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Decision Making in Liver Transplant Selection Committees

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Abstract

Background—In order to receive a liver transplant, patients must first be placed on the waiting list – a decision made in most transplant centers by a multidisciplinary committee. The function of these committees has never been studied.

Objectives—To describe decision making in liver transplant committees and identify opportunities for process improvement.

Design—Observational multi-center

Setting—We observed 63 meetings and interviewed 50 committee members at 4 liver transplant centers.

Study Subjects—Transplant committee members.

Measurements—Recorded transcripts and field notes were analyzed using standard qualitative sociological methods.

Results—While the structure of meetings varied by center, the process was uniform and involved reviewing possible reasons for patient exclusion using primarily inductive reasoning. Stated justifications for excluding patients were a) too well, b) non-hepatic comorbidities or advanced age, c) too sick in the setting of advanced liver disease, d) substance abuse, or e) other psychosocial barriers. Dominant themes identified included members' angst over deciding who lives and dies, a high correlation between psychosocial barriers to transplant and patients'

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socioeconomic status, and the influence of external forces on decision making. Consistently identified barriers to effective group decision making were: 1) unwritten center policies, and 2) confusion regarding advocacy versus stewardship roles.

Limitations—The use of qualitative methods provides broad understanding but limits specific inferences. These four centers may not be reflective of every transplant center nationwide.

Conclusion—The difficult decisions made by these committees are reasonably consistent and always well-intentioned, but might be improved by more explicit written policies and clarifying roles. This process may help inform resource allocation in other areas of medicine.

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Each year more than 40,000 patients die of liver disease in the United States(1), but only 6,000 liver transplants are performed(2). The problem of fairly allocating this limited organ supply has interested transplant professionals, ethicists, and the general public for years. However, the overwhelming majority of this literature has focused on determining priority on the waiting list. The necessary first step, access to the waiting list, has garnered considerably less attention.

In order to be placed on the waiting list for transplantation, a patient must first be referred to a transplant center. At most centers these patients are evaluated in clinic or as inpatients, various tests are performed, and the patient is then discussed in the weekly transplant selection committee meeting. Despite the importance of these meetings, their structure and function has not been clearly delineated. Although the United Network for Organ Sharing (UNOS) has issued policies regarding the composition of personnel at a transplant center(3), and the American Association for the Study of Liver Disease (AASLD) has put forth guidelines on the criteria for determining candidacy(4), no policy, guideline, or empirical research exists regarding the *process* by which candidacy for liver transplantation is determined.

Understanding the actual decision-making process is important for several reasons. The first is transparency: as stewards of a scarce resource, transplant professionals owe society a clear view of their actions(5). The second reason is process improvement. Cognitive science has demonstrated that decision making is often automatic, based on previously constructed prototypes, or images stored in memory that may not correspond to actual objects(6). Thus, decision makers can learn about aspects of decisions that may not have been conscious, and a taxonomy of the types of decisions made in committee meetings might facilitate clearer discussions. Additionally, transplantation remains one of the few areas in American medicine where physicians explicitly ration care, and lessons learned in this arena can be used to better understand resource allocation as a whole. For these reasons, we undertook a multi-center study of decision making in liver transplant selection committees. The aim of our study was first to describe the process of decision making about adult liver transplant candidacy using qualitative research methods. The second aim of our study was to identify potential opportunities for process improvement.

Methods

Data Collection

This study was performed at four distinct adult liver transplant centers in the United States, as shown in **Table 1**. These centers were chosen by purposeful sampling, based upon their geographic location, transplant volume, and severity of organ shortage as determined by the proportion of recipients with Model for End-stage Liver Disease (MELD) score >20 at transplant. Data was gathered using the qualitative methods of observation and interviewing,

methods that have gained increasing acceptance in medicine and the social sciences(7). An experienced sociologist (RA) observed 63 meetings of selection committees, made audio recordings when permitted by institutional review boards (28 meetings at hospital 1, 4 meetings at hospital 2, and all 10 meetings at hospital 4) and took field notes during the remaining meetings (14 meetings at hospital 1, 3 meetings at hospital 2, and all 4 meetings at hospital 3). A transplant hepatologist (MV) observed 31 of the 63 meetings (at least one meeting per center). Both researchers read all the transcripts and compared their observations and interpretations, which were quite consistent.

