

**Restriction and Dependence to Autonomy and Freedom: Transformation in Adolescent
Heart Transplant Recipients**

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Running Head: Heart Transplant in Adolescence

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Abstract

The process of heart transplantation poses numerous challenges and adaptive tasks for pediatric patients and their families. Few studies have examined how the experience of transplant interacts with developmental transitions such as adolescence, a period of significant change and adjustment in itself. We explored adolescent heart transplant recipients' and their parents' experience of transplant from the point at which their heart condition was diagnosed to several months after transplantation. We adopted a developmental focus, to consider how participants negotiated the tasks of adolescence in the context of their transplant experiences. A qualitative approach was used to interview five adolescent-parent dyads, who reported few post-transplant complications, and the data was analysed according to the principles of Interpretative Phenomenological Analysis. Our findings revealed transplant to be a transformative experience, with two themes marking a contrast between pre- and post-transplant states: 'Restriction and Dependence' and 'Autonomy and Freedom'. The themes are considered in relation to adolescent development. We propose that clinicians working with pediatric heart transplant recipients and their families need to consider the particular developmental challenges faced by adolescent patients, and view the attainment of developmental milestones alongside physical and psychological markers of successful adjustment.

Keywords: heart transplantation, pediatrics, adolescence, parents, qualitative research.

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Introduction

Heart transplantation is considered for children and adolescents with end-stage heart disease and a life expectancy of less than twenty-four months unless transplanted (1). Approximately thirty pediatric heart transplants occur in the UK each year (2). Each stage of the transplant journey (e.g., assessment, being placed on the waiting list, the operation, and post-transplant adjustment) poses distinct challenges and requires different adaptive tasks for pediatric patients and their families (3). Although there is a growing body of research exploring psychological factors in pediatric heart transplant, the literature is limited by i) a focus on post-transplant adjustment which neglects how earlier stages of the transplant process might be implicated in observed outcomes, ii) little consideration of how the experience of heart transplant interacts with developmental transitions such as adolescence; a period of significant change and adjustment in itself (4).

Heart transplant is a longitudinal experience rather than a discrete one-off event. A number of congenital or acquired cardiac diseases may necessitate the need for transplant, with variation in the number and severity of symptoms and the degree of functional impairment. To date, only one study has examined levels of psychosocial morbidity in pediatric heart and heart-lung transplant candidates (5). This revealed that 25% met diagnostic criteria for a psychiatric (emotional) disorder, and 60% were reported as having impaired psychosocial functioning. As levels of morbidity were similar to those found in children undergoing other forms of cardiac surgery, the authors suggested that it was the effects of illness, rather than the need for transplant, that influenced the observed psychopathology.

Most of the research literature has focused on post-transplant adjustment. Physically, recipients tend to enjoy marked functional improvement, and are able to return to age-

appropriate activities (6). Research has therefore attempted to examine whether this is matched by psychological gains. Whilst the majority of pediatric transplant recipients appear to adjust well following surgery (7, 8), a number of studies have identified a substantial minority who experience emotional difficulties (7), poor academic attainment and behavioural problems (9) and lower social competence (10,11). Psychological distress has also been identified as one factor implicated in pediatric recipients' adherence to post-transplant medication regimes (12). Parents of pediatric transplant recipients are also reported to experience a number of psychosocial stressors in relation to their child's transplant (3). Studies have found greater levels of stress in parents of transplant candidates compared to healthy norms (13), with levels of parenting stress being greatest at six months post-transplant compared to pre-transplant and one month post-transplant (14). It has been suggested that once the 'acute' crisis phase is over and the child and family return home, support networks withdraw and families must attempt to return to 'normal' and come to terms with post-transplant care (14).

Paediatric transplant recipients are a rare population, therefore studies have tended to use extremely small but heterogeneous samples, with variability in the age of participants, type of organ transplanted, age at transplantation and time elapsed since transplant. One repercussion of conflating so many variables is that potential developmental differences in the way young people experience and adjust to heart transplant may be masked. Suris, Michaud and Viner (15) highlight the reciprocal relationship between chronic illness and child development, suggesting that illness can both affect and be affected by developmental processes. Of particular interest is how young people negotiate the process of heart transplant within the context of adolescence, a time of considerable physical, psychological and social change (16). Young people with chronic illness need to negotiate the same developmental tasks as

their healthy peers (e.g., attaining autonomy and independence, separation from parents, development of identity) (17), yet it has been suggested that the presence of a medical condition may create additional challenges, and that managing illness may be at odds with typical development (18,19).

Whilst there are review papers that describe the interplay between adolescent development and chronic illness generally (e.g. 15), and pediatric transplant specifically (20), there has been a lack of empirical research that systematically explores these issues. One attempt to isolate factors relating to adolescent experiences of transplant was conducted by Tong, Morton, Howard and Craig (21). The authors undertook a systematic review of eighteen qualitative studies and attempted to identify the experiences of adolescent solid organ transplant recipients. These were organised into five themes: i) redefining identity, ii) family functioning, iii) social adjustment, iv) managing medical demands, and v) attitude towards the donor. Whilst the study provides useful insights into the experiences of adolescent transplant recipients, there are a number of methodological limitations. The samples included in the review involved young people between the ages of 4-32 in receipt of heart, lung, kidney or liver transplants. The age at which participants received their transplant, and the time elapsed since transplant were not recorded. It is likely, therefore, that participants had different illness experiences and trajectories (for example, a live donor organ for renal transplantation compared to a deceased donor for heart transplantation). Furthermore, only a small proportion of studies included in the review focused specifically on issues relating to adolescent development, the majority reporting on transplant experiences more generally.

