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Selection criteria for recipients of scarce donor livers: a public opinion survey in Hong Kong

香港市民對接受肝臟移植的病人的選擇標準意見調查

Objective. To explore the public preference in determining the selection criteria for recipients of scarce donor livers.

Design. Structured interview survey.

Setting. Hong Kong community.

Participants. Participants from Hong Kong households, randomly drawn from 18 districts in Hong Kong by the Census and Statistics Department.

Main outcome measures. Age of patients, causes of liver failure, capacity for survival and benefit, time spent on the waiting list, and transplantation status.

Results. A total of 281 participants were recruited with the response rate of 26.2%. In all sections of the questionnaire, there was a strong preference for the young over the old, non-drinkers over drinkers, those more likely to survive, those who had waited longest on the list, and primary candidates over re-transplant candidates. Approximately 91% of participants agreed or strongly agreed that priority should be given to patients most likely to survive and benefit from a liver transplant, and 39% of participants also ranked 'survival and benefit' as the most important criterion in determining allocation of donor livers. Nonetheless when participants were asked to allocate a finite number (100) of donor livers to two groups of individuals with different characteristics in a set of eight hypothetical scenarios, they preferred giving priority to patients who had waited longer on the waiting list.

Conclusion. Although comparatively the general public surveyed had dominant preferences to maximise benefit and survival, they were unlikely to rely on one criterion for allocation. Overall cost-effectiveness of the intervention was not the sole deciding factor.

Key words:

Liver transplantation;
 Patient selection;
 Public opinion;
 Social justice;
 Tissue and organ procurement

關鍵詞：

肝臟移植；
 選擇病人；
 大眾意見；
 社會公平；
 組織及器官購買

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目的：探討公眾在決定誰應接受肝臟移植時考慮的標準。

設計：結構性訪問統計。

安排：香港社區。

參與者：透過香港政府統計處在十八個地方分區中隨機抽樣的家庭成員。

主要結果測量：接受移植者的年齡、肝臟衰竭原因、存活能力及得益、輪候時間和移植情況。

結果：是次調查共有281人參加，回應率達26.2%。對問卷各部份的回應均顯示，受訪者傾向將優先機會給予年齡較小、不飲酒、有較大機會存活、輪候時間較長和未接受過肝臟移植的病人。約有91%受訪者同意或非常同意，移植機會應給予存活率和得益最大的病人，亦有39%受訪者將「存活率和得益」作為決定誰獲得捐肝的首要考慮因素。然而，當問到要在八個假設情況下，如何把一定數量的(100個)捐肝分配給兩組不同特質的輪候病人的先後次序時，受訪者較傾向將優先權給予輪候時間較長的病人。

結論：雖然普遍受訪市民傾向把獲得最大利益和高存活率作為決定誰獲得捐肝的考慮因素，他們亦不會只依賴單一標準作分配。而治療的整體成本效益並非單一決定因素。

Introduction

Liver transplantation offers a long-term management strategy for end-stage liver disease.¹ In Hong Kong, the first successful liver transplant was performed at Queen Mary Hospital in October 1991 and overall, the 1-year and 5-year

patient survival rates were 82% and 77%, respectively.² Transplantation techniques have advanced greatly but there remains an organ shortage in Hong Kong. According to the Organ Transplant and Donation Statistics of the Hong Kong Medical Association (HKMA), 100 patients were awaiting a liver transplant in 2000 and over 36 000 donors were registered with the HKMA Organ Donation Registry.³ Nonetheless the number of liver organ/tissue donated was 41 in July 2000.³ The Hong Kong Liver Foundation has been promoting the concept of “organ donation to save lives”, but traditional thinking that an individual should be buried with their body intact has greatly hindered organ donation.⁴ The disparity between demand and supply of donor livers means that patients may spend up to 2 years on a waiting list. The mortality rate among such patients is over 40%, and as high as 90% in some cases.² With such a scarcity of organs, strict criteria are necessary to determine who receives a transplant.