Additionally, the sociologist conducted individual interviews with key personnel at each center. Fifty of the sixty-eight committee members (74%) were able to be interviewed. The interviews used a semi-structured format, in which the lead-in questions use the same wording but the subsequent probes are variable (see Appendix A for Interview Guide). This standard sociological format provides a balance between validity and reliability: open-ended questions maximize validity by eliciting respondents' perspectives with minimal semantic structuring by the researcher, while asking comparable lead questions maximizes reliability(8). These interviews were audio-recorded and transcribed and addressed subjects' conceptions of the goal of transplant committees, the roles of key participants, logistical problems that interfere with the work of the committee, approaches for dealing with disagreements, and the most difficult issues faced by the committee. The interviews were also used as a validation method to determine whether committee members' perspectives on the meetings were consistent with the researchers' observations.

Data collection took place between February 2008 and December 2009, and an overview of the numbers of meetings and interviews at each center is shown in **Table 2**. Individual patient records were not included as part of the data collection. In order to preserve confidentiality of transplant center personnel, no identifiable center-level data will be presented. This study was approved by the Institutional Review Board at each center.

Data Analysis

Analysis was performed using the method of grounded theory, which was originally developed as part of a study on end-of-life care(9). Rather than developing hypotheses before beginning the research and seeking to test them, this well-established method involves systematically developing findings inductively from the data(7). Transcripts and field notes were imported into NVivo 9®(QSR, Doncaster, Australia), a qualitative data analysis package for storing files and organizing information. In an iterative fashion, segments of text were assigned codes (categories), and codes were organized into themes which combine to create a unified framework. Regular meetings between the main investigators (MV, RA) allowed analysis of these categories and themes from the perspectives of a transplant physician and a medical sociologist. The centers were compared and contrasted, as was data from transplant committee meeting observations and interviews. Observation and interviewing are distinct qualitative methods, each having its own strengths and weaknesses. Observation gives the researcher detailed information on meetings as they occur, but carries the risk of misinterpreting what is occurring. Interviewing allows the researcher to explore group members' meanings and interpretations, but yields highly selective accounts and narratives(8). Comparison of data from these two complementary methods was used to develop a more complete and balanced account of the decision-making process, which will be presented below using direct quotes as examples.

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Results

Structure

Each center conducted weekly selection committee meetings which invariably included transplant coordinators, surgeons, hepatologists, and social workers. However, the composition of other members and the structure of the discussions differed substantially by location. At some centers the committee included experts in neuropsychology, chemical dependence, finance, while in other centers the social workers assumed the majority of these roles. One of the committees included an ethicist, on a part-time consultative basis. The flow of the meeting discussions was coordinated by a different person in each center – coordinator, medical director, or surgical director. The actual patient presentations were given by hepatologists in some centers and by coordinators in others. Finally, some centers waited to present patients once all the information was acquired to make the final decision, while other centers had multiple discussions over time as new information became available.

Function

Despite substantial variation between centers in the structure of committee meetings, their function was fairly uniform. The committees would first review the patient's liver history and other medical problems, and then discuss issues of substance abuse, social support and finances. In this manner, the decision-making process involved an ordered review of possible reasons for exclusion. None of the committees used a formal vote, but rather spent considerable time building informal consensus – discernable in most cases by the lack of any further objections to the decision. When the group appeared unable to reach a decision, the Medical or Surgical Director typically formulated a plan that incorporated participants' concerns and brought the decision to closure. Despite the occasional strong individual personality who would dominate some discussions, the atmosphere was civil. In fact, when interviewed, committee members, including coordinators, noted that the decision-making process was democratic and were pleased that their views were solicited. Comments included "we're really a team" and "the process is very democratic."

