Are older people willing to give up their place in the queue for cardiac surgery to a younger person?

Ann Bowling, Aldo Mariotto¹. Olga Evans²

Centre for Ageing Population Studies, University College London, UK*

Address correspondence to: A. Bowling, Centre for Ageing Population Studies, Department of Primary Care and Population Sciences, Royal Free and University College Medical School, Royal Free Campus, Rowland Hill Street, London NW3 2PF, UK. Fax: (+44) 207794 | 224. Email: a.bowling@pcps.ucl.ac.uk

Abstract

Objectives: to measure whether people aged 65 and over living in Britain would be willing to give up their place on the cardiac surgery waiting list for someone younger than them.

Methods: two British surveys, based on random types of people sampled for the Office for National Statistics Omnibus Surveys, identified respondents aged 65 and over for a module on waiting lists. They were asked to imagine they had a heart condition that required surgery, and that they were on an NHS waiting list. They were then asked if they would be prepared to give up their place on the cardiac surgery waiting list to a younger person (aged 45). The study compared responses to one of two relative waiting list time frames (6 and 12 months).

Setting: two national random samples of the British public aged 65 and over.

Results: fifty eight per cent and 62% of Omnibus respondents aged 65 and over responded that it was *not right* to give up their place on the cardiac surgery waiting list for someone younger in relation to a 6 and 12 month wait respectively. Thirty seven per cent and 34% of each group of Omnibus respondents aged 65 + said it *was right* to give up their place on the cardiac surgery waiting list for someone younger than them, in relation to a 6 and 12 month relative waiting period respectively. Thus the length of the wait had little effect on response among British respondents. The proportions who were willing to cede priority are far less than that reported in a comparable Italian survey. Consistent with the Italian survey, willingness to cede priority increased with age.

Conclusions: most older people in Britain do not wish to cede priority on the waiting list for cardiac surgery to people younger than themselves, although willingness to give up one's place increased with age. The specific time frame did not have an impact on people's responses.

The increase in willingness to cede priority with older age could be interpreted as older people valuing themselves less, or that they feel that they have had their 'fair innings' and are willing to give younger people the chance of reaching their age. It could even reflect a cohort effect. It is likely that ageing 'baby boomers' may be even less willing to give up their place in the health service queue and will be more assertive about their right to equity in health care provision.

Keywords: cardiology, elderly people, rationing, waiting lists

Background

When the National Health Service (NHS) was instituted in 1948, queuing and rationing were part of British life;

the NHS was paternalistic and 'producer dominated', and patients had little involvement in its management and process [1]. While the relationship between patients and their doctors is slowly changing towards

Community Medicine Service, Health Authority No. 6, Friuli Occidentale, Padova, Italy

²Omnibus Survey, Social Survey Division, Office for National Statistics, London, UK

^{*}University College London is a member of the MRC Health Services Research Collaboration, of which Bristol is a lead centre.

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a partnership model of care, there is still well documented evidence of inequity in the provision of health services in England. One example is in cardiac surgery. Patients with heart disease in some health districts apparently have four times the chance of obtaining heart surgery than others [2]. The ethics of 'postcode prescribing', or treatment, has often been called into question, and it is foreseeable that patients who have been denied treatments might invoke Article 3 of the European Convention on Human Rights, which specifies that 'no-one should be subjected to torture or to inhuman or degrading treatment' [3]. Lack of access to treatment from which a patient might benefit could be deemed 'degrading', and thus affected patients could challenge clinical decisions and health policy [3].

However, the extent to which the style of patient management is due to clinical appropriateness, patients' or doctors' treatment preferences, or to the prioritisation of scarce health care resources is largely unknown. Research in cardiology suggests that older people in particular are more likely to have more severe coronary artery disease, to be treated less vigorously and less effectively than younger people; to be treated medically rather than surgically; and to be denied access to many cardiac facilities [4–12]. It appears that implicit age based prioritisation policies and biases are operating in health care [13], reflecting ageism apparent in wider society [14].

