Patients' perceptions of need for primary health care services: useful for priority setting?

Jane L Hopton, Maria Dlugolecka

Abstract

Objectives—To assess the feasibility of using patients' perceptions of need for primary health care services to develop priorities.

Design—A postal survey of a random sample of 3478 patients registered with five general practices.

Setting—Lothian, Scotland.

Main outcome measures—Comparison of rankings of 36 different kinds of help or advice according to (a) popularity in the sample size as a whole and in healthy and unhealthy subgroups and (b) health status (severity of need) of potential service users.

Results—Popularity rankings differed between the healthy and unhealthy subgroups and the whole sample. Popularity rankings were almost the inverse of rankings based on health status. The analysis identified two areas of substantial need both in terms of popularity and severity: pain management and advice about welfare benefits.

Conclusions—Methodological efforts to ensure equal participation in the processes of assessing health needs and of priority setting do not in themselves promote equity. To promote equity some opinions may need to be given greater weight.

hypothetical priorities in health care are popular²⁻⁹ as they provide direct rankings. Survey researchers have long been aware that responses differ according to whether questions are asked in general or personal terms.¹⁰ The extent to which responses to public opinion questionnaires are influenced by perceptions of current personal health care needs and those of family and friends or by the media rather than by more abstract values such as equity is not known. Surveys of perceptions of current personal health needs are less ambiguous in this respect.

Furthermore, different conceptualisations of need may have different implications for priority setting.^{11,12} One possible definition of need is that of "perceived" need or "popularity." An alternative definition of need is the degree of ill health that some groups of potential service users are experiencing compared with others. This definition of need is underpinned by the argument that priority should be given to services that target those groups of people in the most severe distress. We used data from a survey of needs for primary health services to examine the feasibility of developing priorities based on individuals' perceptions of their own health needs.

Introduction

Interest in incorporating users' views into the planning and development of services is now high, and several methods for incorporating users' views are being used.^{1,2} Population surveys offer the potential to obtain a representative sample of views and experiences of non-users as well as of users of services and are being widely used in the assessment of health needs and in priority setting.^{3,4} Several important methodological criticisms of surveys of users' views have already been raised.^{4,5}

Firstly, an uncritical social marketing approach may lead to more services for the healthy majority, with those in most need being least able to influence findings.⁶ Looking at minority subgroups within a sample has been proposed as one way of addressing this issue.^{4,6,7} There is, however, a prior issue of comprehensiveness. Both the method and the content of a questionnaire may exclude people with important needs, and a danger exists that only the needs that have been formally assessed are considered in the planning process.

Secondly, respondents may not understand the nature of the services on which they are asked to comment or the key issues in evaluating or prioritising service provision.⁴ Recent research has pointed to the difficulties that patients may have in evaluating service provision if they have no knowledge of how things could be different. Including illustrations as part of the questions could help to overcome this difficulty.⁸

In addition to these methodological issues there is the more complex issue of how users' views may be used in priority setting. Surveys of public opinion on

Background and method

We carried out the survey as part of a study aimed at developing a general practice based model for assessment of health needs. A broad interpretation of health needs would acknowledge that these needs may not be needs for health services.^{12,13} We investigated the needs relevant to purchasing primary health services but incorporated elements of primary social service provision when possible.

The questionnaire incorporated three sets of indicators of need: measures of health status (severity of need) with both medical and lay terms and a standardised measure of health status, the SF36 questionnaire¹⁴; perceived helpfulness of different kinds of services; and patterns of service use.

DEVELOPING THE LIST OF DIFFERENT KINDS OF SERVICES

We devised a format in which we asked respondents whether particular services would currently be of some help, great help, or no help to them personally. In two multidisciplinary meetings and several one to one interviews we had asked a range of professionals to suggest possible areas of primary health and social care—on the basis of current care provision and possible future developments—for inclusion in this section of the questionnaire. An important reason for this "top down" approach to developing the questionnaire was to overcome the difficulty of users' limited knowledge of potential or available services.

We developed a draft questionnaire on the basis of this consultation. We interviewed face to face 18 patients chosen at random from the list of one general practice. These interviews confirmed that on

Department of General Practice, University of Edinburgh, Edinburgh EH8 9DX
Jane L Hopton, research psychologist

Lothian Health, Edinburgh
Maria Dlugolecka, consultant in public health medicine

Correspondence to:
Ms Hopton.