In Hong Kong, the primary factors that determine allocation of a liver are compatible blood group and body size.¹ The need for a transplant is based on a set of medical variables derived from a model of end-stage liver disease from the US. Candidates are assigned a score (0 to 40) that corresponds with their risk of dying. Priority is given to those with the highest mortality risk and to those with a failed transplant.⁵

When the liver transplantation programme commenced, due to a lack of donors, poor funding, and the prevalence of hepatitis B virus-related end-stage liver disease, only the fittest patients qualified for a transplant. Patients in whom a poor outcome or recurrent disease were likely excluded: patients with fulminant hepatic failure, a high urgency status requiring intensive care, and hepatitis B-related liver disease or hepatocellular carcinoma. Increased experience and advances in therapy nonetheless now enable such high-risk patients to be considered for transplantation.² In spite of this, there are still disputes about the medical criteria applied to determine who most needs a transplant and criticism that the system lacks transparency.⁵

In addition to medical criteria, social and moral factors will influence the decision of who should receive a transplant. One argument is to treat patients for whom a transplant is most likely to produce the greatest possible improvement in health status regardless of the severity of the underlying condition and other considerations such as time on the waiting list.⁶ An alternative view is that consideration of other relevant factors, such as time already spent on the waiting list and previous transplant history, is a fairer means by which to determine who receives a transplant. In the UK, there are no formal criteria to determine who receives a liver: time spent on the waiting list is the principal consideration.⁷ A UK survey carried out in 2000 to determine public opinion of how donor organs should be allocated concluded that most respondents would be prepared to sacrifice some gain in the efficiency

Table 1. Attributes and levels in the pair-wise hypothetical scenarios

Attributes and their descriptions	Levels
'Age' refers to the age range of the group of individuals at the time of the transplant operation (AGE)	40 years 50 years 60 years
'Alcoholic liver disease' where 'Yes' indicates that this group of individuals have a type of liver disease that is acquired by the consumption of alcohol, and 'No' indicates that this group of individuals have a type of liver disease that is naturally occurring (ALCO)	Yes No
'Expected length of survival' where this is defined in years and relates to the life expectancy following the transplant operation (SURV)	5 years 10 years 15 years
'Time already spent on the waiting list' where this refers to the amount of time in months the individuals have already spent on the waiting list for a liver transplant (WAIT)	3 months 6 months 12 months
'Re-transplant' where 'Yes' indicates that the individuals have received a previous liver transplant, and 'No' indicates that the individuals are being transplanted for the first time (RETRAN)	Yes No

of the transplantation programme for an increase in equity or fairness in the allocation of donor livers.⁷

The objective of this study was to examine the preference and values of the general public in Hong Kong in determining which patients should receive a donor liver. This information may assist decision makers and transplant teams in ensuring that the most deserving patients are treated.

Methods

Sampling method

A sample list of 2000 household addresses—a list of addresses of permanent quarters in built-up areas—covering 18 geographical districts in Hong Kong was drawn by the Census and Statistics Department from the Register of Quarters. The Department applied systematic replicated sampling with a fixed interval in sample unit selection. An invitation to participate in the study was sent to each household before the interview. Fieldwork was carried out between 20 December 2003 and 28 February 2004. A total of 1072 households were approached for face-to-face interviews: all household member(s) aged 18 years or above were eligible to participate. The individual with the closest next birthday was selected.

Questionnaire and variable descriptions

The survey was based on a face-to-face structured interview conducted at the selected households' home, using a Chinese version of a previously used questionnaire in a UK study.⁷ Five attributes—'age of patient', 'liver disease history: naturally occurring or induced by excess consumption of alcohol', 'survival and benefit'; 'waiting list for longest period', and 'transplantation status: first transplant over a re-transplant candidate'—were generated. These attributes reflect the major decision criteria in selection

Table 2. Variables and their coding for data analysis

Variable	Type	Coding
DL—difference in the number of livers allocated as move from group A to group B	Continuous	-100 to +100
AGE—difference in age as move from group A to group B*	Continuous	-20 to +20
ALCO—difference in alcoholism as move from group A to group B	Discrete Alcohol: Yes = 1 Alcohol: No = 0	-1, 0, +1
SURV—difference in expected survival time as move from group A to group B	Continuous	-10 to +10
WAIT—difference in waiting time as move from group A to group B	Continuous	-9 to +9
RETRAN—difference in transplantation status as move from group A to group B	Discrete Re-transplantation: Yes = 1 Re-transplantation: No = 0	-1, 0, +1

