

Provider, Recipient and Caregiver Perspectives on Cardiovascular Disease and
Related Risk Factors after Liver Transplantation: A Qualitative Study

Culminating Experience – Northwestern University Masters of Public Health

Lindsay Adamski

Abstract:

Introduction: Liver transplant (LT) is the only life-saving therapy for end-stage liver disease stemming from a multitude of causes though cardiovascular disease (CVD) is the leading cause of early (<1 year) mortality, and the third leading cause of late (> 1 year) mortality after LT. (1-5) This study examined liver transplant recipient (LTR), caregiver, and provider perspectives on CVD after transplant. Barriers to proper care have not been identified for each group and we do not know how each group would describe these barriers.

Methods: We conducted seven focus groups to better understand these barriers. The focus groups lasted 90 minutes and were split based on LTR, caregiver, and provider-specialty. The transcriptions for these focus groups were coded.

Results: Four major themes found across all groups and are as follows: the lack of awareness of CVD risk after LT, the lack of confidence in ability to provide proper care to LTRs, barriers to care without transplant center review, and barriers caused by having to touch base with multiple providers on the complex care team.

Conclusions: Potential solutions to eliminate these barriers include increased education on the risk factors of CVD amongst LTRs done by the transplant team, EMR alerts for providers, increased utilization of the transplant coordinator and the transplant pharmacist, multidisciplinary team meetings to discuss patients' care plans, and an additional document detailing the roles of each member of the LTRs' care team.

Introduction:

Liver transplant (LT) is the only life-saving therapy for end-stage liver disease stemming from a multitude of causes. In the United States at the beginning of 2018, roughly 13,000

individuals were on the LT waiting list, but only 57% received an organ due to organ shortage.

(6) In 2018 the rate of death for adults on the LT waitlist was approximately 10%. (6)

Cardiovascular disease (CVD) is the leading cause of early (<1 year) mortality, and the third leading cause of late (> 1 year) mortality after LT. (1-5) Approximately 30% of liver transplant recipients (LTRs) will have a CVD complication (myocardial infarction, heart failure, cardiac arrest, atrial fibrillation, pulmonary embolism, or stroke) after LT. (1, 2) Therefore, early identification and management of modifiable CVD risk factors provide significant opportunities to reduce CVD complications and death after LT. (7)

CVD amongst LTRs is expected to increase in the coming years, with traditional CVD risk factors, such as older age (≥ 50 years) and diabetes becoming more common. (1, 2, 8-10) Furthermore, there is an increase in the number of LTRs requiring prolonged intensive care as there is an increased prevalence of subclinical and clinical CVD amongst patients with the highest model-for-end-stage-liver-disease (MELD) scores. Those with higher MELD scores are given priority on the LT waitlist. (5, 11) The prevalence of non-alcoholic steatohepatitis (NASH) is an obesity-related cause of end-stage liver disease also associated with increased CVD morbidity and mortality, (3, 12) and has become the second most common indication for LTs within the United States. (13, 14) Lastly, it has been shown that immunosuppression post-transplant leads to increased CVD risk in the form of hypertension and renal disease. (15)

With LTRs being at higher risk of developing CVD after transplantation, additional supportive care is needed to mitigate these risk factors; however, there appears to be a practice gap between knowing CVD risk factors and managing these risk factors. A study looking at over 600 LTRs found that only 29% had blood pressure controlled to a guideline-recommended target of <140/<90mm Hg, which was associated with improved survival and decreased CVD events

amongst LTRs, at any point in time during the 6-year study. (16) Furthermore, less than 1/3 of those who were unable to properly manage their blood pressure were referred to a hypertension-specialist for additional support. (16)

LTRs, their caregivers (e.g. family, friends), and their healthcare providers (e.g. physicians, nurses) each play a role in mitigating the risk of CVD. With the increased risk of CVD after transplant, we wanted to understand patient, caregiver, and provider perspectives on CVD after transplant. Barriers to proper care have not been identified for each group and we do not know how each group would describe these barriers. Therefore, we conducted a series of focus groups to better understand these barriers to CVD care.

Methods:

This study was exploratory in nature and used focus groups of LTRs, their informal caregivers, and formal caregivers (professional healthcare providers). To be eligible, participants must have been a LTR or an informal or formal caregiver to a LTR, aged 18-79 years old, English-speaking, and able to participate in informed consent. Recruitment and interviews were completed between August 2018 and September 2018. Convenience sampling was used to recruit participants. All LTRs who were transplanted between May 2015 and June 2018 at Northwestern Medicine (n=292) and their informal caregivers were identified using the electronic health record (EHR) and invited to participate in the study via email or mail. Respondents (n=42) and their informal caregivers were then recruited in-person during a previously scheduled clinic appointment on the Northwestern Medicine Chicago campus. Multi-specialty (e.g., general nephrology, transplant surgery, transplant hepatology, transplant nephrology, endocrinology, primary care, or cardiology) formal caregivers were identified

through the EHR. A formal caregiver was eligible for participation if they had at least five documented encounters within the Northwestern Medicine network with a LTR between May 2015 and June 2018 (n=317). Formal caregivers were invited to participate in the study via email. Respondents (n=61) and their multi-provider support staff (e.g., nurses, mid-level providers, pharmacists, and social workers) were invited to participate in a scheduled in-person focus group on the Northwestern Medicine Chicago campus. To accommodate the clinical commitments of participants, groups were offered at various times throughout the early morning or late evening. Recruitment goals were to enroll approximately 30 total LTRs their caregivers and 50 specialty-specific providers for a total enrollment of approximately 95 participants with equal numbers of men and women in each group. In the end, 15 LTRs, nine informal caregivers, and 22 formal caregivers participated in the study (Tables 1, 2, & 3). The Northwestern IRB approved the study, and all participants gave their informed consent.

The Focus Group:

A set of seven separate focus groups were conducted at the Northwestern Medicine Chicago campus with 8-10 participants in each focus group based on whether participants were a LTR, LTR informal caregiver, or a specialty-specific formal caregiver:

1. Cardiology Providers
2. Liver Transplant Caregivers
3. Liver Transplant Recipients
4. Nephrology and Endocrinology Providers
5. Liver Transplant Recipients
6. Transplant Providers
7. Primary Care Providers

An experienced facilitator moderated each focus group for a 90-minute discussion based on a standardized moderator guide with questions tailored specific to the focus group participants (Appendix A). The moderator guide was developed by study team members who had previous experience in qualitative research studies. Additional study staff members were in each focus group recording observations and assisting the facilitator as needed. All group sessions were audio recorded.

Moderator Guide and Survey Development Methods:

The focus group schedule used open-ended questions that were developed based on the Health Belief Model, which explains behavior in terms of people's behavioral responses to health-related conditions. (17) This model introduces six constructs to assess health behaviors: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. (17) Questions asked within the focus groups and on the post-interview survey varied based on provider, patient, or caregiver focus group and were mapped to one of the six constructs in order to better understand behavior based on this model (The FG questions are provided in Appendix B). The majority of the questions assessed the construct of self-efficacy; however, the constructs of perceived severity, perceived susceptibility, and perceived benefits were also assessed. The content of the moderator guide was modified throughout the study as new topics emerged from the group interviews. At the end of each session, participants were asked to fill out a brief survey that captured demographics and focus group experience (displayed in Appendix C).

Data Analysis:

Audio recordings of each focus group were transcribed verbatim into text for analysis, which the use of MAXQDA software (VERBI GmbH, Berlin, Germany) facilitated. Six investigators from diverse professional backgrounds (TH and BA, general internal medicine; LVW and AD, transplant medicine; JH and DF, healthcare delivery science) independently reviewed each transcript, generating codes for sections of text to classify observations, concepts, and themes. Higher-level conventional content analysis was performed during meetings of at least three investigators through the exploration of codes, themes, and trends. Consensus codes were collated, and the collection was revised and applied to subsequent transcripts in an iterative process. It was determined that theoretical saturation was reached when concepts and themes became redundant with previous observations.

Results:

All focus groups were coded into themes indicating perspectives on CVD care amongst LTRs as well as barriers to receiving or providing appropriate CVD care after transplantation. The four common themes across focus groups are lack of awareness of CVD risk, barriers to care without transplant review, lack of confidence in ability to provide care, and a complex care team.

Demographic Data

This study consisted of 15 LTRs with a mean age of 63.0 years of which 73.3% were male (Table 1). Within this cohort, 73.3% identified as Caucasian, 6.6% identified as Native Hawaiian or other Pacific Islanders, and 20.0% identified as Hispanic, Latino, or Spanish origin (Table 1). In terms of education, 6.6% had less than a high school education, 13.3% were high school graduates, 40% had completed some college, and 40% had graduated from college (Table 1). 73.3% were married, in a domestic partnership or civil union, 20.0% were separated or

divorced and 6.6% single (Table 1). In regards to employment, 33.3% were not employed, 30% were employed part-time, 33.3% were employed full-time, 6.6% were disabled and 6.6% were homemakers (Table 1). Amongst this cohort, 66% had hypertension, 20% had high cholesterol, 26.6% were overweight or obese, 20.0% had chronic kidney disease, 53.3% had diabetes, 6.6% had a stroke, 13.3% had arrhythmia, 6.6% had a blood clot that required thinning medication, and 13.3% were regular smokers for at least 3 months prior to the study (Table 1).

There were eight caregivers involved in this study, all identifying as females with the mean age of 59.0 years (Table 2). Within the cohort, 66.6% identified as Caucasian, 16.6% identified as Asian, and 16.6% identified as Hispanic, Latino, or Spanish origin (Table 2). 66% were married in a domestic partnership or civil union, and 33.3% were single, never married (Table 2). In terms of education, 16.6% had some college education, 50% were college graduates, and 33.3% had postgraduate training (Table 2). At the time of the study, 16.6% were students, 33.3% were employed full-time, 33.3% were employed part-time and 16.6% were not employed (Table 2).

A total of 22 providers participated in this study with a mean age of 43.15 years and 40.9% classifying as male (Table 3). 63.6% of providers identified as Caucasian and 36.4% classified as Asian (Table 3). 9.1% were college graduates with 90.1% obtained postgraduate education (Table 3). Over half of the providers were certified as MDs (60.0%), with 12.0% certified as an APP, PA or NP, 12.0% certified as an RN or BSN, 4.0% certified as a PharmD, and 12.0% not certified as any of the options previously listed (Table 3). The specialties for these providers are as follows: 14.8% general cardiology, 3.7% transplant cardiology, 3.7% endocrinology, 18.5% transplant hepatology, 22.2% general nephrology, 18.5% transplant nephrology, 7.4% transplant surgery, and 11.1% not specializing in any of the previous options

(Table 3). Almost all providers were employed full-time (95.5%), and over half of providers had the primary healthcare role of a clinician (65.4%), 19.2% had the primary healthcare role as a clinical researcher, 7.7% had the primary healthcare role as an educator, 3.8% had the primary healthcare role as a basic or translational scientist, and 3.8% had a primary healthcare role not within the previous options (Table 3). 31.8% of the providers were in practice for less than five years, 18.2% were in practice for five-ten years, 27.3% were in practice for 15-20 years and 22.7% were in practice for over 20 years (Table 3). In terms of their interaction with LTRs within the previous year, 20.0% had seen less than ten, 50.6% had seen 10-50, 25.0% had seen 51-100, and 5.0% had seen over 100 (Table 3).

Perceptions

Prior to the focus group, 93.3% of LTRs were unaware that CVD is a leading complication after LT. After the focus group, almost all LTRs agreed (33.3%/40.3%) or strongly agreed (53.3%) that CVD is a serious condition after LT and LTRs have a higher chance of developing CVD than the general population (Table 4). Similarly, most LTRs agreed (33.3%) or strongly agreed (60.0%) that it was important to discuss their chances of developing CVD with their non-transplant providers, though 13.2% were not confident in their ability to talk to their providers about their CVD risk (Table 4). 93.3% of LTRs said they strongly agreed that it was important to discuss their chance of developing CVD with their LT providers, with all LTRs saying they were confident talking to their LT providers about this (Table 4). This is similar to what was determined in the focus groups that LTRs believe that their LT provider should be telling them about their increased CVD risk and that they tend to feel more confident in their ability to talk with these providers. 66.6% of LTRs stated that their transplant physicians seemed informed and up-to-date on CVD risk factor care they received from non-transplant doctors,

though only 40% thought that their non-transplant doctors seemed informed and up-to-date on this (Table 4). When asked which member of their healthcare team should be primarily responsible for providing information on risk factors for CVD, 73.3% said their hepatologist, 13.3% said their cardiologist and 13.3% said their primary care provider; however, when asked who should be treating the CVD risk factors, 26.6% said their hepatologist, 53.3% said their cardiologist and 20.0% said their primary care provider (Figure 1).

When LTRs were asked about CVD preventative actions 33.3% said they were not confident (not responding strongly agree or agree) in their ability to maintain a food diary, 35.6% were not confident in their ability to eat a healthy diet, 33.2% were not confident in their ability to get at least 30 minutes of exercise most days of the week, 13.2% were not confident in their ability to eat a diet low in sodium, 6.6% were not confident in their ability to not smoke, and 23.1% were not confident in their ability to maintain a healthy body weight (Table 4).

