments should be available to them, such as NICE guidance or the National Service Frameworks. It was notable that NICE guidance was not available for all the treatments where informants had experienced rationing, but it was relevant to all of those with morbid obesity, who were clearly all eligible to be offered both weight-reduction drugs and surgery under current NICE guidelines.[32–34]

It was notable that many patients had not heard of NICE, and where they had, the role and status of guidance were often misunderstood. Those that did have a clear understanding of the role of NICE were usually those who were NHS employees themselves.

> We've all heard about NICE and how they regulate drugs and how they do trials and what have you. (Pa24)

> Even NICE have reported on [gastric] banding and said that it's a worthwhile procedure—as far as I'm concerned that should be it. (Pa5, also NHS consultant)

Of those who did know about the existence of NICE guidance relevant to their care, some patients sought it out prior to approaching their clinicians about treatments, particularly if they thought they were likely to encounter rationing, and others consulted it later after being informed that treatments were not available. Either way, NICE guidance was not useful to patients, since, even when they were clearly eligible for care, they were unable to use it to gain access to treatments that had been withheld.

> I said to him [GP] 'look I fit the criteria here—I'm entitled to NHS treatment'. And he said 'fair do's, but I don't know where you'll get it … and just the politics of getting the funding means it'll take years.' (Pa9)

Professionals did not always direct patients towards relevant NICE guidance where it was available, and interviews with clinical professionals showed they often did not see it as an important or relevant factor in deciding who should get access to treatments.

> Where GPs agree with NICE guidance, we've taken it on board very strongly. … Where we perceive that NICE has come up with politically correct statements, I think we are pretty sceptical and probably ignore it. (GP)

Other sources of information

Information presented in the popular media was important to many informants for finding out about treatments that were relevant to their healthcare condition, and was a common method for patients to find out about previously implicit rationing. Some patients (particularly those with morbid obesity) seemed prepared to accept that it was part of their role to find out about new ideas for treatment and present them to their clinicians, but others were distressed by the 'hit and miss' nature of communication when it came to something as important as their healthcare.

> If I had not seen Barbara Clark on the television, I would not have known anything about it [Herceptin]. (Pa29)

Many patients carried out research about treatment options available on the internet. Some used this information simply to open discussions with clinicians, and others used it in a more targeted way, sometimes to check information previously provided by professionals, to consult NICE guidance where they knew it existed, or to research the routes available for them to contest decisions or access private care.

> I built a folder up with all the things that we've looked into and everything like that. I went down [to GP] armed with it—my ammunition. (Pa6)

Patient support groups were important to many informants, particularly in the breast cancer group, and were sometimes a means by which they found out information about rationing. This information was viewed as very helpful by patients, and support groups sometimes became important allies in helping them contest rationing decisions.

> They [patient support group] sent me obviously what's on their website … it explains what Herceptin does, how it's administered … and they put this in about postcode prescribing, and I thought 'that's not relevant to me'. Well they obviously knew more than I did, because it was very relevant to me. (Pa29)

Informal networks of support were also an important source of information to some. This particularly applied in the breast cancer group where support networks were often established between patients attending clinics for radiotherapy or chemotherapy.

> [Fellow patient] said to me 'have you been offered a [Herceptin] trial?' And I thought 'oh God no, they haven't offered it to me' … and I felt really quite put out. (Pa24)

More broadly, informants' family and friends were often important in helping them both to research available treatments, and in providing financial and emotional support if they decided to contest decision-making or access care in the private sector.

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DISCUSSION

Nearly all informants wanted to know how financial factors affected their access to healthcare, although all recognised the emotional distress that might result from rationing explicitly, and some felt it would not be the right approach in all situations. The key source of information about rationing was clinical professionals, and many felt that the provision of all available information was an essential element of clinical advocacy. However, information needs were not always understood by professionals, and cases of implicit rationing were common.[18] Most patients were understanding of the competing demands on professionals, and were usually forgiving when cases of implicit rationing became apparent. National guidance detailing entitlements to care was of surprisingly little use to patients; many had not heard of such guidance where it existed, and those who had were unable to use it to access appropriate care. Other sources of information about rationing included the popular media, patient advocacy groups, other resources available on the internet, and informal networks of support.

