

Ethical principles and the rationing of health care: a qualitative study in general practice

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ABSTRACT

Background

Researching sensitive topics, such as the rationing of treatments and denial of care, raises a number of ethical and methodological problems.

Aim

To describe the methods and findings from a number of focus group discussions that examined how GPs apply ethical principles when allocating scarce resources.

Design of study

A small-scale qualitative study involving purposive sampling, semi-structured interviews and focus groups.

Setting

Twenty-four GPs from two contrasting areas of London: one relatively affluent and one relatively deprived.

Method

Initial interviews asked GPs to identify key resource allocation issues. The interviews were transcribed and themes were identified. A number of case studies, each illustrative of an ethical issue related to rationing, were written up in the form of vignettes. In focus group discussions, GPs were given a number of these vignettes to debate.

Results

With respect to the ethical basis for decision making, the findings from this part of the study emphasised the role of social and psychological factors, the influence of the quality of the relationship between GPs and patients and confusion among GPs about their role in decision making.

Conclusion

The use of vignettes developed from prior interviews with GPs creates a non-threatening environment to discuss sensitive or controversial issues. The acceptance by GPs of general moral principles does not entail clarity of coherence of the application of these principles in practice.

Keywords

decision making; ethics; focus groups; healthcare rationing.

INTRODUCTION

The rationing of scarce healthcare resources is a subject that is both politically sensitive and raises a number of ethical dilemmas for those charged with making treatment decisions. This paper reports findings from a study of decision making in primary care. The study aimed to describe the way in which the allocation of scarce resources is perceived and addressed implicitly and explicitly by GPs in consultations with patients.¹

Our starting point was the view that if patients are to participate in decision making then explicitness (in the sense that decisions, and the reasons for decisions, are clearly communicated) is a necessary prerequisite for involvement.²⁻⁵ By this it is meant that GPs have to be clear, both to themselves and their patients, about the criteria they use when engaging with a patient in decision making. For example, if a decision is made not to give a particular treatment on the basis of cost, this would be explained to the patient.

In its summary of the conclusions and recommendations of a House of Commons report on priority setting with the NHS,⁶ the Health Committee maintained:

'We ... need an honest and realistic set of explicit, well understood ethical principles at national level to guide the NHS into the next century'.

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However, the committee then went on to claim:

*'There is no such thing as a correct set of priorities, or even a correct way of setting priorities.'*¹⁶

In this study, we set out to examine how GPs set priorities at the level of the individual consultation and the ethical principles they felt they used in this task. The study involved interviews and focus group discussions with GPs to identify and clarify ethical issues involved in decision making about the allocation of scarce resources. We describe the methods used to generate vignettes for use in focus groups. Additionally, we report the findings from two focus group discussions relating to prescribing and referrals.

METHOD

We recruited GPs working within the catchment area for two health authorities in Greater London. Our aim was to examine the rationing experiences of GPs working in a relatively affluent and a relatively deprived area. Starting with a list of every GP practice in the health authority area, the sample was stratified according to a number of selection criteria: ward-based data on deprivation, practice list size and the numbers of whole-time equivalents (to reflect workload) and sex. Practices were assigned to the categories 'high' or 'low' deprivation and 'high' or 'low' workload on the basis of being in the highest or lowest quartile for the whole health authority area. We then randomly sampled from each category. One of the project researchers contacted each GP to arrange an interview and in total, 24 GPs agreed to participate. All interviews took place in GP surgeries. Equal numbers of male and female GPs took part. The age range of the GPs was 31–63 years (mean age = 44 years) and time spent working as a GP was 3–41 years (mean = 14 years). The majority of GPs worked in group practices, with only two working single-handed.

GP interviews

The interview covered a range of topics including: key resource allocation issues in day-to-day practice; definitions of 'scarce' resources; views on involving patients in the decision-making process; explaining rationing decisions to patients; practice policies on patient participation; and the influence of the structure of primary care on resource allocation decisions.

In addition to discussing these topics, we asked GPs to provide a specific example of a recent consultation where a rationing dilemma came to the fore. From the interview data, we selected accounts

How this fits in

Explicit ethical principles are necessary to guide NHS priority setting. While GPs are aware of the need for an ethical basis to healthcare rationing, the realities of the external constraints they have to work under means that this ethical basis is moderated by the daily necessities inherent in running a surgery.

of four consultations to be rewritten in vignette form for use in focus group discussions. Vignettes are, 'detailed hypothetical cases or scenarios in which responders are invited to choose the correct interpretation or the likeliest course of action.'^{17,8} In this paper we present data from the focus group discussions concerning two vignettes.