The current study therefore sought to explore the experiences of adolescent heart transplant recipients and their parents, from the point at which their heart condition was diagnosed to

several months after their transplant occurred. Historically, parental views have been sought as a proxy for understanding children's perspectives, however, they are likely to have a different frame of reference and place different values on what is considered to be important compared to their child (22). As the parent-child relationship provides an important context for both paediatric heart transplant and adolescent development, this study sought both perspectives for the valuable insights each could bring to the understanding of transplant during adolescence. A qualitative approach was employed to access the perceptions and experiences of those who have undergone heart transplant and their parents. Qualitative approaches seek to elicit meanings attached to little known or little understood phenomena so that they can be better understood (23). As adolescence has been a relatively neglected topic within studies of heart transplant, this approach facilitated exploration of these issues, captured within the terms and expressions of participants.

The research contributes to the extant literature by providing a contextual account of adolescent transplant, one which considers the transplant process as a whole, explores both parent and child perspectives, and is explicitly developmental in its focus. In this respect, 'adjustment' can be viewed in terms of a child's journey towards and achievement of normative developmental milestones, rather than a measure of psychosocial impairment (24). Exploring these issues may foster greater understanding of adolescents' and their parents' experiences of heart transplant, thereby enabling difficulties to be more readily predicted and identified, promoting optimal development and enhancing psychological care.

Patients and Methods

The study used a cross-sectional qualitative design, employing semi-structured interviews which were analysed according to the principles of Interpretative Phenomenological Analysis

(IPA, 25). IPA provides a practical and theoretical framework for exploring the processes through which people make sense of and attribute meaning to their experiences (26). Whilst a detailed review of the theoretical tenants that underpin IPA is beyond the scope of this article, a brief overview is useful in understanding the focus of this study. IPA is phenomenological in that explores participants subjective, lived experiences, and is subject to both the participants' and researcher's interpretations. Core features of IPA include i) its idiographic focus which necessitates the detailed exploration of a small number of cases rather than seeking general theories or principles; ii) its inductive approach which allows new insights to emerge rather than attempting to test specific hypotheses; and iii) its interrogative nature which seeks to apply findings to existing research (27). IPA has become a popular methodology in the fields of nursing, psychology, management and has gained considerable purchase in health research because of its interest in transformative experiences that provoke reflection (28). IPA was considered appropriate for this study and the proposed research questions as it seeks to explore the processes embedded in participants' experiences, rather than focusing on outcomes (29), and is sensitive to the context in which events occur (25).

Participants

Participants were recruited from a specialist cardiothoracic transplant clinic at a tertiary children's hospital in the United Kingdom. Ethical approval was granted by an NHS and a University Research Ethics Committee. IPA is purposive in its sampling strategy to recruit participants for whom the research question is meaningful. Adolescent heart transplant recipients and one of their parents were considered eligible for participation if the adolescent was between the ages of 11-18, they had been at least 11 years of age at the time of transplant, and had received their heart transplant in the previous 3 to 24 months. As IPA studies require homogenous samples (30), adolescent heart transplant recipients with a

diagnosed learning disability were excluded from participating as it was felt that they would have different and/or additional concerns compared to their non learning disabled peers.

Adolescents whose primary language was not English were also excluded as using an interpreter would have added a further layer of meaning to the analysis (see 31). Adolescents who were experiencing post-transplant complications were also excluded as it was felt inappropriate to burden them with the research in the context of their current difficulties.

Twelve adolescent-parent dyads were identified as eligible to participate. Eleven of the dyads were sent an invitation letter, information sheets and a reply slip. The twelfth was excluded as the adolescent was experiencing post-transplant complications. Families who had not returned their reply slips after two weeks were contacted by the transplant team psychologist to ask whether they were interested in taking part. Those who expressed an interest were telephoned by the first author to arrange a mutually convenient time to conduct the interviews.

Six adolescent-parent dyads volunteered to participate in the study; however one dyad was excluded as they were taking part in another research project. The sample comprised of 5 adolescents (3 males, 2 females) and 5 parents (one parent of each adolescent, including 1 father and 4 mothers). The adolescents were aged between 14-18 years old at the time of interview. All participants reported their cardiac condition to have an early onset and a chronic course. All adolescents had undergone at least one previous cardiac surgery. Four dyads described themselves as White-British, and one dyad reported their ethnicity as White-Irish. All adolescents resided in two-parent families (3 had step-parents), and all had siblings. Table 1 summarises the sample characteristics. It is not possible to describe the characteristics of non-respondents as consent was not obtained to use their data.

Insert Table 1 about here.