Taxonomy of decisions

Decisions made by the committees fell into three categories: 1) list, 2) defer pending further information, and 3) rule out. The stated justifications for a "rule out" decision were as follows:

1. Too well. Everyone seemed to happily accept this reason, and it generated little controversy. Note that the group tended to defer to the hepatologists in these cases.
2. Non-hepatic comorbidities or advanced age. While this reason did generate some discussion, only the physicians participated and the discussion had a relaxed feeling. There was a clear effort to distinguish illnesses unrelated to liver disease. For example, one physician remarked "You want to make sure the patient dies of something other than your disease."
3. Too sick, in the setting of very advanced liver disease. This reason generated lots of discussion and verbal expressions of guilt. The sense of guilt seemed particularly strong with long-standing patients of the physician committee members, and in cases where the current medical situation was related to past treatments (such as prior transplant or antiviral therapy for hepatitis C). For example, one physician remarked "He was a robust guy, and we did this to him." In these and other cases, medical and psychosocial factors were explicitly weighed against one another such that a borderline medical candidate might be deemed appropriate if he/she was exceptional from a psychosocial perspective.

4. Recent or active substance abuse. With a few exceptions, there was relative consensus among committee members that this constituted sufficient grounds for ruling out a prospective patient. All committees required six months of abstinence for these patients, but the requirements for substance abuse counseling were individualized.
5. Other psychosocial barriers, including psychiatric disease, lack of or inadequate social support, noncompliance or failure to complete testing, and inadequate insurance. These discussions were at times protracted and contentious. Social workers and other mental health professionals were asked to assess the adequacy of patients' social support and potential psychosocial impediments to treatment. In contrast to other parts of the conference, non-physician committee members played a more active role in these discussions. These decisions rarely concluded in one meeting, but rather were usually drawn out over several meetings. At one point a committee member commented "Look, this is ridiculous, let's not talk about this for four eval meetings in a row." When interviewed, members routinely cited psychosocial issues as among the most difficult topics addressed by the committees.

Methods of reasoning

Whenever possible, committee members began discussions using deductive, or rule-based reasoning (i.e. the 6-month rule for substance abuse, or appealing to transplant center policy as a source of authority)(10). Since this was not possible in many cases, members relied primarily on inductive, or judgment-based reasoning. In contrast to rule-based reasoning they tended to soften their stance ("In my opinion this patient is too sick, what do you think Dr. X?"). Only in the most difficult cases did the committee resort to casuistry, or case-based reasoning ("This case reminds me of Mr. Y, and we transplanted him"). This rarely resolved the dilemma because details of former cases were not immediately available.

Dominant themes

Several themes emerged from these observations. First, committee members are clearly uncomfortable deciding who lives and dies. Even very experienced members seemed to agonize over the decisions, and would make statements that appeared to deflect responsibility. For example, it was frequently stated that transplant is "not in the patient's best interest" or "risk outweighs benefit" rather than the more nuanced assessment that the patient would actually benefit, but not sufficiently to justify use of a scarce organ. The second theme was the high correlation between psychosocial barriers to transplant and socio-economic status. While there was no evidence that committees overtly judged candidacy on the basis of social worth, assessments of a patient's ability to carry out necessary treatment plans would include such factors as education, intelligence, and financial resources. Examples include: "She's a simple lady", "Yes, but do you think she's sophisticated enough?", "He's been working throughout his adult life", "He seems like an upstanding citizen", "He is notable because he is high functioning, articulate, and sophisticated." A third dominant theme that emerged was the influence of external forces. In an ideal world, deciding which patients to transplant would be based exclusively upon maximizing benefit from the limited organ supply. However, the real world is such that transplant programs must consider things like their reputation, performance statistics, and business relationships(11), and these factors were clearly considered by transplant committees when evaluating patients. Thus, in three of the four centers, some meetings contained discussions of the centers' performance statistics, and references were made to these statistics throughout patient discussions: "Actually it does make a difference – if you're delisted, it's a death on the waiting list", and "If we were a 15% tumor program I wouldn't

worry about it, but we're at much higher risk than a smaller place (referring to expanding criteria for hepatocellular carcinoma).” Other considerations such as potential malpractice lawsuits and referral relationships also entered the discussions: “There we were driven by fear of litigation” and “If we don't transplant her then (that doctor) will stop referring to us.”