GP focus groups

Prior to the focus groups, GPs were sent a pack containing some background literature on the project and the vignettes for them to consider. The verbatim quotes on which the vignettes were based were not included. This was to avoid the possibility that the GPs quoted might recognise themselves and/or their patient and, thus, introduce a potential bias into the discussion. The vignettes were suitably anonymised to address both this and the issue of patient confidentiality. Out of the 24 GPs who gave an interview, 17 attended the focus groups.

At the beginning of the focus groups, there was a brief introduction to issues of equity in the allocation of scarce healthcare resources. The focus of this discussion was the idea of fairness presupposed by NHS policy — equal access to health care based on equal need, free at the point of delivery — and what this might mean in practice. From the initial interviews with GPs, it was clear that no-one questioned this basic moral premise, whatever their concerns about what it meant to apply it. The GPs were then split into two groups and given a vignette to discuss. For each discussion, we aimed to have a roughly equal mix of GPs from the two areas from which we had sampled. This created a forum wherein the GPs were able to explore, accept or reject different reasoning suggested to them by peers, working in widely differing settings, with routine experience of different rationing issues. The discussions lasted approximately 45 minutes. Each discussion was facilitated by a member of the research team with other members acting as observers. After a 15-minute break, we gave the groups a second vignette, which they then spent another 45 minutes debating. At the end of the second discussion, a plenary was held to feed back the main points from

individual group discussions and to have an open discussion on the day's proceedings.

Despite the well-documented problems of recruiting participants, particularly from a profession where time is recognised as a scarce commodity,^{9,10} focus groups remain a popular method with those researching both general practice¹¹⁻¹⁵ and other aspects of primary care.¹⁶ The use of vignettes has proved useful in research on sensitive topics with participants who are difficult to access,¹⁷ and, more recently, have been adapted to make use of video technology.¹⁸

Analysis

The interviews and focus groups were transcribed, coded and the data analysed using the constant comparative method to generate themes. NUDIST NVivo qualitative data analysis software was used. Coding frames were discussed by the core team. Preliminary data analyses were further discussed with the project steering group. Our methods were guided by quality criteria for ensuring rigour in qualitative research.¹⁹

For the main body of the research, we framed our analysis using Doyal's work on ethical decision making.⁴ Doyal's work corresponded with common

perceptions among GPs of the moral foundation of the NHS, irrespective of disagreements about the practice of, or attitudes accompanying, such allocation. These perceptions are captured by the phrase:

*'Equal access to health care on the basis of equal need, free at the point of delivery.'*²⁰

Doyal argues that the substantive principles for ethical decision making within the NHS are:

- health care needs should be met in proportion to their distribution within the population;
- within areas of treatment, resources should be prioritised on the basis of extremity of need;
- those in morally similar need should have an equal chance of access to health care;
- scarce resources should not be provided for ineffective health care; and
- lifestyle should not determine access to health care.

The procedural part to Doyal's framework states that:

- the public should advise but not determine policy concerning the allocation of health care; and
- healthcare rationing should be explicit.

While a number of other theoretical models for resource allocation exist (for example, merit-based or lottery-based), Doyal's model specifically concerns principles of just resource allocation within the NHS — as opposed to other possible approaches to more general ethical decision making within health care. Doyal's model is directly related to the widely-accepted moral belief that resources should be allocated on the basis of equal need. While other approaches offer alternative understandings and resolutions to problems of decision making within medicine, they do not constitute a coherent theory of justice.

From the interview data, we chose examples of rationing dilemmas described by GPs that related to or illustrated a number of the ethical principles in Doyal's model. In this paper, we include two vignettes (Figures 1 and 2), the verbatim quotes on which they were based and the ethical principles to which they relate. In analysing the focus group discussions, Doyal's model was instrumental in identifying how far GPs' decision making in practice accorded with or deviated from theoretical ethical principles.

RESULTS

In the focus groups debating the vignette in Figure 1, two main themes arose: difficulties in determining the

Figure 1. Example of ethical principle and related vignette.

Ethical principle

- ▶ Within areas of treatment, resources should be prioritised on the basis of extremity of need.

Vignette

A man in his early fifties needs a hip replacement. You make a referral and he is placed on a waiting list of approximately 6 months for his first outpatient appointment. Five months later he is told that his appointment has been postponed and he will have to wait a further 12 months. During the 5 months since he was first referred, his condition has deteriorated and he is now on regular pain-killers. His hip problems are now seriously affecting his ability to do his job. You decide to start to make representations on his behalf in order to try and bring his appointment forward.

