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'You Have to Be Well, to Be Sick'—A Qualitative Study of Young Adults' Experiences of Undergoing Liver Transplantation

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ABSTRACT

Background: Compared to children or older adults, young adults (age 18–29) who undergo liver transplantation are more likely to have poor psychological health and a higher risk of graft failure. Understanding patient needs and perspectives is important for caring for young adults and improving long-term health outcomes.

Aims and Objectives: To (1) understand young liver recipients' experiences, needs and views throughout the transplantation process and (2) identify possible improvements in their care.

Methodological Design and Justification: Three focus group interviews were conducted to investigate young people's experiences.

Ethical Issues and Approval: The study was performed in compliance with the Helsinki Declaration and was approved by the Danish Data Protection Agency (P-2020-559).

Research Methods: Ten young liver recipients (aged 19–34) who had received a liver transplantation aged 18–29 at Rigshospitalet, Copenhagen University Hospital, Denmark were divided into three focus groups. The focus groups were carried out and transcribed.

Instruments and/or Interventions: We have adhered to relevant EQUATOR guidelines in accordance with COREQ.

Results: Data was analysed thematically. We identified three main themes: (1) Balancing illness and youth, (2) Being mentally resourceful and (3) Facing a new kind of chronic illness. We found that young liver recipients struggled with the conflict between youth and chronic illness, even after transplantation. To address this, they emphasised the need for more age-appropriate information and improved mental support from healthcare professionals or peers.

Study Limitations: Because liver transplantation is a rare outcome, especially among the younger population, this study could include only a small group of participants.

Conclusion: Our findings indicate that young liver transplant recipients are a vulnerable group who would benefit from specialised care, emphasising mental support before and after the transplant, along with transparent and honest communication.

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1 | Introduction

Youth is a delicate time of life characterised by hormonal, biological, physiological and social changes [1]. Many young people struggle to navigate and balance their social lives, studies, friends and society's expectations. These factors can contribute to the growing public health issue of mental health problems among young people [2]. Managing chronic illness adds an extra layer to young adulthood, as research has shown that chronic illness in youth is associated with depression, anxiety and a general fear of the future [3]. Furthermore, the mental health-related impact of living with long-term conditions is more significant in young adulthood compared to older adulthood, related to disruptions to the development of identity and routine life events [3].

Young liver transplantation recipients frequently present with a complex medical history, often marked by chronic illness [4]. As their disease progresses, liver transplantation emerges as the treatment of choice for young adults with severe liver disease [5]. Ultimately, transplantation becomes the last viable option, as the alternative is a significant risk of mortality. Poor psychological well-being has been reported among liver transplantation recipients across all ages post-transplantation [6]. Studies have shown that young (age 21–29) recipients of various organs, including liver, are at higher risk of graft failure compared to older or paediatric recipients [7–9]. The increased risk for graft failure can be explained, in part, by a higher rate of non-adherence among young adults [7, 10]. Adherence to treatment among adolescents might be influenced by a higher prevalence of depression, anxiety and low levels of self-management skills [11]. Thus, young recipients are a vulnerable group of patients who might have specific and significant needs regarding health care.

Since 2001, it has been a priority for the World Health Organization (WHO) and other to focus on making health care systems youth-friendly worldwide. To support this goal, WHO published international guidelines [12]. Subsequently, various national guidelines have been issued by different sources [13, 14]. The National Danish guidelines for youth-friendly health services, by Thomsen et al., recommend youth participation, developmentally appropriate communication and care, and a focus on youth life and mental health, including the opportunity to receive support and counselling after long-term illness. Existing qualitative literature in the field focuses mainly on paediatric patient perceptions [15–17] and those of their parents [18–20].

To our knowledge, no studies have yet explored young adults' perspectives and caring needs of young adults. Research on this age group has previously focused primarily on medical outcomes rather than patient experiences [21]. However, understanding patient needs and perspectives is important to care for young adults and improving long-term health outcomes [21]. Thus, the study aims to explore the views and perspectives of young adults who had undergone liver transplantation between the ages of 18–29 to: (1) understand young liver recipients' experiences, needs and views throughout the transplantation process and (2) identify possible improvements in their care.

2 | Methods

A qualitative explorative study was performed using focus group interviews. Focus groups are suitable for gaining insight into a shared understanding of a topic while allowing for individual differences [22].