Strengths and Weaknesses of the Decision- Making Process

At the end of each interview, members were asked about their views on current functioning of the committee and what, if anything, they would change. Responses were grouped into categories as shown in **Figure 1**, according to whether the member was commenting on a strength or a weakness(12). Medical, psychosocial, and administrative members commented favorably on the climate of collegiality and the positive working relationships between committee members. The most common criticisms of the current process concerned professional roles, organization/efficiency, or consistency/fairness. Physicians were most likely to comment on professional roles, including the perception that meeting participants would often make comments outside their area of expertise. For example, in two hospitals some physicians made comments such as “Before long you start thinking you know more than you really do about a subject.” Comments on organization/efficiency included complaints of chatter and side conversations, failure to document thought process such that in subsequent meetings cases would be “re-hashed” from the beginning, and written transplant center policies not being available to all members. Comments on consistency/fairness tended to focus on perceived deviations from policies and lack of consistent attendance such that patient decisions would depend in part on the members present. Quotes included “We're not being consistent” and “This is not what we did in past cases.” Based on all these comments and on meeting observations, two main barriers to effective group decision making became apparent:

1. Unwritten or unavailable policies. In interviews and in meetings, we found numerous references to transplant center policies that were unclear, or not written. – “The new rule is that if someone is transplanted within 24 hours of intubation, it's OK” and “So do we have a policy then?” (transplant coordinator), and “I'm not advocating a position, I'm just trying to understand whether, what our policy kinda is I guess”. These unwritten policies were referenced at all four centers by both medical and non-medical personnel. They sometimes reflected decisions made by program leadership, and sometimes reflected past practices. Even in centers which had written policies, some committee members reported being unable to locate them.
2. Confusion regarding advocacy versus stewardship. Consistent with our observations, physicians reported in interviews a tendency to argue more strongly for patients with whom they had a long-standing relationship, and patient discussions in meetings without a physician advocate present tended to be shorter and more negative in tone, contributing to perception of inconsistency expressed by coordinators and social workers as well as physicians. However, at times this advocacy also led to role confusion. In several instances, after a heated debate in the meeting, members were interviewed and remarked “I was just advocating for the patient – I actually don't think he's a good candidate.” Members complained that they were never sure if a physician was defending a firmly held position or merely acting the role as patient advocate.

Discussion

This multi-center study of liver transplant committees found significant variation in structure by center, but relative uniformity in function. The process of determining candidacy

involves a systematic search for exclusion criteria, relying primarily on inductive reasoning in a search for informal group consensus. Patients are ruled out on the basis of a well-defined group of reasons – either they are too well to need a transplant, or for medical or psychosocial reasons they would have poor outcomes despite receiving a transplant. This practice follows the time-honored rule of medical triage(13). Overall, the process seems to work well, and the general public should be reassured that these committees take their organ stewardship responsibilities very seriously.

Nonetheless, our observations of decision making at the four centers suggest some dominant themes which deserve further attention. The distinction between “unlikely to benefit” versus “unlikely to benefit enough to justify use of a scarce organ” is a subtle but important one. While the simpler version may be easier when discussing this complex calculus with patients, we contend that internal honesty should be maintained within committees. And although committee members are forced to judge psychosocial factors such as ability to adhere to the treatment plan, it is important to be cognizant of the overlap with judgments about social worth. Finally, efforts should be made to minimize the influence of external forces on candidacy decisions, both at the institutional and the public policy level. For example, decisions about which performance metrics to publicly report should consider not only methodological factors but also the impact these metrics might have on transplant center behavior(14, 15). Transplant centers with poor performance metrics risk closure or losing contracts with insurance companies. Given current constraints, it may not be possible to eliminate such considerations from decision making. However, centers should attempt to follow what Rawls(16) calls a “lexical ordering”, in which medical risks and benefits are addressed before external constraints are considered. It is possible that the involvement of a medical ethicist, at least as a periodic attendee, would help transplant centers wrestle with these difficult conundrums.