Before the caregiver focus group, 93.3% of caregivers were unaware that CVD is a leading complication after LT (Table 5). After the focus group, all caregivers agreed that CVD is a serious condition after LT and LTRs have a higher chance of developing CVD than the general population (Table 5). All caregivers agreed that discussing the chance of developing CVD is important to discuss with LT providers and non-transplant providers, and all were confident in speaking with the transplant providers about this, though 12.5% were not confident in their ability to talk to their LTRs' non-transplant providers (Table 5). All caregivers agreed that their LTR's transplant physicians and non-transplant physicians seemed informed and up-to-date on CVD risk factor care (Table 5). In terms of who the caregivers believe should be primarily responsible for providing information about risk factors for CVD after LT caregivers agreed upon multiple members of the care team: 14.3% surgeon, 85.7% hepatologist, 42.9%

cardiologist, 14.3% nephrologist, 28.6% endocrinologist, and 57.1% primary care provider (Table 5). On the other hand, in terms of who should provide CVD care, 14.3% said the surgeon, 57.1% said the hepatologist, 71.4% said the cardiologist, 14.3% said the nephrologist, endocrinologist, and primary care provider.

In terms of assisting the LTR they care for with CVD preventative actions, 25% were not confident in their ability to help the LTR maintain a food diary, 12.5% were not confident in their ability to help the LTR eat a healthy diet, and 14.3% were not confident in their ability to help the LTR stop smoking, eat a diet low in sodium, or maintain a healthy body weight (Table 5).

Prior to the provider focus group, 36.4 % of providers were unaware that CVD is a leading complication after LT, though all agreed after the focus group that it is (Table 6). Almost all providers agree (95.5%) that CVD risk is an important topic to discuss with LTRs under their care, though 45.4% were not confident in their ability to talk with LTRs about CVD risk (Figure 2 & Table 6). Only 13.6% of providers thought that CVD risk factors were well-controlled amongst the LTRs under their care, and only 36.3% were confident in their ability to manage CVD risk factors amongst LTRs (Figure 2 & Table 6).

In terms of managing different aspects of CVD care amongst LTRs, 86.3% were confident in their ability to manage blood pressure, 59.1% were confident in their ability to manage lipids, 27.2% were confident in their ability to manage blood glucose, 54.5% were confident in their ability to manage renal dysfunction, 45.4% were confident in their ability to manage smoking, and 40.9% were confident in their ability to manage weight (Table 6). In terms of managing CVD care, 36.3% of providers were confident in their ability to coordinate CVD risk factor care amongst LTRs. Communication about CVD risk factor care amongst LTRs

seems to be lacking with as only 45.4% of providers communicate regularly with healthcare providers within their institution, and 18.1% communicate regularly with those external to the provider’s institution, on changed to CVD risk factor care amongst LTRs. Further, 27.3% of providers say they receive accurate communication from providers within their institution on changes to CVD risk factor care amongst LTRs, and 9% saying they get this information from external providers (Figure 2 & Table 6).

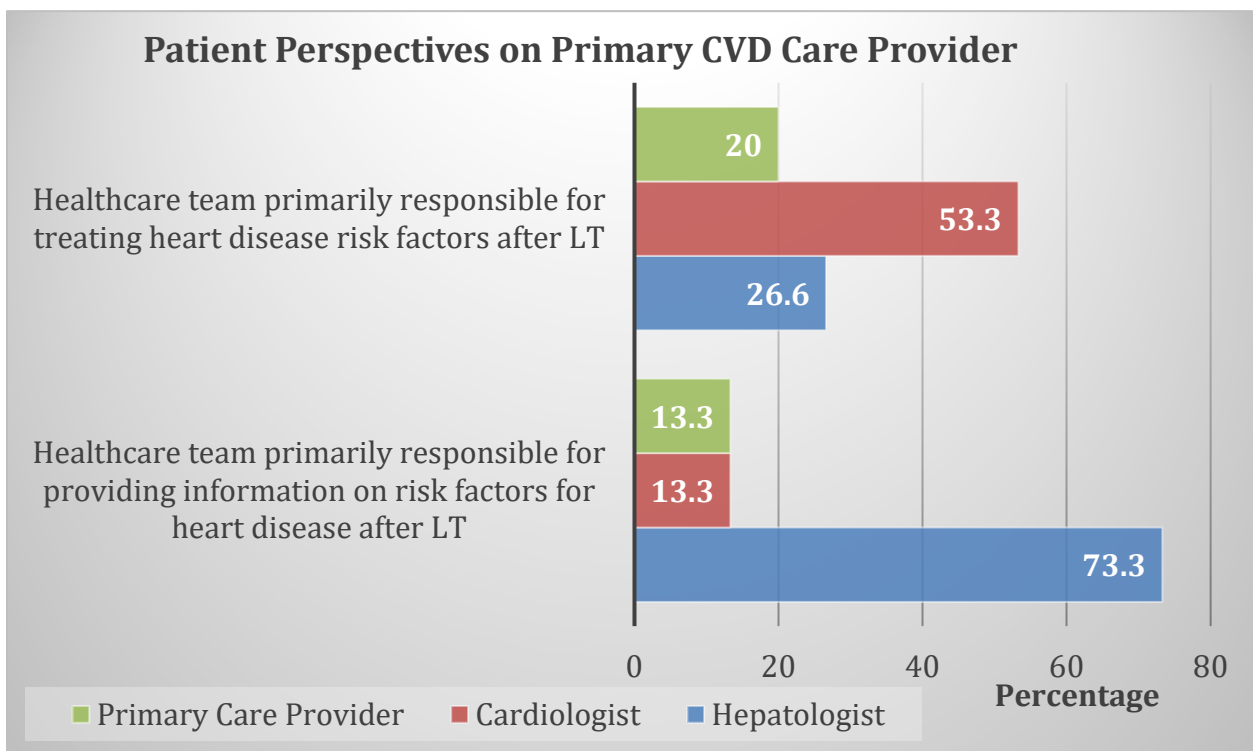


Figure 1: Patient Perspective on Primary CVD Risk Factor Care Provider. Data obtained from Table 4.

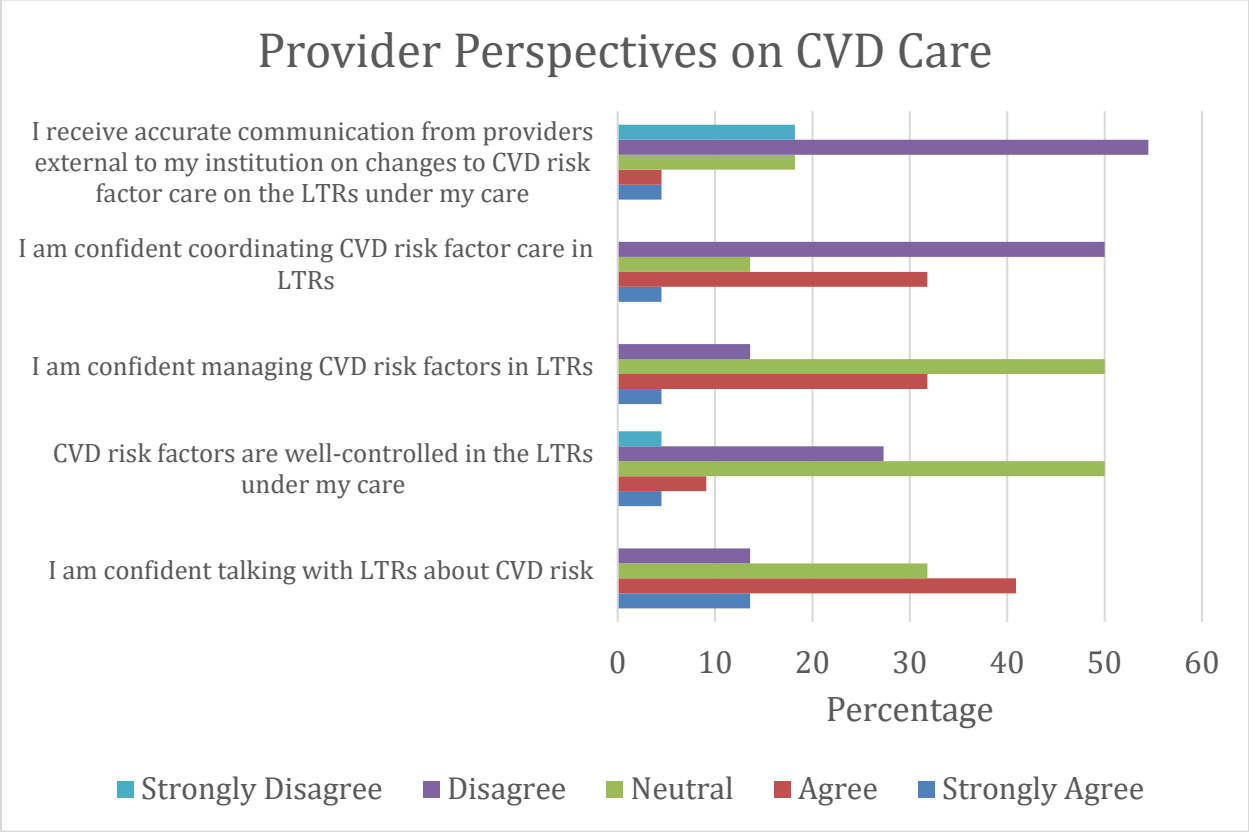


Figure 2: Provider Perspectives on CVD Care Amongst LTRs. Data obtained from Table 6.

Perceived Barriers to CVD Care Amongst LTRs

Lack of Awareness of CVD Risk:

It was almost universal (14/15) for LTRs and caregivers (5/7) to not fully understand their increased risk for CVD after transplantation (Tables 4 & 5). It was also very common (14/22 for providers) across all focus groups to believe that CVD is not one of the major health concerns they are thinking about post-transplantation (Table 6). Patients stressed the fact that prior to transplant they are very sick and only concerned with staying alive, so after

transplantation they have more, pertinent health concerns directly impacting organ rejection that they are concerned with.

“When I had to go through all the tests that you have to go through to get a liver, I thought, “Okay, my heart—because they wouldn’t have given me a liver if my heart was bad,” and I’ve never given it another thought.” (Liver Transplant Recipient)

“I focus on my liver as being the cause why I’m not the same person I was eight years ago, why I’m fatigued, why my memory doesn’t work well, why a lot of other systems are not working. Therefore, I might get winded if I go up a flight of stairs. It all could be heart-related. I have a lot of issues that could be heart-related, but I’m so focused [on] just the liver that I don’t need another problem. Going to a cardiologist is like taking my car to a mechanic and saying, “Is there anything wrong with this car?” They’re going to find something, and I have enough problems.” (Liver Transplant Recipient)

“I don’t think my transplant patients perceive that they are at increased risk for cardiovascular disease. They are very focused on their transplant and I think sometimes they discount other things.” (Primary Care Provider)

Providers had a similar perspective and stated that checking for CVD risk factors after LT is not high on the priority list. With limited time to spend with each patient, there are other health concerns that the practitioners are more likely to check. Further, some providers seemed to be unaware of the increased risk of CVD after LT.

“I mean, I guess, yeah, the liver grafts, number one and the—I mean, I always rank them in my impression and plan on sort of order of importance by liver grafts, immunosuppression, their prophylaxis, antibacterial or antifungal or antiviral... And then the other things like cardiovascular disease, renal disease—those come lower down, but not necessarily because I’m less interested and less prioritizing them. There’s just—that’s sort of the order of my thinking.” (Transplant Provider)

“If you’re confused, you should be because there’s not clear evidence (referencing aspirin use amongst LTR for CVD prevention).” (Cardiology Provider)

“I don’t view that the liver transplant per se is that much substantially higher risk for cardiovascular disease, at least in my understanding.” (Endocrinology Provider)

Lack of Confidence in Ability to Provide Care

Within the various caregiver and provider focus groups, many mentioned the lack of confidence they have in their ability to provide care to LTRs, as this population has a unique and complex set of healthcare needs. In particular, the caregivers stressed the hardships associated with becoming a full-time caregiver and feeling undertrained to take on this role.

“I think non-transplant doctors are scared of transplant drugs, as they should be. These are bad drugs. We should be scared of them.” (Endocrinology Provider)

“It’s hard to make what’s guideline-driven to patient-specific, right? Every patient, especially our complicated liver transplant/kidney transplant patients are very—they have reasons for X, Y, and Z of not being on things or being on certain things, so I’m not sure. I just don’t know if—I don’t know the best way. I don’t know the right answer there.” (Nephrology Provider)

“But we, kind of, almost became professionals because of all the knowing that happened and what’s going on. And they’re wonderful preparing the patient but for us, it was, like, shocking and brand new and you become the nurse, you become this, you become that.” (Caregiver)

“So, it was very—that was the most frightening experience, I think. From saying “You’re discharged.” (Caregiver)

For caregivers and providers, this means that they must seek direction on the proper treatment for their LTR from the transplant team, which in itself presents barriers to proper CVD care.

Barriers to Care Without Transplant Review

Unanimously across the patient focus groups, transplant providers were considered the center of any health complication patients may experience after transplantation, including CVD with 73.3% of patients saying that their transplant hepatologist should be responsible for informing them about CVD risk factors after transplantation (Table 3). This extended out to

multidisciplinary providers as they had the understanding that the transplant providers were the center of any type of care within LTRs.

“A couple of the nurses that were handling the intake, said, “From now on, everything you do once we accept you into the liver clinic goes through the liver clinic....I sat there one day and talked to a guy while I was waiting in this clinic; he’s been 25 years since his transplant. He was one of the first ones done here. They told him, “Always be in touch.” He was going for a new hip and they wanted him to go through the clinic.”

