

[MUSIC PLAYING]

SWAYTHA

I'm Swaytha Ganesh, one of the transplant hepatologists. And also I oversee the living donor liver program from the medical side. Thanks for being here. And I apologize for not being there in person. We are at the outreach clinic. I think I'm not able to advance. I have no conflict of interest disclosure.

GANESH:

I thought the topic of my presentation today is I wanted to discuss the barriers to LDLT, and what we have done at UPMC, and focus on doing in future, to engage the patients on the wait list, and what we have learned from the kidney literature. We all know that despite the benefits of LDLT, living donor liver transplant accounts only for less than 6% of all the liver transplants done in the country.

And there has been a lot of efforts to identify the barriers and propose solutions across the entire living donor programs in the nation. And there has been quite a few data on various programs aimed to increase knowledge, education, and communication with regards to LDLT are emerging.

This is a slide you're all familiar with this. This is the status of liver transplant in USA, especially living donor, at this time. The number of LDLT in USA is still disproportionately low compared to the need for the number of liver transplants and the number of patients on the wait list. This is the waitlist. And this is the number of transplants for disease donor. And this is the living donor.

And there has not been much literature with the liver transplant on how to do waitlist engagement, but however, there is a lot of kidney literature on barriers to living donation. And maybe we could translate that information for liver.

And what we learned from kidney living donor literature can be potentially translated into living donor liver literature. They have recognized and addressed each barrier, including at the level of the physicians, donors, recipients. And they have also identified ethnic and racial barriers, and have proposed solutions.

And they have identified the barriers for living donation in the kidney population include inadequate education, lack of public awareness and outreach. And they also have said discrepancy in gap and knowledge and attitude towards transplantation between the recipients and donors, and it is important to bridge the gap.

This is a slide, which shows that the barriers to LDKT may be attributable to multiple factors, including recipient factors, the donor factors, health care provider reasons, and also the donor attitudes and beliefs, and clinical and health care provider knowledge and behaviors, including population awareness and disease burden. So they have also suggested proposing solutions at every level of the barriers they have identified.

So they also said that in some of the barriers they identify also include lack of outreach and also inadequate education, potential inefficiencies in the living donor evaluation process, and also the huge barrier is also the disincentives, such as uncompensated costs for the donor, and ongoing needs to support and advance donor safety. It is also important to evaluate the risk assessment to sustain public trust in the donation process.

So there is definitely a lot of barriers. And the kidney workgroup consensus conference happened, I believe, 10, 12 years ago, or even longer than that. And they proposed that the LDKT guidelines identified barriers and recommended solutions to overcome barrier, which also includes pre-emptive discussion of living donation at the level of the [INAUDIBLE] MD, PCBs, community nephrologists, the dialysis center. They also proposed partnerships between community organizations, organ procurement organizations, and transplant centers.

And after the LDKT consensus guidelines, every kidney program has adapted to the guidelines and the recommendations. And LDKT, as we know, is much more prevalent than LDLT across the USA. However, as far as the background on identifying the barriers and waitlist engagement, we do not have many studies in relation to waitlist engagement for patients on the liver-- with the liver disease as much as the kidney literature. However, some of these strategies can be effective, including development of an education toolkit, donor website, and utilization of technology, and social media for education and awareness. So we need a lot more data for the living donor liver.

And there are a couple of studies which shows that in-person or virtual patient contact with the waitlist recipients can also help with the expansion of LDLT. That is one of the strategy, but not all of them. But we will continue to work on getting more data for what could work for the waitlist engagement for the living donor.

In an effort to do that, it's important to identify the barrier at each level. So we can do the same as the kidney team has done for the kidney patients. There are barriers at each level, starting from referral MDs hepatologist for a referral hepatologist from outside of UPMC, PCPs. There are barriers at the level of insurance companies, patients, families, and caregivers.

And it's also very important to overcome the culture within the transplant center and the transplant team. And the paradigm shift is required in each center in the region. And building a strong dedicated LDLT program, and identification of all the barriers and effective strategies to overcome each.

So I just wanted to touch base on a couple of things about the recipient barriers and the health system barriers. As far as the recipient barriers to access to living liver donation, the barriers are with the denial and avoidance of the severity of their disease. The most important barrier is the reluctance, hesitancy, and the discomfort to approach and discuss with the potential donors, and difficulty to broach the subject with them.