2.1 | Design

Three semi-structured focus groups were conducted with 10 recipients divided between three focus groups (seven female; age range 19–34). All interviews were conducted in Danish; all quotations used in this article have been translated from Danish to English by D.A.J. We have adhered to the relevant EQUATOR guidelines in accordance with COREQ (Appendix S2).

2.2 | Study Setting and Recruitment

The study was carried out at the Department of Transplantation, Digestive Disease and General Surgery at a highly specialised hospital in the Capital Region of Denmark. In the clinic, 60–65 transplants are carried out annually, of which approximately five are for young adults (age 18–29). After the transplantation, the recipients attend lifelong follow-up care at an outpatient clinic every 3–6 months. Here, they are seen by a nurse and a medical doctor. The young recipients usually attend by themselves, but can be accompanied by a relative.

2.3 | Inclusion and/or Exclusion Criteria

Participants were recruited from the outpatient clinic in the Department of Transplantation, Digestive Disease and General Surgery. Eligible participants were young adults with the following inclusion criteria:

- age 18–29 at the time of the transplantation
- the transplantation had taken place within the last 5 years
- participating in lifelong follow-up care at Rigshospitalet, Copenhagen University Hospital

Based on these criteria, 15–17 potential participants were identified. Exclusion criteria were cognitive impairment or having a psychiatric diagnosis at the time of recruitment. We aimed for 4–5 recipients in each group, as smaller groups are suitable when the participants have substantial opinions to share [22]. Potential recipients were invited by M.D.J. and L.M.H. to participate while attending their follow-up care. If the recipients declared their interest, M.D.J. contacted them to inform them about the study. If they agreed to participate, M.D.J. emailed them participant information, a demographic data sheet, and a consent form to fill out.

2.4 | Data Collection

Two potential focus group interview dates were pre-selected, and participants could choose the date that was the most convenient for them. Due to cancellations from participants for the two previous focus groups, a third focus group was later conducted to ensure data saturation [23]. The interviews were recorded verbatim and took place in a quiet meeting room at the hospital between January and April 2023.

M.D.J. and L.M.H. (both female clinical nurse specialists with a previous professional relationship with the patients) conducted the interviews. D.A.J. (a female research assistant without connection to the participants) observed and transcribed the interviews following the transcription manual. All three interview conductors wore clinical clothes (scrubs) to create a safe and familiar environment for the participants, who knew the conductors in their roles as clinical professionals.

2.4.1 | Preunderstanding

As nurses, the two interviewers M.D.J. and L.M.H. had a professional relationship with the young recipients, which contributed to certain preconceptions about their caring needs and experiences. M.D.J. and L.M.H. expected the patient group to highlight a need for increased mental support and to express that the medical language is difficult to understand. Authors D.A.J., K.D. and E.L.T. had no prior knowledge of the patients, which minimised the influence of pre-existing assumptions on their perspectives. Throughout the research process, we maintained a reflexive stance, continuously examining how our preconceptions could influence the research outcomes when developing the interview guide and when analysing the data. This involved regular team discussions between all authors.

2.4.2 | Interview Guide

We created an interview guide to explore the young recipients' experiences, needs and views regarding their liver transplantation [22]. It followed Krueger and Casey's guidance regarding start-up, key and final questions [22]. The questions were designed to be open-ended to prevent influencing the data with pre-existing assumptions or predefined themes. The guide was developed by following the chronological process of the patient trajectory. It was divided into four stages: medical investigation, waiting list, hospitalisation at the surgical department and outpatient follow-up (Appendix S1). The interview guide was pilot-tested prior to the interviews by asking a young recipient (who did not participate in the focus groups) to read and evaluate the questions. No changes were made to the interview guide.

2.5 | Data Analysis

Reflexive thematic analysis [24] was used to analyse the views and perspectives of young liver recipients, drawing on a hermeneutic epistemology that emphasises the interpretation of participants' experiences and meaning.

We adhered to Braun and Clarke's six phases in the following way: D.A.J., L.M.H., M.D.J. and K.D. became familiar with the transcribed data, then identified and coded relevant features in collaboration and generated them into 32 initial themes. Initial themes were then reviewed, and a thematic map of the analysis was created and presented to E.L.T., an experienced qualitative researcher with no prior knowledge of the specific patient group. All authors discussed and refined the themes into seven subthemes under three main themes that captured the story of each perspective. Finally, we wrote the main themes and incorporated selected quotations [24]. Table 1 illustrates the process from coding to themes.