Materials

Two interview schedules were created for use in the study: with parallel versions for the parents and adolescents. The content was developed from an extensive literature review, and from anecdotal experiences of clinicians working in the transplant team. Questions related to each stage of the transplant experience (diagnosis of the cardiac condition, assessment for transplant, waiting for transplant, the operation, and life after transplant). The interview schedules were reviewed by members of the transplant team and by two adolescents and their parents who did not meet the inclusion criteria (having received their transplant over two years previously) to assess clarity and relevance.

Procedure

Participants were interviewed separately either at the hospital or in their home. Interviews were conducted by the first author, a doctoral student in clinical psychology, who was undertaking a training placement at the recruiting hospital, and had received tuition in clinical and research interview skills. The researcher had little previous knowledge or experience of working in the field of paediatric transplant, however had substantial knowledge and experience of qualitative methodology, psychological theory and clinical practice.

Written informed consent was obtained from adolescents above the age of 16 and their parents. Adolescents aged 11-15 completed an assent form, with their parents providing additional consent. Adolescent participants rehearsed how they could inform the researcher if they did not want to answer a question, wished to stop the interview or withdraw from the

study. Interviews lasted between 50 and 135 minutes. On completion of each interview, participants reflected upon the experience and were given the opportunity to ask questions. Provision was made to refer participants to the transplant team psychologist if necessary.

Interviews were recorded using a digital recorder and transcribed verbatim for analysis. All identifiable information were changed or removed. Data was analysed according to the principles of IPA (e.g., 25), using the following steps:

- 1) The first transcript was read several times. Notes were made documenting initial thoughts, observations and points of interest or significance.
- 2) Initial notations were transformed into emerging themes and given a descriptive label.
- 3) Themes that were conceptually similar or related were clustered together and labelled to convey the master theme.
- 4) A summary table of each theme was compiled with illustrative quotes.
- 5) The summary table from the first transcript was used to guide analysis of subsequent transcripts. New themes that emerged were checked against the original transcript and then added to, or used to refine the original list of themes until a master list was generated that captured participants' shared experiences. Themes that appeared less prominent, not well represented across the corpus of data, or irrelevant to the research questions were discarded.

As traditional notions of reliability, validity and generalisability are thought to be inappropriate means of evaluating qualitative research (32), the authors attended to Yardley's (33) criteria to enhance the quality and credibility of the research. Firstly, we sought to demonstrate 'sensitivity to context' by keeping a reflective diary to identify potential biases in our data collection and analysis. Extracts from the data are also presented to support our analysis and allow readers to evaluate our interpretations, with findings discussed in relation

to existing literature. Secondly, ‘commitment and rigour’ were employed in the thoroughness of our data collection and analysis, which was subject to verification checks by two independent raters (ME, TLW). Participants were also invited to comment on the credibility of the analysis, but although the findings were sent to them, no feedback was received. Thirdly, we have attempted to show ‘transparency and coherence’ by providing a detailed account of our methodology and a narrative of our findings. Finally, we hope to demonstrate that the study has ‘impact and importance’ by situating the findings in relation to existing literature and discussing the contribution made to the current evidence base.

Results

Central to participants’ accounts was the concept of transplant as a transformative experience, revealing a stark contrast between pre- and post-transplant states. These were captured under the themes ‘Restriction and Dependence’ and ‘Autonomy and Freedom’, each with corresponding subthemes to further illuminate each case (see Table 2). A narrative account is presented below, with extracts from the transcripts to support and illustrate each theme. The adolescents are designated by the letters A to E, and the parents numbered from 1-5, with no correspondence between the two (i.e. Parent 1 is not related to adolescent A).

Insert Table 2 about here

Restriction and Dependence

Physical Limitations:

Prior to their transplant, the adolescents reported experiencing substantial disability as a result of their cardiac illness. The effects of the disease restricted activities and affected basic abilities:

'I couldn't hardly do anything, I couldn't really. There was one bad point when I couldn't even get out of my bed, because I would just drop¹ if I tried to get out. Even in the middle of the night, I couldn't even get out of my bed if I was thirsty' (C)

'when she was first diagnosed with her heart condition, all physical activities were stopped...she wasn't allowed to do any running or um go to any dancing or anything physical because that's what would bring on her turns.' (Parent 5)

The adolescents' physical limitations seemed to undermine their sense of autonomy and contrasted with beliefs about what they *should* be doing at their age:

'you can understand that they want to run down the road and kick the ball about and all this, so it must have been...he's got to be on the go all the time, and it must be very, very frustrating for him the fact that he couldn't do what he wanted to do basically' (Parent 4)

'couldn't run far at all, struggled with sport...I missed scouts when it's like hiking and climbing stuff...I mean that's not a lot, that's not a huge list but at that age, that is like the biggest thing' (E)

Implicit within participants' accounts was an expectation that physical activity was a normative feature of adolescence. Being unable to participate, or engaging in activities that did not require physical exertion, was perceived as *'lazy'* (B): a presumed idleness rather than inability to take part:

'[I] read books, played games, listened to music, watched TV, just the usual lazy things'
(E)

Disruption to Teenage Life:

¹ Several of the adolescents in the study experienced frequent, unpredictable 'drop attacks' where they would pass out with little or no warning.