And they also have concerns with the donor health. These are all well published. And their desire to maintain the privacy of their health status, and psychological barriers, are some of the barriers which have been identified. But the most important barrier is the reluctance, and hesitancy, and discomfort to approach and discuss the potential donors.

And the physician referral barriers also exist. It's the health care system barrier. It's the lack of communication between the referral and the transplant teams, and continue to improvise that and close the gap. And the health providers' attitude and perceptions, and the timing of the LDLT, and that's an ongoing education. And lack of the PCP or the referral MD's education and training and information with regards to living donor.

Even for a gastroenterologist who is well trained in liver, they are not aware of the timing of when to refer for a LDLT. And also, there is not well-established guidelines for the referral guidelines, including the timing. And there are some negative attitudes of the health practitioners towards living donation.

It's because they all want to help their patients. It's because of the lack of education and awareness. And the limitation to expose healthy people to the risks of surgery because some of the referral MDs may not want their recipients go through living donation because they're worried about the donor risks.

And it's important to educate them about the risks of that surgery as well. And need for culture and paradigm shift, like I said before. And identifying the right candidate for living donation. And that is an education, which will be ongoing.

And most importantly, education of the insurance companies. Even though there has been studies, multiple studies, that show that LDLT have better outcomes and they reduce the waitlist mortality, I think educating the insurance company would also be an ongoing effort from all the living donor centers.

So multifactorial-- this is a little bit redundant for the previous slides, but most importantly recipient belief, donor beliefs, public opinion, including the negative attitudes, limited knowledge overall with the benefits of the LDLT, and psychological denial for the recipient for the need to do a transplant, and also adding in the cultural and the religious concerns, and the race and ethnicity has a role, and socioeconomic status for sure, because of the travel, lodging, all those expenses.

And this is just touching on the donor barriers. This is just to have one slide. The most important donor barrier seems to be the direct and the indirect costs incurred by the donors. Lost wages for the donor, use of employer PTO. And those are real and important. And the direct costs to the donor includes the transportation to the center, testing, surgery, follow-up care, food, lodging, and incidentals.

And also encountered with a negative response from others about their desire to donate. These are real donor barriers, even though we have-- the nation has done a few-- with regards to the donor barrier, I think we still have ongoing work in place.

In overcoming the barriers in LDLT, in attempt to closing the gap, we have done a few things at UPMC as a team to bridge the gap in the knowledge and to raise awareness about living donation. We created a targeted education, including physician, patients, family, and general public.

And the Champion Program is important to help the recipients to find the donors. And many of the tools which we used includes printed materials, including brochures, web, which is online resources, living donor campaign, social media, interactive workshop-- workshops-- excuse me-- and living donor Champion Program.

The Champion Program in UPMC was developed with the primary goal to overcome the biggest recipient barrier, which is their hesitancy in approaching a potential donor. The program was developed to help the recipients overcome the challenge of finding a potential living donor. And also to educate and create awareness about living donation.

The goal is primarily to help the recipients identify a donor through their champion. This way, asking for a donor does not heavily weigh on the recipient. The champion does that for them. A champion is someone who is identified by the patient within their support system, who is willing to provide emotional support and also work with us in identifying a donor in a multitude of ways, utilizing the resources we provide them.

The conceptual framework of the Champion Program is a multi-pronged approach, comprising the immediate and extended family, community, public, and support network. It's a structured program. It's an educational structured program, including targeted education, utilizing social media, incorporating educational webinars with our advocacy groups, like Donate Life, CLA, UNOS, and CORE.

Though we do not know what clearly works in the living donor level waitlist engagement, since we need more data, at least we know that the Champion Program seems to have worked at UPMC to grow our living donor program. And this is the outline of the program, which consists of a series of structured and supervised exercises, which includes that there is a champion-- the resources available to the champion is the champion toolkit, which is a website and online video conferences, town hall meetings, living donor Facebook support page, and a series of other interactive patient exercises, including living donor champion workshops. The key of the Champion Program is the coach and the ambassador support, which is one-on-one support to the champions.