2.6 | Ethical Considerations

Written and oral information was given to all recipients before their written consent was obtained. All participants were informed that their participation and views would not affect their treatment at the clinic. The study was performed in compliance with the Helsinki Declaration and was approved by the Danish Data Protection Agency (P-2020-559). According to Danish law, qualitative research does not require approval from the Central Science Ethics Committee [25]. Participants did not receive any compensation for participating in the study.

3 | Findings

3.1 | Characteristics of Participants

Ten recipients participated in the study. We aimed for a group size of 4–5, but, because of cancellations from some participants, the three groups consisted of 2–5 participants. 3 were male and 7 were female. The mean age of the participants was

TABLE 1 | Example of data analysis using reflexive thematic analysis.

Codes	Initial themes	Subthemes	Themes
The mental load	Mental strength	Mental resources	Being mentally resourceful
Mental strength			
Standing alone	Being unwell mentally		
Comparisons to other people			
Social media	Coping strategies	Mental support	
Parent support			
Talking with other transplant recipients			

26.5, min–max (19–34), and their age at transplantation was between 18 and 29 (mean age 23.9). All young recipients had been transplanted within 1–5 years prior to the focus group. Two recipients suffered from acute liver disease and 8 had chronic liver disease. Two were diagnosed with liver disease during infancy, four during childhood, two during adolescence, and two were diagnosed in early adulthood. The interviews lasted between 60 and 120 min.

3.2 | Major Themes

Our analysis revealed three major themes: Balancing illness and youth, Being mentally resourceful and Facing a new kind of chronic illness. Themes have been broken into subthemes to provide a closer description of the data (Table 2).

3.3 | Balancing Illness and Youth

A consistent theme was the recipients' experience of a clash between being young and being sick. Fatigue was described as a prominent symptom, affecting recipients' everyday lives. The recipients also experienced that it was challenging to feel understood by peers and relatives before, during and after surgery.

3.3.1 | Being Unwell in Secret

Related to fatigue, the recipients often had to prioritise and schedule their time to attend every individual social activity, as this one activity could leave them drained for days. This view affected their daily lives in different ways. Several participants compared their social lives to those of their friends', causing the recipients to feel distanced from peers who were not chronically ill.

> … my older sister, she doesn't see me that often. She only sees me on my good days, because then I get it together […]. Then I am like the old me. Then she cannot fathom how I cannot go to her place again the next day and take care of her children, because there's absolutely nothing wrong with me, and I should just get out on the job market […]. I see that it can be difficult for your social circle and friends and family [to understand that you are still “sick”] … they just think you're well, because you got a new liver.

Young woman 4

TABLE 2 | Themes and subthemes.

Balancing illness and youth – Being unwell in secret – Fear of missing out – The points of no return
Being mentally resourceful – Mental resources – Mental health support
Facing a new kind of chronic illness – Information needs about the new life – Transition from hospital to home

The recipients discussed that, due to this fatigue and social exhaustion, they only saw friends and family on their ‘good days’, and the days of fatigue and recovery that would follow were invisible to their families and social networks.

3.3.2 | Fear of Missing Out

Post-transplantation, the recipients described an arising feeling of anxiety. This anxiety was often driven by the fear of potential complications that could occur after the transplantation. Consequently, the recipients occasionally avoided social activities and other engagements, preferring the security of home over the uncertainty of the outside world. This caused ‘the fear of missing out’ on social events.

> You are really impatient as well because of the fear of missing out. Everyone else is having a good time, and then there's a party at one of your friends' places, and then I have to sit at home because I am scared of getting infected with something.

Young woman 3

The recipients described the clash between trying to get on with living their lives while simultaneously struggling with ailments related to the disease. This feeling existed throughout the process of transplantation, from the first signs of illness until the aftermath after the liver transplantation. While their friends seemed preoccupied with what the recipients considered more trivial matters, like choosing the best day for a party, the recipients struggled with serious concerns about navigating their daily lives.

3.3.3 | The Points of No Return

The recipients generally had a positive experience at the hospital throughout the process and felt a sense of relief and security once their diagnosis and plan were established. However, accepting their disease became one of the first experiences that contrasted with the identity of youth. The first point of no return occurred when they got on the waiting list. This time was stressful for several participants. Many underwent a personal transformation; they had to live a more restricted lifestyle, such as not leaving the country. The surgery was yet another point of no return:

> It's a point of no return, as soon as I get the liver transplantation, I will have to take that medicine for the rest of my life.