(Liver Transplant Recipient)

“Who’s taking care of you?” they say, “The transplant team.” But you may know that they’re not—it depends on the provider. Their patients’ perception is the transplant team is taking care of everything, even if it’s years past and you yourself know that they are not. It feels like they don’t listen to anyone but—even years later, the transplant team”

(Nephrology Provider)

It is clear that from acceptance into the transplant program that the transplant recipients believe that everything else they do must go through their transplant providers. However, transplant recipients and providers expressed the barriers to care this can cause.

“I’ve gone to the emergency room before where the doctor in the emergency room wants to give me Advil and I’m like, “I’m not taking Advil. And he’s telling me, “I’m the doctor.” I said, “You call Dr. F and he says, “Okay, okay.” So, we can’t do anything

without the transplant team. However, if you call the transplant office in off hours or the weekend, there's not an emergency person there's nobody there. Basically, unless you call during the day—and an emergency, you cannot get an answer from the transplant team at all.” (Transplant Recipient)

“They feel like their primary doctor—not primary care doctor—primary doctor is their hepatologist. It's not anyone's fault but it's a trust issue in terms of their hepatologist is their primary doctor and without interacting with them or us talking to them—may sure you talk to them before—have you talked to them before you started this? Like do they know that you're starting this? I think that becomes a little bit of a barrier.” (Nephrology Provider)

Transplant providers being seen as the center of any type of care for LTRs means that they are then the ones who have to talk with their patients about mitigating CVD risk factors.

“Dr. V told me already, “Next time I see you, I need 10 pounds lighter.” And I've got a watch now that counts how many steps I take, so I do 10,000 a day and I'm working on it. It comes through with more emphasis from the liver doctor than my primary.” (Liver Transplant Recipient)

“The transplant team needs to be very proactive, send them back to get re-risk-assessed and see what needs to be done from a cardiovascular perspective.” (Cardiology Provider)

Barriers Caused by Complex Care Team

LTRs have a large care team, which has created barriers to receiving proper care. Having a complex care team has made communication between all parties difficult, with many stating that the most important take away from the focus group is that there needs to be more communication between all parties. This leads to frustrated and confused LTRs who are not sure who to contact when complications arise and end up feeling like they have to communicate pertinent information with the entirety of their care team and be their own advocate. The complex care team is also seen as a barrier by providers, as they themselves have trouble understanding who is taking care of different aspects of the recipient's health.

“Myself and my wife actually called transplant to talk to a nurse or a doctor and they said, “You have to go through your primary.” They didn’t answer any questions. I just think that everybody who’s had this isn’t in the right frame of mind. You’d like to hear somebody when you call here. And I was told specifically, “We take care of the liver and that’s it.” (Liver Transplant Recipient)

“If there’s a cardiac issue or a pulmonary issue that there should be team work immediately without having to say much...you (the patient) shouldn’t be the person to be bringing information back and forth.” (Liver Transplant Recipient)

“A lot of times that blood work never does make it to my primary care doctor. I have to follow up with it even though I handed them the card; I watched them fill it out that

they're going to fax it. It may be three times out of ten that they'll get it there." (Liver Transplant Recipient)

"Who is managing solid organs with kidneys or I don't know who." (Cardiology Provider)

Discussion:

This paper presents the first account of LTR, informal caregiver and provider perspectives on barriers to CVD care after LT. The major themes across all groups centered on the lack of awareness of CVD risk after LT, the lack of confidence in ability to provide proper care to LTRs, barriers to care without transplant center review, and barriers caused by having to touch base with multiple providers on the complex care team.

Lack of Awareness of Cardiovascular Disease Risk After Liver Transplantation

This study confirmed that LTRs, caregivers, and providers were largely unaware of or dismissive of the increased risk of CVD after LT as 93.3% of LTRs, 93.3% of caregivers, and 63.6% of providers said they were unaware that CVD is a leading complication after LT prior to the study (Tables 4, 5, & 6). LTRs often cited having other health concerns to worry about and were living with a false sense of security, pointing to the fact that they had to be healthy enough to get a transplant; therefore, they assumed they were still healthy and at no increased risk for CVD once receiving a transplant, deferring preventative measures. Without being aware of their increased risk of CVD, preventive measures such as blood pressure management, weight loss and exercise were likely not occurring.

In line with the focus group guide built based on the health belief model, LTRs, caregivers, and providers expressed a low perceived susceptibility to CVD. In other words, LTRs, caregivers, and providers do not perceive that CVD would harm themselves or the LTR. Further, there was largely a low perceived severity as providers, caregivers, and LTRs alike mentioned not giving adequate thought to the increased risk of CVD this population has.

Lack of Confidence in Ability to Provide Proper Care to Liver Transplant Recipients

The lack of confidence in one's ability to provide proper care to LTRs after transplantation was also a common theme. This was most common for caregivers and providers to express. Caregivers continually mentioned the fear and anxiety associated with leaving the hospital and becoming the primary provider for the LTR. They felt undertrained and overwhelmed with the complex medical care they would now need to provide. This low self-efficacy was also expressed by providers as it was frequently mentioned how changing one medication that the LTRs was receiving could have drastic impacts on the LTR's overall health. Considering self-efficacy is a mediator associated with positive health outcomes, it is imperative that LTRs, caregivers and formal caregivers have high self-efficacy so that the best possible CVD outcomes after LT are obtained. (18, 19) This complexity of care is why the transplant team is seen as the primary caregiver to this population, especially within one year post-transplantation.

Barriers to Care Without Transplant Center Review

The common understanding amongst LTRs, caregivers, and providers is that any type of healthcare need should go through the transplant team prior to implementation; however, this creates a barrier to quality, timely care. The number of patients that the LT team cares for continually increases as more patients are considered for transplantation. It is not feasible for the

transplant team to be continually available when complications arise in their LTRs to assist the LTRs, caregivers and formal caregivers. Other providers in the care team, such as primary care physicians, must be utilized so that a bottleneck does not form as the LT team provides care.

LTRs and their caregivers stressed the difficulty that having the transplant team at the center of care cause when an urgent health concern arises and they are unable to talk to anyone on the transplant team. Without being able to speak with anyone on the transplant team, many transplant recipients are unwilling to allow other providers to continue with care as the LTRs fear organ rejection.

The inability to contact a member of the LT team often occurred when LTRs would enter the emergency department after normal hours or on weekends. LTRs would end up waiting before any care was given until the providers were able to reach someone from the transplant team. If the complication is time-sensitive, this could end up causing more harm than good as LTRs may refuse any type of care without approval from the LT team due to fear of organ rejection.

On the other side of this, providers expressed an understanding of the importance of contacting the transplant team before providing care to this population, as their care is very complex, but they mentioned it is difficult to get into contact with someone on the transplant. Providers have limited time with patients, and when providers are unable to contact the transplant team within the time-frame they have to treat the LTR this can lead to providers not making a change to a medication that could improve patient health in order to avoid the potential of making a disastrous mistake. The inability to contact the transplant team, who is central to the care of transplant recipients, is a system failure and supports the need to make a systems-level change.

Barriers Caused by a Complex Care Team

Finally, the complex care team was seen as a barrier to CVD care amongst LTRs. LTRs noted that due to their complex healthcare needs they have a lot of providers, and they themselves do not know what all the providers are doing for them. Without the understanding of why all their providers are necessary and what their role is, it understood why LTRs and their caregivers see this as a barrier. Providers also alluded to the complex care team being a barrier, as providers mentioned how they were unsure who to contact as there were so many providers caring for the same patient. Further, LTRs expressed how they often felt as though they had to be their own advocate and make sure that records and information were being shared across providers. When this happens, important information is likely to be lost. Again, this is a system-level failure and points to the need for a new system to improve CVD care amongst LTRs.

Potential Solutions

With the prominent barriers to CVD care amongst LTRs identified by the LTRs themselves, caregivers, and providers, potential solutions can be developed. Solutions to increase awareness about the increased risk of CVD amongst LTRs include additional education done by the transplant team for LTRs and caregivers. LTRs frequently mentioned how they trust their transplant team with their care more than the other providers. This means transplant teams have the platform to encourage patients to manage their CVD risk factors more than their traditional providers. To make providers more aware, EMR alerts are suggested when they are seeing LTRs. In terms of an additional paper handout with CVD information, LTRs, caregivers, and providers alike had mixed feelings on this. Some said they would like a hardcopy to read and others said they already receive too many papers.

A potential way to improve the self-efficacy of caregivers and providers when caring for LTRs could be to improve the utilization of the transplant coordinator who can provide additional education for proper CVD care after LT. Caregivers who have received additional training on providing at-home care have been shown to have significant increases in reported self-efficacy when compared to caregivers who did not receive additional training. (20) High ratings of self-efficacy have been shown to support better clinical outcomes for those being cared for. (21) Further, for physicians, guidance on how to effectively communicating CVD risk factors to their patients and caregivers can assist with improved self-efficacy, as communication skills training has been shown to increase long-term self-efficacy amongst physicians. (22) With the increased growth of the transplant department each year, it is suggested that more transplant coordinators be available to the LTRs, caregivers, and providers to offer additional education and support to decrease the barrier of transplant review.

It appeared that most perceived the major barriers associated with getting into contact with the transplant team after hours or on weekends. Potential solutions to decrease or eliminate this barrier include having a covered email address or a hotline for the LTRs and their caregivers to utilized when concerns arise. These would ideally be covered by transplant coordinators. Further, a facts and question page with common concerns could be created for patients to use.

Another solution to address the barrier of transplant review always being needed is to utilize the transplant pharmacist more frequently. Often times, providers need to get into contact with the transplant team when trying to make modifications to medications that LTRs are taking. The transplant pharmacist can assist with these decisions to determine possible drug interactions and negative side effects. Additionally, after the LTRs are discharged, transplant pharmacists can

be involved in a pharmacist-led multidisciplinary team, shown to assist with the detection of medication discrepancies and increase adherence to guideline-directed medical therapy. (23)

The complex care team perceived as a barrier to proper CVD care amongst LTRs is similar to the complex care teams seen within the field of oncology. Recent research on the effectiveness of complex care teams within the field of oncology has shown that multidisciplinary meetings are believed to lead to improved clinical decision making, more coordinated patient care, and overall improved treatment for the patients. (24) Further, when nurses and coordinators are seen as equally as important within the care team as other members, the teams are regarded as more effective with the patients' preferences and comorbidities more likely to be considered. (24) In this way, it is suggested that all members of the complex care team, including the nurses and coordinators, meet before and after LT to enable clear communication about patient care plans and promote team cohesiveness, with the option to utilize telemedicine so that all care team members are able to participate in the meetings.

Additionally, to address the barrier of the complex care team, LTRs, and their caregivers can receive a document detailing all of their providers and what their role is in providing care for the LTR. Further, LTRs and their caregivers should be educated from the beginning that if any concerns or complications arise, they should contact the transplant coordinator. Having this made clear from the beginning of the transplant process will hopefully mean that after transplantation LTRs and caregivers will be familiar with making the transplant coordinator their first point of contact when questions and concerns arise.

In terms of informing the providers, the contact information for the transplant coordinator and the transplant pharmacist can be placed in the LTRs' EMR for providers to easily contact.

Additionally, answers to common questions in regards to CVD care can be placed within the LTRs' EMR as well.

Limitations:

There are limitations to our study that must be noted. Though the goal of this study was to enroll a total of around 95 participants, we only enrolled 46 participants. This smaller study population, therefore, lacked the diversity desired. Further, all participants were recruited from the same medical center, further excluding patient experiences from different medical centers. Recall bias was also a limitation, though all LTRs had received their liver within three years of the focus group, and all providers had seen at least one LTRs within the previous year.

Conclusion:

This study is the first study to formally identify perceived barriers to CVD care amongst LTRs by LTRs, caregivers, and providers. The themes of the barriers identified were the lack of awareness of CVD risk after LT, the lack of confidence in ability to provide proper care to LTRs, barriers to care without transplant review, and barriers caused by the complex care team. Increased education on the risk factors of CVD amongst LTRs done by the transplant coordinators as well as EMR alerts were suggested solutions to the barrier of lack of awareness. The increased utilization of the transplant coordinator and the transplant pharmacist is provided as potential solutions to the lack of confidence in the ability to provide proper care to LTRs and the barriers associated with needing transplant review prior to making healthcare changes. Finally, multidisciplinary care team meetings before and after transplant to review patient care plans, an additional document detailing the roles of each member of the liver LTRs' care team,

and allowing the transplant coordinator to be the first point of contact for LTRs and caregivers can be used to overcome the barrier associated with a complex care team.

Moving forward, additional research with a larger, representative population size of LTRs, caregivers, and providers is suggested. Further, research should be done to determine if these potential solutions overcome the barriers identified so that quality CVD care can be provided to LTRs.