And this is just the summary of the number of events and engagements and activities of the Champion Program, which this was launched in June of 2017. And since that time, there has been several Champion events, social media presence, Champion support, and also the Champion website, which has also taken off since that time. The living donor ambassador has worked with our champions, at least more than 100 of them in the last few years. And so that has worked in identifying a donor for our patients.

And these are some resources available, educational brochure and video series. We also have a strong support group on the Facebook for the champions and also for the donors. And this is just a slide to show the living donor numbers at UPMC. We launched the Champion Program somewhere around here. And the number of living donor and the volume has grown in the last few years. Because we all made a concerted effort as a program, as a team, to grow our program together.

And this is the early volume of LDLT in US Centers. In 2020, there were only 10 to 12 centers in the US who did more than 10 LDLTs, and 23% of the LDLTs performed in the US were at UPMC. So as a team, we made a concerted effort. And the number of donor evaluations have also grown. As you can see, since the introduction of the Champion Program we have brought in more donor for the evaluation. I think the education-- this goes back to the information we already know from the kidney literature, and some from the liver literature, that education and awareness, raising public awareness and educating the patients and the general public is the key to grow any living donor program.

And what's new at UPMC for the living donor program, we already talked about living donor Champion Program. And I wanted to touch base a little bit on the liver paired exchanges and altruistic donation in LDLT for novel criteria indication, which the protocols were created by Dr. Chris Hughes, and he has been-- he and Dr. Humar have done quite a few living donor surgery for extended and novel criteria, which otherwise, these patients would not have lived, or could not have gotten transplant anywhere else, or could not have gotten a disease donor liver transplant. So these novel criteria and indications, these protocols were developed by Chris Hughes. And we have helped quite a few patients in the last few years.

As far as the non-directed anonymous LDLT at UPMC, the number of altruistic donors have also-- there are a lot of people who want to help patients on our waitlist. And the number of altruistic donors have also been growing at UPMC, which I think is phenomenal. And it's all because of not only the education, it's the altruistic nature of the people in USA who want to help other people.

And as you can see, this is a slide from Dr. Humar. There was a random survey which shows that 70% of the people would be willing to donate to anyone they know. And 40% would donate to someone they don't know. And that's phenomenal. I think this country is very altruistic. They want to help. I think just the key is to try to educate and also explain to them that liver can regenerate. And also explain to them some of the risks involved with living donor surgery, but also for them to know that liver can regenerate.

And this is a slide which shows that there is-- one of our Fellows, Stella, wrote this up. It shows that UPMC performed 28% to 42% of all non-biological anonymous liver donation across the 50 living donor transplant programs in the US. This is an increase in the number of living donor liver transplant by non-biological, non-directed altruistic donors.

Because we had increased the number of altruistics in the last few years. But at the same token, the number of altruistic donations increased in other centers as well. We do not know what spiked that, but definitely ongoing awareness campaign about living donation, which marketing had helped us. And also trying to bridge the gap in the knowledge of living donation has partly contributed to the increase in the number of altruistic anonymous donations across the entire nation.

And this comes to our own data, which shows that the donor relationships have also changed in our institution since 2017. So there were a few non-directed donations in our center prior to 2017. The percentage of non-directed donors have increased since 2017. In addition, we also noted that we have increased in directed non-biological donation.

Previously, it was predominantly biological donation either from a first degree or second degree relative. And since 2017, where we focused on education and creating awareness, then there is more and more non-biological directed donors, but also we have increased in the number of altruistic donors too, which are non-directed donors.

So you can see 4% to 6% is directed, non-biological. 38% plus 11% is all first and second degree relatives. Also 5% are non-directed, non-biological anonymous donors, which also proves the point that education and awareness is very important to try to educate the public and more donors are signing up, even though they are not biologically related to the recipients.

And just to touch upon the paired exchange program at the SDI, since October 2019, we did 12 pairs, 24 transplants. Even though there are other studies which shows that LPE can be done for volume and other matching purposes, but our majority of the paired exchanges have been done for ABO incompatibility.

So it can be done in two ways. One is utilizing a non-direct donor, who is an altruistic donor with a blood type O who would be donating to the recipient number one. And recipient's number one donor will donate to recipient number two. So it's paying forward.

