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Understanding the long-term impact of living-related liver transplantation on youth and young adults and their family

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ABSTRACT

Purpose: The purpose of this mixed methods study was to better understand the long term impact of living-related liver donation (LRLD) on youth and young adult (YYA) recipients and their family.

Design and methods: Semistructured interviews were conducted with YYA, aged 11–18 years, who received a living donation from a parent. Interviews were audiotaped, transcribed, and analyzed to aggregate themes that represented the participants' social behavior. At interview, participants completed a demographics questionnaire and the Youth Quality of Life Instrument-Research Version (YQOL-R).

Results: Thirteen adolescents were interviewed; six were re-interviewed as key informants. Three major categories were created from the data: Developing Identity, Redefining Family Relationships, Feeling Gratitude to Donors. The overarching theme was Resiliency. Findings from the YQOL-R showed no difference in overall scores or separate domains when compared with a reference population with no chronic illness.

Conclusion: Qualitative and quantitative data highlight the positive effect that LRLD can have on pediatric patients as they transition from childhood to adolescence to young adulthood. Practice implications: As pediatric transplant centers in the United States soon mark 30 years of performing live-liver donation, recipients are becoming adults and understanding more clearly that the long-term effects of such donations will lead to improvements in future care.

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Introduction

Youth and young adults (YYA) with end-stage liver disease must depend on deceased donors or live-liver donation to sustain life. Live-liver donation, a viable option, has evolved to address the paucity of deceased donors. However, despite remarkable survival rates, only 10% of all children who receive a liver transplant in the United States receive donation from a live donor (Przybyszewski et al., 2018). Live-liver donation is a process by which a healthy adult voluntarily donates a portion of their liver to a patient with end-stage liver disease. Over three decades have passed since the first successful live-liver transplantation was performed in 1989. That historic event involved a 29-year-old mother who donated her liver to her 17-month-old son who had biliary atresia

(Strong, 2001). This event opened the door for live-liver donation worldwide.

In 2019, the United Network for Organ Sharing (UNOS) reported that roughly 7526 liver transplants were performed, 529 of which were on patients <18 years old. Thirty of these cases involved living parental donors. Although the number of parental donors are low, this liver transplant option offers patients and families an alternative to deceased donor organs and waiting list mortality (Schemmer et al., 2005). Most pediatric transplants are performed on patients <1 year old, the most common indication being biliary atresia. Pediatric recipients who received a parental live-liver donation in infancy are now reaching adolescence. Unfortunately, little scientific literature has been published on the youth perspective of the long-term effects of parental live-liver donation. This study was designed to fill that gap. The live-liver recipients in this study were aged 11–18. This span of years covers three distinct age ranges: children, adolescents, and young adults. We refer to them by age range as appropriate and collectively as YYA.

Adolescents experience many changes during development, ranging from the physical, behavioral, emotional, to the cognitive, making it an extremely stressful time for them and their caregivers. Several salient articles have addressed the psychosocial impact of kidney transplantation

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on adolescents such as barriers to achieving normality (Tong, Morton, Howard, McTaggart, & Craig, 2011), concern about their body, and reporting poor relationships with peers (Manificat et al., 2003). One qualitative study revealed that pediatric recipients of a liver transplant seem to use effective and ineffective coping strategies as they mature into adulthood (Sarigol Ordin, Karayurt, Unek, & Astarcioglu, 2017). Receiving an organ transplant affects identity formation, quality of life, and perceived health. Quality of life and psychological responses were used in one study to create a comparison between liver, heart, lung, and kidney transplant recipients. This research team found that ethno-religious and psychosocial variables can have a positive effect on quality of life (Tarabeih, Bokek-Cohen, & Azuri, 2020). Depressive symptoms and loneliness have been reported in adolescents with congenital cardiac disease (Luyckx, Goossens, Van Damme, & Moons, 2011). A multicenter study reported poorer health-related quality of life in preadolescent recipients of a liver transplant than age-matched norms (Miserachs et al., 2018). Based on the narratives of children who received an organ donation, one qualitative study found that they possessed a positive attitude on life; no differences were observed in the experiences of male and female children who received different organs or transplants from live-donors or deceased donors (Olausson et al., 2006). Other studies that have explored the impact living kidney donation has on donors concluded that organ donation should be encouraged and awareness should be increased (Krespi et al., 2017). A systematic review found that living donation creates a unique bond between donors and recipients, a bond that is manifested by gratitude and admiration. However, only 7 of 23 relevant studies include both children and adolescents, not just adolescents (Thys et al., 2015). Findings from an ethnographic qualitative study show that parental donors describe their experience as *transformational* at the individual, family, and community level (Nasr & Rehm, 2014).