A feature of many of the adolescents' illness experiences was the occurrence of frequent, unpredictable drop attacks, where they would pass out with little or no warning:

'Just 'cause anywhere you are even, just like in the middle of the street you would pass out....Or even in the middle of a shop, just pass out in the middle of a shop as well. Just pass out anywhere' (C)

'he just kept going, he just kept passing out, you know, at the drop of a hat' (Parent 2)

An inherent aspect of these attacks was the lack of control the adolescents had over themselves and their bodies:

'sometimes when she was passing out, she was being a bit incontinent as well' (Parent 5)

The attacks also interfered with the adolescents' plans and activities, rendering them powerless, much as a younger child:

'there was one night that I was really excited to go out and like I'd got all my bags packed because I was staying overnight, and then I just dropped down in the middle of the street. I just didn't feel right, everybody just put me down to the ground, 'cause I didn't feel right at all. So mum had to come and get me at that point' (C)

Subsequently, the illness seemed to prevent the adolescents from engaging in age appropriate activities, or experiencing socially regarded 'rites of passage' associated with normative adolescent development:

'all kids need to drink before they're supposed to. He never could, because of all the medication he was on...when you're growing up, around the sort of seventeen mark...most kids have had a drink by then, they've been to a party or something like that where there's been booze. But he could never do that because of all the medication he was on' (Parent 4)

Dependence:

A shared theme across the participants' accounts was the degree of dependence the adolescents experienced prior to transplant. This manifested in their reliance on their parents for day-to-day care, and in the high levels of monitoring and supervision they required. The time references given emphasised the relentless and demanding nature of this task:

'Ever since I started getting ill, it was just I had someone there constantly and they would phone every minute, every half hour really' (C)

'he needed that care, he needed sort of twenty-four hour care almost (Parent 2)

Striking within the participants' accounts was the recurrent reference to babies, which evoked images of helplessness and dependency. For Parent 2, there was a sense that her teenage son was *more* than a baby due to the attention he required:

'[it was] like not going back to having a baby in the house, but it's that, you know, you're constantly watching them. So it was like having two little ones and [child], but [child] needed the attention more than the little ones I think' (Parent 2)

Indeed, several of the participants described the use of equipment such as buggies (A), baby monitors (C) and stair-gates (Parent 2), further highlighting the infantilising effects of illness:

'we couldn't leave him on his own...so where we'd stopped getting the baby sitters and things, it all had to come back and somebody had to be with him all the time, and he hated that, at fifteen, you don't want to do that' (Parent 2)

The adolescents reported mixed responses to parental vigilance. Some found the monitoring and supervision to be stifling, and curtailed their independence and freedom. A's description evokes images of fragility, however each layer of protection was perceived as increasingly restrictive and unwanted:

'My mum has wrapped me up in cotton wool, drove me a mile away from the cliff and stuck me there with glue' (A)

'I couldn't go anywhere by myself, I had to have somebody at the side of me at all times. (I: So what was that like having someone with you all the time?) Quite annoying...Just 'cause it was like you've got somebody following you every step you're taking. I just didn't really want that' (C)

However, for C, such vigilance and dependence also seemed to confer a sense of security, in that she would be 'rescued' should she feel unwell:

'It was alright that they phoned, because there was maybe some nights that I'd like to come home and then they would just come and pick me up in the car' (C)

Feeling Different from Friends:

For many of the adolescents, the experience and effects of cardiac illness created a sense of difference between themselves and their peers:

'it was annoying....cause none of my friends have anything wrong... so it's kind of like it's not fair' (D)

'she found that difficult because she couldn't be like her friends ... she used to love playing football and just being with her friends running about and having a carry on...I think that's what she found the hardest, that she couldn't be, do the same as what, what they were doing' (Parent 5)

Being part of a group appeared to be important for the adolescents. E, for example, had developed friendships with other disabled young people, thus generating a sense of belonging:

'all my friends and stuff, they're all in wheelchairs and disabled, so it was just like a group which I could really get along with' (E)

Several of the adolescents expressed their perception of missing out on activities or being unable to participate at the same level as their peers. This connoted a sense of difference, positioning the adolescent outside of their group:

'I couldn't keep up with them' (C)

'I used to go outside and watch my friends play football and stuff and like cheer them on ... it was a lot of fun to watch, but it would have been even more fun to probably play with them' (E)

Whilst some of the adolescents reported their friends' attempts to accommodate their illness, there was a sense that they were fitted around rather than fitting in:

'All my friends would be really good, they'd just take it slowly. There'd be quite a lot of them away in front, but there's quite a lot of them that will always stop back for me ... Sometimes they forget I'm there and sometimes they don't' (C)

Others recalled how friends kept their distance:

'she wouldn't particularly go out at all, her friends....maybe didn't understand, you know, but they took a while for them to come to her. She might be talking to them on that thing on the phone that MSN or whatever, that Bebo on the internet, but they were kind of distant, they came eventually' (Parent 3)

Two of the adolescents seemed to perceive themselves to be a burden to others, thereby creating further barriers to their friendships:

'Everyone was like "oh my word, he's got, you know, a bad heart, you know that's a lot of responsibility, I don't think we can take on that as well as look after him". Everyone was just like really scared of like, you know, 'cause if anything went wrong and I was under their care, then obviously that would, they, you know, that wouldn't, they'd make them feel pretty bad ...it was kind of gutting because I wanted to hang out at my friend's house' (E)

'I've [passed out] a few times with my friends ... It was scary for me and some of my friends as well. I didn't like to put them in that position but I can't help it... I didn't think they would want to take me out again ...just in case it would happen again' (C)

Autonomy and Freedom

Liberation:

In contrast to participants' experiences of being restricted by their cardiac illness, their accounts of life after transplant portrayed a sense of liberation. This was evident just a few days after their operation:

'when I was getting up, out of bed, and I could like walk about on the ward and I wasn't getting out of puff, and then I could like go away and not be out of breath and that, walking all the way to the toilet and walking back again. It was quite a lot to do that. And not taking your time in the bathroom, taking so long. I mean I could just do it myself, it was really easy....it was just like totally different for me' (C)

The adolescents' improved physical health was experienced as a novelty, highlighting the transformative nature of transplant. For Parent 2, this extended beyond the child's physical gains:

'I'm better than I were before I even started getting ill' (B)

'[he is a] completely different child, full of energy, full of life, full of cheek' (Parent 2)

With the adolescents' renewed physical health, there was a sense that the restrictions that they had previously endured were suddenly lifted:

'[seeing] just how lively she was, how she was able to do everything for herself, she was able to catch up with her friends, go out and do whatever....everything didn't have to be done for her, like previously things had to be done for her' (Parent 3)

For A, freedom was defined in terms of his ability to participate in a sport that would have been impossible prior to transplant:

'the realisation that when I got out, I would be free...it's allowed me to do a lot of things that I can do now. I've currently been taking part in kung fu for six hours a week...I would never have been able to do that before 'cause it takes, it involves taking shots to the chest....I can take that, would never have been able to do that before. So that's my definition of freedom' (A)

Not only did the transplant afford a sense of physical liberation, it provided a psychological release and freedom from the anxieties that had dominated the pre-transplant phase:

'now I just go out, no need to worry about anything, that anything's going to happen' (C)

Catching Up:

Having been liberated by their transplant, the adolescents appeared driven to get on with life as soon as possible. A expressed an urgency to do *everything* straight away:

'I was keen to get out as soon as possible. 'Cause now I've got the new heart, I want to race ahead and do everything I possibly can....I was racing, I wanted to do everything, everything within the first day' (A)

'I think he's trying to catch up all the, all the things that he probably should have done years ago' (Parent 4)

For one adolescent, 'catching up' meant engaging in potentially reckless behaviour shortly after his transplant:

'my friend's got a moped and I had a skateboard....I held onto the back of the moped and I fell off at forty miles an hour and bruised myself really bad' (E)

A described a sense of invincibility: as though by surviving transplant, he was immune to potential danger:

'I have actually clinically died seven times, and I've come back, so it's given me a sort of feeling of immortality...and coming through transplant has heightened that. If that ain't going to get rid of me, then nothing is' (A)

The adolescents' apparent desire to 'catch up' on missed experiences appeared to exacerbate and accelerate the adolescents' drive for autonomy and independence, creating tension between the young person and their parent. Parent 2 described how her child used his mortality as a bargaining tool for independence:

'the freedom that he's got now with his health is wonderful but it's made the teenage bit worse....Cause I'm sure he would have wanted to have done all these things but he's, it's like he's on a mission now, he's got to do them...very occasionally something will be said and he'll say "well I could be dead in five years time, so I've got to do it now" and I find that very hard' (Parent 2)

Whilst appreciating their child's newfound freedom, their parents attempted to regulate the adolescents' behaviour, encouraging them to pace themselves and to slow down:

'I'm sure there's nearly everything she can do....she can do virtually anything now at this stage. I wouldn't like her to overdo it, overtire herself or anything like that, at the end of the day she still needs that bit of rest' (Parent 3)

'All he's got to do is, I've told him, is just calm down a bit, you ain't got to try catch up with things you might have missed, cause they'll come along anyway' (Parent 4)

However, for the adolescents, being cautious contradicted the very meaning of transplant:

'It completely defies the point of having a transplant to be able to do things, an oh if you can't do this, this and this, then what was the point' (E)

'Live it, you only get one' (A)

Participating in Teenage Life:

In contrast to their illness experiences, participants described how receiving a transplant enabled the adolescents to participate in normal teenage life:

'it was getting her freedom...just being like any other teenager and doing what they do.'