Similarly, the paired exchange can be done with two related donors. If recipient one's blood type is compatible with the recipient two's donor, so that related donor will donate to recipient two. And recipient one will get the liver from the related donor for the recipient number two.

And that has worked. But majority of our LPE has been utilizing a non-directed donor. And that is only possible because there are people who come forward to donate altruistically. All donors are altruistics, but the non-directed, non-biological donors, the anonymous donors are the ones whom we utilize in the LPE.

And like I said, the novel and extended protocols, the majority of these protocols are developed by Chris Hughes, Dr. Chris Hughes. And Chris Hughes and Humar have done quite a few transplants for unresectable colorectal mets, neuroendocrine tumor, and also patients with the cholangiocarcinoma, HCC, extended criteria. So those patients could not have gotten a liver anywhere else and could not have survived without a living donor liver transplant at our institution.

And you all know about this, obviously because of our growth of our living donor program, we were able to reduce the waitlist mortality due to increased access to living donation. And our transplant rate has also increased significantly. But you all know about this.

So to keep with the topic, the goals of education. So the goals of education, what we could focus in future and continue to focus more in future could be partnerships between community organizations. And use of technology has worked very well for us. But continuing to use the social media to educate and also have more donors sign up for our patients.

And outreach should also be improved for patients. In rural areas, we do think that there is not a huge presence of living donor education in these areas. And I think it's, I believe, consistent reimbursement policies to cover donors out of pocket expenses. And maybe the other thing to continue to work on is shifting the burden of finding a donor from the patient to the champion. And continue to work with the Champion Program.

And so I think continuing with the goals of the education is the time-- many times when we speak to the referral MDs, I think the most important education piece is the timing of transplantation, when to refer, and to talk about the benefits of living donation. And also to talk about the novel protocols we have for the extended cancer criteria. And so those are something very important. Can be ongoing efforts to continue to grow our program.

And also creating a champion toolkit which we did. But I think the ASD is working on developing a toolkit for all the living donor programs across the nation, and a financial toolkit as well. And also, a consensus-driven evidence-based public message about LDLT should be developed.

And while these are all the potential solutions to overcome the barriers, and also, most important is the awareness and education, and the timing of LDLT, as we talked about before. And also, resources individualized for each, targeting the messages towards physician, referral MDs, GI physicians, the hepatologists, and donors, public, and also the champions. There are different messages to be created for different entities.

And also, the direct waitlist engagement, including the champion workshops and also the ambassador coach program. And so there was a recent LDLT consensus guidelines conference. And the consensus statements as a team was brought up. And this is all approved right now, which is the LDLT Consensus Guidelines Committee.

The major barrier, we identified barrier number one, is there are low levels of acceptance of donor rates among the transplant candidates, which is partly due to lack of education, understanding the benefits of LDLT among patients and families.

The strategies recommended by the LDLT consensus conference is to develop fact-based educational materials and risks and benefits of living donation, develop strong outreach programs across transplant and community settings for patients, families, and additional supports on benefits on living donor liver transplantation. And dispelling any myths about living donation, including the champion and the coaching programs.

The second barrier we identified in the LDLT Consensus Committee is gaps in the knowledge on benefits and timing of living donor liver transplant across transplant physicians and referral providers. And the strategies to address the barrier number two is targeted education on candidates who may benefit from living donor liver transplant, including appropriate timing of referral and candidate selection.

The barrier number three is fostering institutional commitment to create a culture of living donor liver transplantation as beneficial for the large proportion of candidates on the waitlist. The strategies proposed to overcome the barrier number three from the LDLT consensus conference is create advocacy strategies between the transplant center and Donate Life America, UNOS, and other community-based agencies, utilization and dedication of resources for community outreach and education, building a dedicated LDLT team, with LDLT surgeon, coordinator, medical director, and LDLT advocate, mental health consultation services, and other system-level resources.

So these are some of the consensus guidelines statement which came, which will be published pretty soon. And that's all for me on the topic. But I would like to really thank the entire team at the Center for Liver Disease and Thomas E. Starzl Transplant Institute, Drs. Humar and Hughes, and all our hepatologists. Special mention to the star of our program, which is all our coordinators, and marketing team, who developed the LDLT brochures and the Champion workshops, our Champion ambassador. And last, but not the least, our donors and patients. Thank you very much, everyone.