Adolescents and young adults experience life stages when behavioral and cognitive systems mature at different rates, is often a time of increased vulnerability and adjustment (Steinberg, 2005). Non adherence to medications in post liver transplantation remains a major source of graft loss and morbidity (Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). Berquist and colleagues (Berquist et al., 2006) showed that nonadherence to immunosuppressive drug therapy in adolescent recipients of a liver transplant can be correlated not only with demographic parameters but also medically related factors. Because pediatric liver transplant recipients are living longer and moving through adolescence into adulthood, transplant teams must understand their experiences so that they can effectively deal with their physical, emotional, and familial well-being throughout the life span. Conclusions from one qualitative study suggested that nurses who focused on their relationship with the young adult kidney transplant recipient had the ability to build trust and as a result lead the patient toward better medication adherence, optimized quality of life, satisfaction with healthcare and self-sufficiency (Gabay Gillie & Tarabeih, 2020). By understanding this phenomenon, the transition to adulthood will be more streamlined and offer recipients and family safer transplant care.

The goal of this mixed methods study was to better understand the long-term impact of living-related liver transplantation from a parent on YYA. The intent was to provide new knowledge that can be translated to the bedside for families as they face the social complexities of this highly dynamic health care situation. This information can guide patients and families as they grow together and develop meaningful relationships as adults. Understanding the perceptions of these YYA may inform the development of clinical interventions that foster regimens that promote a high quality of life for recipients and their families. Conversations between transplant clinicians, donors, and recipients about the long-term effects of live-liver donation is not well-documented and reflects a gap in the literature. Few studies have focused on YYA who received a live-liver transplant from a parent because most of these operations occur during infancy, and recipients are only now moving into adulthood. The goal of this study was to address this gap

by investigating the experiences of recipients of a live-liver donation from a parent, as those recipients reach adolescence and young adulthood.

Methods

Study design

To gather information from YYA live-liver recipients, we used ethnographic methods: interviews and the Youth Quality of Life Instrument-Research Version (YQOL-R), a conceptual measurement model that has four perceptual domains: Self, Relationships, Environment, and General Quality of Life (Edwards, Huebner, Connell, & Patrick, 2002). We selected this approach because it allowed us to understand a group of people connected by a common life experience (Cruz & Higginbottom, 2013): YYA who received a live-liver donation from a parent. This method allows one to understand how individuals of a certain group assign meaning to their experiences (Tzeng, Yang, Tzeng, Ma, & Chen, 2010).

Ethnography offers researchers a method to answer questions about the social and behavioral aspects of patients' everyday lives. It generally uses three data collection techniques: participant observation, formal interviews, and informal interviews, all of which help researchers better understand the cultural or social situations they are studying (Cruz & Higginbottom, 2013). We used symbolic interactionism as our framework to understand the perceptions of YYA who share common life experiences. This theory enables researchers to understand the meanings individuals assign to their actions or situations and how they inform their actions and related decisions (White & Klein, 2002).

Recruitment

Participants were live-liver recipients aged 10–18 who were recruited from two transplant centers on the West Coast of the United States. One recipient was recruited from a transplant center on the East Coast. The YYA were clinically stable and free of rejection. All of the participants spoke English. Assent was obtained from adolescent participants. The principle investigator's institutional review board approved the study, ethics, and human subjects' activity.

Data collection

Twelve initial interviews were conducted and 12 surveys were administered at a West Coast transplant center; one interview and survey were administered at the East Coast Medical Center. Six of the West Coast participants were identified by the research team as “key informants” and were re-interviewed to discuss preliminary analysis and expand upon their experiences. These second interviews were individualized based on preliminary analysis and included topics such as identified fears and family relationships.

