## Quality of Life and Liver Transplantation in Patients With Polycystic Liver Disease

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Chronic and end-stage liver diseases negatively affect many aspects of patients' physical functioning and quality of life. 1-4 Orthotopic liver transplantation (OLT) is the standard of care for patients with end-stage liver disease and has been shown to improve patients' survival and health-related quality of life (HRQL).5,6 Although the deterioration of hepatic function and the development of complications due to cirrhosis (i.e., ascites, hepatic encephalopathy, spontaneous bacterial peritonitis, and hepatorenal syndrome) are the main indications for OLT, improvement in HRQL may be important from the patients' perspective. For some patients with cholestatic or polycystic liver disease, symptoms of pruritus and abdominal pain may be the main reasons to consider liver transplantation.<sup>7</sup> In addition to the importance of HRQL from the patients' perspective, HRQL has also been associated with physiological functioning, adherence to treatment regimens, and mortality.8,9

A considerable amount of research in the past few decades has been devoted to the measurement of HRQL. Global (generic) aspects of health-related quality of life are commonly assessed, which allows for comparisons between patients with different diseases. <sup>10,11</sup> As the popularity of generic instruments increased, disease-specific quality-of-life instruments have also become more common. <sup>3,12</sup> These instruments are important because they are more responsive to the specific nature of a disease and treatment regimens.

Over the last few years, assessment of HRQL for patients undergoing OLT has become increasingly important. Despite problems with acute cellular rejection and side effects of medications, studies among transplant recipients have demonstrated that quality of life largely

improves after transplantation. <sup>13-17</sup> In fact, liver transplantation has been shown to markedly improve both patient's physical and mental health components of HRQL. <sup>17</sup> In one study, a rapid improvement in HRQL after OLT was associated with better health resource utilization. <sup>5</sup>

In this issue of Liver Transplantation, Kirchner and colleagues 18 report their outcomes, including HRQL for 36 adult patients with polycystic liver disease who underwent either OLT or combined liver-kidney transplantation. This is one of the first studies to report quality-of-life assessments for this patient population. In their series, both a generic (Medical Outcomes Study Short Form-36; SF-36) and a self-designed, diseasespecific HRQL instrument were administered. Their disease-specific assessment focused on symptoms experienced before and after transplantation and how patients' marital status and employment situations changed before and after transplantation. This diseasespecific instrument measures outcomes that are commonly assessed by researchers interested in the quality of life of patients who have undergone transplantation. 19,20 However, no explanation is given for how and why they created a new instrument, given the existence of psychometrically validated instruments for assessing HRQL for patients with liver disease.<sup>2,19</sup> Furthermore, the psychometric properties (i.e., reliability, validity, responsiveness) of this HRQL instrument are not presented in the article.

Nevertheless, the data presented suggest that less than 10% of patients reported that their well-being worsened after transplantation. Although marital status largely remained the same after transplantation, several of the transplant patients entered early retirement after transplantation. Common symptoms experienced by patients, including vomiting, tiredness,

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sleeplessness, and depression, largely improved after transplantation, as did perception of physical attractiveness and interest in sex. As far as physical health, which was evaluated years after transplantation, all patients had normal liver graft function, and 10 of the 13 patients who underwent combined liver and kidney transplants had unimpaired kidney function.

In this study, quality-of-life outcomes were compared between patients with polycystic liver disease who had liver transplants and those who had combined liver-kidney transplants. Liver transplant recipients and liver-kidney transplant recipients had similar quality-of-life scores on 6 of the 8 general quality-of-life domains. Liver-only transplant recipients had better physical functioning and role-physical (i.e., limitations in usual activities because of physical health problems) than combined liver-kidney transplant recipients. Combined transplant recipients were also less likely to engage in sports after transplantation than liver transplant recipients, and they were the only patients to report worsened well-being after transplantation.

Finally, SF-36 scores were compared with German population norms. After OLT, patients' SF-36 scores were not significantly different from those of the general German population. This was surprising because research generally finds that patients with liver disease have lower HRQL scores than population norms.  $^{1,21,22}$  Although no explanation was given for why the two sets of scores did not differ, a type II error may have occurred as a result of the small sample size (n = 23).

Kirchner and colleagues' findings among patients with polycystic liver disease support previous research that transplantation has many positive effects on physical health and quality of life. 15,16 Measurement of health and quality of life both before and after transplantation remain an important step in understanding how transplantation affects polycystic liver disease patients' quality of life. Future research should also consider how the quality of life of patients with polycystic liver disease differs compared with patients with other types of liver disease, assessed by both generic and disease-specific HRQL instruments.

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