

Adapting patient education for potential liver transplant recipients in a climate of chronic donor organ shortfall

Liver transplantation is the established treatment for selected patients with acute liver failure or decompensated chronic liver disease. The procedure is not without its risks, however, and not every patient will survive. Although seldom recognized in the literature, education of patients is vital to the safety and success of transplantation. Before patients are accepted onto the transplant waiting list, both the patients and their families/caregivers must gain a complete understanding of the transplant process. In Birmingham, patients are not accepted onto the waiting list until a support package is agreed upon and in place. Patients and their partners/caregivers are required to attend a group teaching session presented by the transplant coordinators. This form of group teaching was introduced in response to the ever-increasing workload of the team due to an increase in the number of patients on the waiting list brought about by the chronic shortage of donor organs. An audit of this method of teaching was undertaken, and its effects on patients, their caregivers, and the coordinator team are described. (*Progress in Transplantation*. 2009;19:59-63)

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Liver transplantation is now the established treatment for selected patients with acute liver failure or decompensated chronic liver disease.¹ About 125 adult liver transplants are performed at the Queen Elizabeth Hospital in Birmingham, United Kingdom, each year. The procedure is not without risks, however, and not every patient survives. Impairments in physical health, emotional well-being, and quality of life² are also reported. Careful selection of patients who are likely to survive and do well after liver transplant is therefore an important responsibility of transplant teams.³

Many patients' "transplant journey" starts months before transplantation after a hospital admission for "transplant assessment" and acceptance onto the transplant waiting list. The assessment process is a physical, social, and psychological evaluation of the person and their liver disease. The aim is to ensure that liver transplant is the right treatment, is done at the right time, and is as safe and as successful as possible.

The Importance of Patient Education

Although seldom recognized in the literature, patient education is vital to the safety and success of a

transplant. Transplant recipients might be assumed to be a highly motivated group, and their compliance with follow-up and medication regimens should be high. Unfortunately, such is not the case.⁴ Comprehensive education of patients and their families can increase compliance through understanding and can enhance many other self-care techniques that may improve outcomes and graft survival.⁵ Before patients are accepted onto the waiting list, they must understand what transplantation involves, from acceptance onto the waiting list to recovery from a transplant and life after a transplant. It is vital that the patients' caregivers understand this process. Both patients and their caregivers need a complete understanding of the transplant process,³ not only to ensure that caregivers understand the issues in order to better support the patients but also for the benefit of the caregivers themselves. Caregivers need to be aware of the potential effects on themselves and their relationship with the patient. The process of transplantation can cause significant deterioration in family relationships that leads to conflict.⁶ In Birmingham, patients are not accepted onto the waiting list until a support package is agreed upon and in place.