* Age being -20 in instances where the age of group A was 20 years older than group B, and +20 in instances where the age of group B was 20 years older than group A

of transplant recipients in some existing transplant programmes and have raised considerable debate in empirical studies.⁶⁻¹⁰ The questionnaire comprised three sections. First, participants were asked to indicate their state of agreement with five selection criteria for transplant recipients by selecting one of the following five responses: 'strongly agree', 'agree', 'no opinion', 'disagree', and 'strongly disagree'. They were then asked to rank the five selection criteria in order of importance. Second, participants were given a set of eight randomly generated pair-wise hypothetical scenarios, and asked to allocate 100 donor livers between the two groups of 100 individuals with differing level of attributes in each scenario. All individuals were awaiting a liver transplant that was their only chance of survival. Table 1 shows five attributes and their associated levels. In three pair-wise hypothetical scenarios, three of the attributes presented had different levels. In the remaining five pairs, two of the attributes presented had different levels (two examples included in the questionnaires are shown in the Appendix). In the third section of the questionnaire, participants were required to supply demographic data such as age, education level, religion, whether they had a personal history of organ transplantation, whether any friends or family members had ever undergone an organ transplant, whether they had private insurance cover, and whether they carried an organ donor card.

Statistical analysis

Statistical package STATA (Windows version 6.0; STATA Corporation, College Station, US) was used for all analyses. For the first and third part of the questionnaire, data were analysed in terms of means or percentages. For the second part, random effects linear regression was used to analyse the difference in the number of donor livers allocated between two groups of individuals in every pair-wise hypothetical scenario. Table 2 shows a summary of the variables and their coding for regression analysis. The following equation was the estimated model:

$$\Delta DL = \beta_1 AGE + \beta_2 ALCO + \beta_3 SURV + \beta_4 WAIT + \beta_5 RETRAN + \alpha + \epsilon$$

where ΔDL (ranged from -100 to +100) was the dependent variable, and indicated the change in the number of donor livers allocated in moving from group A to group B. Coefficients β_1 to β_5 were the parameters of the model to be estimated that showed the relative importance of the different attributes. The associated P value indicates whether the attribute had a statistically significant effect on choices. Two-tailed P values of less than 0.05 were considered statistically significant. α represented the term due to the difference among observation and ϵ was the error term due to differences among respondents.

Results obtained from this study were compared with the UK study⁷ in 2000.

Results

A total of 1072 households were visited during the research period. There were 277 complete interviews (I), four partial interviews (P), one break-off interview, 289 refusals (R), and 501 non-contact (NC) cases. The response rate (RR) was 26.2% and 281 questionnaires were successfully administered. The RR was calculated using the formula¹¹:

$$RR = (I+P)/(I+P+R+NC)$$

Table 3 shows the demographic data for the participants: 55.9% of participants were female and 43.8% were male, mean age of the whole group was in the range of 36 to 45 years, 76.2% of participants had completed at least secondary education, 67.6% of participants were married, most participants (61.9%) had no spiritual or religious beliefs, no participants reported a personal history of organ transplant and only 3.2% knew friends or family members who had undergone an organ transplant, 13.5% of participants indicated that they carried an organ donor card.

Level of agreement with the five social and medical criteria for selection of transplant recipients

Table 4 shows the level of agreement with the five criteria for allocation of donor livers. The strongest level of