(Parent 5)

'I get a lot of joy out of seeing him able to go out and do as he would do at his age, go out and have a couple of pints or meet some mates and have a meal' (Parent 4)

Being able to take part in activities enabled the adolescents to enjoy a more active relationship with their peers:

'I've got a much more better relationship with my friends....cause I can do a lot more, I can handle a lot more' (A)

'I didn't used to bother phoning them and stuff, and now I'm knocking for them all the time, phoning them up all the time' (B)

Although the adolescents continued to experience some restrictions that limited or prevented their participation in behaviours associated to adolescent experimentation, they did not perceive this to be particularly problematic. Only one adolescent reported episodes of binge drinking:

'I drink myself, don't tell the doctors...I binge, I can go two weeks without a drink and I'll binge. Otherwise I'm more than fine. I'll get up the next morning and have a bit of a hangover. I'm like, if I'm really bad, I'll throw up a bit, but otherwise I'm fine.' (A)

For the majority, maintaining good health was seen as a priority:

'I wouldn't smoke, or anything, I'd never smoke at all...I really will like listen to the doctors when they tell me not to do this and that...when they told me at first you know and I was just kind of like, whatever, but now I really do like agree with them and do what I'm told basically....I don't want to get sick again' (D)

The adolescents appeared to find ways of accommodating their transplant within the context of peer experimentation, thereby balancing their health needs with their wish to join in:

'my main drink that I prefer is a vodka and coke, so if ever I don't want to drink I just say, yeah, I'll have a coke – "What's in that mate? Vodka?" "Yeah, yeah, yeah", so it's alright for me' (A)

'that just means I have to drive everyone home' (E)

Negotiating Independence:

The sense of liberation generated by the adolescents' improved physical health appeared to merge with developmental changes in the period after transplant, creating new opportunities for independence. Although this was understood to be a normative part of adolescent development, the novelty of this change seemed to make it harder to adjust to:

'we argue constantly at the moment, but I probably did the same with my parents. I'm sure I did. But I'm not used to it because he wasn't like that before the transplant, because it wasn't particularly an option before the transplant to, you know, go off here there and everywhere with his girlfriend...none of that was an option before' (Parent 2)

Much of the conflict between the adolescents and their parents seemed to revolve around typical teenage issues:

'He didn't come on holiday with us last week, and I found that very, very hard, very, very hard....he's like "well I'm not coming on holiday with you, I'm too big and old to come on holiday with you" (Parent 2)

'we have disagreements, not what they get up to, like hanging around, I don't like her being out late and she don't see anything wrong with it' (Parent 3)

E appeared to welcome this shift in focus towards *'normal scary things'* as opposed to the anxieties and restrictions that had dominated the pre-transplant period:

'It's just a bit weird, it's like yeah, don't get mugged, don't talk to strangers, don't do this, it's just normal. It's nice' (E)

However, many of the parents described an undertone of how the transplant added to the typical dilemmas of parenting an adolescent:

'he's still costing me money, he still wants me to do his ironing for him....I still worry a little bit when he goes out.....But I'd probably worry even if he didn't have the heart problem, or the heart transplant that he's had now.....but being the age that he is, then you still worry anyway....So yeah, I worry, I still worry, probably more so than if he was perfectly normal' (Parent 4)

'I think I'd be worried about her at this stage anyway but more so because of what she's actually been through and I wouldn't like anything to undo that, you know what I mean, you'd be afraid that anything would happen' (Parent 3)

To support the adolescents' emerging autonomy, some of the parents' emphasised the importance of allowing their child to make their own choices, and their own mistakes:

'Very rarely I'll say no, you look knackered, you're not going....I do step in because you know he's fifteen, he's got to start making a life for himself and decisions for himself.'
(Parent 1)

'you can't smother him and not let him do anything. He's got to go, go out there and make his own mistakes, find his limitations' (Parent 4)

However, negotiating the adolescents' burgeoning independence given their earlier fragility and dependence seemed to be particularly difficult, with parents contemplating the issue of *'letting go'* (Parent 4):

'Teenage years are horrible.....he's a teenager. He thinks he's a man, but he's not... so it's...letting him lead his life but kind of not completely letting go... he still needs that sort of arm around him, it's just not, not as tight as it was and...when you've got a child that has been ill, I think you're kind of more protective than certainly I am with the others...it's harder to let go I think, it's harder to let them grow up and sort of be free of your sort of I don't know, you're always looking after them I suppose, I've always had to look after him so much, much more than normal that it's even harder no to let him sort of do his own thing' (Parent 2)

Managing Medication:

Adherence to medical regimes to guard against the dual threat of infection and rejection was an essential part of the adolescents' post-transplant care. Several of the parents perceived their child to be old enough to take responsibility for their medication, and to understand the consequences of non-adherence:

'I said to him "you're a big boy now, if you don't take your drugs, you die...it's for you to sort out, I can't be there all of the time...I can't keep chasing you. You're at the age now where you've got to sort yourself out."' (Parent 4)

'she may forget them today, tomorrow and the next day, all her tablets, but she may forget herself then, they might not be able to do much for her, they mightn't be able to save her...she's at that age now that she needs to know all those things' (Parent 3)

The adolescents appeared to be fully aware of the importance of taking their medication, viewing it as facilitating their health and freedom rather than being restrictive or inducing independence:

'I need by tablets, I need them, they're one of my most important things to keep on going'

(C)

'no medication, no me' (E)

Whilst medication was not viewed as problematic in itself, difficulties seemed to arise from the way in which responsibility for it was negotiated. Many of the parents provided reminders about taking medication, citing this as an inevitable need of their child:

'I stop off on my way to work at the right time and phone him and say get up and take your tablets...because teenagers just want to be in bed don't they' (Parent 2)

'she gets mad now sometimes "I know I have to take them" she might say to you, but like it's easy to forget isn't it?' (Parent 3)

