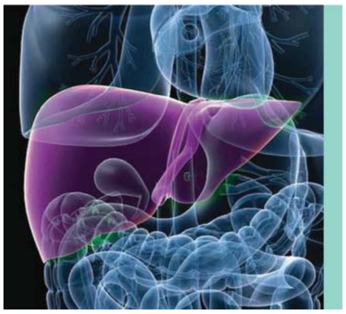

Patient-Centered Liver Transplantation

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The field of liver transplantation remains one of the last bastions of paternalism in medicine. Whether constrained by geography or insurance contracts, most patients have little choice about which transplant program they visit. To get on the transplant list, they must undergo a long list of tests, a list that is unpublicized and keeps changing based on results of initial testing. During this process their compliance is constantly scrutinized. After jumping through all these ''hoops,'' their fate is determined by a committee of medical professionals who meet privately behind closed doors.[1] Those fortunate enough to overcome these hurdles are then ''on call 24/7'' for organ offers, often being called in for a possible transplant and then sent home with little explanation. This disempowering experience is further exacerbated by constant harassment from the insurance company with denials of payment for tests that are mandatory to receive a lifesaving transplant. Then, after every shred of initiative and autonomy has been stripped away, patients who undergo transplantation are expected to serve as responsible stewards of an organ for the rest of their life.

FOSTERING PATIENT AUTONOMY AND PERSONAL RESPONSIBILITY

The earlier hyperbole is intended to make a point. Liver transplantation is far from the only service line that occasionally fails to treat the patient as a person. And there are very good reasons for the system just described. Patients being considered for liver transplantation often suffer from progressive debilitation and encephalopathy that compromise their ability to care for themselves. Furthermore, some patients have a long history of substance abuse that raises concerns about them serving as good stewards of a precious societal resource. Given the scarcity of organs, some type of selection process is needed. However, it is critical to avoid conflating ability to care for an organ with value judgments about social worth. Just because some of the patients we care for have histories of substance abuse does not mean we should not strive for the ideal patient experience. The more educated and empowered patients become, the more they can serve as active partners rather than passive consumers in health

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care. In other words, patient-centeredness can improve outcomes. This causal inference has been demonstrated in various settings including acute myocardial infarction, primary care, and kidney transplantation.[2-4]

PATIENT-CENTERED CARE

In its landmark report ''Crossing the Quality Chasm,'' the Institute of Medicine defined patient-centered care as ''care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions.''[5] How can ''patient-centeredness'' be achieved? Many find this term to be nebulous and subjective, that is, difficult to define and measure. Others assume that being patient-centered means letting the patient make unguided medical decisions (it most certainly does not). Rather than struggling toward a consensus definition, it may be useful to instead focus on a related yet more concrete concept: patient involvement. If patients are heavily involved in their care, chances are that this care will be patient-centered. Possible ways to achieve this goal include motivational interviewing, prehabilitation, using technology, developing a sense of community, and program leadership.

Motivational Interviewing

This is a technique originally developed for substance abuse counseling, which seeks to bring out the patient's intrinsic motivation rather than attempting to impose behavior change externally. Steps in this technique include: (1) *engaging* the patient in a discussion of his/her hopes and fears, (2) *focusing* on the changes necessary to achieve these hopes or mitigate fears, (3) *evoking* the patients intrinsic motivation to meet goals that they themselves set, and finally (4) *planning* for how to accomplish those goals. A common example would be a 55-year-old man who needs to lose 30 pounds in order to be eligible for liver transplantation. Rather than simply telling him, ''You have to do this,'' the motivational interviewing approach would use the earlier steps to guide the patient in setting this goal. Motivational interviewing has been shown to be effective in multiple randomized controlled trials, and use of this technique may have longer-lasting benefits by increasing patient engagement and personal responsibility for health care.[6]

Prehabilitation

Now that our obese patient has set his own goal of losing 30 pounds, we need to help him accomplish that goal. Multiple randomized trials have demonstrated that structured weight-loss programs are more effective than simply telling the patient to lose weight, yet the latter is typically what is done.[7] Even patients who do not need to lose weight would benefit from smoking cessation, dietary improvements, and increased physical activity. (We measured physical activity among 40 of our listed patients using an electronic pedometer, and they averaged only 1,000 steps/day; the average American takes just more than 5,000 steps/day).[8] Furthermore, it can be very empowering for patients to tell them, ''Here's what you can do to improve your chances of getting and surviving a transplant,'' rather than waiting helplessly.