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Table 1: Liver transplant recipient demographic and clinical characteristics

Characteristics	n= 15
Male	73.3
Mean Age (Years)	63.0
Education	
Less than high school graduate	6.6
High school graduate	13.3
Some college	40.0
College graduate	40.0
Race/Ethnicity	
White/Caucasian	73.3
Native Hawaiian or Other Pacific Islander	6.6
Hispanic, Latino or Spanish origin	20.0
Marital Status	
Married/Domestic partner/Civil union	73.3
Separated or divorced	20.0
Never married/Single	6.6
Employment	
Not employed	33.3
Employed part-time	20.0
Employed Full-time	33.3
Disabled	6.6
Homemaker	6.6
Household Income	
More than \$95000	46.6
Between \$55000 and \$74999	46.6
Less than \$15000	6.6
Primary Health Insurance	
Private health insurance (through employer or self-pay)	60.0
Medicaid/Medicare	33.3
Other	6.6
Donation Type	
Living	14.3
Cadaveric	86.6

Current Heart Disease Risk Factors

Hypertension	66.6
High Cholesterol	20.0
Overweight or Obesity	26.6
Chronic Kidney Disease	20.0
Diabetes	53.3

Current Heart Disease Conditions

Stroke	6.6
Arrhythmia	13.3
Blood clot requiring blood thinning medication	6.6

Regular Smoker for at least 3 months

13.3

Table 2: Caregiver demographic and clinical characteristics

**incomplete survey leading to missing data points*

Characteristics	n= 7
Female*	100
Mean Age (Years)*	59.0
Education*	
Some college	16.6
College graduate	50.0
Post graduate	33.3
Race/Ethnicity*	
White/Caucasian	66.6
Asian	16.6
Hispanic, Latino or Spanish origin	16.6
Marital Status *	
Married/Domestic partner/Civil union	66.6
Never married/Single	33.3
Employment*	
Not employed	16.6
Employed part-time	33.3
Employed Full-time	33.3
Student	16.6
Household Income	
More than \$95000	28.6
Between \$55000 and \$74999	28.6
Between \$35,000 and \$54,999	28.6
Less than \$15000	14.3
Primary Health Insurance	
Private health insurance (through employer or self-pay)	85.7
Medicaid/Medicare	14.3

Table 3: Provider demographic and clinical characteristics

Characteristics	n=22
Male	40.9
Mean Age (Years)	43.15
Education	
College graduate	9.1
Post graduate	90.9
Certification Type	
MD	60.0
PharmD	4.0
RN/BSN	12.0
APP/PA/NP	12.0
Other	12.0
Race/Ethnicity	
White/Caucasian	63.6
Asian	36.4
Marital Status	
Married/Domestic partner/Civil union	72.7
Separated or divorced	9.1
Widowed	4.5
Never married/Single	13.6
Employment	
Employed part-time	4.5
Employed Full-time	95.5
Specialty	
General Cardiology	14.8
Transplant Cardiology	3.7
Endocrinology	3.7
Transplant Hepatology	18.5
General Nephrology	22.2
Transplant Nephrology	18.5
Transplant Surgery	7.4
Other	11.1
Primary Healthcare Role	
Clinician	65.4

Clinical Researcher	19.2
Basic or Translational Scientist	3.8
Educator	7.7
Other	3.8

Years in Practice

< 5 years	31.8
5 - 10 years	18.2
11 - 14 years	0.0
15 - 20 years	27.3
> 20 years	22.7

Unique Liver Transplant Recipients Seen in Past Year

<10	20.0
10-50	50.6
51-100	25.0
>100	5.0

Table 4: : Liver transplant recipient post-focus group survey

Question	n=15
Heart disease is a serious condition after liver transplantation.	
Strongly Agree	53.3
Agree	33.3
Neutral	6.6
Disagree	0.0
Strongly Disagree	6.6
Liver transplant recipients have a higher chance of developing heart disease than the general population.	
Strongly Agree	53.3
Agree	40.6
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6
My chance of developing heart disease is important to discuss with my non-transplant providers.	
Strongly Agree	60.0
Agree	33.3
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6
My chance of developing heart disease is important to discuss with my liver transplant providers.	
Strongly Agree	93.3
Agree	0.0
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6
I am confident talking about heart disease risk factors with my non-transplant providers.	
Strongly Agree	66.6
Agree	20.0
Neutral	6.6
Disagree	6.6
Strongly Disagree	0.0
I am confident talking about heart disease risk factors with my liver transplant providers.	
	66.6

Strongly Agree	33.3
Agree	0.0
Neutral	0.0
Disagree	0.0
Strongly Disagree	0.0

I am confident in my ability to check my blood pressure.

Strongly Agree	60.6
Agree	6.6
Neutral	13.3
Disagree	0.0
Strongly Disagree	0.0

I am confident in my ability to maintain a food diary.

Strongly Agree	20.0
Agree	46.6
Neutral	20.0
Disagree	0.0
Strongly Disagree	13.3

I am confident in my ability to eat a healthy diet.

Strongly Agree	35.7
Agree	38.6
Neutral	21.4
Disagree	7.1
Strongly Disagree	7.1

I am confident in my ability to get physical activity at least 30 minutes per day on most days of the week.

Strongly Agree	40.0
Agree	33.3
Neutral	26.6
Disagree	0.0
Strongly Disagree	6.6

I am confident in my ability to eat a diet low in salt (sodium).

Strongly Agree	60.0
Agree	26.6
Neutral	0.0
Disagree	6.6
Strongly Disagree	6.6

I am confident in my ability to not smoke.

Strongly Agree	80.0
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Agree	13.3
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6

I am confident in my ability to maintain a healthy body weight.

Strongly Agree	46.2
Agree	23.1
Neutral	15.4
Disagree	7.7
Strongly Disagree	0.0

I am confident in my ability to schedule clinic appointments with multiple healthcare providers.

Strongly Agree	66.6
Agree	26.6
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6

I am confident in my ability to attend clinic appointments with multiple healthcare providers.

Strongly Agree	71.4
Agree	21.4
Neutral	0.0
Disagree	0.0
Strongly Disagree	6.6

My transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from non-transplant doctors.

Strongly Agree	53.3
Agree	13.3
Neutral	33.3
Disagree	0.0
Strongly Disagree	0.0

My non-transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from non-transplant doctors.

Strongly Agree	40.0
Agree	0.0
Neutral	40.0

Disagree	6.6
Strongly Disagree	6.6

Which member of your healthcare team should be primarily responsible for providing information about your risk factors for heart disease after liver transplantation?

Surgeon	0.0
Hepatologist	73.3
Cardiologist	13.3
Nephrologist	0.0
Endocrinologist	0.0
Primary Care Provider	13.3

Which member of your healthcare team should be primarily responsible for treating your heart disease risk factors after liver transplantation?

Surgeon	0.0
Hepatologist	26.6
Cardiologist	53.3
Nephrologist	0.0
Endocrinologist	0.0
Primary Care Provider	20.0

Prior to the today's discussion were you aware that heart disease was a leading complication after liver transplantation?

Yes	6.6
No	93.3

Table 5: Caregiver post-focus group survey

**incomplete survey leading to missing data points*

Question	n=8
Heart disease is a serious condition after liver transplantation.	
Strongly Agree	87.5
Agree	12.5
Liver transplant recipients have a higher chance of developing heart disease than the general population.	
Strongly Agree	87.5
Agree	12.5
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their non-transplant providers.	
Strongly Agree	100.0
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their liver transplant providers.	
Strongly Agree	100.0
I am confident talking about heart disease risk factors with my liver transplant recipient's non-transplant providers.	
Strongly Agree	75.0
Agree	12.5
Neutral	12.5
I am confident talking about heart disease risk factors with my liver transplant recipient's liver transplant providers.	
Strongly Agree	100.0
I am confident in my ability help the liver transplant recipient that I care for check their blood pressure.	
Strongly Agree	100.0
I am confident in my ability help the liver transplant recipient that I care for check their blood sugar.	
Strongly Agree	87.5
Agree	12.5

I am confident in my ability to help the liver transplant recipient that I care for maintain a food diary.	
Strongly Agree	75.0
Agree	0.0
Neutral	25.0
I am confident in my ability to help the liver transplant recipient that I care for to eat a healthy diet.	
Strongly Agree	62.5
Agree	25.0
Strongly Disagree	12.5
I am confident in my ability to help the liver transplant recipient that I care for not smoke or stop smoking.*	
Strongly Agree	71.4
Agree	14.3
Neutral	14.3
I am confident in my ability to help the liver transplant recipient that I care for get regular physical activity (regular = least 30 minutes per day on most days of the week).*	
Strongly Agree	85.7
Agree	14.3
I am confident in my ability to help the liver transplant recipient that I care for eat a diet low in salt (sodium).*	
Strongly Agree	71.4
Agree	14.3
Neutral	14.3
I am confident in my ability to help the liver transplant recipient that I care for to not smoke.*	
Strongly Agree	85.7
Agree	14.3
I am confident in my ability to help the liver transplant recipient that I care for maintain a healthy body weight.*	
Strongly Agree	66.6
Agree	28.6
Neutral	14.3

I am confident in my ability to help the liver transplant recipient that I care for schedule clinic appointments with multiple healthcare providers.*	Strongly Agree	100.0
I am confident in my ability to help the liver transplant recipient that I care for attend clinic appointments with multiple healthcare providers.*	Strongly Agree	100.0
The transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from non-transplant doctors.*	Strongly Agree	100.0
The non-transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from non-transplant doctors.*	Strongly Agree	100.0
Which member of your healthcare team should be primarily responsible for providing information about your risk factors for heart disease after liver transplantation? *		
	Surgeon	14.3
	Hepatologist	85.7
	Cardiologist	42.9
	Nephrologist	14.3
	Endocrinologist	28.6
	Primary Care Provider	57.1
Which member of your healthcare team should be primarily responsible for treating your heart disease risk factors after liver transplantation?*		
	Surgeon	14.3
	Hepatologist	57.1
	Cardiologist	71.4
	Nephrologist	14.3
	Endocrinologist	14.3
	Primary Care Provider	14.3

Prior to the today's discussion were you aware that heart disease was a leading complication after liver transplantation?

Yes	6.6
No	93.3

Table 6: Provider post-focus group survey

Question	n=22
Cardiovascular disease is a serious complication in liver transplant recipients.	
Strongly Agree	72.3
Agree	27.3
Neutral	0.0
Disagree	0.0
Strongly Disagree	0.0
Liver transplant recipients have a higher chance of developing cardiovascular disease than the general population.	
Strongly Agree	68.2
Agree	31.8
Neutral	0.0
Disagree	0.0
Strongly Disagree	0.0
Cardiovascular disease risk is an important topic to discuss with the liver transplant recipients under my care.	
Strongly Agree	68.2
Agree	27.3
Neutral	4.5
Disagree	0.0
Strongly Disagree	0.0
I am confident talking with liver transplant recipients about cardiovascular disease risk.	
Strongly Agree	13.6
Agree	40.9
Neutral	31.8
Disagree	13.6
Strongly Disagree	0.0
Cardiovascular disease risk factors are well-controlled in the liver transplant recipients under my care.	
Strongly Agree	4.5
Agree	9.1
Neutral	50.0
Disagree	27.3
Strongly Disagree	4.5

I am confident managing cardiovascular disease risk factors in liver transplant recipients.

Strongly Agree	4.5
Agree	31.8
Neutral	50.0
Disagree	13.6
Strongly Disagree	0.0

I am confident managing blood pressure in liver transplant recipients.

Strongly Agree	31.8
Agree	54.5
Neutral	0.0
Disagree	13.6
Strongly Disagree	0.0

I am confident managing lipids in liver transplant recipients.

Strongly Agree	18.2
Agree	40.9
Neutral	13.6
Disagree	27.3
Strongly Disagree	0.0

I am confident managing blood glucose in liver transplant recipients.

Strongly Agree	4.5
Agree	22.7
Neutral	27.3
Disagree	45.5
Strongly Disagree	0.0

I am confident managing renal dysfunction in liver transplant recipients.

Strongly Agree	22.7
Agree	31.8
Neutral	18.2
Disagree	22.7
Strongly Disagree	0.0

I am confident managing smoking in liver transplant recipients.

Strongly Agree	13.6
Agree	31.8
Neutral	27.3

Disagree	27.3
Strongly Disagree	0.0

I am confident managing weight in liver transplant recipients.

Strongly Agree	4.5
Agree	36.4
Neutral	40.9
Disagree	18.2
Strongly Disagree	0.0

I am confident coordinating cardiovascular disease care risk factor care in liver transplant recipients.

Strongly Agree	4.5
Agree	31.8
Neutral	13.6
Disagree	50.0
Strongly Disagree	0.0

I regularly communicate with healthcare providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.

Strongly Agree	4.5
Agree	40.9
Neutral	31.8
Disagree	18.2
Strongly Disagree	4.5

I regularly communicate with healthcare providers external to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.

Strongly Agree	4.5
Agree	13.6
Neutral	22.7
Disagree	50.0
Strongly Disagree	9.1

I receive accurate communication from providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.

Strongly Agree	9.1
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Agree	18.2
Neutral	31.8
Disagree	36.4
Strongly Disagree	0.0

I receive accurate communication from providers external to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.

Strongly Agree	4.5
Agree	4.5
Neutral	18.2
Disagree	54.5
Strongly Disagree	18.2

Prior to the today's discussion were your aware that cardiovascular disease was a leading complication after liver transplantation?

Yes	63.6
No	36.4

Appendix A

Patient Focus Group Moderator's Interview Guide (version 4)*

*Note: new, albeit unanticipated, focus group questions may emerge based on the discussion as it unfolds.

Introduction

My name is [moderator], and I am a [role] working with Dr. Lisa VanWagner, a transplant liver doctor at Northwestern's transplant center. We are working on improving heart disease risk factor care after liver transplantation. I will be moderating this discussion alongside my research staff [co-moderator(s)].

