

The Internet as a Tool for Liver Transplant Programs to Combat Stigma Related to Alcohol Use Disorder

Currently, the most common indication for liver transplant (LT) is alcohol-associated liver disease (ALD) (Fig. 1), reflecting, in part, a decline in LT for hepatitis C virus, previously the most common indication for LT. This trend also reflects changing policies regarding LT for alcohol-associated hepatitis and ALD, and possibly an increased prevalence of advanced liver disease due to ALD.⁽¹⁾ The rise of alcohol use disorder (AUD) in the United States, particularly among younger adults, women, and underrepresented minorities, is alarming and portends a continued, or heightened, need for LT in ALD in the future.⁽²⁾ There are currently no approved therapies to ameliorate liver injury and fibrosis in ALD, other than

abstinence, and LT remains the only treatment option for those with complications of end-stage disease.

Medical and social stigma related to AUD and ALD are well-recognized. Central to this stigmatization is the concept of personal responsibility for one's own health and that those with self-inflicted liver diseases are less deserving of access to a limited resource. However, transplant centers have a responsibility to ensure that potential transplant recipients are evaluated without the influence of stigma.⁽³⁾ Addressing stigmatizing attitudes in the context of caring for patients with liver disease is critical. An acceptable first step has been the change in terminology to "alcohol use disorder" rather than "alcoholism," and "alcohol-associated liver disease" rather than "alcoholic liver disease." A bigger, more effective next step would be increased physician and public acknowledgment of AUD as a chronic disease that requires life-long management. A notable effect of stigma is exemplified in the contrast between how we as physicians evaluate patients with ALD compared to patients with nonalcoholic fatty liver disease (NAFLD). Both represent liver diseases related to lifestyle choices, but the restrictions and requirements to be eligible for transplant are often very different. For patients with ALD, evaluation of "insight" and commitment to sobriety are viewed as essential. However, such criteria are not typical for the individual whose overeating has contributed to NAFLD-associated cirrhosis. Patients with ALD who are being considered for LT are required to engage in sobriety programs as well as provide documentation of abstinence, to be listed at some transplant centers. In contrast, there are still few programs that require documentation of weight loss or achievement of a normal glycohemoglobin for patients with NAFLD to be considered eligible for LT. While one may argue that relapse of alcohol use after LT more rapidly leads to graft loss, and thus a higher "bar" is necessary to be eligible for LT, the fact remains that one addiction is viewed as a barrier to

Abbreviations: ALD, alcohol-associated liver disease; AUD, alcohol use disorder; LT, liver transplant; NAFLD, nonalcoholic fatty liver disease; UNOS, United Network for Organ Sharing.

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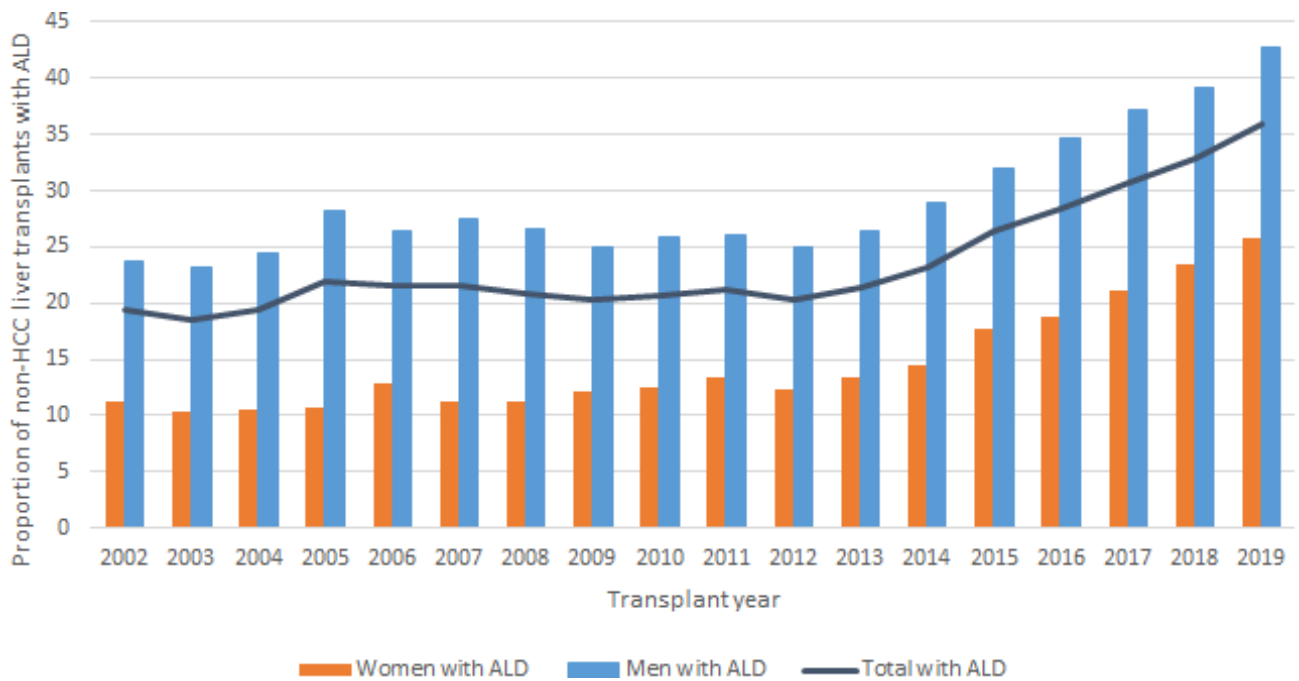