The concept of *prehabilitation* has recently proved successful in a variety of surgical settings and could be particularly valuable for organ transplantation given the prolonged waiting times.[9] Therefore, we created and pilot-tested a simple prehabilitation program at our center. Medical students enrolled the patients, helped them set goals, and called them weekly to track their progress. Each patient was given an activity tracker (Fitbit), a log for tracking their diet and activity, a daily protein and calorie supplement (Nestlé Boost Breeze Juice Drink or BOOST Glucose Control), and access to individualized resources as needed, such as smoking cessation programs or weight-loss counseling. Eight patients were enrolled and participated in the program for 3 months. All patients completed the program and were compliant with requirements of the program, and recorded very high satisfaction scores about their participation (4.8 on a 5-point Likert scale). Participants had measurable increases in activity, with an average increase of daily steps from 6,122 (week 2) to 8,954 (week 8; $P < 0.001$), and an increase in average 6-minute walking distance from 392 to 455 m ($P = 0.05$). Two patients who had weight-loss goals as part of the program lost 11 and 15 pounds, respectively.

Using Technology

The liver transplant process involves quite a few high-stakes decisions, including whether to undergo transplantation, which organ to accept, or even when it is necessary to proceed to the emergency department. Truly engaging patients in shared decision making is difficult because of time constraints and challenges in risk communication. Many patients are functionally innumerate and cannot mentally process the difference between a 5% and a 10% risk. Close monitoring of patients is likewise limited by resource availability. We all know that patients would have better outcomes and satisfaction with care if we called daily to check on them, but few transplant programs can afford to do that. Here is where technology can help. For organ acceptance decisions, we have developed a patient decision aid to help educate patients on risk tradeoffs.[10] In our validation study, use of the decision aid resulted in better knowledge scores and increased willingness to accept marginal organs.[11] This may not only increase patient engagement, but also decrease the risk that a patient will decline a perfectly usable organ in the middle of the night. For pretransplant monitoring, we have pilot-tested the use of automated phone systems to prevent unnecessary hospitalization.[12] Others have used technology for posttransplant monitoring: the group at the University of Cincinnati has developed a telehealth tablet program with daily tracking of symptoms and vital signs, medication and testing reminders, and the ability to videoconference with staff at the transplant center.[13]

Developing a Sense of Community

Liver transplantation can be an isolating experience. Many patients feel stigmatized, even if their liver disease is unrelated to substance abuse.[14] As the illness progresses, patients are typically unable to participate in the work and social activities that used to keep them connected to other people. This social isolation can have negative psychological and biological health consequences.[15] Many programs have patient support groups, which can help develop a new sense of community with other patients and the transplant program, thus increasing patient involvement. We have recently begun using technology to videoconference with patients who cannot attend in person because of distance or infirmity. Another way to develop this sense of community would be a formal peer-mentoring program, which has been shown to be effective in other disease such as diabetes.[16] In our early experience with a peer-mentoring program at our centers, patients and caregivers have often cited their peer mentor as an ''essential'' or ''critical'' piece of their successful journey to transplant.

Program Leadership

It occurred to us while writing this review that to be truly patient-centered, transplant programs should involve patients in leadership and governance. At a macrolevel this could take the form of a patient advisory board or patient presence at strategic retreats. At a microlevel, one or more patients could be assigned as an advisor to the office manager, to help improve things such as response to phone calls, things that have a large impact on patient satisfaction but are often invisible to physician leaders. We plan to try out this idea in our own programs.

SUMMARY

We are in the midst of an information revolution in health care. Tools such as the Internet, patient portals, and mobile health devices are in the process of decreasing information asymmetry between patients and providers. The trick is to use this technology to increase patient involvement without eroding the ''mastery, autonomy and purpose'' that foster professional satisfaction.[17]

The inherent complexity of liver transplantation means that it will take more effort to make care patient-centered than in other areas of medicine. However, the effort should pay dividends, not only in patient satisfaction but in better outcomes, which all transplant programs carefully and nervously scrutinize. Finally, harnessing the energy of patients and families is a cost-effective approach for programs to improve care. The earlier list is far from exhaustive, and we encourage readers to share their ideas. One forum for this might be the newly developed ''Public Health/Health Care Delivery'' Special Interest Group of the American Association for the Study of Liver Disease. We are in the process of creating a Web site for members to share resources and best practices for improving patient care.[18] Although there are likely diverse approaches to achieving patient-centered liver transplantation, it is clear that increasing patient involvement is the critical component.

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