Focus of Discussion:

Before we get started, I'm going to share some background information for our discussion. Feel free to ask questions as we go along.

As you know, liver transplantation is a lifesaving therapy for people with liver cancer and liver failure. The problem is that heart disease is the leading cause of complications after liver transplantation. Death due to heart disease after liver transplantation has increased by 50% since 2002. The term "heart disease" includes problems with the blood flow, pump function, valves and electrical system of the heart. Conditions that increase the chances of heart disease are known as heart disease "risk factors" and include high blood pressure or hypertension, high blood sugar or diabetes, high cholesterol, smoking, poor kidney function, being overweight, physical inactivity, and poor diet. Doctors and patients can prevent heart disease complications after liver transplant if we identify risk factors or symptoms of heart disease early.

Any questions?

Unfortunately, little is known about what kind of heart disease risk factor care liver transplant recipients receive, what barriers to receiving heart disease risk factor care may exist and how healthcare providers can deliver the best heart disease risk factor care to liver transplant patients.

Any questions?

Purpose of the Focus Group:

Now, I would like to tell you a little more about the study we are doing. We are trying to understand your experiences, perceptions, and information needs about heart disease risk factors after liver transplantation. Our goal is to help liver transplant recipients obtain the best heart disease risk factor care in order to reduce heart disease complications after liver transplantation.

Our discussion will last about 90 minutes. We will talk about your concerns after liver transplant, your experiences of obtaining heart disease risk factor care after liver transplantation, your

perceptions of potential barriers to heart disease risk factor care, and your ideas for making your healthcare providers more sensitive to the needs of liver transplant recipients when talking about heart disease risk factors.

Please help yourself to the refreshments during the discussion. If you need to use the restroom, there is one down the hall, please feel free to go when you need to.

We have 2 goals for doing this focus group:

1. We are interested in your opinions. So, it will be very helpful for us if you can:
 - Be specific when you're speaking/explaining something: provide details and examples.
 - Share stories of your own experiences. Even if you think your experience is just like everyone else's, don't just say, 'I agree.' We want to hear your story, because there's always something unique in each person's own experience.
 - Say why you agree or disagree with another person's responses.
 - The more you compare your experiences to others', the fuller our discussion will be and this will help us see the full range of perspectives.

2. Next, we are here to learn from you. You are the expert on these topics. If you do not understand any question, please let me know and I will rephrase it.

Audiotapes:

I am audio-taping the discussion so that we can remember what you said. Only the research staff will listen to the tapes.

Ground rules:

I ask of you that:

- Only one person speak at a time
- No side conversations among neighbors
- Everyone participate with no one dominating
- Everyone be allowed to speak freely and openly, so let's have common courtesy and respect while others are talking
- After all of the discussion ends, I'll ask you to fill out a brief survey about your views of the discussion. When you hand that in, I will compensate you \$40 in the form of a gift card and provide your parking voucher.

Participant Introductions:

Before we start, I'd like to go around the room and introduce ourselves (note: we will use name tents to assist participants and staff). Please tell us your name, when you received a liver transplant, and how you're generally feeling.

QUESTION GUIDE

Emotional Response

First, let's talk about your concerns after liver transplant and what heart disease means to you.

- What are your biggest health concerns after liver transplantation?
- What are you prioritizing right now in regards to your health?
- What would it take to make heart health a priority for you?
- What do you think about your chances of getting heart disease?
- How does your chance of getting heart disease differ from someone who has not had a liver transplant?
- Is heart disease something that liver transplant recipients are concerned with?
- How serious of a condition is heart disease for liver transplant recipients?
- How does heart disease affect the health of liver transplant recipients?

Now I would like to take a moment and switch gears a little bit to make sure that we are all on the same page.

There are several medical conditions and behaviors that increase the chance of future heart disease. These are known as heart disease "risk factors" and include things like: high blood pressure or hypertension, high blood sugar or diabetes, high cholesterol, poor kidney function, being overweight, poor diet, physical inactivity and smoking. Every liver transplant recipient has at least one of these risk factors at some point after transplant.

- Which heart disease risk factors have worried you the most after liver transplantation?
Which have worried you the least?

Current Experience

Before we move into the next section, I want to again make sure we are all on the same page. Most liver transplant recipients have many different healthcare providers who take care of them after transplant. Healthcare providers include nurses, doctors, physician assistants, nurse practitioners, medical technicians, pharmacists, and social workers. Many healthcare providers

provide care across multiple areas of medicine and are known as “general” or “primary care providers”. On the other hand, some healthcare providers have specific expertise in a particular area of healthcare such as the liver (hepatology), heart (cardiology), kidney (nephrology), operations and procedures (surgery) and blood sugar or diabetes (endocrinology).

Now let’s talk about your experiences with heart disease risk factor care after liver transplant.

- Which of your healthcare providers typically provides information about heart disease and heart disease risk factors to you?
PROBE: If patient mentions a general specialty, such as *cardiology* or *primary care* ask, “Which person(s) in that clinic provides that information?” (e.g., the nurse, doctor, etc.)
- How is information about heart disease and heart disease risk factors after liver transplant typically provided?
PROBE: verbally, printed, video, etc.
- When has this information typically been provided to you?
- Which heart disease risk factors or conditions are most challenging for you to talk about with your healthcare providers?
- What makes them challenging?
- What kinds of barriers have you had getting heart disease care or heart disease risk factor care after liver transplant?
- What types of benefits have you experienced after getting heart disease or heart disease risk factor care since your liver transplant?
- How would you describe the quality of the care you’ve received for heart disease or heart disease risk factors since your transplant?
- Can you describe a time since your liver transplant when you realized that one of your doctors did not have all the information that they needed from your other doctors in terms of your heart disease or heart disease risk factors?

Information Needs

Let’s talk a bit more about information that people need about heart disease risk factors after liver transplantation.

- What kinds of information should liver transplant recipients know about heart disease and heart disease risk factors?

- What questions should liver transplant recipients ask their healthcare providers about heart disease and heart disease risk factors?
- What is the best way for liver transplant recipients to obtain information about heart disease and heart disease risk?
- When is the optimal time for liver transplant recipients to learn about heart disease and heart disease risk factors?
- What would encourage you to talk to your healthcare providers about heart disease and heart disease risk factors after liver transplant?
- What are the benefits of talking about heart disease and heart disease risk factors with your healthcare providers?
- What are the barriers to talking about heart disease and heart disease risk factors with your healthcare providers?
- What ideas do you have to overcome these barriers

Conclusion

We've got to wrap up our discussion in the next 5 minutes.

I'd like to use this time to ask each of you two general questions:

1. Can you give me a final statement summarizing your recommendations for improving heart disease care after liver transplant?
2. What do you think the most important elements of the discussion have been?

Before you leave, please fill out the **survey** and return it to [the moderator].

Practitioner Focus Group Moderator's Interview Guide (version 4)*

**Note:* new, albeit unanticipated, focus group questions may emerge based on the discussion as it unfolds.

Introduction

My name is Lisa VanWagner, and I am a transplant hepatologist working at Northwestern's transplant center currently trying to improve cardiovascular disease care for patients who have received a liver transplantation. I will be moderating this discussion alongside my research staff [co-moderator(s)].

Focus of Discussion:

Before we get started, I'm going to share some important background information for our discussion today. It can be a bit confusing, so please feel free to ask questions as we go along.

As you know, liver transplantation is a lifesaving therapy for people with liver cancer and liver failure. But, new studies show that cardiovascular disease (CVD) is the leading cause of early complications and the third leading cause of late complications after liver transplant. Since 2002, death due to cardiovascular disease after liver transplantation has increased by 50%.

Cardiovascular disease includes MI, heart failure, stroke, arrhythmias, and pulmonary embolism. As you all know, potentially modifiable CVD risk factors include elevated blood glucose, blood pressure, cholesterol, renal dysfunction, obesity, physical inactivity, smoking, and poor diet. Cardiovascular disease complications are potentially preventable if risk factors or symptoms of cardiovascular disease are identified early.

Any questions?

Unfortunately, in a recent survey of transplant physicians less than 10% believed that cardiovascular disease risk factors were well controlled in their liver transplant patients. Little is known about what kinds of cardiovascular disease risk factor management liver transplant recipients are receiving, what barriers to providing cardiovascular disease care may exist and how we can best deliver optimal care to patients.

Any questions?

Purpose of the Focus Group:

Now, I would like to tell you a little more about the study we are doing. We are trying to understand your experiences, perceptions and information needs surrounding cardiovascular disease care after liver transplantation. Our goal is to help liver transplant recipients obtain early and goal-directed cardiovascular disease care in order to reduce cardiovascular disease complications after liver transplantation.

Today, I'll be guiding the discussion with you, and it will last about 90 minutes. We will talk about your experiences providing cardiovascular disease care to liver transplant recipients, your perceptions on potential barriers to cardiovascular disease care and your ideas for improving cardiovascular disease care in this high risk population.

Please help yourself to the refreshments during the discussion. If you need to use the restroom, there is one down the hall, please feel free to go when you need to.

We have 3 goals for doing this focus group:

1. We are interested in your opinions. So, it will be very helpful for us if you can:
 - Be specific when you're speaking/explaining something: provide details and examples.
 - Share stories of your own experiences. Even if you think your experience is just like everyone else's, don't just say, 'I agree.' We want to hear your story, because there's always something unique in each person's own experience.
 - Say why you agree or disagree with another person's responses.

- The more you compare your experiences to others', the fuller our discussion will be and this will help us see the full range of perspectives.
2. Next, we are here to learn from you. You are the expert on these topics. If you do not understand any question, please let me know and I will rephrase it.

Audiotapes:

I want to let you know that I am audio-taping the discussion so that we can remember what you said. Only the research staff will listen to the tapes.

Ground rules:

I ask of you that:

- Only one person speak at a time
- No side conversations among neighbors
- Everyone participate with no one dominating
- Everyone be allowed to speak freely and openly, so let's have common courtesy and respect while others are talking
- After all of the discussion ends, I'll ask you to fill out a brief survey about your views of the discussion. When you hand that in, I will compensate you \$30 in the form of a gift card. .

Participant Introductions:

Before we start, I'd like to go around the room and introduce ourselves (note: we will use name tents to assist participants and staff). Please tell us your name, your position at Northwestern, the specialty you work in and what your experience has been to date working with liver transplant recipients.

QUESTION GUIDE

Emotional Response

Thank you. Now that we are a little bit more familiar with everyone participating in the focus group I would like to start the discussion. First, let's talk about what cardiovascular disease means to you in the context of liver transplantation

- What are your main clinical concerns in liver transplant recipients?
- In general, what are your clinical priorities in the liver transplant recipients who you see?
- What would it take to make cardiovascular health a clinical priority for you in liver transplant recipients?
- How does CVD risk compare between liver transplant recipients versus the general public?
- How concerned are you about liver transplant recipients experiencing a CVD complication?
- How does the severity of CVD compare between liver transplant recipients and the general population?
- Which CVD risk factors worry you the most in liver transplant recipients?
- Which worry you the least?

Current Experience

Now let's talk about your experiences caring for liver transplant recipients after transplantation.

- What is your experience in managing CVD risk factors in liver transplant recipients compared to the general population?
- How does managing CVD risk factors in liver recipients differ from managing CVD risk factors in the general population?
- Who typically provides CVD risk factor care for the liver transplant recipients that you follow in your clinic?
- Who do you think should be responsible for providing CVD risk factor care for a liver transplant recipient? Why?
- Does your recommendation on who should be responsible differ based on the CVD risk factor? Why does your recommendation differ?

- Who do you think should be responsible for providing information to the liver transplant recipient about CVD and CVD risk after liver transplantation? Why?
- Which CVD risk factors or conditions are more challenging for you to manage in liver transplant recipients?
- Why are these more difficult?
- What can you do to better manage CVD risk factors or conditions in the liver transplant recipients that you follow in your clinic?
- What types of barriers have you had providing liver transplant recipients with CVD or CVD risk factor care?
- What types of benefits or successes, if any, have you encountered in providing liver transplant recipients with CVD or CVD risk factor care?
- What are the challenges in coordinating care between healthcare providers in terms of CVD risk factor care in liver transplant recipients?
- What suggestions do you have on how to improve coordination of care between healthcare providers?

Information Needs

Let's talk a bit more about information that health care providers need about cardiovascular disease risk after liver transplantation.

- What kinds of information would be helpful for you to know about CVD risk and CVD risk factor management in liver transplant recipients?
- How would you like to receive information about CVD risk and CVD risk factor management in liver transplant recipients?
- What would encourage you to talk to liver transplant recipients about CVD risk and CVD risk factor management during your clinical encounters?
- What are the benefits of discussing CVD risk and CVD risk factor management with liver transplant recipients?
- What are the barriers to discussing liver CVD risk and CVD risk factor management with liver transplant recipients?
- What ideas do you have to overcome these barriers?

Conclusion

We've got to wrap up our discussion in the next 5 minutes.

I'd like to use this time to ask each of you two general questions:

1. Can you give me a final statement summarizing your recommendations for improving cardiovascular disease care for liver transplant recipients?
2. What do you think the most important elements of the discussion have been?

Before you leave, please fill out the **survey** and return it to one of the moderators.

Caregiver Focus Group Moderator's Interview Guide (version 4)*

*Note: new, albeit unanticipated, focus group questions may emerge based on the discussion as it unfolds.