Table 3. Descriptive characteristic of the respondents

Characteristic	Respondents, n=281 No. (%) [*]
Sex	
Male	123 (43.8)
Female	157 (55.9)
Missing data	1 (0.4)
Age (years)	
18-25	31 (11.0)
26-35	29 (10.3)
36-45	91 (32.4)
46-55	66 (23.5)
56-65	32 (11.4)
>65	31 (11.0)
Missing data	1 (0.4)
Education level	
Primary or below	66 (23.5)
Secondary	136 (48.4)
Matriculated	18 (6.4)
Professional institution	23 (8.2)
University or above	37 (13.2)
Missing data	1 (0.4)
Marital status	
Single	73 (26.0)
Married	190 (67.6)
Divorced/separated	8 (2.8)
Widowed	7 (2.5)
Missing data	3 (1.1)
Private insurance	
Yes	107 (38.1)
No	173 (61.6)
Missing data	1 (0.4)
Religion	
None	174 (61.9)
Buddhist	57 (20.3)
Taoist	3 (1.1)
Christian	45 (16.0)
Missing data	2 (0.7)
Self-transplant history	
Yes	0 (0)
No	280 (99.6)
Missing data	1 (0.4)
Transplant history of other family member/friend	
Yes	9 (3.2)
No	271 (96.4)
Missing data	1 (0.4)
Donor card holder	
Yes	38 (13.5)
No	241 (85.8)
Missing data	2 (0.7)

^{*} Because of rounding, not all percentages total 100

agreement was accorded to 'survival and benefit': 91.1% of participants agreed or strongly agreed that "preference should be given to people who are likely to survive and benefit". Most (75.0%) participants agreed or strongly agreed that "preference should be given to those individuals whose need for a transplant arises as a consequence of naturally occurring liver disease rather than personal behaviour". A total of 73.7% agreed or strongly agreed that "preference should be given to young rather than old people", and 68.7% agreed or strongly agreed that "preference should be given to those who had been on the waiting list for the longest period of time".

A total of 59.5% agreed or strongly agreed that "preference should be given to those individuals awaiting their first transplant over those awaiting re-transplantation". A relatively high percentage (27%) of participants nonetheless expressed no opinion on this selection criterion.

Ranking of the five social and medical selection criteria

Table 5 shows the ranking of criteria in order of importance. 'Survival and benefit' was ranked first by the majority of participants, 'younger rather than older' ranked second, and 'waiting list for the longest period' ranked third. Similar to the previous section, 'first transplant over a re-transplant' was the only criterion that most participants (71.5%) ranked fourth or fifth overall. The result of this part is consistent with the level of agreement with the five criteria: 'survival and benefit' seems to be the most important criteria (39.1%). The percentages for 'younger rather than older', which was ranked second, also accounts for 37.0% participants who ranked it as first criteria, with only 2.1% difference.

Pair-wise hypothetical scenarios

The results of the random effects linear regression model and the coefficients and significant values of the five decision criteria are shown in Table 6. The coefficient of 'AGE' was -1.29; the negative sign indicates that more livers were allocated to the younger group than the older group. The coefficient of 'ALCO' was -25.55; the negative sign indicates that participants generally preferred patients with naturally occurring liver disease to those with alcoholic liver disease. The coefficient of 'SURV' was 2.70; the positive sign indicates that more livers were allocated to patients with an expected longer post-transplant survival time. The coefficient of 'WAIT' was 3.44; the positive sign indicates that more livers were allocated to patients on the waiting list for a longer period of time. The coefficient of 'RETRAN' was -14.69; the negative sign indicates that the number of livers allocated to the group of individuals who were being re-transplanted was generally lower than that of the primary transplant candidate. Of the 281 respondents, a total of 16 (5.7%) respondents exhibited dominant preferences. Nine of them exhibited the same attribute—'expected length of survival': they allocated all of the donor livers to the group of individuals with the longer length of survival regardless of the levels of the other attributes in every choice situation. A total of five (1.8%) respondents exhibited a strict egalitarian preference; they chose to allocate equal numbers of livers to both groups for every choice situation, irrespective of the variation in the levels of the attributes presented.