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TABLE I—Response rates and age-sex distribution among respondents compared with age-sex distribution in Lothian region as a whole. Values are numbers (percentages)

Age (years)	Response rate		Distribution in Lothian (n=612 427)
	Total*	Among respondents (n=3381†)	
Men:			
16-44	697/1565 (45)	697 (20.6)	170 554 (27.8)
45-64	510/759 (67)	510 (15.1)	78 787 (12.9)
65-74	166/211 (79)	166 (4.9)	27 913 (4.6)
75 and over	66/90 (73)	66 (2.0)	15 161 (2.5)
Women:			
16-44	1003/1741 (58)	1003 (29.7)	167 146 (27.3)
45-64	617/833 (74)	617 (18.2)	84 585 (13.8)
65-74	195/261 (75)	195 (5.8)	35 975 (5.9)
75 or over	126/186 (68)	126 (3.7)	32 306 (5.3)

*Denominator reflects number of questionnaires sent out excluding those that were returned later by post office.

†Questionnaires that contained data on age and sex.

TABLE II—Mean scores (number of respondents) on general health scale of SF36* among 3293 respondents according to age, sex, and socioeconomic position†

Variable	Score
Age (years):	
16-44	74.5 (1803)
45-64	67.4 (866)
65 or over	60.4 (557)
	P<0.0001
Sex:	
Men	70.6 (1579)
Women	69.7 (1678)
	P<0.05
Home owner:	
Yes	73.9 (2108)
No	64.3 (1155)
	P<0.0001
Respondent or partner receives income support:	
Yes	62.1 (554)
No	72.0 (2636)
	P<0.001
Car owner:	
Yes	73.6 (2011)
No	64.9 (1188)
	P<0.0001

*Standardised measure of health status; 0=poor health, 100=excellent health.

†Not every respondent answered every question.

the whole the questionnaire was understandable and comprehensive. The draft list of different kinds of help, however, contained items about several different professionals including, for example, district nurses, health visitors, clinical psychologists, and counsellors. Respondents who did not know about the work of these professionals had difficulty in understanding their roles. This was also the case with items referring to the structure of services, such as some health promotion clinics. When possible we tried to replace items about service providers or structures with statements about the content of the service.

A pilot postal survey of 606 patients included an open ended question to give respondents an opportunity to add to the list of services. The final questionnaire listed 36 different kinds of help (see appendix).

SURVEY SAMPLE

The study was based in five general practices in the Lothian region. We chose the practices on the basis of the age, sex, and deprivation distributions of their populations to capture a broad social mix and a population similar to that of Lothian as a whole. We posted questionnaires and reply paid envelopes to 6328 patients (mean 1264.6 per practice) aged 16 or over with a covering letter signed by a partner from the relevant practice. The sample was stratified by sex and by age groups (16 to 44, 45 to 64, 65 to 74, and 75 or over). A reminder (with a second questionnaire) was posted after three weeks. We followed up a sample of non-respondents by telephone or with a visit.

DATA ANALYSIS

The data were weighted so that the age-sex distribution of the respondents matched that of Lothian. We ranked the different kinds of help according to popularity in healthy and unhealthy subgroups and in the sample as a whole. We also ranked the different kinds of help according to the health status of groups of potential service users—that is, the respondents who reported that a particular service would be helpful.

We asked respondents whether different services would be of no help, some help, or great help. No assumptions can be made about the magnitude of difference between the categories. To give more weight to responses of great help than to those of some help, we devised two sets of ranks. In the first set the categories of some help and great help were combined. The second set was based only on the category of great help. An overall popularity ranking was based on the sum of these two ranks.

The analysis used the general health scale of the SF36 questionnaire as a measure of health status. This is a measure of perceived overall health status. A more specific measure of health status would have weighted the ranking towards particular services. Lower scores

indicate poorer health. The healthy and unhealthy subgroups used in ranking the popularity of different kinds of help were respondents scoring below the lowest and above the highest 10th centiles of the distribution of scores on this scale. The rankings according to health status were based on the mean general health scores of respondents who reported that a particular service would be helpful.