However, parental reminders were perceived as unnecessary nagging, causing frustration for the adolescents:

'(what's that like having them remind you?) Like oh god, I know, not again. Even if I've taken them they're "have you taken your tablets?'" (B)

'my mum and dad think they still have to remind me, they always say "did you take your tablets?" and they'd say it I don't know how many times. It's really annoying but I'm like "I did, I told you like, you don't have to keep reminding me".' (D)

The parents subsequently appeared to develop more surreptitious ways of monitoring their child's adherence:

'she went away the other weekend....and I kept saying will I won't I ring her and tell her to take her tablets or will I take a chance that she knows she has to take them herself. So I said she's a teenager now, I said I have to give her that bit of space, so I let her take them herself, so just at one stage I just rang her or text her to see how it went, at the end of it I just wrote a little note "did you take your tablets?" and of course "I did." [laughs] and I knew by the way she said "I did" as if to say "don't you trust me?"' (Parent 3)

Indeed, for many of the parents, it seemed difficult to trust their child to manage their medication regimes autonomously. Thus reminders served as a source of reassurance against the intolerable consequences of non-adherence:

'I just worry about him taking them, you know, and the consequences of him not taking them, I just think is unbearable for me, so I do have to, for myself if anything. I don't want to go through any more, I don't want him to go through any more so for the sake of saying "have you taken your pills", you know, it's the easy option really isn't it?'

(Parent 2)

Discussion

This study highlights the transformative nature of transplant for the adolescents and parents who participated in this study. By comparing participants' pre- and post-transplant experiences, the findings provide valuable insights into the processes that potentially underpin the improvements documented in the literature in the psychological functioning and quality of life of paediatric recipients who experience few post-transplant complications. Furthermore, it reveals the particular challenges faced by these adolescents and parents in relation to the achievement of autonomy and independence: an important developmental task, and marker of adjustment (24). Including adolescent-parent dyads captured the reciprocal nature of the transplant experience, providing a systemic context that has not previously been explored.

Given the high levels of morbidity and impairment experienced by those with cardiac failure, it is unsurprising that themes of restriction and dependence dominated participants' pre-transplant experiences. Physical limitations, disruptions to teenage life, dependence on parents and feeling different from peers goes against the grain of typical adolescence,

creating dissonance in terms of the adolescents' emerging autonomy and independence. Consequently, the adolescents in this study appeared to be in a state of 'enforced dependency' (34) at a time when they should be becoming increasingly independent, with relationships being renegotiated and redefined (35). Similarly, functional limitations associated with chronic illness and interference with daily activities can impact on peer relationships and evoke feelings of difference (36) at a time when homogeneity, conformity and acceptance are desired (37). La Greca (38) has suggested that social adjustment is an area of vulnerability for young people with chronic or life threatening illness. Indeed, the experience of being excluded from peer activities, perceptions of difference and prolonged dependence on parents may contribute to difficulties in this area for adolescent transplant candidates.

The physical improvements afforded by transplant, and corresponding sense of freedom, is likely to be an important mechanism through which the increased quality of life that is observed in the literature occurs. Indeed, the ability to take part in desired activities, spend time with friends and live a 'normal' life are benefits that have been cited by other qualitative studies of life after transplant (6, 39, 40). Furthermore, it appears that the adolescents' improved physical functioning impacted upon their developmental trajectory, bringing their level of autonomy and independence in line with what would be expected for young people of their age.

Whilst the findings indicate that receiving a transplant was perceived to be largely positive for the adolescents, the process of adjusting to post-transplant circumstances seemed to evoke particular difficulties for their parents. This was captured particularly within the themes 'Catching Up', 'Negotiating Independence' and 'Managing Medication'. Negotiating the

balance between autonomy and control is a considerable challenge in adolescent-parent relationships. The transformation from dependence to independence is considered to be most successful when it occurs gradually over a period of time (41, 42). However, the novelty of the adolescents' health after transplant and accompanying sense of liberation made this transition quite rapid and dramatic, captured by the adolescents' drive to 'catch up'. This seemed to inspire a more daring approach to life and desire to live life to the full. In contrast, several of the parents cautioned the need for their child to slow down. Risk-taking and experimentation are considered to be a normative part of adolescent development, and are means of expressing and asserting the young persons' growing independence and conformity to their peer group (43). Accepting these behaviours and adjusting to a new phase of their child's life may be particularly hard for parents, given the context of their child's earlier fragility and perceived vulnerability.

Similar to Steinberg and Silk's (42) observations of normative adolescent development, it appeared to be the parents, rather than the adolescents, who struggled to adapt to change. Difficulties are said to arise when there is a mismatch between adolescents' developmental need for autonomy and independence, and the opportunities provided by their parents (44). Whereas dependency appeared somewhat inevitable, and therefore accepted, prior to transplant, the fusion of the adolescents' improved physical health with normative developmental changes resulted in parents' struggling to separate their anxieties about their child's condition from their general concerns about the adolescent period (a phenomenon observed by Eiser and Berrenberg (34)), generating tension between themselves and their child. This mirrors previous findings, where parental over-protection was viewed as hampering the freedom granted by transplantation (21), and as a source of conflict between adolescent liver transplant recipients and their parents (45). Parents' difficulties 'letting go'

and adjusting to their child's sudden capacity for independence may hinder adolescents' achievement of this developmental milestone.

