

**Title:** Experiences of Adolescent Lung Transplant Recipients: A  
Qualitative Study

**Authors:** Anderson, S M<sup>1</sup>; Wray, J<sup>2</sup>; Ralph, A<sup>2</sup>; Spencer, H<sup>2</sup>; Lunnon-Wood, T<sup>2</sup> ;  
Gannon, K<sup>1</sup>

**Affiliations:** <sup>1</sup> School of Psychology, University of East London, Stratford, London, United  
Kingdom

<sup>2</sup> Cardiothoracic Transplant Team, Great Ormond Street Hospital, London,  
United Kingdom

**Running Title:** Adolescents' Lung Transplant Experiences

**Corresponding author:** Sara Anderson; [sara.anderson3@nhs.net](mailto:sara.anderson3@nhs.net)

## Abstract

**Authors:** Anderson, S M ; Wray, J ; Ralph, A ; Spencer, H ; Lunnon-Wood, T ; Gannon, K

**Title:** Experiences of Adolescent Lung Transplant Recipients: A Qualitative Study

**Journal:** Pediatric Transplantation

Many young transplant recipients experience psychological distress and adjustment difficulties, yet there is little research investigating lung transplantation from the recipients' perspective. This qualitative study aimed to explore experiences of young people who underwent lung transplantation. Semi-structured interviews were conducted with six lung transplant recipients (aged 15 – 18). Interviews were analysed using Interpretative Phenomenological Analysis, a qualitative research approach examining how people make sense of their major life experiences. The analysis revealed three master themes: *'Living with Dodgy Lungs'* outlined how participants dealt with their experiences; managing through accepting or discussing their feelings with others, although talking was often difficult. *'The Big Deal'* reflected participants' experiences of the process, their expectations and the contrast of their lives pre- and post-transplant. Inherent in their accounts was the profound meaning ascribed to transplantation, the emotional turmoil and impact on their lives. *'A Sense of Self'* illustrated participants' developing identities within their social contexts and at times isolating experiences. The results highlight key areas where adolescent lung transplant recipients could be supported by clinicians, enabling the promotion of psychological wellbeing. Examples include supporting identity integration post-transplant; facilitating social inclusion; considering alternative means of support; and involving adolescents in healthcare decisions.

**Key Words:** adolescents; transplant; pediatric; lung transplant; quality-of-life; psychosocial

## Introduction

Organ transplantation is stressful with numerous adaptive challenges including lifestyle readjustments, social limitations and treatment side-effects (1, 2). Many young transplant recipients experience psychological distress and adjustment difficulties (3, 4). Depression, anxiety, school phobia and post-traumatic stress disorder (PTSD) have been reported (4), together with 'feeling different' from healthy peers and 'struggling to be normal' (5). Low quality of life (QoL) in adolescent transplant recipients (6) indicates a need for an in-depth awareness of the range of issues relevant to patients to aid in optimising transplant related QoL (7).

Median survival of paediatric lung recipients worldwide has improved in recent years from 3.3 years (1988 to 1999) to 5.8 years (2000 – 2012) (8). However, lung transplantation exchanges one chronic condition for another with an uncertain prognosis and on-going physical and psychological stresses (9, 10).

In 2014, 107 paediatric lung transplants were reported worldwide, 73% of which were in young people aged 11 to 17 years (11). Thus, adolescents represent the majority of this population (12, 13). Adolescence is a difficult time for healthy young people but is further complicated for transplant recipients as they struggle with identity development and seek normality post-transplantation (13). Historically transplant care focused on monitoring physiological outcomes and medication adherence, which often conflicted with adolescent concerns of peer acceptance, physical appearance and independence (7). The needs of adolescent patients differ significantly from other age groups as they face a transformational period making vocational decisions, taking increasing responsibility and exploring values and identity (13, 14). A meta-analysis examining QoL in various types of transplants showed variability across types (15). However, adolescent lung transplants were not included and, while lung transplant outcomes are progressively improving, they remain poorer than for other solid organ transplants (16). The increasing numbers and survival of adolescents undergoing lung transplantation confirms the need for a better understanding of the experience and

psychosocial impact to help tailor care (17, 18), particularly as they have been underrepresented in research to date when compared to other transplant recipients (19). Lung transplant recipients are unique in many ways, for example, they need a complete and continuous awareness of how much breathing will be involved in their every movement, with oxygen being a scarce resource to them (20). Carel (20) describes the miracle of lung transplant being anchored in the mundane, the everyday, being able to put on one's own socks or being able to walk upstairs.