Results

Of the 6328 questionnaires sent out, 680 were returned by the post office. Of the remaining 5648 that were considered to have been delivered to the correct address, 3478 were returned (response rate 61.6%). Table I shows the response rate for each age group of the sample (by sex) and compares the age-sex distribution of the sample with that of Lothian as a whole.

In all, 1040 (47.9%) of the 2170 non-respondents were followed up. We found that 18 (1.7%) had been unable to complete the questionnaire because of health problems and four (0.3%) because of language difficulties. Of the respondents who completed the questionnaire, 253 (7.5%) reported that they had had help filling in the questionnaire.

HEALTH STATUS AND SOCIODEMOGRAPHIC FACTORS

Scores on the general health scale ranged from 0 (poor health) to 100 (excellent health) with a mean of 70.1 (SD 22.8, n=3293). The scores at the 10th and the 90th centiles were 35 and 95 respectively. Table II shows that the mean scores on the general health scale decreased significantly with increasing age and with lower socioeconomic position. No significant difference in scores existed between men and women.

POPULARITY OF DIFFERENT KINDS OF HELP OR ADVICE IN HEALTHY AND UNHEALTHY SUBGROUPS AND WHOLE SAMPLE

Table III shows the 10 (of 36) most popular kinds of help or advice, for the healthy and unhealthy groups and the sample as a whole. A full list of rankings of all 36 different kinds of help or advice is given in the appendix. Table IV shows the 10 services with the greatest discrepancy in popularity rankings between the healthy and the unhealthy groups.

SEVERITY OF NEED OF GROUPS OF POTENTIAL SERVICE USERS

Table V shows the 10 kinds of help or advice wanted by those whose health status as potential service users was poorest and the rank according to popularity in the whole sample. Thus, although few people reported that "more help getting out and about" would be helpful, the severity of need among this group of potential service users was greatest.

Discussion

The findings of the ranking exercise show that important differences exist in the popularity of different services between healthy and unhealthy respondents and that the assessment of need based on popularity differs appreciably from an assessment of need based on distress or ill health.

METHODOLOGICAL ISSUES: COMPREHENSIVENESS AND COMPREHENSIBILITY

Although some of the problems and ambiguities of other surveys have been avoided, several important issues merit consideration. Although we tried to ensure that the list of different kinds of help was as comprehensive as possible, inevitably it has gravitated towards majority issues and away from minority issues. When

TABLE III—Ten most popular kinds of help or advice in healthy and unhealthy subgroups and in whole sample. Values are numbers (percentages) of respondents

	Response	
	Some or great help	Great help
<i>Unhealthy group* (n=352)</i>		
1 Regular visits to the practice for health checks	200 (68.7)	82 (28.1)
2 Help or advice about coping with pain	176 (59.5)	79 (26.6)
3 Help or advice about coping with stress	166 (56.1)	83 (28.0)
4 Having the opportunity to talk through a problem at length with someone	174 (57.7)	74 (24.5)
5 Help or advice about preventing heart disease	165 (56.1)	63 (21.4)
6 Help or advice about backache	142 (49.4)	76 (26.3)
7 Help or advice about getting benefits you may be entitled to	147 (50.0)	71 (24.2)
8 Help or advice about healthy eating	150 (51.8)	50 (17.3)
9 Help or advice about taking exercise	149 (50.8)	53 (18.0)
10 Help or advice about losing weight	120 (41.3)	60 (20.7)
<i>Healthy group† (n=360)</i>		
1 Regular visits to the practice for health checks	112 (34.4)	43 (13.3)
2 Help or advice about preventing heart disease	89 (27.8)	34 (10.5)
3 Longer surgery opening hours at your practice	85 (28.7)	29 (9.3)
4 Help or advice about taking exercise	59 (18.6)	22 (6.8)
5 Help or advice about coping with stress	62 (19.6)	21 (6.4)
6 Help or advice about healthy eating	82 (25.7)	19 (6.0)
7 Help or advice about losing weight	59 (18.4)	20 (6.1)
8 Help or advice about giving up smoking	10 (14.9)	21 (6.5)
9 Help or advice about backache	51 (15.8)	18 (5.7)
10 Help or advice about alternative or complementary therapies such as acupuncture or homoeopathy	49 (15.7)	13 (4.1)
<i>Whole sample (n=3482‡)</i>		
1 Regular visits to the practice for health checks	1552 (51.9)	481 (16.1)
2 Help or advice about preventing heart disease	1572 (53.0)	428 (14.4)
3 Help or advice about coping with stress	1271 (42.9)	423 (14.3)
4 Help or advice about healthy eating	1298 (43.9)	287 (9.7)
5 Having the opportunity to talk through a problem at length with someone	1121 (38.0)	368 (12.5)
6 Help or advice about taking exercise	1202 (40.7)	285 (9.6)
7 Longer surgery opening hours at your practice	1060 (37.0)	317 (11.0)
8 Help or advice about losing weight	1059 (35.5)	370 (12.4)
9 Help or advice about backache	969 (32.7)	347 (11.7)
10 Help or advice about alternative or complementary therapies such as acupuncture or homoeopathy	854 (29.2)	203 (7.0)