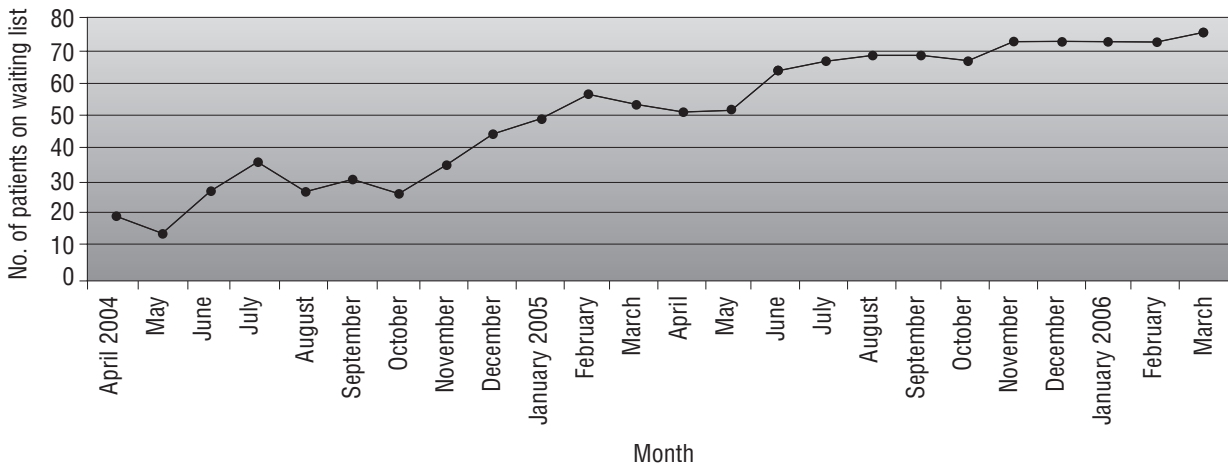


Figure 1 Number of patients on the waiting list from April 2004 to March 2006.

Role of Liver Recipient Transplant Coordinators

At the Queen Elizabeth Hospital, the education of potential liver transplant recipients is the responsibility of the liver recipient transplant coordinators, a team of 4 nurses with more than 50 years of experience in hepatology and liver transplant nursing between them. In a typical week, 1 coordinator is working with transplant recipients, 1 is working with patients undergoing transplant assessment, 1 is working in the liver outpatients department or with pre-transplant pediatric patients at Birmingham Children’s Hospital, and 1 is on study leave, annual leave, working on personal or team projects, or manning the office telephones.

Each week, 3 to 5 patients are admitted electively or referred as inpatients to the liver recipient transplant coordinators for transplant assessment. At the start of the week, the coordinator meets each patient and has a relatively informal talk about the assessment process, explaining what investigations will be undertaken, who the patient will meet, what the outcome of the assessment may be, and what will happen if the patient is accepted onto the transplant waiting list. Coordinators obtain information about patients, check patients’ understanding about their liver disease, determine what patients’ expectations are, ascertain what family or other social support patients have, identify any problems that may affect the transplant process, and answer any questions. Patients also are given comprehensive written information about liver transplantation.

The Change to “Group” Teaching

Patients admitted to Queen Elizabeth Hospital for transplant assessment may have travelled from as far away as Northern Ireland, southwest Wales, or the south coast of England. Many patients are accompanied by their partner/caregiver, who stays in accommodations

Table Increase in waiting time from listing to transplant from 2003 to 2007

Year of liver transplant	Mean wait, days
2003	53
2004	49
2005	87
2006	143
2007	148

on the hospital site during the assessment period. Patients and their partners/caregivers are required to attend a group teaching session presented by the liver recipient transplant coordinators on Wednesday morning of the assessment week.

This form of group teaching was introduced in May 2006 in response to the ever-increasing workload of the team (Figure 1). This increase in workload was largely due to an increase in the number of patients on the waiting list brought about by the chronic shortage of donor organs.

The increase in numbers on the waiting list and the subsequent increase in waiting time (see Table) meant that the coordinators were spending much more time managing the list than before. This management includes following up blood results on patients who are unwell, checking on the progress of patients who are currently inpatients in their local hospital, taking telephone inquiries from patients, and responding to requests to see patients in the outpatient department to discuss their position on the waiting list and waiting times. In addition, the number of patients who become unwell and must be removed from the waiting list or who die while on the waiting list has increased (Figure 2).

The liver recipient transplant coordinators thought that this increased burden of work was not sustainable.