Analysis of the content of adolescent-parent interaction has revealed that conflict generally occurs over 'mundane and recurring' issues or 'daily hassles' (e.g., curfews, appearance) rather than fundamental values (46). Within the context of transplant, medication regimes may become a new source of 'daily hassle' for young people, increasing the level of conflict between themselves and their parents. Hanna and Guthrie (47) propose that parents of adolescents find it particularly difficult to let their child manage their medication independently despite their child's perceived capabilities and desire to do so. Although they want their child to become autonomous, parents worry that medication will not be taken correctly, and fear the consequences of this. These sentiments were echoed in the current study. Thus for parents, the task of negotiating independence was doubly affected by both their pre-transplant experiences of their child's illness and dependence, and their fears regarding post-transplant non-adherence and the consequences of this.

Whilst this study makes a valuable contribution to the field of adolescent heart transplant, there are a number of limitations that future research may seek to address. The retrospective nature of the research may compromise the validity and reliability of the data collected, as participants' recollections of life before transplant may be subject to recall biases. Future research may benefit from adopting a longitudinal approach, whereby transplant candidates are interviewed in depth at pertinent stages during the transplant journey. This type of design would also permit longer term follow-up. As medical adherence has been found to decline over time (48), and the reality of living with a transplanted organ is thought to 'sink in' approximately three years after transplantation (9); it would be useful to examine whether

adolescents' perceptions change as the novelty of their health wears off. As this may coincide with further transitions related to independence (e.g., entering the job market, attending university), a longer-term follow-up of their experiences would be of value.

Whilst this research sought a more homogenous sample compared to previous studies, clinical data (i.e. diagnoses, medical trajectories and status, presence of any morbidities or side effects) was not explicitly collected owing to a focus on participants' subjective, lived experiences. The collection of clinical data could have helped to provide further contextual information. Despite potential differences in clinical presentations, the themes reported were strongly represented across the data collected, and the credibility of the analysis checked in a number of ways (see above). Future research would benefit from a more detailed exploration of transplant recipients' medical histories and trajectories, and how this might shape their subjective accounts.

To be considered for, and ultimately receive a heart transplant, candidates and their families undergo rigorous assessment to determine their suitability for the procedure and maximise the chance of graft survival. Those who participated in the study may therefore be particularly conscientious and keen to present themselves favourably. As this study lacks data regarding non-respondents, it is not possible to offer a comparison of their experiences, or provide a commentary on whether the themes identified in this study would have relevance for them. The adolescents who participated in the study described themselves as physically well and had experienced few complications related to the transplant. A useful extension of this research would be to explore the accounts of those who have had post-transplant complications, as they may have qualitatively different experiences. Similarly, as those who participated in the study were of White-British or White-Irish origin, the potential to apply

the findings to other cultural and ethnic groups is limited as it is likely that cultural beliefs and practices would shape the experience of adolescence and heart transplant.

It is possible that additional contextual and individual factors affect adolescents' experiences of heart transplant. Although there did not appear to be any significant variance between the accounts of participants who had received their transplant more recently compared to those who had had theirs for a longer period of time, that is not to say that such differences do not exist. Whilst it is difficult to ascertain clear differences given the small sample size, issues such as risk-taking and experimental behaviours did appear to be more relevant to the two older adolescents (A and E). Whether the views of younger adolescents change as they get older and the norms and expectations of their peer group alter would be a worthy line of future enquiry. Similarly, further exploration of issues such as gender, identity and sexuality is likely to enhance understanding of adolescents' transplant experiences.

The research findings provide preliminary insights into the interaction between the heart transplant journey and adolescent development in relation to autonomy and independence. As this is a topic that has received little attention in the literature, future researchers may wish to test the relevance of these findings on a broader sampling frame, including those who have experienced different transplant trajectories. The findings may also be usefully applied to adolescents undergoing other forms of transformative medical treatment (i.e. other types of transplant) where there is a sharp and sudden contrast between pre- and post- intervention functioning. Due to the challenges this may evoke in terms of the development of autonomy and independence, future studies could explore these issues within a broader sampling frame, including other adolescent transplant groups, for example.

Due to the apparent interaction between adolescent development and heart transplant, clinicians in the field should attend to how young people and their parents negotiate developmental milestones and transitions, in addition to transplant related tasks. Successful attainment of these normative developmental processes is an important marker of adjustment (24). Systemic therapies may be useful to help families adjust to post-transplant circumstances, particularly in relation to the developing child, and subsequent role changes for family members. Supporting adolescent heart transplant recipients to manage the demands of their transplant regimes alongside the pressures of adolescence is likely to have positive benefits for both their physical health and psychological wellbeing.

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Joanna Adams developed the concept and design of the study, conducted the data collection and analysis and drafted the manuscript.

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Tracy Lunnon-Wood contributed to the design of the study, provided credibility checks of the data and critical review of the manuscript.

Michael Burch supported the ethical review process, and provided a critical review of the manuscript.

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