FIG. 1. The proportion of LTs performed for ALD (excluding those with liver cancer) among all transplants has been increasing by 2.4% per year since 2014. In 2019, 6,252 LTs for noncancer indications were performed in the United States: 36% had a diagnosis of ALD (with or without other chronic liver diseases). Among all men transplanted for non-hepatocellular carcinoma (HCC) indications in 2019, 43% had ALD. Among all women transplanted for non-HCC indications in 2019, 26% had ALD. Source: UNOS.

LT (alcohol use), whereas the other (overeating) is viewed as a chronic disease to manage following LT. Acknowledging AUD as a chronic condition, often involving cycles of abstinence, treatment, and relapse, is central to reducing stigmata and optimizing the care of patients with ALD.

In November issue of HEPATOLOGY COMMUNICATIONS, investigators from the University of Wisconsin examine the accessibility and content of publicly available online selection criteria among all United Network for Organ Sharing (UNOS)-registered LT centers in 2018. They focused on factors subject to stigmatization, including alcohol and substance use.⁽⁴⁾ In an era of expanding online communication and information sharing, and with coronavirus pandemic further emphasizing the use of the internet for patient-provider connectivity, this is a timely study. A study by the Pew Internet & American Life Project found that approximately 80% of internet users have used the internet to research health-related topics.⁽⁵⁾ The University of Wisconsin investigators evaluated 141 transplant centers representing all UNOS regions and found

53% included some information on selection criteria for LT on their website. However, only 32% of programs included information related to substance use and substance use disorders (e.g., tobacco, marijuana, illicit drugs, alcohol, prescription drugs), and only 17% included requirements regarding alcohol use for candidates with a diagnosis of AUD. Among these, 25% had a required abstinence period (varying from 3 to 24 months), and 50% required therapy for AUD, although the type of therapy was unspecified. Given the lack of publicly shared information and variability in criteria across LT centers, the study’s authors concluded that greater transparency regarding policies on alcohol and substance use was needed.

Importantly, the investigators found that 25% of programs with AUD-specific recommendations used a mandated sobriety period. The use of the “6-month rule” for alcohol abstinence has been widely criticized as an insufficient predictor for post-LT alcohol relapse.^(6,7) An often-cited rationale for an abstinence period is to provide the opportunity for natural liver recovery that may ameliorate the need for LT. However, decision algorithms can include consideration of

improving liver status, without mandating the completion of an abstinence period. In 2019, new practice guidelines from the American Association for the Study of Liver Diseases highlighted that candidate selection should not be solely based on a fixed timeframe of abstinence.⁽⁸⁾ The benefit of a comprehensive and rigorous selection process by multidisciplinary teams is emphasized. Engagement of the appropriate experts for patients with AUD or substance use disorders (i.e., addiction specialists, psychiatrists, and social workers) can also minimize the risk of stigmatization.

It is essential to consider how LT programs can best use the internet to convey health information to patients. A recent study found poor health literacy was associated with less access to LT.⁽⁹⁾ Examining barriers such as language and health literacy is crucial. If the program has absolute requirements for persons with AUD or substance use disorders, such as abstinence or requirement for treatment, this should be stated, preferably with rationale. A better approach would be to state that like other chronic conditions, AUD requires a comprehensive assessment and plan of management to guide decisions on transplant eligibility. Indeed, the transplant eligibility information presented by LT programs to patients and other providers through the internet could be a useful “destigmatizing tool,” although it must be acknowledged that increased transparency on substance use policies, if stigmatizing, could further perpetuate negative stereotypes. As clinicians, we must be aware and be prepared to combat these potential and unwanted effects.

In summary, German et al bring light to the scarcity and lack of LT selection policy disclosure on the internet by LT centers in the United States, particularly with regard to alcohol and substance use. As use of online health information continues to rise, the lack of transparency related to these disorders is not only problematic for potential patients and their families as they choose health care facilities, but also for referring health care providers. The authors propose a standardized set of publicly shared online criteria regarding LT considerations, eligibility, and inclusions to be adopted across all LT center websites, with specific mention

of substance use disorders and abstinence periods that are center-specific. We agree with their recommendation of standardized, transparent, and patient-centered information sharing. In the grander scheme, a continued shift in health care providers’ attitudes is needed—away from viewing hazardous alcohol use as a behavioral vice toward AUD as a chronic disease requiring ongoing management.

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