GP quote

'Well, the person I'm particularly cross about at the moment, for instance, and am about to send the details to the PCT, was referred on the 1st June last year for an extremely bad hip. This is a man who's in his forties or fifties. I think he might be in his early fifties actually. He's in full time work, he has to walk to the bus stop, and he's got a kind of clerical job. He is finding it increasingly difficult to manage. He's in pain. He is now taking regular pain killers and his x-ray looks bad. He's got lots of problems with his hip. And I've recently spoken to him because having referred him on the 1st June, he had an appointment in January for the orthopaedics, which I suppose to a degree is relatively good for them. They've now cancelled that appointment from January and given him an appointment for August, which then puts the time to first wait, to the first outpatient, at 14 months. And then he has to get on the list for surgery, which is no service at all. So I'm about to try and make some representation to try and get that appointment brought forward from August.'

extremity of need and the criteria used in priority setting. At one level, GPs described problems in the consultation arising from differences in the perception of urgency between themselves and their patients:

'The problem would be if they [the patient] thought they were the urgent end of the spectrum and I didn't.' (GP1.)

'It's invariably because we haven't matched agendas or we haven't agreed to not match agendas.' (GP2.)

On a different level, there was an acknowledgement that social and psychological criteria were often a component of the decision-making process. This could take two forms. There could be a judgement by the GP that the personal circumstances of a patient would result in them being deemed a higher priority:

'If two people have got identical need but one of them is going to stop working and the other one didn't work anyway, I think that person who is working goes into a slightly higher morally needy, category.' (GP2.)

Alternatively, GPs said that their own relationship with a patient had a bearing on how urgent to make a referral; those patients with whom the GP gets on well being more likely to be considered urgent. However, this does not necessarily imply conscious preferential treatment for 'favourite' patients. As the following GP illustrates, one consequence of having 'rapport' with a patient is that the GP is more likely to be aware of aspects of the patient's life other than the purely clinical, and may be more able to draw upon that knowledge when making a decision regarding a referral:

'But you think, well, there may be someone else in just as much pain who's not told me that they aren't able to go jogging, something which they really enjoyed and opened up a social scene and now they haven't been able to do that and their life is becoming awfully kind of introverted, and I'm just not aware of that because I don't have the rapport with that patient.' (GP3.)

As this GP notes, there are implications for equity when such factors come into play in decision making. It also raises issues concerning unmet need, in that the patient with whom there is less of a relationship may well be of equal or indeed greater need, but is unable or unwilling to make their GP aware of the full details of their situation.

Figure 2. Example of ethical principles and related vignette.

Ethical principles

- ▶ Scarce resources should not be provided for ineffective health care.
- ▶ Those in morally similar need should have an equal chance of access to health care.

Vignette

A female patient in her 70s presents with shingles. She reports that she has had a small rash on her stomach for the past 4 days. Zovirax is effective only if started at the onset of infection. You have known this patient for many years and decide to prescribe, even though Zovirax is an expensive drug and you will not be prescribing strictly according to indications.

GP quote

'I had a lady last week with shingles and with shingles there's an expensive drug you can get for that, an antiviral drug, something called Zovirax, and it costs a lot of money, so we don't always use that, and this lady had come in, an older lady, she'd had her shingles for probably 3 or 4 days and you really need to give it real early. But in fact she'd got such a bad case of it, I said to her, "Look, I'll give you the medication. Even though it's very expensive I'm going to give it to you because I think you're worth it." I actually said that to the patient, "You're worth it." Mind you, having said that, she's still in a lot of pain and despite having had this expensive medication. I did actually think because her clinical situation justified it, I decided to give that to her. I wouldn't to every patient, because certain types of painkillers will be sufficient on that.'

At another level of the referral process, GPs were quite clear that they were not in a position to set priorities. It was felt that, necessarily, it is those working in secondary care who are in a position to determine local priorities:

'The reality is we're not in a position to judge what the priorities are or what the needs are of the other patients that have been referred, I mean we're not. They have to do that in secondary care.' (GP4.)

'I think one of the benefits of me writing would be I'd be handing back the rationing responsibility to them [consultants] in a way, because you're providing them with information ... But really, it's their decision, they've got much more information about everybody else than you have.' (GP1.)

GPs often complained of having to explain or justify decisions made by others but which patients believed had been made by their GP her/himself.

In the focus groups debating the vignette in Figure 2, the main themes that arose were the role of social and psychological factors in decisions surrounding prescriptions and the problems that surface when articulate, demanding patients seek access to certain treatments. With regard to the provision of

treatments that GPs may believe are ineffective, but that patients nevertheless request, there was confusion over the role of the GP and the rights of patients. The following exchange illustrates this uncertainty:

'We can't blanket refuse homeopathic treatments.' (GP6.)