Discussion

Most respondents agreed that priority should be given to those individuals with higher expected survival and benefit and this was also reflected in the order of importance of the first section of the questionnaire. The results

Table 4. Comparison of the opinion on the use of specific social and medical criteria in the selection of transplant recipients, Hong Kong (HK) and the United Kingdom (UK)⁷

Criterion	Strongly agree (%)		Agree (%)		No opinion (%)		Disagree (%)		Strongly disagree (%)	
	HK	UK	HK	UK	HK	UK	HK	UK	HK	UK
Younger rather than older people	16.4	14.8	57.3	51.5	9.6	9.8	16.7	18.9	0	5.1
Naturally occurring liver disease	11.7	24.0	63.3	47.6	11.4	7.1	13.5	14.5	0	6.8
Survival and benefit	23.1	53.7	68.0	37.4	4.6	2.0	3.9	5.1	0.4	1.7
Waiting list for the longest period	13.5	15.2	55.2	47.6	16.7	14.2	14.6	20.6	0	2.4
First transplant over a re-transplant	7.5	11.1	52.0	44.6	27.0	24.3	13.2	16.6	0.4	3.4

Table 5. Comparison of the ranking of specific social and medical criteria in order of importance, Hong Kong (HK) and the United Kingdom (UK)⁷

Criterion	First (%)		Second (%)		Third (%)		Fourth (%)		Fifth (%)	
	HK	UK	HK	UK	HK	UK	HK	UK	HK	UK
Younger rather than older people	37.0	12.6	23.4	32.4	17.4	23.9	12.8	14.7	8.5	16.4
Naturally occurring liver disease	4.6	8.1	14.6	18.5	26.7	27.2	29.2	21.6	23.8	23.0
Survival and benefit	39.1	66.7	27.8	19.2	16.0	5.9	10.3	6.6	6.4	3.3
Waiting list for the longest period	16.7	9.8	26.3	19.2	22.1	27.2	21.0	29.3	13.5	14.5
First transplant over a re-transplant	2.5	2.8	7.5	10.7	17.4	15.8	25.6	27.8	45.9	42.8

Table 6. Comparison of the random effects regression model, Hong Kong (HK) and the United Kingdom (UK)^{7*}

Attribute	Coefficient		P value		95% CI	
	HK	UK	HK	UK	HK	UK
AGE	-1.2926	-1.4937	0.000	0.000	-1.6911 to -0.9061	-1.7343 to -1.2531
ALCO	-25.5501	-38.1816	0.000	0.000	-29.6587 to -21.4415	-41.2835 to -35.0797
SURV	2.6976	4.0472	0.000	0.000	1.9311 to 3.4642	3.6224 to 4.4719
WAIT	3.4427	1.1372	0.000	0.006	2.8666 to 4.0189	0.3307 to 1.9438
RETRAN	-14.6878	7.8922	0.000	0.003	-19.3632 to -10.0123	2.6800 to 13.1043
Constant	1.3457	-0.5046	0.230	0.606	-0.8520 to 3.5435	-2.4241 to 1.4150

* HK: No. of observations=2240; n=280; $\chi^2=1454.66$ (P=0.000); $R^2=0.39$
 UK: No. of observations=2413; n=303; $\chi^2=1632.4$ (P=0.000); $R^2=0.43$

were similar to findings in the UK study⁷ (Tables 4 and 5). Nevertheless, when faced with a choice between the two groups of individuals in the second section, participants would allocate relatively more donor livers to those who had waited longer or had a higher expected life year gain after transplantation. Fewer organs were allocated to those groups who were older or re-transplanted candidates or had alcoholic liver disease. The mean coefficient for 'waiting time' (WAIT) was larger than that for 'survival and benefit' (SURV) in Hong Kong, contrary to results from the UK study (Table 6). This indicates that participants in Hong Kong were more concerned about the time candidates had already spent on the waiting list and allocation should be on a 'first-come-first-served' basis. The underlying premise might be that all individuals on the waiting list were considered to be deserving cases who should be treated equally. This is in agreement with several empirical studies.^{10,12,13} People are also concerned about 'fairness' in allocation decisions and they do not agree with the utilitarian view that health maximisation should be the only objective of health policy when there is a need to prioritise between different patients and different interventions.