Consistent with this literature, the British Social Attitudes Survey for the year 2000 found that while four in five respondents disagreed with health service rationing, 56% thought that a younger person would currently take priority over an older person for an NHS heart operation [15]. Previous research on the public's priorities for health services reported that they prioritised treatments for life-threatening conditions in children at the top of their priority list, and treatments for life-threatening conditions in people aged 75 and over at the bottom [14].

Treatment differences with age of patient result in a 'care gap' between the actual and optimal application of effective therapies to the whole population at risk [16]. The existence of age discrimination in the NHS has now been openly acknowledged by the British Government for the first time in its history. Standard 1 of the Department of Health's (2001) National Service Framework for Older People [17] targeted the elimination of age discrimination, and specified that NHS services will be provided, regardless of age, solely on the basis of clinical need.

But what are older people's views of this? A survey of residents aged 65 and over in Padova, Italy, which asked respondents to imagine they were on a waiting list for heart surgery and expected to undergo surgery in one month's time, found that about half of the respondents deemed it right to give up their place on the (one month) waiting list for cardiac surgery to

a 45 year old (with a further 15 days wait) [18]. Multivariate analyses showed that people aged closer to age 65 ('young' elderly respondents), married respondents, university graduates and those who were formerly self-employed were less likely to be willing to give up their place. The study we report here used similar methodology to that employed on the Italian survey and investigated older people's willingness to give up their place in the queue for cardiac surgery, by varying lengths of waiting times (6 and 12 months). Direct comparison with the Italian survey was not possible as that survey asked about a 15 day relative waiting time period, which is less realistic in the UK context with much longer overall waiting list times.

Aim

The aim of the study was to measure whether people over 65 would be willing to give up their place on the cardiac surgery waiting list to someone younger than them (i.e. swap their place). The objectives were to i) analyse the characteristics of respondents who were willing to give up their places and ii) compare differences in responses when relative waiting times were varied (between 6 and 12 month waits).

Methods

The vehicles for the waiting list enquiry were two Office for National Statistics (ONS) Omnibus Surveys in Great Britain. These were face-to-face interview surveys, in respondents' homes, based on a national random sample of households taken from postcode files (see below). The Omnibus Surveys were conducted in September and November 2000. These surveys formed the sampling frame for a separate follow-up survey module on Quality of Life in older age (it identified all those sample members aged 65 and over for the latter study). The opportunity was also taken to ask those sample members aged 65 and over the waiting list module presented here. The September Omnibus Survey respondents were asked the waiting list module during their actual Omnibus Survey interview; the November Omnibus Survey respondents were asked the waiting list module during their re-interviews for the Quality of Life Survey two months later (a late decision was made to take advantage of these interviews to assess the effects of varying the waiting list time frame).

Around 100 interviewers were used by ONS for each Omnibus Survey. The sampling frame used was the British postcode address file of 'small users'. This file includes all private household addresses. A new sample of 100 postal sectors is selected for each Omnibus Survey. They were stratified by region, the proportion

of households renting from local authorities, and the proportion in which the head of household is in socio-economic group 1–5 or 13 (i.e. a professional, employer or manager). The 100 postal sectors were selected with probability proportional to size. Within each sector, 30 addresses were selected randomly with a target sample size per survey of about 2000 adults aged 16 and over (one per sampled household with the use of a random numbers table). Proxy interviews were not undertaken. Because only one household member is interviewed, people in households containing few adults had a better chance of selection than those in households with many. A weighting factor is applied to correct for this unequal probability.

Response rates

The response rate to the September Omnibus Survey of adults of all ages (16+) was 62%, which is within the usual range of response for these national surveys. Of the 3000 selected addresses there were 282 (9%) ineligible addresses and 2728 eligible addresses. Of these eligible addresses, there were 748 (28%) refusals to participate, 278 (10%) non-contacts and 1691 (62%) successful interviews. There were 339 respondents aged 65+ and who were asked the waiting list module (with the correction weighting ('wta') for household size for people aged 65+ applied).