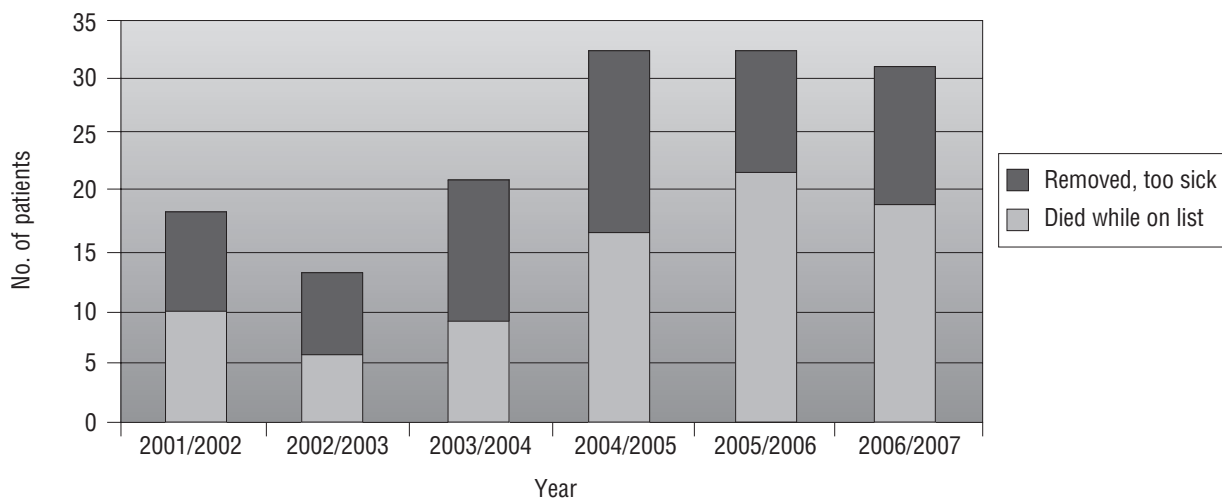


Figure 2 Numbers of patients who died while on the waiting list or were removed from the list from 2001/2002 to 2006/2007.

It was decided to move from a system of individualized patient education to group teaching for patients admitted for transplant assessment. Previously patients and their partner/caregiver, possibly along with a small group of other family members or friends, were seen individually. This arrangement meant that the coordinator had to repeat teaching sessions up to 5 times each week; with each session taking around 2 hours, this process was very time consuming. However, the benefits of this individualized and personal approach were thought to outweigh the costs; coordinators were able to respond to the particular needs of each family group. If a patient was not particularly well, or was getting tired, or if the group were having difficulty taking in all of the information, the situation would easily become evident to the coordinator and a break could be scheduled or the talk could be stopped and continued at another time. Patients and their family members could easily interrupt and ask questions that were particularly pertinent to their own individual needs. Very often, the talk would become as much a counselling session as a teaching session.

Audit

For the group teaching sessions, the liver recipient transplant coordinators developed a Windows-based presentation, which was presented on a laptop linked to a 32-inch (81-cm) television. Three months after the introduction of group teaching, an audit was undertaken and feedback was obtained from patients and their caregivers and from the team of liver recipient transplant coordinators. Thirty-two patients were included in the audit, and 31 questionnaires were returned. Six sessions involved 2 patients and their families, 4 sessions involved 3 patients and their families, and 2 sessions involved 4 patients and their families.

After each session, patients were asked to complete the following questionnaire:

1. Did you think that the information given was too simple, too complicated, or about right? (Circle your choice)
2. Did you think the teaching session was too long, too short, or about right? (Circle your choice)
3. Did the teaching session provide you with the information you felt you needed to know? (Please comment)
4. Did you think that the information given about transplant and its risks was overall positive, negative, too frightening, or about right? (Circle your choice)
5. Did you feel that having the opportunity to interact with other patients and relatives was helpful, supportive/unhelpful, or intrusive/not relevant? (Circle your choice)
6. Do you think the group teaching session is appropriate or would you prefer to have been seen individually as a family group? Group teaching or individually as a family (circle your choice)
7. Do you think it would be helpful to have this information given in the form of a CD to take home and listen to again? Yes, no, or not necessary (circle your choice)
8. Do you feel that you and your family were given enough notice about the need to attend the teaching session? Yes or no (circle your choice)

All 31 patients who completed the questionnaire thought the session was suitable. Five patients (16%) thought the session was too long, 26 (84%) thought it was the right length. Twenty-nine patients (94%) thought they heard what they needed to know; 1 patient (3%) thought it was too negative; 24 patients (77%) thought that the interaction between patients

and relatives was helpful and supportive; 24 patients (77%) preferred this format to an individual approach; 22 patients (71%) said that they would like the session recorded on a CD so that they could listen to it again at home; and 28 patients (90%) thought that their family had been given enough notice to attend the session.