This study constituted the first empirical research of patients' views about knowing about rationing, and enhances our understanding of the experience of accessing NHS treatment. The use of qualitative techniques meant the research could adopt a flexible approach and allowed informants to reflect on issues that were important to them, which generated a number of insights including the broad range of information sources patients use to find out about treatment options. The structuring of the research around two clinical case studies made the research programme manageable and enabled some consistency by which to compare individual accounts. However, this also meant that the sample was heavily weighted towards middle-aged females (see table 1), and it is unknown whether other patient groups share the views and experiences reported. Additionally, the research was carried out solely through in-depth interviews, which means that conclusions are reliant on the accounts of individual patients and professionals, and no direct observation of consultations was undertaken.

Clinical professionals need to be aware that most patients want to know about rationing decisions, and to realise that they are the main gateway for the transmission of this information. Despite the fears expressed by clinicians in previous research[15–17] explicit rationing did not habitually damage relationships with patients, although these were threatened if clinicians did not respond honestly to direct questioning about treatment options, or tried to control patients' reactions to rationing (eg, through discouraging protests against decision-making). This implies that clinicians need to be sensitive to patients who want to take on a consumer role within the doctor–patient relationship and not resort to a paternalistic model when they feel vulnerable due to factors outside their individual control. Additionally, professionals need to be aware that patients use a number of different information sources to research the availability of particular treatments, notably including the popular media and a variety of internet sites. This is of concern, since the use of the internet to research health conditions is increasing steeply, yet information may be incomplete, inaccurate or subject to the influence of vested interests.[35] Furthermore, reliance on electronic media to distribute information may result in social inequalities in access to information,[36] and therefore potentially exacerbate inequalities in access to health and healthcare.

Table 1 Demographic characteristics of patient informants

Age (years)	
20–39	7
40–59	17
60–79	7
Gender	
Male	2
Female	29
Occupational group	
Non-manual employment	13
Manual employment	1
Home-worker/carer	9
Retired	6
Unemployed and claiming benefits	2

Both clinical professionals and policymakers need to be aware that many patients in this study had not heard of NICE guidance, and of those who had, many lacked a clear understanding of its role and purpose. Even those who knew they were entitled to care according to NICE guidance were unable to use this information to advance their case for treatment. Clinicians need to be prepared to discuss the existence of national guidance and its potential utility with patients to ensure an equitable approach to information provision, and this needs to be supported by an effort by policymakers to make information about NICE guidance more accessible and useful to patients when they need to assert their right to access care. This finding also has implications for the usefulness of the NHS Constitution,[10] where, given the relatively small amount of publicity awarded to its launch compared with the ongoing media attention paid to NICE guidance, policymakers are likely to encounter even greater difficulties in promoting patient knowledge and understanding.

However, there are clearly concerns raised by the prospect of making information about rationing decisions more widely available, and the impact of this on the ongoing viability of the NHS needs to be considered. In this research, the most common reason for wanting to know about rationing was to assess whether the decision could be contested or care could be accessed in the private sector, and the implications of increasing access to such information for the ongoing political and financial sustainability of the NHS clearly warrants consideration. Additionally, this research showed that knowing about healthcare rationing could be very distressing if patients had no other means to access healthcare, and explicitness may not be the right approach in all clinical contexts. This implies that professionals need to consider how to reliably elicit preferences for information, and how to make information available in a sensitive manner.

Future research in this area should focus on the experience of rationing for different patient groups and in different clinical contexts, particularly with a view to uncovering whether there are particular situations where it is better for rationing to be carried out implicitly. Observation of clinical consultations where rationing issues are discussed would be a useful means to consider how rationing issues are currently raised and explained, and to consider the effectiveness and acceptability of ongoing means of communication in this area. Other areas for future research include investigating the acceptability of more open healthcare rationing to clinical professionals, and considering the impacts of explicit rationing on doctor–patient relationships over longer periods of time. Additionally, research exploring how national guidelines on entitlements to care can be more successfully communicated to patients would be of benefit.

In conclusion, this research found that patients require detailed information on how financial factors affect their access to healthcare but often do not receive sufficient information

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from professionals, meaning they are frequently reliant on other sources of information. Both clinicians and policymakers need to consider how they can most sensitively fulfil the information needs of patients across the social spectrum, and the academic community should contribute to this through ongoing rigorous research into how these needs might vary by context, and what the most effective and acceptable ways are to make this information available.

Contributors The original idea for the research was conceived by JC and JD. AOS planned and undertook the fieldwork, under the supervision of JC and JD, and all authors contributed to the analysis and interpretation of the data. AOS had the idea for the article and wrote the first draught, which was then reviewed and amended by JC and JD. All authors have reviewed and approved the submitted manuscript. AOS acts as the guarantor for this article.

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Competing interests None.

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