The response rate to the November Omnibus Survey of adults of all ages (16+) was 57%. Of the 3000 selected addresses there were 263 (9%) ineligible addresses and 2737 eligible addresses. Of these eligible addresses, there were 869 (32%) refusals to participate, 320 (12%) non-contacts and 1546 (57%) successful interviews. There were 328 respondents aged 65+, with the weighting applied. As stated earlier, the respondents aged 65+ to this November 2000 ONS Omnibus Survey were reinterviewed during February 2001. The opportunity was taken to repeat the waiting list question. Of the 328 respondents aged 65+ to the November ONS Omnibus Survey, 309 (94%) agreed to be reinterviewed and 19 (6%) refused. Of the 309 who consented, 2 (6%) were found to have ineligible addresses at follow-up (moved or died) leaving 303 eligible respondents. Of these, 52 (17%) refused reinterview, 8 (3%) were not contactable and 243 (80%) were successfully reinterviewed (this includes one partial

Comparisons of the characteristics of respondents of all ages to the Omnibus Surveys against Census and General Household Survey data showed that males aged under 25 were the group which was underrepresented, and the distribution of people aged 65 and over who responded to each survey equalled estimates from their distribution in the population. The characteristics of respondents aged 65 and over to each survey were also similar.

Measures

The study compared responses to one of two relative waiting list time frames (6 and 12 months), based on the question wording designed by Mariotto et al. (1999) [18] for an Italian survey. Respondents aged 65 and over on the ONS Omnibus survey in September 2000 were asked: 'I would like you to imagine that you have a heart condition that requires surgery. You are on an NHS waiting list and expect to have your surgery in a month's time. Another patient, who is younger than you, aged 45, is also on the waiting list for the same surgery, but he/she will have their operation six months later than you. Do you think it would be right to give up your place for him/her just because he/she is younger than you? (Women were asked in relation to women, and men in relation to men—this was in contrast to the Italian survey in which only men were the referent). Interviewers were briefed to make it clear that the question meant swapping places, not giving up their place altogether.

The November 2000 Omnibus respondents, during their two month follow-up interviews, were asked an identical waiting list question, but in relation to a longer 12 month wait, in order to assess the effects of varying the time frames.

Both sets of respondents were included in the Quality of Life Survey follow-up modules, which enabled linkage of data between the Omnibus Survey and the Quality of Life Survey. The latter survey included well known and tested questions and scales on self-assessed health status, ability to walk 400 yards, functional ability, reported long standing illness, or diagnosed heart condition; psychological variables (optimism–pessimism bias, self-efficacy, feelings of control over life, health values, self-perception of risks of adverse life events, depression and anxiety); and a Likert scale for self-rating of overall quality of life. Too few respondents (1%) were members of a minority ethnic group for analysis (as expected in a national sample).

The Omnibus Surveys included standard Omnibus Survey questions on age, sex, socio-economic status, social class, self-employed or employed status before retirement, highest educational qualification, marital status, annual income, housing tenure, household size and other indicators of social circumstances. These were classed as the independent variables, and their effects on willingness to cede place on the waiting list for heart surgery, by waiting list time frame, were analysed.

Bivariate analyses included Chi-square tests. Logistic regression analyses (odds ratios) were used to assess the effects of each of the independent variables listed above, controlling for the effects of other variables, on willingness to cede place on the waiting list. The effects of the socio-demographic variables and the effects of the social and psychological variables were analysed

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Table I. Agree to give up place on waiting list for cardiac surgery by length of wait

Agree to give up place	Britain						Italy [18]		
	6 month wait ^a			12 month wait ^b			15 day wait		
	%	(n)	CI	%	(n)	CI	%	(n)	CI
Yes	37	(124)	32-42%	34	(82)	28-40%	51	(226)	46–56%
No	58	(194)	53-63%	62	(150)	56-68%	23	(102)	19-27%
Don't know	1	(5)	0-3%	1	(2)	n/a	26	(115)	22-30%
Refused to reply	4	(14)	2-6%	3	(8)	1-6%	_	_	_
Total		(337)			(242)			(443)	

^aSeptember 2000 ONS Omnibus Survey respondents (in addition, 2 missing cases due to partial/incomplete interviews).

in separate models for each time frame. Attention has not been drawn to differences that statistical tests suggested might have occurred by chance five or more times in 100.