Introduction

My name is Dr. Lisa VanWagner, and I am a transplant liver doctor working at Northwestern's transplant center. We are working to improve heart disease care after liver transplantation. I will be moderating this discussion alongside my research staff [co-moderator(s)].

Focus of Discussion:

Before we get started, I'm going to share some background information for our discussion. Feel free to ask questions as we go along.

As you know, liver transplantation is a lifesaving therapy for people with liver cancer and liver failure. The problem is that heart disease is the leading cause of complications after liver transplantation. Death due to heart disease after liver transplantation has increased by 50% since 2002. The term "heart disease" includes problems with the blood flow, pump function, valves and electrical system of the heart. Conditions that increase the chances of heart disease are known as heart disease "risk factors" and include high blood pressure or hypertension, high blood sugar or diabetes, high cholesterol, smoking, poor kidney function, being overweight, physical inactivity, and poor diet. Doctors and patients can prevent heart disease complications after liver transplant if we identify risk factors or symptoms of heart disease early.

Any questions?

Unfortunately, little is known about what kind of heart disease risk factor care liver transplant recipients receive, what barriers to receiving heart disease risk factor care may exist and how healthcare providers can deliver the best heart disease risk factor care to liver transplant patients.

Any questions?

Purpose of the Focus Group:

Now, I would like to tell you a little more about the study we are doing. We are trying to understand your experiences, perceptions, and information needs about heart disease care after liver transplantation. Our goal is to help liver transplant recipients obtain the best heart disease care in order to reduce heart disease complications after liver transplantation.

Our discussion will last about 90 minutes. We will talk about your concerns after liver transplant, your experiences assisting your loved one with obtaining heart disease risk factor care after liver transplantation, your perceptions of potential barriers to heart disease risk factor care, and your ideas for making healthcare providers more sensitive to the needs of liver transplant recipients and their caregivers when talking about heart disease and heart disease risk factors.

Please help yourself to the refreshments during the discussion. If you need to use the restroom, there is one down the hall, please feel free to go when you need to.

We have 2 goals for doing this focus group:

1. We are interested in your opinions. So, it will be very helpful for us if you can:
 - Be specific when you're speaking/explaining something: provide details and examples.
 - Share stories of your own experiences. Even if you think your experience is just like everyone else's, don't just say, 'I agree.' We want to hear your story, because there's always something unique in each person's own experience.
 - Say why you agree or disagree with another person's responses.
 - The more you compare your experiences to others', the fuller our discussion will be and this will help us see the full range of perspectives.
2. Next, we are here to learn from you. You are the expert on these topics. If you do not understand any question, please let me know and I will rephrase it.

Audiotapes:

I am audio-taping the discussion so that we can remember what you said. Only the research staff will listen to the tapes.

Ground rules:

I ask of you that:

- Only one person speak at a time
- No side conversations among neighbors
- Everyone participate with no one dominating
- Everyone be allowed to speak freely and openly, so let's have common courtesy and respect while others are talking
- After all of the discussion ends, I'll ask you to fill out a brief survey about your views of the discussion. When you hand that in, I will compensate you \$40 in the form of a gift card or check and provide your parking voucher.

Participant Introductions:

Before we start, I'd like to go around the room and introduce ourselves (note: we will use name tents to assist participants and staff). Please tell us your name, when the person you cared for received a liver transplant, your relationship to the person you cared for after liver transplant, and how you believe the person who received a liver transplant is feeling now.

QUESTION GUIDE

Emotional Response

First, let's talk about your concerns after liver transplant and what heart disease means to you.

- What are your biggest health concerns after for the liver transplant recipient that you care for?
- In general, what are your health priorities in the liver transplant recipient that you care for?
- What would it take to make heart health a priority for you in the liver transplant that you care for?
- What do you think about the chances of the liver transplant recipient that you care for getting heart disease?
- What do you think about the chances of the liver transplant recipient that you care for getting heart disease?
- How does their chance of getting heart disease differ from someone who has not had a liver transplant?
- Is heart disease in liver transplant recipients something that liver transplant caregivers are concerned with?
- How serious of a condition is heart disease for liver transplant recipients?
- How does heart disease affect the health of liver transplant recipients?

Now I would like to take a moment and switch gears a little bit to make sure that we are all on the same page.

There are several medical conditions and behaviors that increase the chance of future heart disease. These are known as heart disease "risk factors" and include things like: high blood pressure, high blood sugar, high cholesterol, poor kidney function, being overweight, poor diet, physical inactivity and smoking. Every liver transplant recipient has at least one of these risk factors at some point after transplant.

- Which heart disease risk factors have worried you the most after liver transplantation in the recipient that you care for?
- Which have worried you the least?

Current Experience

Before we move into the next section, I want to again make sure we are all on the same page. Most liver transplant recipients have many different healthcare providers who take care of them after transplant. Healthcare providers include nurses, doctors, physician assistants, nurse practitioners, medical technicians, pharmacists, and social workers. Many healthcare providers provide care across multiple areas of medicine and are known as “general” or “primary care providers”. On the other hand, some healthcare providers have specific expertise in a particular area of healthcare such as liver (hepatology), heart (cardiology), kidney (nephrology), operations and procedures (surgery) and blood sugar/diabetes (endocrinology).

Now let’s talk about your experiences with heart disease risk factor care after liver transplant

- Which healthcare provider typically provides information about heart disease and heart disease risk factors to you about the liver transplant recipient that you care for?
- PROBE: If caregiver mentions a general specialty, such as *cardiology* or *primary care* ask, “Which person(s) in that clinic provides that information?” (e.g., the nurse, doctor, etc.)
- How is information about heart disease and heart disease risk factors after liver transplant typically provided?
- PROBE: verbally, printed, video, etc.
- When has this information typically been provided to you?
- Which heart disease risk factors or conditions are most challenging for you as a caregiver to talk about with your liver transplant recipient’s healthcare providers?
- What makes them challenging?
- What kinds of barriers have you had getting heart disease care or heart disease risk factor care for the liver transplant recipient that you care for?
- What types of benefits have you experienced after getting heart disease or heart disease risk factor care for the liver transplant recipient that you care for?
- How would you describe the quality of the care that the liver transplant recipient that you care for has received for heart disease or heart disease risk factors since their transplant?
- Can you describe a time since the liver transplant when you realized that one of the doctors did not have all the information that they needed from the other doctors about heart disease or heart disease risk factors in the recipient that you care for?

Information Needs

Let's talk a bit more about information that liver transplant caregivers need about heart disease risk after liver transplantation.

- What kinds of information should liver transplant caregivers know about heart disease and heart disease risk factors?
- What questions should caregivers ask their liver transplant recipient's healthcare providers about heart disease and heart disease risk factors?
- What is the best way for liver transplant caregivers to obtain information about heart disease and heart disease risk?
- When is the optimal time for liver transplant caregivers to learn about heart disease and heart disease risk factors?
- What would encourage you to talk to your liver transplant recipient's healthcare providers about heart disease and heart disease risk factors after liver transplant?
- What are the benefits of talking about heart disease and heart disease risk factors with your liver transplant recipient's healthcare providers?
- What are the barriers to talking about heart disease and heart disease risk factors with your liver transplant recipient's healthcare providers?
- What ideas do you have to overcome these barriers?

Conclusion

We've got to wrap up our discussion in the next 5 minutes.

I'd like to use this time to ask each of you two general questions:

1. Can you give me a final statement summarizing your recommendations for improving heart disease care after liver transplant?
2. What do you think the most important elements of the discussion have been?

Before you leave, please fill out the **survey** and return it to one of the moderators.

Appendix B
Question Construct Mapping: PATIENTS

Health Belief Model explains behavior in terms of people's behavioral responses to health-related conditions

<http://www.med.upenn.edu/hbhe4/part2-ch3-main-constructs.shtml>

PATIENT

Question	HBM Construct	HBM construct definition
<p>EMOTIONAL RESPONSE <i>First, let's talk about your concerns after liver transplant and what heart disease means to you.</i></p>		
<p>What are your biggest health concerns after liver transplantation?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>What are you prioritizing right now in regards to your health?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>What would it take to make heart health a priority for you?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>What do you think about your chances of getting heart disease? How does your chance of getting heart disease differ from someone who has not had a liver transplant?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>Is heart disease something that liver transplant recipients are concerned with?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>How serious of a condition is heart disease for liver transplant recipients?</p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>
<p>How does heart disease affect the health of liver transplant recipients?</p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>
<p><i>Now I would like to take a moment and switch gears a little bit to make sure that we are all on the same page.</i> <i>There are several medical conditions and behaviors that increase the chance of future</i></p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>

<p><i>heart disease. These are known as heart disease “risk factors” and include things like: high blood pressure, high blood sugar, high cholesterol, poor kidney function, being overweight, poor diet, physical inactivity and smoking. Every liver transplant recipient has at least one of these risk factors at some point after transplant.</i></p> <p>Which heart disease risk factors have worried you the most after liver transplantation?</p> <p>Which have worried you the least?</p>		
<p>CURRENT EXPERIENCE</p> <p><i>Before we move into the next section, I want to again make sure we are all on the same page. Most liver transplant recipients have many different healthcare providers who take care of them after transplant. Healthcare providers include nurses, doctors, physician assistants, nurse practitioners, medical technicians, pharmacists, and social workers. Many healthcare providers provide care across multiple areas of medicine and are known as “general” or “primary care providers”. On the other hand, some healthcare providers have specific expertise in a particular area of healthcare such as liver (hepatology), heart (cardiology), kidney (nephrology), operations and procedures (surgery) and blood sugar/diabetes (endocrinology).</i></p> <p><i>Now let’s talk about your experiences with heart disease risk factor care after liver transplant.</i></p>		
<p>Which of your healthcare providers typically provides information about heart disease and heart disease risk factors to you?</p> <p>PROBE: If patient mentions a general specialty, such as <i>cardiology</i> or <i>primary care</i> ask, “Which person(s) in that clinic provides that information?” (e.g., the nurse, doctor, etc.)</p> <p>How is information about heart disease and heart disease risk factors after liver transplant typically provided?</p> <p>PROBE: verbally, printed, video, etc.</p> <p>When has this information typically been provided to you?</p>		

Which heart disease risk factors or conditions are most challenging for you to talk about with your healthcare providers? What makes them challenging?	Self-efficacy	One's confidence in one's ability to take action
What kinds of barriers have you had getting heart disease care or heart disease risk factor care after liver transplant?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What types of benefits have you experienced after getting heart disease or heart disease risk factor care since your liver transplant?	Perceived benefits	Belief about the potential positive aspects of a health action
How would you describe the quality of the care you've received for heart disease or heart disease risk factors since your transplant?		
Can you describe a time since your liver transplant when you realized that one of your doctors did not have all the information that they needed from your other doctors in terms of your heart disease or heart disease risk factors?		
INFORMATION NEEDS <i>Let's talk a bit more about information that people need about heart disease risk factors after liver transplantation.</i>		
What kinds of information should liver transplant recipients know about heart disease and heart disease risk factors?		
What questions should liver transplant recipients ask their healthcare providers about heart disease and heart disease risk factors?		
What is the best way for liver transplant recipients to obtain information about heart disease and heart disease risk?		
When is the optimal time for liver transplant recipients to learn about heart disease and heart disease risk factors?		
What would encourage you to talk to your healthcare providers about heart disease and heart disease risk factors after liver transplant?	Cues to Action	Strategies to activate one's "readiness"

What are the benefits of talking about heart disease and heart disease risk factors with your healthcare providers?	Perceived benefits	Belief about the potential positive aspects of a health action
What are the barriers to talking about heart disease and heart disease risk factors with your healthcare providers?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What ideas do you have to overcome these barriers?	Cues to Action	Strategies to activate one's "readiness"

PATIENT POST SURVEY CONSTRUCTS

LIKERT SCALE QUESTIONS		
Rate how much you agree or disagree with the statements below. (scale 1=strongly disagree to 5=strongly agree)		
Heart disease is a serious condition after liver transplantation.	Perceived severity	One's belief of how serious a condition and its sequelae are
Liver transplant recipients have a higher chance of developing heart disease than the general population.	Perceived susceptibility	One's belief regarding the chance of getting a condition
My chance of developing heart disease is important to discuss with my non-transplant providers.	Perceived benefits	Belief about the potential positive aspects of a health action
My chance of developing heart disease is important to discuss with my liver transplant providers.	Perceived benefits	Belief about the potential positive aspects of a health action
I am confident talking about heart disease risk factors with my non-transplant providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident talking about heart disease risk factors with my liver transplant providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to check my blood pressure.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to check my blood sugar.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to maintain a food diary.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to eat a healthy diet.	Self-efficacy	One's confidence in one's ability to take action

I am confident in my ability to get regular physical activity (by regular, we mean at least 30 minutes per day on most days of the week).	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to eat a diet low in salt (sodium).	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to not smoke.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to maintain a healthy body weight.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to schedule clinic appointments with multiple healthcare providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to attend clinic appointments with multiple healthcare providers.	Self-efficacy	One's confidence in one's ability to take action
My transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from non-transplant doctors.		
My non-transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from my transplant doctors.		