The semistructured interview guide for initial interviews covered three areas: perceived physical and emotional consequences of transplantation, perceived impact of transplantation on the family and family dynamics, and the ethical context of the donation (Table 1). Participants were encouraged to expand upon questions and were given time to reflect before sharing their thoughts. To make participants feel more comfortable during the interviews, we used strategies to build positive rapport with them: finding a mutually agreed upon location, beginning interviews with a personal question, and ensuring that they were comfortable. For consistency, interviews were conducted by one researcher. YQOL-R surveys were completed by adolescents at the time of their interview. Interview questions are listed in Table 1. Interviews lasted from 45 to 90 min, and participants were advised to answer only “comfortable” questions. The interviews were audiotaped and professionally transcribed.

Table 1
Semistructured interview guide.

I. Perceived physical and emotional consequences of transplantation: Tell me a little about yourself. How many brothers and sisters do you have? What do you like to do during your free time? When did you receive a liver transplant? Tell me about your transplant? How does it feel to you to have received a liver from your mom or dad? Do you talk to anyone about it? Do your friends know that you had a liver transplant? Do you have any worries about the transplant? Describe to me the way in which being a liver recipient affects your life day to day. Do you remember being sick? What grade are you in school? How did you feel today? Do you remember the hospital? Do you go to clinic now? Do any of your friends ask you about the transplant? Do any of your brothers or sisters ask you about the transplant
II. Perceived impact of transplantation on the family and family dynamics: Do you feel different than your brothers or sisters? Describe your relationship with your mother and father. Which brother or sister do you talk to when you are upset? Do you go to your mom or dad for advice? Do you celebrate the day of your transplant with your family? Can you talk a little about how the transplant has benefited or challenged your family? Are you stressed out sometimes about the transplant? Do you fear anything about the transplant? What do you do for fun? Who do you spend time with outside of school?
III. Ethical context of donation: Were you old enough to remember the transplant? Do you know anyone else who has a transplant? Do you feel all your questions are answered in clinic? Do you understand most of what the doctors and nurses tell you? If one of your friends needed a transplant what would you say to them?

Data analysis

Health care and well-being has long been the subject of qualitative research (Braun & Clarke, 2014). We used thematic analysis to analyze the interviews because it allowed major categories to be created that best described the lives of these YYA and their perceptions of life as live-liver recipients. Three major categories were identified through repeated reading, coding, and interpretation of the narratives that lead to the synthesis of one overarching theme (De Santis & Ugarriza, 2000).

The goal of thematic analysis was to transform the raw data of the narratives into a meaningful description of the phenomenon of live-liver donation. The categories and theme were derived from the interview transcriptions. To ensure rigor, team meetings were held on a regular basis with peers and scholars to discuss and compare interpretive findings.

The YQOL-R distribution of demographic characteristics was presented as *count and frequency* for discrete variables and as mean, median, and range for continuous variables. Because of the skewed distribution, individual survey scores were presented only with median and range. Distribution of each composite score was presented as mean, median, interquartile range, and total range.

To determine whether survey results were different in our sample, findings were compared with a general reference population of youth with no illness. This validated our survey. Total scores and domain-specific scores were compared using the one-sample *t*-test. All analyses were performed using the open source statistical package R (version 2.13.0) or Excel 2007 (Microsoft, Redmond, WA).

Participants

Nine (69%) of participants in our cohort required liver transplantation due to biliary atresia; this is higher than the national average,

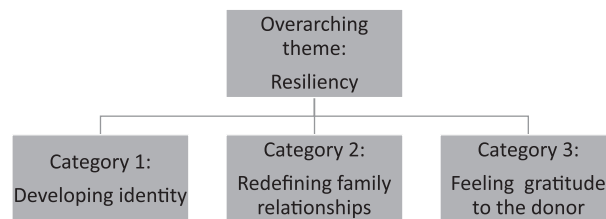


Fig. 1. Analysis of “Understanding the long-term impact of LRLD on the pediatric patient and their families”.

which is roughly 34% of all pediatric liver transplants (UNOS, 2019) (Table 4). The ethnicity of the participants was diverse: 62% Caucasian, 8% Hispanic, and 31% Asian; the national average for parental donors is 58%, 35%, and 6%, respectively. Sixty-two percent of mothers and 46% of fathers reported that they earned a 4-year college degree. By comparison, only 33% of Americans earned a college degree, which indicates a highly educated cohort (Schmidt, 2018).