Results

Fifty eight per cent and 62% of Omnibus respondents aged 65 and over responded that it was *not right* to give up their place on the cardiac surgery waiting list for someone younger in relation to a 6 and 12 month wait respectively.

Thirty seven per cent and 34% of each group of Omnibus respondents respectively said it was right to give up their place on the cardiac surgery waiting list for someone younger than them in relation to a 6 and 12 month relative waiting period (Table 1). Thus the length of the wait had little effect on response among British respondents. These proportions are far less than that reported in the comparable Italian survey (51% of people aged 65+ were willing to give up their place in relation to the same one month left on the waiting list but with a shorter 15 day relative wait). It is possible that this difference in response was due to the longer waiting list time frame, which more accurately reflects waiting times in the British NHS. The Italian survey [18] also had a much larger proportion of people responding 'Don't know', which might also have reflected the relatively short waiting period asked about.

Consistent with the Italian survey [18], altruism increased with age, with agreement to give up their place on the waiting list for a younger person increasing with older age. For example, in the British surveys, 26% (48) (CI: 22–36%) of respondents aged 65–74, and 57% (76) (CI: 38–62%) of respondents aged 75+, were willing to give up their place in relation to a 6 month wait (chi-square: 30.578; 1 df; P < 0.001). Twenty nine per cent (48) of respondents aged 65–74, and 50% (34) of respondents aged 75+, were willing to give up their place in relation to a 12 month wait (chi-square: 9.041; 1 df; P < 0.01).

Further bivariate analyses showed that there were no significant or consistent differences with agreement to give up places on the waiting list, by either time frame, and the remaining socio-demographic, social or psychological variables. Logistic regression analysis confirmed the non-significance of these variables.

In contrast, the Italian survey had found that people who were married, those who were university graduates and those who were formerly self-employed were significantly less likely to report that they would give up their places on the waiting list [18].

Discussion

Similar percentages of Omnibus respondents aged 65 and over responded that it was *not right* to give up their place on the British cardiac surgery waiting list for someone younger than them in relation to a 6 and 12 month wait (58% and 62% respectively). However, a substantial minority (37% and 34% respectively) were willing to give up their place.

Willingness to give up one's place increased with age. Thus, there was consistency in response to the general principle of giving up one's place on the NHS waiting list, and the increase with age. The specific time frame did not have an impact on people's response. The conclusion of this study is that most older people in Britain do not wish to cede priority on the waiting list for cardiac surgery to people younger than themselves.

The limitation of any relatively large national survey is that questions have to be simply worded in order to be understood by a wide range of respondents. If they had been given the information that older patients being considered for cardiac surgery are often more symptomatic than younger patients, have a worse prognosis, and therefore have much more to gain from a similar procedure, it is likely that even fewer respondents would have been willing to give up their places.

^bFebruary 2001 ONS November Omnibus Survey follow-up respondents (in addition, 1 missing case due to partial interview).

Correction weighting applied for household size for people aged 65+; CI: confidence intervals; n/a: not applicable due to small base.

The overall increase in willingness to cede priority with older age in the British and Italian [18] surveys could be interpreted as some older people (i.e. just over a third in the British surveys and about half in the Italian survey) valuing themselves less, or that they feel that they have had their 'fair innings' and are willing to give younger people the chance of reaching their age.