*Respondents with lowest 10% of scores on general health scale.

†Respondents with highest 10% of scores on general health scale.

‡Adjusted because of weighting.

TABLE IV—Service with greatest discrepancy in popularity ranking between healthy and unhealthy groups

	Ranking		
	In healthy group	In unhealthy group	In whole sample
<i>Higher ranking in healthy group:</i>			
Help and advice about HIV infection or AIDS	11	34	26
Longer surgery opening hours in own practice	3	20	7
Family planning advice or information	20	36	24
Medical advice about overseas travel	17	30	21
Should be easier to see woman general practitioner	13	25	16
<i>Higher ranking in unhealthy group:</i>			
Help or advice about coping with pain	24	2	12
Help or advice about gadgets or equipment that may make things easier	34	16	29
More home visits to check up on how patient is coping	29	14	23
More help in getting out and about	36	21	33
Help or advice about getting benefits that patient may be entitled to	22	7	12

TABLE V—Ten kinds of help or advice according to health status (poorest) of potential service users*

	Response of some or great help		Popularity rank in whole sample
	Mean general health score	No of respondents	
1 More help in getting out and about	45.9	209	33
2 Advice about gadgets or equipment that may make things easier	46.8	231	29
3 More practical help around the house	49.2	241	29
4 Help or advice about coming off or cutting down on medicines on prescription	53.5	234	31
5 More home visits to check on how patient is coping	53.7	387	23
6 Help or advice about coping with pain	57.0	734	12
7 More help to understand how to take medication	57.4	242	34
8 More discussion of the possible side effects of medication	58.1	511	20
9 Help or advice about being on a special diet	59.5	328	25
10 Help or advice about getting benefits patient may be entitled to	59.9	708	12

we later interviewed professionals working with the five general practices we found that we had omitted services such as speech therapy and help for non-English speaking patients and sensitive issues such as child abuse. Respondents to the pilot study had added some services, but it should not be assumed that the same list would have emerged had the questionnaire been developed from discussion with patients rather than professionals.

Our attempts to explain the roles of health professionals and the components of different services seem valid, and this approach seems promising. The extent to which we adequately captured the range of work undertaken by different professionals was limited, and no simple description of the work of two of the professional groups—physiotherapy and chiropody—was reached within the time available for developing the questionnaire.

COMPARISON OF POPULARITY RANKS IN HEALTHY AND UNHEALTHY GROUPS

An analysis based on more than the two extreme subgroups of the most and least healthy patients is beyond the scope of this paper. The association of general health scores with age and socioeconomic position suggests that the analysis presented will also have partially covered these subgroups.

Given the comprehensiveness of the list of potential services it was unrealistic to ask respondents to draw up their own rankings. No limit was set on the number of different kinds of help which respondents could report as being helpful. In general, less healthy respondents reported more services as being helpful. Some kinds of help and advice, particularly on different aspects of lifestyle, were universally popular. It is interesting and important that very unhealthy respondents reported that these would be helpful to them. Important differences existed, however, in the relative popularity of different kinds of help within the healthy and unhealthy subgroups.

SEVERITY OF NEED

Rankings on the basis of severity of need of groups of potential service users were almost the inverse of popularity rankings in the whole sample. Services reported as helpful by small numbers of people in poor health—such as help getting out and about, home visits, and advice about equipment—were among those that showed the widest discrepancy in rankings between the healthy and unhealthy groups and did not appear in the 10 most popular services within the sample as a whole.