Young woman 2

The lifelong medical treatment highlighted the long-term commitment and responsibility associated with liver transplantation for several recipients.

3.4 | Being Mentally Resourceful

Mental health was described as an important factor throughout the transplantation process.

> You really have to be well to be sick. I mean it requires a sharp head to be able to absorb all that, take it [dealing with illness] all in, and work with it.
>
> Young man 1

The recipients described that it is not only physical strength that is required to go through the process of a liver transplantation, but it also demands a significant amount of mental strength and cognitive ability to face the challenges and discomfort of chronic illness and a lengthy hospitalisation.

3.4.1 | Mental Resources

The recipients experience a clash between their perceived societal expectations of mental strength and the physical and emotional realities of undergoing a major medical procedure. The healthcare professionals' preoperative information also contributed to putting mental pressure on the young people, as they felt an obligation to be mentally strong throughout the process of transplantation.

> This thing that you are told that you must be mentally strong if you want to go through a liver transplantation. You are straight up told that [...]. And then you get out on the other side, and you feel physically weak. You don't want to say that out loud, because suddenly you were not as mentally strong as the doctors commanded, so you don't want to go and talk about the fact that you actually feel quite mentally sore.
>
> Young woman 5

The above statement/quote reflects an interplay between societal expectations, medical narratives and the personal experience of vulnerability.

3.4.2 | Mental Health Support

The young recipients described the need for more mental health support. They argued that one solution could be professional support (e.g., a psychologist or healthcare professional) or peer support from someone who has experienced the same process. One recipient described:

> I also think it could help to talk to someone who has been in the same situation, because I can talk to my friends and my family about it, but they don't know ... I mean they can try to relate, but they don't know shit about anything. But if you are sitting talking to someone else ... they have experienced it on their own body.
>
> Young woman 4

While acknowledging the support from friends and family, the young recipients discussed the need for validation and support from someone who has gone through the same experience, highlighting the potential therapeutic effect of peer support. Another way to get mental support is through social media, a resource used by most recipients to some degree. The young recipients furthermore explained that they actively use social media as a strategy to get familiar with the illness and gain insight into how other young adults have experienced the surgery and are living with a transplanted liver. This further highlights the use of peer support for mental support. However, the recipients described that the use of social media could have negative effects because of exposure to reading about a wide range of negative outcomes, incorrect medical advice from non-clinicians, and irrelevant information, which the recipients had to learn to navigate through:

> Do not let the bad stories get too close. You can be aware that there are potential risks associated with this. But let's think that you are among the 86%, where it goes really well. Let's hope that.
>
> Young man 1

The statement encapsulates an approach to coping with uncertainty while acknowledging the potential risks of actively using social media for mental support.

3.5 | Facing a New Kind of Chronic Illness

During and after the process of transplantation, the recipients expressed some unmet needs related to being adequately informed about what to expect but also described struggles related to getting home and being alone outside the hospital.

3.5.1 | Information Needs About the New Life

The recipients explained a need for correct and precise information regarding their medicine intake, side effects and generally what to expect after the surgery, for example:

> One thing that surprised me, I know well about Prednisolone [...] but I did not think about the fact that you can get diabetes, like temporary diabetes [...]. I didn't think about it. I had eaten some grapes, they resulted in me not being able to get my dessert [served at the hospital, due to high sugar intake]. But maybe it would have been nice to know “don't eat too many grapes” [...] “don't eat too much candy” [...]. That would have been nice to know.
>
> Young woman 2

The recipients highlighted that they wanted to be taken seriously, hear the truth and not feel as if the details were sugarcoated because they were young. At the same time, they recognised that they were a more fragile group of people who would suddenly have a significant responsibility placed on their shoulders.

> But I think it is especially with the young age, then it is a lot, especially the fact that you must take medicine for the rest of your life, and you have a certain kind of responsibility there. And that is a big responsibility to have, because if you don't take your medicine, well, then you'll die'.
>
> Young woman 2

This statement highlights the psychological and emotional weight of the lifelong responsibility of a medical condition, particularly in a young patient.

3.5.2 | Transition From Hospital to Home

After the recipients had undergone surgery, they generally felt well taken care of at the hospital. Initially, after the transplantation, the recipients felt that it was impossible to be under any physical strain, but being surrounded by healthcare staff provided them with a feeling of security, which helped them get out of bed.