'But we can.' (GP4.)

'You have a right.' (GP8.)

'Say it's not available on the NHS.' (GP7.)

'Our trust have said, they've explicitly said, "Yes, there is homeopathy available and you cannot say no to patients".' (GP6.)

'You can. You have a right to refuse a treatment in which you do not believe or which you may think be detrimental or not effective.' (GP8.)

'Yes, but what if a patient knows that they have a right to see a homeopath?' (GP6.)

There was both recognition and concern that articulate patients often successfully access care at the expense of less articulate patients; a feeling that 'those that shout the loudest get the most.' In addition to such worries, there was a recognition of the difficulties in maintaining consistent, equitable standards, be they for writing referral letters or prescriptions:

'I'm absolutely totally inconsistent and it completely depends on their expectations, the day of the week, how late I'm running.' (GP6.)

As with the vignette in Figure 1, a recurring theme seemed to be one of differential expectation. One GP noted that often he felt like he had to give something to the patient, even if he had doubts about whether it was actually necessary or would be efficacious. GPs believed that patients often harboured unrealistic expectations as to the services that their GP was able to provide.

From a variety of perspectives, it appeared that although the GPs involved did, at a general level, agree that concepts like clinical need and equality are central to the just distribution of NHS resources, in practice they experienced a range of problems in putting these concepts into practice.

DISCUSSION

This paper examined the ethical issues surrounding

the allocation of scarce resources by GPs. It identified a number of difficulties faced by GPs in determining 'equal need' and the dilemma they face in drawing upon psychological and social criteria when priority setting. Within general practice, there exists tensions between the role of GPs as the gatekeepers of NHS resources and their role as advocates for their patients.

Summary of the main findings

The use of Doyal's model informed this study in two ways. The principles were used as a standard to measure the ways in which practice conformed or deviated from the ethical principles. GPs are clearly aware of the need for an ethical basis to healthcare rationing, but the realities of the external constraints that they have to work under means that this ethical basis is moderated by the daily necessities inherent in running a surgery. Discussion within the focus groups confirmed wide agreement on general principles of equitable resource allocation, consistent with Doyal's model. Equally, provided that cases remained straightforward; that is, they did not raise difficult practical dilemmas about how these principles should be put into practice, the GPs participating in the study saw few problems in their application. However, the existence of such agreement on principles did little to solve the problem of how more difficult and troubling cases should be resolved. Here, GPs were thrown back on a variety of other assumptions and strategies.

The study of potential inconsistencies between general moral values and specific professional practice raises a number of methodological issues. To deal with these problems, we collected second order accounts from GPs and patients of their experiences, feelings and understandings of rationing dilemmas. This raised questions about how the vocabulary of particular motives, actions, beliefs and intentions could be interpreted.^{21,22}

The GPs in our study reported inconsistencies in the way that they prescribed and referred. They recognised that it was often the case that social and psychological factors had a bearing on their decisions. The role such criteria play in decision making has been well documented. Factors such as the character of the patient, the consultation style of the doctor, the doctor-patient relationship and the organisational set-up of the practice are all held to have an influence.¹

Strengths and limitations of the study

The multistage nature of our research meant that we were able to develop greater levels of trust with the GPs than we would have with a simple one-off interview. This trust facilitated more in-depth and

open discussion on potentially sensitive topics. Given that the focus of our research was decision making in general practice, at first sight the 'ideal' approach would appear to have been observation of individual consultations. These observations could then be followed by in-depth interviews and focus groups with GPs and patients. However, in situations where rationing is not explicit and there is no clear communication of the reasons why treatment is being denied, research has the potential to make patients aware that their GP is denying them access. It was felt that this would be an unethical intervention, with a real possibility that in individual cases the doctor-patient relationship would be adversely affected by our research.

Implications for clinical practice

In using a focus group methodology, we were able to examine points of fracture and agreement among GPs concerning different ethical principles before examining different practices and their correspondence with ethical principles. Where a sense of a 'theory-practice gap' emerged we were able to question the reasons for this, GP perceptions of it and the justifications given for the gap.

While at some general level GPs did accept basic moral principles of fairness and equality as regards the distribution of scarce NHS resources, in practice they were sometimes not aware of the ethical principles they used in decision making or what criteria they employed when priority-setting. This suggests the applicability of other approaches to understanding how GPs make decisions about resources than one that focuses primarily on principles of need and equality.²³

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Ethical approval

Names of committees supplied, but not published to protect the anonymity of participating doctors

Competing interests

None

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