Results

Three major categories were created from the data: developing identity, redefining family relationships, and feeling gratitude to the donor. Interpretation of these categories led to the development of an overarching theme: the adolescents’ resiliency in adjusting and adapting positively to the transplant experience (Fig. 1). We used the resilience model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) as a framework to understand the lives of these live-liver recipients. This model defines resilience as a process of adjustment and adaptation. In the narrative that follows, we present quotations from our participants that epitomize each category and define the central theme: resiliency.

Developing identity

As described by the adolescents, developing identity is the act of understanding their vulnerability and having confidence in who they are as individuals. As with healthy adolescents, our cohort faced the challenges of peer pressure, body image, medication adherence, sexuality, drugs, identity, and discovery. They were searching for clarity in their lives and trying to understand their coming responsibilities as adults, as that related to their health and transplanted liver.

One 11 year old female adolescent reflects on how she is becoming more aware of her medications and the importance of adherence which is an important factor in her care as a transplant recipient. When asked about whether she needs reminding when taking medications her response was:

I’m usually pretty good about it. In the morning, I take them pretty early, like 6:00. So my parents will wake me up either with like knocking on my door or calling up to me and I’ll take them and sometimes I’ll go back to bed for 30 min. But during the evening, I’m usually pretty much in charge of the meds.

When asked about his surgical scar, a 12-year-old boy described it in a way that seemed to define him as a person, yet may be a way he has found to cope with the scar. As reflected in field notes this participant seemed proud of his scar and perceives it as just the way he is at this specific point in time.

I definitely embrace the fact that I got bit by a shark. It definitely puts me out of the norm-like most kids at this age are really super-skinny and like have a 6-pack. I don’t really care about image. It’s just me!

Another participant, describing a situation in his physical education class, revealed a confident, self-assured transplant recipient who considers his scar to be cool:

During PE, I'll have my shirt off and they're (his peers) like "Uggg!" or some kids just stare, just like...what is that? And I am like "you don't have to worry I'm not self-conscious about my scar." They're liked "oh what happened?" "I'll tell you, I'd love to tell you I had a liver transplant." They are like "Ahhhhh," then they are all freaked out. Some people are nervous about asking about it, but I really don't mind. I think it's cool.

When asked how he handles drinking and drugs, a 15-year-old participant explained how he has adapted to the impact of liver transplantation on his life. Positive consequences define his life choices. He identifies with YYA who do not drink and chooses that option. It actually helps him deal with peer pressure to drink:

The fact I can't drink and don't plan on drinking because I think it is stupid, it is poison basically. People don't offer me drinks. Most people know "He can't drink" which luckily I take advantage of. The fact that most of my peers are pretty gullible I'll usually just say "I can't do drugs either" which is truly a fact, it's not as harmful as alcohol, because it goes straight to our liver. But then people automatically think...oh he can't do drugs either, which helps me with the whole people issue of pressuring me into doing drugs.

A 15-year-old girl, anticipating adulthood, wrestled with the fact that her grandmother (her caretaker) will not always be around. She worries about the added responsibility of caring for her own health, but not too much:

What would happen if I didn't take my meds for a long time, do I have a shorter life? I worry sometimes that when I get older. I know I've got to order my meds and I got to make my doctor's appointments and make sure I do this and that. Sometimes I just worry like my grandma is always here for me, and when I get older. I have to make sure I know what needs to be done, I just have to make sure! It's OK, though. I think about it, but I don't worry too much.

Redefining family relationships

Redefining family relationships, the second category developed during analysis, articulates the role our participants play in their family. They have come to realize and understand the implications of this wonderful parental "gift." YYA think deeply about their relationship with their donor and come to view the donation as something wholly special and not something shared by their peers. Family, of course, plays an important role as children grow through their teenage years, but the relationship with the parent who donated their liver to them in infancy is especially strong. The YYA described with clarity how they adjusted, adapted to, and accepted their life as a liver recipient.

In the following narrative, a 13 year old female visited her donor mother who was in hospice during the time of our interview. She discussed the visit and her mother's reaction to her queries about the transplant operation. The girl sought validation from her mother and wanted to know the role she played in her life. Although she has adjusted to life as a transplant recipient, adaptation has been rocky. She sought answers to her questions and wanted to see the scar she and her mother share:

Like now, when I go see her, it's like—do you remember what you gave it to me? But I never really asked her, I've never really talked about that. She asked me—are you doing OK? But I don't know if she's talking about the transplant or just about me, I'm just like—OH, yeah, I'm good. I've never talked to her about it, but I want to, but I just don't know what to do. I would like to ask her if she has a scar too, but we'll see. Maybe soon.