Two services—pain management and the provision of advice on welfare benefits—deserve particular attention as they had high popularity rankings within the unhealthy subgroup and relatively high popularity rankings within the sample as a whole, and they also ranked highly in terms of the severity of need among potential service users. These services have recently been identified as areas for development, although they remain marginal.^{15 16} Our analysis confirms their importance.

EQUALITY OR EQUITY?

Most importantly this analysis illustrates one of the paradoxes at the centre of the development of health and social policy: that equality is different from equity and that giving everybody an equal say may actually be at odds with promoting equity.^{17 18} This issue is more easily identifiable in quantitative user surveys such as ours. It may also be intrinsic in qualitative research that uses validity methods based on confirmation, rapid appraisal methods that claim triangulation, and so called participatory methods based on consensus.^{19 20} All methods of assessing health needs have to be

Key messages

- Interest in incorporating service users' views in the assessment of health needs and in priority setting is high
- The ranked popularity of services was different for a group of healthy people than for a group of unhealthy people
- Priorities for services based on popularity were different from those based on severity of need
- A great danger exists that the needs of minority groups are neglected if too much emphasis is placed on giving everyone an equal say
- All methods of assessment of health needs and priority setting should be explicit about principles of equity

explicit about their comprehensiveness and exclusions as well as any principles of equity that inform the work.

In the introduction we pointed to an important criticism of research on users' views: that users may not understand the purpose or implications of the study. This may be merely a reflection of general confusion and uncertainty about what has been termed "the new political game of purchasing," in which the relation between satisfaction, assessment of health needs, priority setting, and purchasing remains a mystery to professionals and lay people alike.²¹ Moreover, there may not be a theoretical or a methodological solution to the continuing difficulty outlined in this paper. Methodological efforts to allow equal participation in the process of assessing health needs or priority setting do not necessarily imply or ensure equity and may distract from the harsh political reality that, to promote equity, some opinions must be given greater weight.

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Appendix

Ranking of 36 different kinds of help and advice

	According to popularity			According to health status (poorest of potential service users§)
	In whole sample* (n=3482)	In healthy subsample† (n=360)	In unhealthy subsample‡ (n=352)	
Help or advice about giving up smoking	14	8	19	23
Help or advice about backache	9	9	6	19
Help or advice about HIV infection and AIDS	26	11	34	23
Help or advice about drinking alcohol	28	23	28	21
Help or advice about coping with pain	12	24	2	6
Help or advice about healthy eating	4	6	8	30
Help or advice about taking exercise	6	4	9	27
Help or advice about coming off or cutting down on medicines on prescription	31	31	24	4
Help or advice about losing weight	8	7	10	30
Regular visits to the practice for health checks	1	1	1	26
Help or advice about preventing heart disease	2	2	5	28
Help or advice about coping with stress	3	5	3	22
Seeing a physiotherapist	17	16	12	12
More help to understand how to take medication	34	28	29	7
Help or advice about coming off or cutting down on illegal drugs	36	32	35	16
Non-medical help with feeling depressed or anxious	11	19	15	11
More discussion about possible side effects of medication	20	21	18	8
More information and advice about alternative or complementary therapies, such as acupuncture or homoeopathy	10	10	13	24
Having opportunity to talk through a problem at length with someone	5	12	4	13
More home visits to check up on how patient is coping	23	29	14	5
More practical help around the house	29	30	22	3
More help getting out and about	33	36	21	1
Advice about gadgets or equipment that may make things easier	29	34	16	2
Easier to see woman general practitioner	16	13	25	32
Advice about debts	27	33	33	18
Help or advice about getting benefits patient may be entitled to	12	22	7	10
Help or advice about a child with behaviour problems	31	26	32	25
Medical advice about overseas travel	21	17	30	35
Help or advice about being on special diet	25	35	23	9
Help or advice about blood pressure	15	18	11	15
Family planning advice or information	24	20	36	36
Help or advice about death of someone close	19	15	26	29
Help or advice about problems with husband, wife, or partner	22	25	27	20
Longer surgery opening hours at own practice	7	3	20	33
Seeing a chiropodist	18	14	17	14
Help or advice about violence or threat of violence	35	27	31	17

*Adjusted because of weighting.

†Respondents with highest 10% of scores on general health scale.

‡Respondents with lowest 10% of scores on general health scale.

§Respondents who reported this would be of some or of great help.