> I remember at some point, I was told I had to bike on one of those machines, and then I thought “absolutely not” [...]. I told the surgeon, and he went “yeah you have to, because it is good for you” and I said “I don't think I can” [...] “just give it a go” [he said]. Then I went and then I biked, and then I was like “ok, I actually can” and then I was motivated to do it the next day and get out of hospital quickly.
>
> Young woman 1

While the recipients all aimed to go home as soon as possible, the intensive care at the hospital starkly contrasted with their homes. Suddenly, they felt all alone and fragile.

> Yes, it was nice [to go home], but it is tough to know that you can't just pull the call cord, and then someone would come and help with whatever you needed.
>
> Young man 1

Although being home was associated with a safe and familiar environment, it could also be associated with uncertainty. For some, this meant that they needed reinforcement and monitoring before they could relax and feel safe:

> I was quite anxious about whether I had even taken the correct dose [of medicine post-surgery]. I had to call [the hospital] and ask, and my mum did a check as well before I took those pills. But that was something I was quite worried about.
>
> Young man 3

This quote highlights the emotional toll of managing health after surgery and the reliance on external support.

4 | Discussion

The purpose of this study was twofold: (1) to understand young liver recipients' experiences, needs and views throughout the process of transplantation and (2) to identify possible improvements in their care. In this study, we found three major themes: Balancing illness and youth, Being mentally resourceful, and Facing a new kind of chronic illness. The findings shed light on a renegotiation of youth identity, as the recipients cope with their lives as chronically ill, while highlighting the mental capacity it takes to navigate life. To cope with this, it was highlighted that more information regarding side effects, medicine and life after transplantation was needed, and a focus on mental support and guidance was desirable, whether it came from healthcare professionals or peers. Healthcare providers should aim to create a supportive environment, considering the unique challenges these patients face, to promote resilience and improve long-term outcomes.

4.1 | Discussion of Findings

The recipients highlighted the importance of a focus on mental health. Chronic illness and liver transplantation challenge the identity of young adults and require a significant amount of mental strength. This encompasses the social and psychological impacts of the transplantation and the sense of isolation that can accompany such a life-altering event, which is seen as a point of no return. The three main themes underscore the importance of acknowledging and addressing the emotional and psychological aspects of health, in addition to the physical aspects, and the need for more open conversations about the complex journey of illness and recovery. This focus is also highlighted in the Danish recommendations for a youth-friendly health care system [13]. Our findings suggested that support was needed, which could be carried out by a healthcare professional or a peer who had undergone the same process. This is in line with findings by Wright et al. [16], which showed that young liver recipients felt different from their peers and struggled to maintain a ‘normal’ life compared to them. The vulnerability of youth is supported by findings from Hames et al. [10], which showed a higher rate of depression and anxiety among young adults undergoing liver transplantation compared to the general population of young adults. Psychosocial needs have also been investigated in young kidney recipients, where the need for emotional support, acceptance and direction was highlighted [26]. Peer interventions are well known to have a positive effect and are well established in some fields, for example, psychiatry [27], but have also shown positive effects for people with chronic illnesses, such as renal failure [28] and diabetes mellitus [29, 30]. Such studies have shown that people with chronic illness benefit from learning about their peers' experiences.

Communication skills are of great importance for healthcare professionals throughout the liver transplantation process, especially considering the lifelong implications for recipients. According to our findings, the recipients require precise and honest information throughout the process of transplantation. From the moment the young recipients wake up in the ICU after surgery to transitioning back home and resuming everyday life, they face a new reality as chronically ill patients, reliant on medication for the rest of their lives. Adolescents, in particular, experience significant biological, psychological and social changes [1], requiring communication tailored to their developmental stage. Therefore, it is crucial to engage with adolescents in a manner that acknowledges their evolving reasoning abilities while addressing their immediate and ongoing concerns both pre- and post-transplantation. Studies by Thomsen et al. [13], Kim and White [31] and Allison et al. [32] underscore the importance of providing honest and precise information to young patients. Adolescents and young adults express a desire to be actively involved in their healthcare decisions [13]. By communicating with recipients throughout the transplantation journey, healthcare professionals can empower them to understand their condition, adhere to medication regimens and navigate the challenges of post-transplantation life more effectively. Therefore, healthcare professionals must possess competent interpersonal communication skills when interacting with this group of patients.