A 12 year old girl described the special bond she shares with her donor father, a bond quite unlike the one he has with her sister and brother. She currently lives with her mother now that her parents are divorced. This girl wanted not only to thank her dad for all that he did for her but also to know if he felt the special bond she does because it is critically important as she adjusts and adapts to her transplant.

I know my sister and brother, miss him too (their dad) but they don't have that kind of bond me and my dad have because I have a part of him inside of me. I want to see him. I want to just thank him, it doesn't have to be long, I just what to thank him for everything he did. I think because he's my dad too, I want to see him for that reason too I'm his daughter and so I hope he would want to see me too.

Feeling gratitude to the donor

In this third category, participants expressed their deep gratitude to their parental donor and consider them to be "life savers," with whom they share an organ and a unique experience for the rest of their lives. In the following narrative, a 10-year-old boy explained how he adjusted to his transplant at a young age and is adapting as an adolescent knowing that his dad gave him a second life and they joke about it:

When I was like 6, my dad (the donor) would always make fun because he has a scar too, he would say 'I was the one who gave birth to you, that's why I have this scar.' He would like always tell me that and I would say 'So dad, does that mean that I have a baby too because I have my scare?' We know it is all because of the transplant, but we like to make fun of it...just joke about it.

A 13-year-old female recipient, separated from her father due to a divorce, realized the impact his donation had on her life and attributed past conversations with him for helping her to adjust to her life as a liver recipient. She sees her dad now in a new light:

Yeah, like I've always asked him how the experience was and he said he always knew his liver was for me and to save my life. He was always so happy for making the donation and happy that it happened. It's like he's my real hero, he actually saved my live, but then he did give me life too and it kind of brought us closer together and our bond is stronger because of that he had to be thinking about me when he gave it to me, he must of wanted to save my his daughter. He really cared about me and yeah, he's like a hero!

Although she does not see her dad often, she yearns to be closer to him as she grows through adolescence:

Yeah, I really do want to get back with my dad and rebuild our relationship because I just don't want to be distant from him for the rest of my life. He was a big part of my life, and I feel he still should be. It (the donation) just shows how much he really did have to go through and how much he was committed to helping me when I was younger, when I couldn't help myself. I used it as a chance to give birth to you—a C-section. He just jokes about it every once in a while.

A 12 year old female participant expressed her feelings of gratitude to her mother and attributed her donation to the strong love and connection they share. She reflected on how committed her mother was to make this donation and is thankful:

It (the scar) just shows how much she really did have to go through and how much she was committed to helping me when I was younger. I'm just like thanks, but I don't really want to say it, but I think she knows, everybody knows around us that without this woman (the donor) we wouldn't have this one (pointing at herself) (laughter).

In addition to the qualitative results the YQOL-R produced quantitative data regarding a quality of life profile for adolescents across four Perceptual Domains: Self, Relationships, Environment, and General Quality of Life (Table 2), scores are translated into a specific 0–100 point scale by using the formula:

$$t_{score} = \frac{\text{actual raw score} - \text{lowest possible raw score}}{\text{possible raw score range}} * 100$$

(Edwards et al., 2002). All four domains were highly skewed toward the favorable end of the spectrum for all questions. For example, all medians were close to either 0 or 10. The total Perceptual Score was high in our sample, with a mean of 86.38. Individual domain scores were also high, ranging from 84.01 for the self-domain, 85.16 for the relationship domain, 89.54 for the environment, 92.56 for the general quality of life

Table 2
Selected survey results from the YQOL-R.