The current study therefore aimed to explore the experiences of adolescent lung transplant recipients, particularly in relation to the challenges and demands of transplantation in the context of chronic lung conditions as well as their strengths and resources, with a view to informing care improvements and enhancing QoL.

## **Methods**

### **Qualitative Design**

The research sought to gain a rich understanding of adolescents' lung transplant experiences and how they make sense of them (21). Qualitative approaches enable in-depth study of personal experiences, particularly in populations with rare disorders representing small treatment groups such as the British adolescent lung transplant population (22).

Interpretative phenomenological analysis (IPA) was selected as it addresses participants' experiences and how they make sense of them (23). IPA adopts an 'insider perspective', allowing participants to tell their own stories, in their own words, in as much detail as possible before reducing the complexity of experiential data through rigorous and systematic analysis (24, 25).

### **Participants**

Following NHS Research Ethics Committee approval (Reference: 13/LO/0837) participants were recruited from a specialist national transplant centre in the United Kingdom. Ten of the eleven adolescent transplant recipients under the care of the centre were invited to participate, one patient

with a diagnosed learning disability was excluded as it was anticipated that they would have additional and different experiences and concerns and the aim was to recruit a homogenous sample, as recommended for IPA (23). Four patients declined participation due to illness or other commitments at the time of data collection. Six young people aged between 15 and 18 years participated (Table 1). Participants had undergone transplantation recently enough to be able to reflect on their experience but were at least six months post-transplant, allowing time to recover from the procedure and return to education. All patients were transplanted from home, with none having required intensive care since being listed for transplant. The median time from listing to transplantation was 11.5 months (range: 1-35 months). Each participant had returned to full time mainstream education (school or college) by the time of the interview. Participant demographics are detailed in Table 1.

### **Data Collection**

Phenomenological accounts were elicited through semi-structured interviews. The interview schedule was developed by drawing on the literature and input from the transplant team whose suggestions stemmed from ideas generated by a group of twelve adolescent heart and lung transplant recipients who attended an annual summer adventure camp organised by the team. The interview schedule was reviewed by a young transplant recipient and her mother, who were not involved in the study, and changes made based on their comments. In considering the limitations of the existing literature and the deductive approach of many studies focusing on particular aspects of the transplant and its implications as well as the lack of personal accounts in the literature, the interview schedule was kept as broad as possible to obtain a holistic, integrated view of the whole experience. Interviews began with a general question about the participants' experience, allowing them to set the course and enabling the researcher to be led by issues pertinent to the participant (23). The interview schedule was not employed prescriptively but rather was adapted and adjusted with each interview. Examples of interview questions are provided in Table 2.

Interviews were conducted between November 2013 and March 2014 by the first author and were conducted in a private setting at the hospital or in participants' homes, depending on their preferences. For two of the hospital interviews participants requested their parent's presence; these parents contributed minimally to the interviews. In the other interviews participants' parents were nearby but not in the room. Interviews were audio-recorded and averaged 57 minutes in duration. All participants and their parents provided written consent.

## Data Analysis

Interview recordings were transcribed verbatim and identifying information removed before analysis using a step-by-step idiographic approach following IPA guidelines (21, 23, 26):

The first transcript was read while listening to the interview recording to capture the nuanced aspects of the interview. The transcript was then re-read several times to develop familiarity, foster immersion and actively engage with the data.

The detailed exploratory analysis step began with close interpretative reading, highlighting points of interest and noting initial responses to each interview in the margin. Descriptive, linguistic and conceptual elements were attended to in line with Smith et al.'s (23) guidance

In the next stage the transcript was read more systematically and notes were translated into preliminary themes at a higher level of abstraction. The task was to reduce the data volume while maintaining its complexity through the identification of patterns and connections between initial notes. The emergent themes were conceptual, aiming to capture the essential quality of what was represented in the text.

Structure was then introduced and themes tentatively organised in relation to one another. To this end themes were organised in a list and then rearranged to form clusters. New themes were added and existing themes were edited or dropped if they were insufficiently evidenced in the text or not relevant to the research question. This was an iterative process that involved going back and forth

between the list and transcript to continually check interpretations were congruent with the quotes from which they arose. Clustered themes were given broad labels in an attempt to capture their essence and a summary table of clustered themes, with corresponding quotations, was produced.

Finally, once each individual transcript was analysed, as described above, themes were mapped out, patterns across interviews were established and themes integrated. Themes were included and developed based on prevalence, richness of supporting data and relevance to the research aims. The aim of this stage of analysis was to obtain a generalised understanding of participants' shared experience of lung transplantation. This process involved a continual cyclical collapsing and reforming of themes to produce a final integrated list of master and subordinate themes, reflecting the researcher's interpretations.