The attitudes of older people are likely to reflect social and cultural patterns at the beginning of the century (i.e. cohort or period effects). The chivalry generally associated with past generations might also influence the altruistic attitudes that were shown in each study to increase with older age. These results might also reflect the lack of assertiveness, or confidence, of older people in relation to demanding health or public services. If the results reflect such a period effect, then in future, the ageing 'baby boomer generation' (those born in the post World War II period, when birth rates increased) may be even less willing to give up their place in the queue for treatment, and will be more assertive about their right to equity of access to effective health care. The next 'baby boomer' generation of older people have been brought up with the advantage of a lifetime of largely free health care at the point of use. They are likely to be more assertive about their continuing rights to health care and be more demanding. It should not be assumed that future generations will have the same (relatively low) expectations of current generations of older people [19], and who spent their early years in a society with no nationalised health service.

The differences between the British and Italian surveys in older people's willingness to cede priority to a younger person may be partly due to the longer waiting list time frames asked about in the former study. These more accurately reflect the longer waiting lists in the British NHS, in contrast with the Italian NHS. In the Italian survey, younger respondents, those people who were married, university graduates, and self-employed before retirement, were less likely to cede priority. However, in the British survey, age was the only predictor of willingness to give up place on the waiting list. There are, however, also profound differences between the two countries that may account for differences in attitude (willingness to cede place).

A far larger proportion of Italian than British respondents also replied that they 'Didn't know' whether they would cede priority on the waiting list. This could be explained by the shorter waiting time included in the Italian survey (15 days). However, older people, and those with physical impairments were more likely to give this response in the Italian Survey (Mariotto, personal communication), suggesting they might be unwilling to give up their place in view of their age and frailty, but were unwilling to express this attitude to an interviewer. It is possible that a 'don't know' response could have reflected a lack of understanding of the issue, although none of the interviewers reported any

difficulties with the question. It is possible that they simply could not imagine themselves in that situation.

Patients are not necessarily in a position to assess the appropriateness of the care they are given. Patients trust their doctors to act in their best interests, though recent national surveys in England have shown that patients' confidence in their doctors (e.g. cardiologists) varies considerably by hospital trust [20]. The same series of patients' surveys shows that older people are less critical than younger people of their health care [21], probably reflecting their lower expectations.

In conclusion, there is a dearth of data on older people's views, values and preferences for invasive and less invasive treatment. In this survey we found that most older people were not willing to give up their places for surgical treatment to younger people. Like the Italian survey, the findings reported here are exploratory, and do not address people's reasonings. However, they do indicate the need for clinicians and health policy makers to take older people's views into account. Health policies and clinical practices that are inequitable are unlikely to reflect the views and values of the older populations on whom they have an adverse effect.

Policy makers might be concerned about an increase in the costs of health care for older people. In contrast, the available evidence suggests that ageing will be a relatively minor determinant of increasing health care costs, which is driven more by demand and supply than the age or health status of the population *per se* [22].

The overall conclusions from this survey are consistent with those of the comparable Italian survey [18] in that future generations of older people are likely to be intolerant of age discrimination and be more assertive about their rights to equity in health care. In the UK, policy is slowly catching up with public opinion. The recently published National Service Framework for Older People aims to provide a more equitable health service for older people [17]. The concept of an ageing population is relatively new. Ageism may be due partly to the time lag between social change and attitudinal change, and become eroded with the ageing of the future generation of 40–50 year olds.

Key points

- The main conclusion of a national survey of attitudes was that most people aged 65 and over in Britain do not wish to cede priority on the waiting list for cardiac surgery to people younger than themselves.
- The greater willingness among very elderly respondents (aged 75+) to cede priority to a younger person could reflect a period effect, consistent with the evidence that future generations of older people will have higher expectations of health services and be more demanding.

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- The length of the waiting list had no impact on response.
- The percentage of British people willing to give up their place on the waiting list to a younger person was significantly lower than that reported in a comparable survey in Italy.

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