Question Construct Mapping

Health Belief Model explains behavior in terms of people's behavioral responses to health-related conditions

<http://www.med.upenn.edu/hbhe4/part2-ch3-main-constructs.shtml>

CAREGIVER

Question	HBM Construct	HBM construct definition
EMOTIONAL RESPONSE		
<i>First, let's talk about your concerns after liver transplant and what heart disease means to you.</i>		
What are your biggest health concerns for the liver transplant recipient that you care for?	Perceived susceptibility	One's belief regarding the chance of getting a condition
In general, what are your health priorities in the liver transplant recipient that you care for?	Perceived susceptibility	One's belief regarding the chance of getting a condition
What would it take to make heart health a priority for you in the liver transplant that you care for?	Perceived susceptibility	One's belief regarding the chance of getting a condition

<p>What do you think about the chances of the liver transplant recipient that you care for getting heart disease?</p> <p>How does their chance of getting heart disease differ from someone who has not had a liver transplant?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>Is heart disease in liver transplant recipients something that liver transplant caregivers are concerned with?</p>	<p>Perceived susceptibility</p>	<p>One's belief regarding the chance of getting a condition</p>
<p>How serious of a condition is heart disease for liver transplant recipients?</p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>
<p>How does heart disease affect the health of liver transplant recipients?</p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>
<p><i>Now I would like to take a moment and switch gears a little bit to make sure that we are all on the same page.</i></p> <p><i>There are several medical conditions and behaviors that increase the chance of future heart disease. These are known as heart disease “risk factors” and include things like: high blood pressure, high blood sugar, high cholesterol, poor kidney function, being overweight, poor diet, physical inactivity and smoking. Every liver transplant recipient has at least one of these risk factors at some point after transplant.</i></p> <p>Which heart disease risk factors have worried you the most after liver transplantation in the recipient that you care for?</p> <p>Which have worried you the least?</p>	<p>Perceived severity</p>	<p>One's belief of how serious a condition and its sequelae are</p>

CURRENT EXPERIENCE

Before we move into the next section, I want to again make sure we are all on the same page. Most liver transplant recipients have many different healthcare providers who take care of them after transplant. Healthcare providers include nurses, doctors, physician assistants, nurse practitioners, medical technicians, pharmacists, and social workers. Many healthcare providers provide care across multiple areas of medicine and are known as “general” or “primary care providers”. On the other hand, some healthcare providers have specific expertise in a particular area of healthcare such as liver (hepatology), heart (cardiology),

kidney (nephrology), operations and procedures (surgery) and blood sugar/diabetes (endocrinology).

Now let's talk about your experiences with heart disease risk factor care after liver transplant.

<p>Which healthcare provider typically provides information about heart disease and heart disease risk factors to you about the liver transplant recipient that you care for? PROBE: If caregiver mentions a general specialty, such as <i>cardiology</i> or <i>primary care</i> ask, "Which person(s) in that clinic provides that information?" (e.g., the nurse, doctor, etc.)</p> <p>How is information about heart disease and heart disease risk factors after liver transplant typically provided? PROBE: verbally, printed, video, etc.</p> <p>When has this information typically been provided to you?</p>		
<p>Which heart disease risk factors or conditions are most challenging for you as a caregiver to talk about with your liver transplant recipient's healthcare providers? What makes them challenging?</p>	Self-efficacy	One's confidence in one's ability to take action
<p>What kinds of barriers have you had getting heart disease care or heart disease risk factor care for the liver transplant recipient that you care for?</p>	Perceived barriers	Belief about the potential negative aspects of a particular health action
<p>What types of benefits have you experienced after getting heart disease or heart disease risk factor care for the liver transplant recipient that you care for?</p>	Perceived benefits	Belief about the potential positive aspects of a health action
<p>How would you describe the quality of the care that the liver transplant recipient that you care for has received for heart disease or heart disease risk factors since their transplant?</p>		

Can you describe a time since the liver transplant when you realized that one of the doctors did not have all the information that they needed from the other doctors about heart disease or heart disease factors in the recipient that you care for?		
INFORMATION NEEDS		
<i>Let's talk a bit more about information that people need about heart disease risk factors after liver transplantation</i>		
What kinds of information should liver transplant caregivers know about heart disease and heart disease risk factors?		
What questions should caregivers ask their liver transplant recipient's healthcare providers about heart disease and heart disease risk factors?		
What is the best way for liver transplant caregivers to obtain information about heart disease and heart disease risk?		
When is the optimal time for liver transplant caregivers to learn about heart disease and heart disease risk factors?		
What would encourage you to talk to your liver transplant recipient's healthcare providers about heart disease and heart disease risk factors after liver transplant?	Cues to Action	Strategies to activate one's "readiness"
What are the benefits of talking about heart disease and heart disease risk factors with your liver transplant recipient's healthcare providers?	Perceived benefits	Belief about the potential positive aspects of a health action
What are the barriers to talking about heart disease and heart disease risk factors with your liver transplant recipient's healthcare providers?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What ideas do you have to overcome these barriers?	Cues to Action	Strategies to activate one's "readiness"
POST SURVEY LIKERT SCALE QUESTIONS (scale 1=strongly disagree to 5=strongly agree)		
Heart disease is a serious condition after liver transplantation.	Perceived severity	One's belief of how serious a condition and its sequelae are
Liver transplant recipients have a higher chance of developing heart disease than the general population.	Perceived susceptibility	One's belief regarding the chance of getting a condition
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their non-transplant providers.	Perceived benefits	Belief about the potential positive

		aspects of a health action
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their liver transplant providers.	Perceived benefits	Belief about the potential positive aspects of a health action
I am confident talking about heart disease risk factors with my liver transplant recipient's non-transplant providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident talking about heart disease risk factors with my liver transplant recipient's transplant providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for check their blood pressure.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for check their blood sugar.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for maintain a food diary.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for eat a healthy diet.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for not smoke or stop smoking.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for get regular physical activity (by regular, we mean at least 30 minutes per day on most days of the week).	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for to eat a diet low in salt (sodium).	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for to not smoke.	Self-efficacy	One's confidence in one's ability to take action

I am confident in my ability to help the liver transplant recipient that I care for maintain a healthy body weight	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for schedule clinic appointments with multiple healthcare providers.	Self-efficacy	One's confidence in one's ability to take action
I am confident in my ability to help the liver transplant recipient that I care for attend clinic appointments with multiple healthcare providers.	Self-efficacy	One's confidence in one's ability to take action
The transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from non-transplant doctors.		
The non-transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from transplant doctors.		

Question Construct Mapping: PRACTITIONERS

Health Belief Model explains behavior in terms of people's behavioral responses to health-related conditions

<http://www.med.upenn.edu/hbhe4/part2-ch3-main-constructs.shtml>

PRACTITIONER

Question	HBM Construct	HBM construct definition
EMOTIONAL RESPONSE		
<i>First, let's talk about what cardiovascular disease means to you in the context of liver transplantation.</i>		
What are your main clinical concerns in liver transplant recipients?	Perceived susceptibility	One's belief regarding the chance of getting a condition

In general, what are your clinical priorities in the liver transplant recipients who you see?	Perceived susceptibility	One's belief regarding the chance of getting a condition
What would it take to make cardiovascular health a clinical priority for you in liver transplant recipients?	Perceived susceptibility	One's belief regarding the chance of getting a condition
How does CVD risk compare between liver transplant recipients versus the general public?	Perceived susceptibility	One's belief regarding the chance of getting a condition
How concerned are you about liver transplant recipients experiencing a CVD complication?	Perceived susceptibility	One's belief regarding the chance of getting a condition
How does the severity of CVD compare between liver transplant recipients and the general population?	Perceived severity	One's belief of how serious a condition and its sequelae are
Which CVD risk factors worry you the most in liver transplant recipients? Which worry you the least?	Perceived severity	One's belief of how serious a condition and its sequelae are
CURRENT EXPERIENCE <i>Now let's talk about your experiences caring for liver transplant recipients after transplantation.</i>		
What is your experience in managing CVD risk factors in liver transplant recipients compared to the general population? How does managing CVD risk factors in liver recipients differ from managing CVD risk factors in the general population?		
Who typically provides CVD risk factor care for the liver transplant recipients that you follow in your clinic?		
Who do you think should be responsible for providing CVD risk factor care for a liver transplant recipient? Why?		
Does your recommendation on who should be responsible differ based on the CVD risk factor? Why does your recommendation differ?		

Who do you think should be responsible for providing information to the liver transplant recipient about CVD and CVD risk after liver transplantation? Why?		
Which CVD risk factors or conditions are more challenging for you to manage in liver transplant recipients? Why are these more difficult?	Self-efficacy	One's confidence in one's ability to take action
What can you do to better manage CVD risk factors or conditions in the liver transplant recipients that you follow in your clinic?	Cues to Action	Strategies to activate one's "readiness"
What types of barriers have you had providing liver transplant recipients with CVD or CVD risk factor care?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What types of benefits or successes, if any, have you encountered in providing liver transplant recipients with CVD or CVD risk factor care?	Perceived benefits	Belief about the potential positive aspects of a health action
What are the challenges in coordinating care between healthcare providers in terms of CVD risk factor care in liver transplant recipients?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What suggestions do you have on how to improve coordination of care between healthcare providers?	Cues to Action	Strategies to activate one's "readiness"
INFORMATION NEEDS <i>Let's talk a bit more about information that people need about cardiovascular disease risk after liver transplantation.</i>		
What kinds of information would be helpful for you to know about CVD risk and CVD risk factor management in liver transplant recipients?		
How would you like to receive information about CVD risk and CVD risk factor management in liver transplant recipients?		
What would encourage you to talk to liver transplant recipients about CVD risk and CVD risk factor management during your clinical encounters?	Cues to Action	Strategies to activate one's "readiness"

What are the benefits of discussing CVD risk and CVD risk factor management with liver transplant recipients?	Perceived benefits	Belief about the potential positive aspects of a health action
What are the barriers to discussing liver CVD risk and CVD risk factor management with liver transplant recipients?	Perceived barriers	Belief about the potential negative aspects of a particular health action
What ideas do you have to overcome these barriers?	Cues to Action	Strategies to activate one's "readiness"

POST SURVEY LIKERT SCALE QUESTIONS (scale 1=strongly disagree to 5=strongly agree)		
Cardiovascular disease is a serious complication in liver transplant recipients.	Perceived severity	One's belief of how serious a condition and its sequelae are
Liver transplant recipients have a higher chance of developing cardiovascular disease than the general population.	Perceived susceptibility	One's belief regarding the chance of getting a condition
Cardiovascular disease risk is an important topic to discuss with the liver transplant recipients under my care.	Perceived benefits	Belief about the potential positive aspects of a health action
I am confident talking with liver transplant recipients about cardiovascular disease risk.	Self-efficacy	One's confidence in one's ability to take action
Cardiovascular disease risk factors are well-controlled in the liver transplant recipients under my care.	Perceived susceptibility	One's belief regarding the chance of getting a condition
I am confident managing cardiovascular disease risk factors in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action
I am confident managing blood pressure in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action
I am confident managing lipids in liver transplant recipients	Self-efficacy	One's confidence in one's ability to take action
I am confident managing blood glucose in liver transplant recipients	Self-efficacy	One's confidence in one's ability to take action
I am confident managing renal dysfunction in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action
I am confident managing smoking in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action
I am confident managing weight in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action

I am confident coordinating cardiovascular disease care risk factor care in liver transplant recipients.	Self-efficacy	One's confidence in one's ability to take action
I regularly communicate with healthcare providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.		
I regularly communicate with healthcare providers <i>external</i> to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.		
I receive accurate communication from providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.		
I receive accurate communication from providers <i>external</i> to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.		

Appendix C
Post Focus Group Survey Caregiver
(Version 4)

The purpose of this brief survey is to get your impression of the focus group overall and to ask some background questions. Your responses will be anonymous. Please respond to questions in as much detail as possible. (Use the reverse side for more space).

1. Please respond to the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Heart disease is a serious condition after liver transplantation.					
Liver transplant recipients have a higher chance of developing heart disease than the general population.					
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their non-transplant providers.					
The liver transplant recipient that I care for chance of developing heart disease is important to discuss with their liver transplant providers.					
I am confident talking about heart disease risk factors with my liver transplant recipient's non-transplant providers.					
I am confident talking about heart disease risk factors with my liver transplant recipient's transplant providers.					
I am confident in my ability to help the liver transplant recipient that I care for check their blood pressure.					
I am confident in my ability to help the liver transplant recipient that I care for check their blood sugar.					
I am confident in my ability to help the liver transplant recipient that I care for maintain a food diary.					
I am confident in my ability to help the liver transplant recipient that I care for eat a healthy diet.					

Continued on next page

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I am confident in my ability to help the liver transplant recipient that I care for not smoke or stop smoking.					
I am confident in my ability to help the liver transplant recipient that I care for get regular physical activity (by regular, we mean at least 30 minutes per day on most days of the week)					
I am confident in my ability to help the liver transplant recipient that I care for to eat a diet low in salt (sodium).					
I am confident in my ability to help the liver transplant recipient that I care for to not smoke.					
I am confident in my ability to help the liver transplant recipient that I care for maintain a healthy body weight					
I am confident in my ability to help the liver transplant recipient that I care for schedule clinic appointments with multiple healthcare providers.					
I am confident in my ability to help the liver transplant recipient that I care for attend clinic appointments with multiple healthcare providers.					
The transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from non-transplant doctors.					
The non-transplant doctors seem informed and up-to-date about the heart disease risk factor care that the liver transplant recipient that I care for receives from transplant doctors.					