Survey question	Scale	N (%)	Median (range)
5. During the past 4 weeks how often have you had serious emotional or mental health problems that you felt you need help with?	Never	6 (46)	
	Almost never	3 (23)	
	Sometimes	3 (23)	
	Fairly often	1 (8)	
	Very often	0 (0)	
8. During the past 4 weeks how often did you miss out on an activity that you wanted to do because of any physical or emotional problems you have?	Never	8 (62)	
	Almost never	3 (23)	
	Sometimes	1 (8)	
	Fairly often	1 (8)	
	Very often	0 (0)	
16. I can handle most difficulties that come my way	1–10		9 (6–10)
17. I am able to do most things as well as I want	1–10		8 (4–10)
18. I feel good about myself	1–10		10 (5–10)
21. I have enough energy to do the things I want to do	1–10		9 (6–10)
23. I feel comfortable with the amount of stress in my life	1–10		7 (2–10)
30. I feel useful and important to my family	1–10		9 (4–10)
32. My family encourages me to do my best	1–10		10 (7–10)
34. I feel my parents / guardians allow me to participate in important decisions which affect me	1–10		8 (6–10)
37. I can tell my friends how I really feel	1–10		9 (2–10)
39. I am satisfied with my social life	1–10		9 (2–10)
42. I feel left out because of who I am	1–10		0 (0–9)
46. I look forward to the future	1–10		9 (6–10)
47. My family has enough money to live a good life	1–10		9 (7–10)
49. I feel I am getting a good education	1–10		10 (6–10)
54. I am satisfied with the way my life is now	1–10		9 (4–10)
56. Compared with others my age, I feel my life is...	1–10		9 (6–10)

domain, and 86.38 for the overall perceptual score. All medians were higher when compared with those of the reference population with no chronic illness (Table 3). This comparison highlights all four domains and offers median, mean, CI, and P scores (one sample *t*-test) for all domains.

Discussion

Our findings elucidate the unique perspectives of YYA who received a live-liver donation from a parent, as they mature from children to adults. Results of this study reflect experiences and feelings relate to growing up as a live liver donor recipient. Though the transplant occurred several years ago, this cohort present themselves as being resilient, which reflects the two phases of the family adjustment and adaptation response model, namely, adjustment and adaption, both of which contribute to one's stability (McCubbin & McCubbin, 1993). This resiliency building is a continuous process involving adjustment and adaptation which for this study group was framed by the development of their identity, defining their family relationships, and individual gratitude to their parental donor. All of this combined with the data provided from the YQOL-R creates evidence to support the conclusion that this cohort exhibited resilience. Logistic regression modeling has been shown to support the idea that one of the main predictors regarding health related quality of life is resilience (Temprado Albalat, García Martínez, Ballester Arnal, & Collado-Boira, 2018).

The YQOL-R results demonstrated that this participant group produced higher perceptual scores than the reference population. The

YYA shared experiences that demonstrate how they had adjusted to being a living-donor transplant recipient and how they were adapting to its long-term effects on their lives. Resiliency in adolescents has been associated with other health care transitions. A study of adolescent kidney transplant recipients revealed how fluidly they transitioned from a pediatric transplant center to an adult nephrology center (Quinn et al., 2019). Contrary to this finding Gabay et al. demonstrated through qualitative data that young adult kidney transplant recipients transitioning to an adult kidney program was not supportive to the patients well-being.

The participants in this study reported that their transplant experience was embedded in their identity, giving them confidence and reassurance in who they are as young adults. Actualized new identity in YYA liver transplant recipients has been described in a recent qualitative study: Adolescents viewed themselves as being normal when conceptualizing themselves as children (Lowton, Hiley, & Higgs, 2017). They described an identity that was formed over time in their home, hospital, and school, even though they were different. As they got older, they became more aware that they were significantly different from peers, the surgical scar being a constant reminder of who they were (Lowton et al., 2017). Although the scar described by participants in that study did not contribute to their personal identity, it did in this study, where participants felt proud and cool.

The category, feeling gratitude to their parental donor, demonstrates adaptation, as described by McCubbin and Patterson (McCubbin & Patterson, 1987). A recent qualitative study identified the unique role resilience constructs play in contributing to a stable health care transition among YYA kidney transplant recipients; the participants also described meaningful relationships with relatives (Quinn et al., 2019). These findings are consistent with the findings of this study. Though the findings of this study do not address Gratitude expressed from recipient to donor has a positive impact on that relationship. In addition, a positive change in one family member can have a positive impact on the entire family (Gyllen, Magnusson, & Forsberg, 2019).

Adjustment and adaptation are challenging and require an effective process of appraisal. YYA perceive their transplant as the “here and now” because their average age at transplant was 17.4 months. Although they cannot remember the transplant experience, they have adjusted to it, and it has become part of their identity the average age of our participants was 13.9 years. The only physical sign to remind them that they had received a liver transplant from a parent is the scar they share with their mother or father. This scar has allowed them to reflect, adjust, and adapt to the positive self-image common to all YYA participants.