The analysis was conducted by the first author and discussed with the other authors as it proceeded. The developing codes and themes were reviewed together.

Quality issues were addressed by utilising the guidelines provided by Smith (26) and Yardley (27) for, respectively, IPA in particular and qualitative research in general. These include a clear focus for the research, good quality data, systematic and rigorous analysis, being analytic rather than simply descriptive and illustrating convergences and divergences in the accounts of participants.

## **Results**

The analysis yielded three master themes presented below as a narrative account supported by verbatim interview extracts from the six participants.

### **Theme 1: 'Living with Dodgy Lungs'**

Participants dealt with their illness, the transplant process and related difficulties in various ways; some through acceptance and others by expressing their feelings, although talking was often difficult. Professionals played a particularly vital role.

### 1.1. "Going with the Flow"

Most participants seemed to deal with the traumatic aspects of their illness and interventions through acceptance. Some expressed mottos *"go with the flow, anything could happen so, hey, yeah!"* (P3) and *"go ahead and like head first with it"* (P5) suggesting resilience, adaptability, forward focus and coping by not worrying or resisting. Others recounted passively accepting having things *"done to"* them and resigning to just *"get on with"* challenges (P4) or *"accepted the fact that... now I was dying"* (P5).

For some, traumatic memories appeared to be forgotten or repressed as recollections were sometimes vague: *"I can't remember all of it... I suppose I just chucked it somewhere in my mind, subconsciously just chucked it somewhere"* (P4).

A number of participants had a pragmatic approach to challenges: *"if something comes up, just try deal with it and move on, simple"* (P3). *"Simple"* being a striking understatement yet this simplified, almost formulaic, approach seemed helpful in coping with hospital visits or medication: *"have them in like one container and I just go box by box taking them"* (P5).

Another means of managing distressing experiences involved focusing on future hopes: *"just everything I haven't been able to do, it just gave me in a way hope of like I will get these lungs and you know these are the things I will be doing, and it just... yeah it helps"* (P2).

### 1.2. Complexities of Talk

Participants described talking as a means of processing distressing experiences: *"me, mum and dad it was nearly every day we would always talk because I would get upset and scared in a way, they would just always like... cheer me up"* (P2). This participant also highlighted the benefits of talking to other *"teenagers"*. Another participant related it was *"easier to talk to people that you don't know"* (P5). The sense was that some things are easier to talk about with certain people and that individual preferences shape when, how and with whom talking is helpful.



Participants also revealed difficulties in sharing their thoughts and feelings, preferring to *“just keep them inside”* (P5) or *“I just talk to them generally, easier”* (P3). Some described physical limitations to speaking enforced by their lung condition: *“I could never talk every breath I took like I couldn’t, doing a sentence would really wear me out so it would take a long time to talk”* (P2).

Opinions and experiences of talking therapies varied. Some participants preferred not to talk and viewed *“psychologist people or whatever”* (P4) negatively. One participant *“found it so hard to talk to them and in a way I thought they were a little bit patronising”* (P5). In contrast another initially hesitant participant expressed surprise at the ease and benefit of talking to psychologists and appreciated the person-centred approach:

*“at first I was a bit anxious but as soon as she started talking to me I just relaxed and I was able to talk to her and it wasn’t at all how you think they are like “hmmm how do you feel?” and it was very like normal ... they were easy to talk to and they just talk about what you wanted to talk about in a way and it just helped me so much”* (P2).

### **1.3. Bonds with Professionals**

As is evident in the previous theme, relationships with professionals emerged as vital to these young people living with chronic conditions. Most mentioned lifelong relationships with professionals, like the participant whose *“nurse who’d known me since I was 3 weeks”* accompanied her to the transplant centre and the consultant, *“known her since I was about 4”* (P6). Clinicians were described as sharing in the excitement and relief about the possibility of transplantation: *“when [consultant] said it I just burst into tears, mum burst into tears and then [consultant] burst into tears”*; *“there were like 10 nurses and doctors running into the room saying ‘you got lungs!’”* (P6). Others described professionals taking roles reminiscent of a parent. These bonds are understandable given the lengthy periods of hospitalisation endured *“they looked after me one-on-one for five weeks”* (P5), so much so that for one participant hospital *“seems like my first home really”* (P6).

Participants considered clinicians as skilled experts and expressed admiration and appreciation. One participant opined *“individually [they’re] all heroes”* (P5) when discussing medics having saved her life. Another participant identified the *“amazing people doing”* his transplant as key to his positive experience (P2). One participant gave examples of things she appreciated:

*“They were just very heart warming, you got a really good vibe off them and they’d always be really positive and they’d get you involved with stuff like your medication... so they’d talk to you and not just be quiet while they’re doing stuff”* (P5).