4.1.1 | Strength and Limitations of the Work

We have chosen to use a qualitative method to explore the views and perspectives of young adults who have undergone liver transplantation. By employing a qualitative method, we were able to gather in-depth insights into their perspectives and needs.

The current study has several strengths. The focus groups were recipients of different ages, albeit all young adults. Thus, they were in slightly different life stages and, therefore, they each potentially had different perceptions of the transplantation process. This created an environment in which different points of view could come forth, thereby increasing the transferability of our results. Furthermore, we believe it was a strength that the recipients were familiar with the interviewers, who were their nurses in the outpatient clinic. Both nurses wore scrubs during the interviews to create a safe and familiar environment when discussing a possibly sensitive subject. The interviewers' prior knowledge of the recipients helped the nurses to facilitate the interviews and ask relevant questions [33]. However, the previous acquaintance and the scrubs might also constitute a limitation, as the recipients might choose not to disclose certain things or be honest about their views on the care and treatment that they had received. To assure the participants that they could be open and honest in the setting, we informed them that their answers would not affect their treatment and that their names would be anonymised when presenting the results. To increase credibility, the interview guide was pilot-tested by L.M.H. and M.D.J. before the focus group interviews took place. In addition, the analysis was carried out in collaboration with all five authors D.A.J., L.M.H., M.D.J., K.D. and E.L.T. The study also has some limitations. We excluded recipients who were diagnosed with a psychiatric disorder, potentially a group who would have expressed a need for more support. Therefore, we cannot be sure that our findings will represent their needs. The recipients were asked to recall their experiences retrospectively, which might have increased the risk of recall bias. However, the focus groups had a mix of recipients with varying lengths of time since transplantation, which meant that they could supplement each other when recalling the transplantation process. There was also a distinct gender bias, with a ratio of 3:7 men compared to women, which might have affected our findings; we can therefore not be sure that our findings represent the male recipients.

4.2 | Recommendations for Further Research

Based on our insights from the study, several recommendations for further research could be proposed. Future research could explore the effectiveness of mental health consultations and peer support in an interventional study. Furthermore, studies could explore how demographic factors such as gender or socioeconomic status influence the experiences and needs of the young liver recipients.

4.3 | Implications for Policy and Practice

4.3.1 | Mental Health Consultations

Our results showed a need for mental support and care during the entire process, from diagnosis to transplantation, and later, during follow-up visits at the hospital. Based on this, we recommend implementing youth consultations throughout the process. If the recipients bring their parents, the consultation can be structured as split-visit consultations, where the nurse and recipient talk alone without a relative present. This setup allows the young adult to talk about more sensitive matters. We recommend that the conversation be based on the communication tool THRxEADS, which can support clinicians in exploring key issues in the young adult's life [34].

4.3.2 | Peer Support

Our study showed that young people needed to talk to peers. We recommend establishing a connection between recipients and former recipients at the start of the recipients' process, initiated upon getting on the waiting list.

4.3.3 | Age-Appropriate Information

The recipients requested honest and transparent information. Care that fosters trust, open communication and emotional support is critical in addressing their psychological well-being and treatment adherence. We recommend that physicians and nurses be trained in how to deliver information honestly and caringly, taking into account the recipient's age, course of disease and developmental stage. We furthermore recommend that written material be adapted to the young patient by using precise and honest information written in clear language.

5 | Conclusion

In conclusion, our study sheds light on the unique challenges young liver recipients face. The need to focus on young adults' care needs, including proving/addressing their psychological well-being and long-term care needs, was highlighted. Our findings revealed the profound impact of balancing youth and chronic illness post-transplantation, including having to be mentally strong while feeling physically weak. This underscores the importance of providing comprehensive information and mental support throughout the transplantation journey, for example, through peer support. In recognising the vulnerability of this patient group, our findings advocate for specialised care that prioritises mental health and fosters open dialogue between healthcare providers and recipients. By implementing these insights into clinical practice, we can strive towards optimising the long-term health outcomes and quality of life for young liver recipients.

Author Contributions

All authors contributed to the design and delivery of the trial. D.A.J., L.M.H., M.D.J. and K.D. planned, prepared and conducted the interviews. All authors contributed to the data analysis. L.M.H. and M.D.J. drafted the initial manuscript. D.A.J., K.D. and E.L.T. significantly supported the drafting of the manual. All authors have contributed to writing the manuscript and have read and approved the final version.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.