Surprisingly, the coefficient of the attribute RETRAN

in Hong Kong was in negative sign (-14.69). This indicates that re-transplant candidates should be given lower priority in receiving a transplant. Public opinion may hold the view that everyone deserves a first chance and that this is more important than giving re-transplant recipients a second chance. This is in contrast to the UK study⁷ in which the coefficient of RETRAN was positive (7.89) [Table 6]. Such decisions may have been made on the premise that re-transplant candidates deserve to be given another chance if their first transplant failed due to medical reasons. The difference shows a robust moral pluralism. There are divergent understandings of the concern for fairness and there is no single moral principle in the health care distribution justice. Some people may feel that everybody is entitled to have his/her life saved once, regardless of the associated costs and benefits, and should have a first chance before others are given a second chance. Nonetheless it can be argued that, other things being equal, re-transplant candidates should be given the same priority in receiving available organs. One can further argue that, as re-transplant recipients are sicker, on average, than primary transplant recipients, to turn these severely ill patients away because of lower chances of survival violates the duty to help patients with most urgent needs.

Three quarters of participants in Hong Kong agreed that preference should be given to candidates with 'naturally occurring liver disease' and the coefficient of 'ALCO' was -25.55. In the UK study,⁷ the corresponding figures were 71.6% and -38.18, respectively. In both studies, respondents believed that fewer chances should be given to candidates with alcoholic liver disease. Nonetheless, the survival of patients receiving transplants due to alcoholic cirrhosis does not appear to be any lower than that of non-alcoholic transplant patients in the US.¹⁴ There is also no significant evidence that alcoholics are more likely than non-alcoholics to drink after their transplant. Some studies suggest that alcoholics and non-alcoholics consume similar amounts of alcohol after their transplantation.¹⁴ Thus alcoholic liver disease should not become a selection criterion for allocation although candidates with such disease may frequently present with other alcoholic-related disorders such as chronic pancreatitis.

It is argued that all allocation policies need to be based on some ethical theories of distributive justice and social utility, and provide all patients in need of a transplant with continuous, fair, and equal treatment, regardless of race or personal/behavioural history (such as alcohol consumption) while maximising the benefits of transplantation. This emphasises the greatest good for the greatest number of people. Yet the concerns for fairness and social utility can conflict. The greatest social good may be achieved if alcoholic patients are aware that they might not receive a liver transplant. This may lead to a drop in the number of alcoholics in society.¹⁴ Nonetheless it may be seen as unfair to deny individuals with an unhealthy lifestyle equal access to a liver if their chance of survival is the same as those with a relatively healthy lifestyle. This presents another organ transplant dilemma that cannot be resolved by relying on one ethical principle or theory.

Conclusion

Respondents in all sections expressed a strong preference for the young over the old, non-drinkers over drinkers, those more likely to survive, those who had waited longer on the list, and primary candidates over re-transplant candidates. Participants were unlikely to rely on one criterion for allocation and would consider criteria besides the overall cost-effectiveness of the intervention. Providing a donor liver for a candidate necessarily means that there will be one less liver available for other candidates on the waiting list. Deciding who should receive a liver is fraught with problems. Apart from considering patients' medical conditions and characteristics, policy makers and transplant teams have also inevitably considered, though not explicitly, social utility and distributive justice. The balance concerns about what is best for society with the fair allocation of scarce livers. It would be unwise for policy makers to draw

a normative conclusion based solely on one public opinion survey. It is inevitable that the basis of efficiency of utilisation will continue to be the major concern of health care policy. Nonetheless, allocation of scarce health resources cannot ignore a society's underlying resource distribution philosophy. Public opinion should be considered.⁶ Further research is needed to examine ways in which collaboration between the public and health care sector can be improved and how best to promote public discussion on all aspects of organ transplantation.

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Appendix

Examples of pair-wise hypothetical scenarios

Choice 1

	Group A	Group B
Age	50 years	60 years
Alcoholic liver disease	Yes	Yes
Expected length of survival	15 years	10 years
Time already spent on waiting list	6 months	3 months
Re-transplant	Yes	Yes
Total = 100		

How would you allocate the available livers between the two groups of individuals (the total for the two groups should add up to 100)?

(Please write the number of livers allocated to each group in the boxes above)

Choice 4

	Group A	Group B
Age	50 years	40 years
Alcoholic liver disease	Yes	No
Expected length of survival	5 years	5 years
Time already spent on waiting list	3 months	3 months
Re-transplant	No	No
Total = 100		

How would you allocate the available livers between the two groups of individuals (the total for the two groups should add up to 100)?

(Please write the number of livers allocated to each group in the boxes above)

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