In addition to the themes observed by the researchers are the problems noted by selection committee members themselves. Based on members’ comments, we propose two possible strategies for process improvement, which should be prospectively evaluated in future studies. The first would be to write down as many transplant center policies as possible. Having accessible written policies may improve efficiency and consistency, particularly when the composition of the committee varies, and when a patient's case is discussed on repeated occasions. Written protocols have been implemented successfully in such diverse areas of medicine as improving hospital safety and reaching end-of-life decisions(17). Written policies could also alleviate some of the burden on committee members of deciding life and death. The second strategy would be to identify a designated patient advocate for each discussion. In other settings, a designated proponent has been shown to improve the quality of group decision making(18). Doing this for transplant committees might eliminate the confusion that is caused when the group does not know whether a committee member is defending a firmly held position, or simply acting as an advocate. It could also improve consistency, particularly in cases where the patient's primary physician is not present at the meeting. To be most effective, the advocate's role would need to be clearly defined at the outset, including the extent to which he or she is expected to argue the case.

These findings should be interpreted in the context of the limitations of this study, which evaluated only four transplant centers. While this sample was adequate for clear patterns to emerge, it is not necessarily representative of all transplant centers nationwide. Furthermore, the qualitative methodology employed allows a “big picture” view of the decision making process, but is unsuitable for answering specific questions. Because the focus of the study was decision making process rather than criteria, data from individual patient charts was not gathered. Details about the specific centers were disguised in order to protect committee members’ confidentiality, and not all members of each committee were able to be

interviewed. Another limitation is that we did not observe bedside discussions about hospitalized patients, and therefore cannot present data about this mechanism for determining candidacy which sometimes occurs outside the usual channels. Finally, as with any observational study there exists the possibility of the Hawthorne effect, whereby study subjects change their behavior while being observed. Despite these limitations, we believe our data provides useful information and new insight into a process which has never been empirically studied.

In summary, liver transplant selection committees at different locations have evolved a remarkably similar process. The difficult decisions made by these committees are reasonably consistent and always well-intentioned, but might be improved by more explicit written policies and a formally designated advocate for each patient. This process may also help inform resource allocation in other areas of medicine.

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Figure 1. Members' (n=45) views on functioning of transplant committees. The scale reflects number of times each topic was mentioned as a problem (negative axis) or strength (positive axis). The responses should not be interpreted as the number of interviewees who agreed with strengths and weaknesses formulated a priori by the researchers. Rather, responses to open-ended questions are considered a measure of salience(12) and the bars indicate the number of respondents who spontaneously voiced these issues.

Table 1
Characteristics of the liver transplant centers studied, with comparison to the 114 adult liver transplant centers in the United States.

	Hospital 1	Hospital 2	Hospital 3	Hospital 4	Average U.S. transplant center
Geographic location	Midwest	West Coast	Southeast	Midwest	25% Midwest 14% West Coast 30% Southeast 31% other regions
Hospital setting	University	University	University	Private	61% University 27% Private 12% other
Liver transplant volume	75-100 transplants/yr	>100 transplants/yr	50-75 transplants/yr	75-100 transplants/yr	75-100 transplants/yr
Recipient disease severity	32% with MELD>20 at transplant	44% with MELD>20 at transplant	32% with MELD>20 at transplant	36% with MELD>20 at transplant	42% with MELD>20 at transplant

Data obtained from the Scientific Registry of Transplant Recipients (www.srtr.org) for the study period.

IQR = interquartile range. MELD = Model for End-stage Liver Disease.

Table 2

Number of Interviews, by Hospital and Type of Committee Member.

	Hospital 1	Hospital 2	Hospital 3	Hospital 4	TOTAL
Hepatologists	7	2	5	3	17
Surgeons	4	1	1	3	9
Coordinators	1	2	3	4	10
Financial coordinators	1		1		2
Social workers	2	2	2	1	7
Psychologists			1	1	2
Other clinical				1	1
Other administrative		1	1		2
Total Interviews	15	8	14	13	50

Tape recording was not allowed by the Institutional Review Board of Hospital 3, while field notes were not needed at Hospital 4 due to ability to record all attended meetings.