After each session, the liver recipient transplant coordinators completed a questionnaire that asked the following questions:

1. How many patients attended the session?
2. How many others attended the session?
3. Did you think the room was suitable?
4. Were there any problems with the equipment?
5. Were there any interruptions?
6. If so, what was the reason for this?
7. Were any patients unable to complete the session?

The liver recipient transplant coordinators commented that, although the location of the sessions in the day room of the liver unit was convenient for patients, it did lead to occasional interruptions from medical staff or patients being called away for examinations. These interruptions were considered acceptable and unavoidable. On 4 occasions, patients had to leave the session early because they felt too unwell to continue.

Patients are informed about the teaching session in writing before their admission for assessment. The written materials emphasize the importance of the session and the need for the patient's family/caregiver to attend. Team members believe that this written information has improved the willingness of families/caregivers to attend. Not all caregivers are able to attend on the day of the session, however, because of work or family commitments such as child care or problems arranging travel; consequently, individual sessions are still occasionally required. In addition, individual teaching sessions are unavoidable for patients who do not speak English and require an interpreter.

In the afternoon after the teaching sessions, the liver recipient transplant coordinators meet each family group individually in order to discuss any issues that the patient or caregiver felt unable to mention in the presence of strangers. This arrangement also provides an opportunity to discuss issues that relate to the particular patient's needs that are likely to be confidential and would be inappropriate to discuss in the group setting.

This individual meeting also provides an opportunity to obtain feedback about how well the patient and their caregiver/family understand the information and to go over anything that needs further explanation or clarification. Despite this opportunity, the general feeling of the liver recipient transplant coordinators was that feedback from the patient and family/caregiver about how well they understood the information was less than with the individualized teaching. In addition,

the liver recipient transplant coordinators thought that they gained less insight into the patient/caregiver's own particular needs and circumstances than was the case with the individualized approach.

The teaching sessions last for about 2 hours, and the liver recipient transplant coordinators are very aware that this is a long time for anyone, let alone a relatively sick patient, to sit and listen and concentrate. For this reason, we normally schedule a 5- or 10-minute "drink and toilet" break halfway through. Despite this break, we are aware that we are giving too much information all at once and probably in too little time. However, as we do not have the luxury of having every patient's caregiver present throughout the week, this situation is thought to be unavoidable.

Although the evidence is only anecdotal and is based on comments and questions asked by some patients or their caregivers when they were called in for transplant, the liver recipient transplant coordinators thought that more patients were asking fairly basic questions about the process of transplantation, which seemed to indicate a poorer understanding than was the case before group teaching.

One issue yet to be resolved is obtaining the best equipment on which to display the "Windows"-based presentation. With a small group, the information is displayed on a laptop; for larger groups, the laptop is fed through a 32-inch television. Some images do not reproduce very well with this format, however, and we have recently moved to using a projector and portable screen. We are waiting for a projector screen to be fitted to the wall of the day room to make setting up and viewing easier.

Conclusion

The introduction of group teaching sessions has saved some time for the liver recipient transplant coordinators, although the amount of time saved is difficult to quantify and depends on the number of patients assessed each week. Advanced notice of the need for patients and caregivers to attend a formal teaching session has improved the willingness of caregivers to attend. Feedback from patients and their caregivers is generally positive, although some expressed concern about the length of the teaching session. The coordinators think that group teaching is an acceptable form of patient education in this setting given the constraints on time; patients and their caregivers, however, have a somewhat poorer understanding of the transplant process than was the case with individualized teaching. Provided that specific needs can be addressed by meeting each patient/caregiver individually after the group teaching session, the transplant coordinators think that patient/caregivers needs are being adequately met with this system. Steps are being made to improve the retention of

information by recording the presentation on a CD or CD ROM that patients/caregivers can take home after their assessment.

Financial Disclosures

None reported.

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