Receiving a live-liver donation is a watershed event. The participants in this study over the course of the years since the transplant recognized view this donation to be a gift of love from their parent. Yet, although they realized the event to be extraordinary, they also want to be normal (Tong et al., 2011). They described moving from active adjustment to adaptation. During adolescence, they adapt to the reality of what it means to be a transplant recipient and how their life was saved by their parental donor. Adapting is intertwined with other life events like parental divorce, college, drinking, and drugs.

YYA face a dynamic stage in their lives, transitioning from childhood to adulthood. They are faced with unique developmental needs, which health care providers must address if care across the continuum is to be seamless. Increasing providers' awareness of the needs of adolescents requires effective communication, advocacy, and dissemination of new knowledge (<https://www.adolescenthealth.org>). Our participants shed light on how they are resilient, within the family, and how they experience and express gratitude to their donor.

Practice implications

By better understanding the long-term impact a living related liver transplant can have on the YYA healthcare providers can be more

Table 3
Distribution of quality of life scores and comparison to reference population.

	Sample		Reference population		P (one sample t-test)
	Mean	Median (Q1–Q3) Range	Mean	95% CI	
Self Domain	84.01	92.14 (76.43, 93.57); 58.57–98.57	78.77	75.70 92.32	0.19
Relationship Domain	85.16	88.57 (86.43, 95.00); 51.43–96.43	80.79	76.61 93.72	0.29
Environmental Domain	89.54	90.00 (84.00, 100); 76.00–100.00	86.85	84.46 94.62	0.41
General Quality of Life Domain	92.56	96.67 (86.67, 100); 66.67–100.00	86.85	86.57 98.56	0.06
Total Perceptual Score	86.38	90.73 (83.90, 94.88); 60.98–98.29	82.20	79.69 93.07	0.20

prepared to guide our families through the transplant trajectory. The new knowledge produced from this study can help to inform clinicians, patients and families about the transplant process and bring meaning to the experience as the recipient moves from pediatrics into the adult setting. Understanding the relationships that develop between the donor, recipient, and healthcare providers while the YYA adjusts and adapts to the transplant can foster healthy and effective communication not only during adolescents but throughout their lifetime.

Limitations

Our findings derive from a cohort of YYA who were culturally diverse (a strength), but their families were highly educated (a limitation). When this study was conducted, our participants were healthy and living at home. All spoke English. Future studies should recruit non-English speakers to better understand the phenomenon from a different perspective. Because this study only recruited 13 YYA, the generalizability of our findings is limited. Qualitative methods, such as ours, are at risk of bias, specifically interviewer bias. To account for that, we held regular meetings with peers and qualitative research scholars to discuss interpretive findings. The perspectives shared in this paper by the YYA are unique and clearly defined by many variables including

family dynamics, culture, and beliefs. As this data was collected from living related liver recipients it can only be speculated that similar data may be present in those YYA receiving deceased donor transplants and should be investigated further.

Conclusion

This study provides a holistic view of life from the perspective of young living-donor recipients. The narratives suggest that they are well-aware of their health history and have adjusted to their clinical situation. They are adapting to their identity as a transplant recipient, redefining their relationships with family, and expressing gratitude to their parental donor. All combined, these YYA exhibited a spirit of resiliency that allows them to adjust and adapt to life as a transplant recipient as they move into adulthood. The outcomes of this study have allowed for better understanding of the YYA living-donor recipient that the transplant community can use to develop educational curriculum and other supportive interventions in order to meet the needs of this vulnerable patient population.

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Table 4
Demographics.

Characteristic		N (%)	Mean Median (range)
Gender	Female	7 (54)	
	Male	6 (46)	
Age at time of interview (years)			13.9 14 (11–17)
Age at transplant (months)			17.4 6 (3–156)
Liver disease pathology	Biliary atresia	9 (69)	
	PSC	1 (8)	
	Other	3 (23)	
Ethnicity	Caucasian	8 (62)	
	Hispanic	1 (8)	
	Asian	4 (31)	
Most recent grade completed in school			8.3 8 (5–12)
Mother's highest level of education obtained	High school graduate	2 (15)	
	Some college	2 (15)	
	College graduate	8 (62)	
	Don't know	1 (8)	
Father's highest level of education obtained	High school graduate	3 (23)	
	Some college	3 (23)	
	College graduate	6 (46)	
	Don't know	1 (8)	

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