Continued on next page
Page 2 of 7

2. Which member of the healthcare team should be PRIMARILY responsible for providing information to you about heart disease risk and heart disease risk factors in the liver transplant recipient that you care for?

- Surgeon (provider who performs the liver transplant operation)
- Liver specialist (hepatologist: provider who prepares the patient for the liver transplant)
- Heart specialist (cardiologist)
- Kidney specialist (nephrologist)
- Diabetes specialist (endocrinologist)
- Primary care specialist (general internal medicine or family practice)

3. Which member of the healthcare team should be PRIMARILY responsible for treating heart disease risk factors in the liver transplant recipient that you care for?

- Surgeon (provider who performs the liver transplant operation)
- Liver specialist (hepatologist: provider who prepares the patient for the liver transplant)
- Heart specialist (cardiologist)
- Kidney specialist (nephrologist)
- Diabetes specialist (endocrinologist)
- Primary care specialist (general internal medicine or family practice)

4. Prior to the today's discussion were you aware that heart disease was a leading complication after liver transplantation?

- No
- Yes

5. Were there some things that you had not been willing to say in the group?

___ No
___ Yes

→ Please specify what you would have liked to say:

**Continued on next page
Page 3 of 7**

6. Were there any questions that should have been asked?

___ No

___ Yes → Please specify questions:

7. Please reflect on the discussion. Do you have any further suggestions on how heart disease care can be improved after liver transplantation?

Please describe here:

**Continued on next page
Page 4 of 7**

Demographics

Please help us learn a little bit more about you by responding to these last few questions. This information will be kept confidential.

1. Are you: Male Female Other

2. How old are you? _____ years

3. What is the highest grade or level of formal education you have completed?

- Less than high school graduate
- High school graduate
- Some college
- College graduate
- Post graduate degree (MA, PhD, MD, DO, etc.)

4. Please identify your race/ethnicity:

- White/Caucasian
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Middle Eastern or North African
- Hispanic, Latino or Spanish origin
- Other (please specify)_____

5. What is your present marital status?

- Married/Domestic partner/Civil union
- Separated or divorced
- Widowed
- Living with partner
- Never married/Single

6. What is your current employment status? *Please check one.*

- Employed full-time
- Employed part-time
- Not employed
- Homemaker
- Disabled
- Student

Continued on next page

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7. What is your total household income for the past 12 months (you + spouse/partner)?

- Less than \$15,000
- Between \$15,000 and \$34,999
- Between \$35,000 and \$54,999
- Between \$55,000 and \$74,999
- Between \$75,000 and \$94,999
- More than \$95,000

8. What primary health insurance do you have?

- Private health insurance (through employer or self-pay)
- Medicaid/Medicare
- None
- Other: _____

9. How many transplants has the recipient that you care for had? _____

10. What was the date of the most recent liver transplant for the person whom you care for?

____ / ____ / ____
 Month / day / year

11. Did the liver come from someone who died or a living donor?

- From someone who died (Cadaveric)
- From someone still living (Living Donor)

12. Which of the following heart disease risk factors has the liver transplant recipient that you care for ever been diagnosed with (*check all that apply*)?

- High blood pressure (hypertension)
- High cholesterol (dyslipidemia)
- Overweight or obesity
- Chronic kidney disease
- Diabetes (high sugar in blood or urine)
- Other: _____
- I don't know

Continued on next page

Page 6 of 7

13. Which of the following heart disease conditions has the liver transplant recipient that you care for you ever been diagnosed with (*check all that apply*)?

- Heart attack

- Angina
- Heart failure
- Stroke or TIA (transient ischemic attack)
- Irregular heart beat (arrhythmia)
- Blood clot in the leg vein or lung requiring blood thinning medication
- Peripheral vascular disease (problems with circulation, blocked arteries to the legs)
- Other: _____
- I don't know

14. Has the liver transplant recipient that you care for ever smoked cigarettes or cigars regularly for at least three months? By "regularly" we mean at least 5 cigarettes per week almost every week.

- Yes
- No
- I don't know

15. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- Never
- Rarely
- Sometimes
- Often
- Always

- **Please hand your completed survey to any of the research study staff members.**
- **After we receive your survey, we will give your payment in the form of a gift card.**
- **If you have any questions please contact Amna Daud at 312-503-1930.**

Thank you very much for your time and contribution to this research!

**Page 7 of 7
End of Survey**

Post Focus Group Survey Patient
(version 4)

The purpose of this brief survey is to get your impression of the focus group overall and to ask some background questions. Your responses will be anonymous. Please respond to questions in as much detail as possible. (Use the reverse side for more space).

1. Please respond to the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Heart disease is a serious condition after liver transplantation.					
Liver transplant recipients have a higher chance of developing heart disease than the general population.					
My chance of developing heart disease is important to discuss with my non-transplant providers.					
My chance of developing heart disease is important to discuss with my liver transplant providers.					
I am confident talking about heart disease risk factors with my non-transplant providers.					
I am confident talking heart disease risk factors with my liver transplant providers.					
I am confident in my ability to check my blood pressure.					
I am confident in my ability to maintain a food diary.					
I am confident in my ability to eat a healthy diet.					
I am confident in my ability to get regular physical activity (by regular, we mean at least 30 minutes per day on most days of the week).					
I am confident in my ability to eat a diet low in salt (sodium).					
I am confident in my ability to not smoke.					
I am confident in my ability to maintain a healthy body weight.					
	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

I am confident in my ability to schedule clinic appointments with multiple healthcare providers.					
I am confident in my ability to attend clinic appointments with multiple healthcare providers.					
My transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from non-transplant doctors.					
My non-transplant doctors seem informed and up-to-date about the heart disease risk factor care I receive from my transplant doctors.					

2. Which member of your healthcare team should be PRIMARILY responsible for providing information about your risk factors for heart disease after liver transplantation?

- Surgeon (provider who performs the liver transplant operation)
- Liver specialist (hepatologist: provider who prepares you for your liver transplant)
- Heart specialist (cardiologist)
- Kidney specialist (nephrologist)
- Diabetes specialist (endocrinologist)
- Primary care specialist (general internal medicine or family practice)

3. Which member of your healthcare team should be PRIMARILY responsible for treating your heart disease risk factors after liver transplantation?

- Surgeon (provider who performs the liver transplant operation)
- Liver specialist (hepatologist: provider who prepares you for your liver transplant)
- Heart specialist (cardiologist)
- Kidney specialist (nephrologist)
- Diabetes specialist (endocrinologist)
- Primary care specialist (general internal medicine or family practice)

4. Prior to the today's discussion were you aware that heart disease was a leading complication after liver transplantation?

- No
- Yes

Continued on next page

Page 2 of 6

5. Were there some things that you had not been willing to say in the group?

No
 Yes → Please specify what you would have liked to say:

6. Were there any questions that should have been asked?

No
 Yes → Please specify questions:

7. Please reflect on the discussion. Do you have any further suggestions on how heart disease care can be improved after liver transplantation?

Please describe here:

**Continued on next page
Page 3 of 6**

Demographics

Please help us learn a little bit more about you by responding to these last few questions. This information will be kept confidential.

1. Are you: Male Female Other

2. How old are you? _____ years

3. What is the highest grade or level of formal education you have completed?

- Less than high school graduate
- High school graduate
- Some college
- College graduate
- Post graduate degree (MA, PhD, MD, DO, etc.)

4. Please identify your race/ethnicity:

- White/Caucasian
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Middle Eastern or North African
- Hispanic, Latino or Spanish origin
- Other (please specify)_____

5. What is your present marital status?

- Married/Domestic partner/Civil union
- Separated or divorced
- Widowed
- Living with partner
- Never married/Single

6. What is your current employment status? *Please check one.*

- Employed full-time
- Employed part-time
- Not employed
- Homemaker
- Disabled
- Student

Continued on next page

Page 4 of 6

7. What is your total household income for the past 12 months (you + spouse/partner)?

- Less than \$15,000
- Between \$15,000 and \$34,999
- Between \$35,000 and \$54,999
- Between \$55,000 and \$74,999
- Between \$75,000 and \$94,999
- More than \$95,000

8. What primary health insurance do you have?

- Private health insurance (through employer or self-pay)
- Medicaid/Medicare
- None
- Other: _____

9. How many transplants have you had? _____

10. What was the date of your most recent liver transplant?

____ / ____ / ____
 Month / day / year

11. Did your liver come from someone who died or a living donor?

- From someone who died (Cadaveric)
- From someone still living (Living Donor)

12. Which of the following heart disease risk factors have you ever been diagnosed with (check all that apply)?

- High blood pressure (hypertension)
- High cholesterol (dyslipidemia)
- Overweight or obesity
- Chronic kidney disease
- Diabetes (high sugar in blood or urine)
- Other: _____

13. Which of the following heart disease conditions have you ever been diagnosed with (check all that apply)?

- Heart attack
- Angina
- Heart failure
- Stroke or TIA (transient ischemic attack)
- Irregular heart beat (arrhythmia)
- Blood clot in your leg vein or lung requiring blood thinning medication
- Peripheral vascular disease (problems with circulation, blocked arteries to the legs)
- Other: _____

Continued on next page--Page 5 of 6

14. Have you ever smoked cigarettes or cigars regularly for at least three months? By "regularly" we mean at least 5 cigarettes per week almost every week.

- Yes

No

15. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- Never
- Rarely
- Sometimes
- Often
- Always

- **Please hand your completed survey to any of the research study staff members.**
- **After we receive your survey, we will give your payment in the form of a gift card.**
- **If you have any questions please contact Amna Daud at 312-503-1930.**

Thank you very much for your time and contribution to this research!

**End of Survey
Page 6 of 6**

Post Focus Group Survey Practitioner
(Version 4)

The purpose of this brief survey is to get your impression of the focus group overall and to ask some background questions. Your responses will be anonymous. Please respond to questions in as much detail as possible. (Use the reverse side for more space).

1. Please respond to the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Cardiovascular disease is a serious complication in liver transplant recipients.					
Liver transplant recipients have a higher chance of developing cardiovascular disease than the general population.					
Cardiovascular disease risk is an important topic to discuss with the liver transplant recipients under my care.					
I am confident talking with liver transplant recipients about cardiovascular disease risk.					
Cardiovascular disease risk factors are well-controlled in the liver transplant recipients under my care.					
I am confident managing cardiovascular disease risk factors in liver transplant recipients.					
I am confident managing blood pressure in liver transplant recipients.					
I am confident managing lipids in liver transplant recipients					
I am confident managing blood glucose in liver transplant recipients					
I am confident managing renal dysfunction in liver transplant recipients.					
I am confident managing smoking in liver transplant recipients.					

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I am confident managing weight in liver transplant recipients.					
I am confident coordinating cardiovascular disease care risk factor care in liver transplant recipients.					
I regularly communicate with healthcare providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.					
I regularly communicate with healthcare providers <i>external</i> to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care					
I receive accurate communication from providers within my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.					
I receive accurate communication from providers <i>external</i> to my institution on changes to cardiovascular disease risk factor care on the liver transplant recipients under my care.					

2. Prior to the today's discussion were you aware that cardiovascular disease was a leading complication after liver transplantation?

- No
 Yes

3. Were there some things that you had not been willing to say in the group?

- No
 Yes → **Please specify what you would have liked to say:**

Continued on next page

Page 2 of 5

4. Were there any questions that should have been asked?

No
 Yes → **Please specify questions:**

5. Please reflect on the discussion. Do you have any further suggestions on how cardiovascular disease care can be improved after liver transplant?

Please describe here:

**Continued on next page
Page 3 of 5**

Demographics

Please help us learn a little bit more about you by responding to these last few questions. This information will be kept confidential.

1. Are you: Male Female Other

2. How old are you? _____ years

3. What is the highest grade or level of formal education you have completed?

- Less than high school graduate
- High school graduate
- Some college
- College graduate
- Post graduate degree (MA, PhD, MD, DO, PharmD, etc.)

4. Please identify your race/ethnicity:

- White/Caucasian
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Middle Eastern or North African
- Hispanic, Latino or Spanish origin
- Other (please specify)_____

5. What is your present marital status?

- Married/Domestic partner/Civil union
- Separated or divorced
- Widowed
- Living with partner
- Never married/Single

6. What is your current employment status? *Please check one.*

- Employed full-time
- Employed part-time
- Not employed
- Homemaker
- Disabled
- Student

7. Approximately how many unique liver transplant recipients have you seen in the past year in your clinical practice? _____

Continued on next page

Page 4 of 5

8. What is your primary specialty area?

- General Internal Medicine/Primary Care
- General Cardiology
- Transplant Cardiology
- Endocrinology
- Transplant Hepatology
- General Nephrology
- Transplant Nephrology
- Transplant Surgery
- Other (please specify) _____

9. What is your primary role?

- Clinician
- Clinical Researcher
- Basic or Translational Scientist
- Educator
- Trainee
- Other (please specify) _____

10. What is your primary certification?

- MD
- MD PhD
- PhD
- PharmD
- RN/BSN
- APP/PA/NP
- Other (please specify) _____

11. How many years have you been in *independent* clinical practice (e.g., years in practice following the completion of residency/fellowship/clinical rotations)?

- < 5 years
- 5-10 years
- 10-15 years
- 15-20 years
- > 20 years

- **Please hand your completed survey to any of the research study staff members.**
- **After we receive your survey, we will give your payment in the form of a gift card.**
- **If you have any questions please contact Amna Daud at 312-503-1930**

Thank you very much for your time and contribution to this research!