In contrast, some experiences were less positive spawning disillusionment. Participants spoke of medics doing things *“badly”* (P1), not taking care. One participant stated *“they’d just be very heavy handed”* causing her to have *“gathered up quite a lot of fear from a young age”* (P5). Another participant presented an underlying scepticism as he hoped professionals involved in his care were competent: *“people who know what they’re doing, hopefully”* (P3).

While many participants appeared to idolise their clinicians through difficult experiences some became sceptical, perhaps paralleling an adolescent developmental relationship whereby children grow to question once omnipotent parents.

## **Theme 2: ‘The Big Deal’**

In narrating their transplant stories participants described expectations, experiences and the accompanying emotional turmoil.

### **2.1. Emotional Maelstrom**

Participants described a maelstrom of emotions accompanying their transplant experience. Some appeared to travel an emotional trajectory; beginning with a powerful reaction to the realisation that their condition had deteriorated to the point where only transplantation offered the possibility of survival:

*“I think because I was very in denial and it was a big shock when [consultant] said ‘I think you need to go on the transplant list [...] all my life I’d always ‘ah I’m alright, I’m fine’ and then it was realising how serious my condition had actually got” (P5)*

*“I went through this really bad time with this, because I used to like cough up blood and things and that used to really scare me and because it was like from the lungs and that was an indication of in a way to me like am I gonna die right there because like yeah it was just the last few years of it before transplant I’d be scared to go to sleep as in not wake up, it was that bad of a thing” (P2)*

These extracts illustrate the tension arising from being placed on the list, which made it clear to the participants how sick they were while simultaneously establishing the fear they would die if a donor was not found in time, with breathing difficulties and ‘coughing up blood’ being a constant reminder of their precarious lung condition. Waiting was thus associated with fear for many participants, yet when the transplant call came it was accompanied by excitement and shock: *“I was a bit like shocked and nervous you know it’s quite a big deal” (P4).*

Following the transplant participants described relief: *“first of all after transplant it was just a relief that I’d be able to do a lot of things I have never been able to do” (P2).* Others experienced a period of despair, regret, mourning and *“being really grumpy and mean to everyone” (P1).*

In time participants seemed to work through their distress, perhaps as they made sense of their experiences and emotions. As one participant said *“things started to actually become good, it wasn’t so dark anymore” (P5).* Reflecting from their current vantage point several participants described the transplant as *“an amazing thing to have done” (P2), “a precious gift” (P5) that “changed near enough everything” (P3).*

## 2.2. "New Life": Dreams and Reality

All participants reported suffering effects of a deteriorating, life-limiting illness and shared ideas about transplantation representing the promise of "new life" as it dramatically interrupted the trajectory towards death; *"I was coming to like end stage... where I was very dependent on my mum and a wheelchair and oxygen"* (P5). One participant expressed her family's hope for a new beginning when they *"wished me a happy birthday, a new life"* (P6). However, unmet expectations and difficulties post-transplant led to disappointment for some: *"sometimes I thought it wasn't even really worth it because it was even worse than before transplant"* (P1) referring to the recovery process and subsequent complications.

Despite initial disappointment most participants described substantial improvements including being able to be *"more sociable after transplant"* (P1), *"not as much hospitals, that's pretty good"* (P3), *"able to play sports more"* (P1) and increased *"time and energy"* (P5). Some participants described transplantation as profoundly transformational, *"everything changed for the best"*, *"before transplant I always like imagine things I could do, now I'm actually doing them"*, *"before it was just a dream because I could never have done them if I didn't have lungs... now I've got that opportunity [...] it's just amazing"* (P2). Others seemed ambivalent about the changes: *"I don't know I sort of preferred it before, but I sort of do prefer it a bit now"*, perhaps due to being overwhelmed by the *"big change"*, *"everything at once is the thing, it wasn't gradual it sort of all just went whoosh"* (P4). Although participants mentioned improved physical robustness, several acknowledged ongoing vulnerability necessitating being *"careful"* (P1) as transplantation is *"not a miracle cure"* (P4).

## Theme3: 'A Sense of Self'

Participants' narratives illustrated their developing identities within their social contexts.

### 3.1. "Finding who I am"

Participants' efforts in understanding their experiences seemed intricately entwined with attempts at making sense of themselves. Influences from illness and transplant experiences as well as

developmental and social influences impacted on how participants described themselves. One extract illustrates aspects, shared with others accounts, of a developing identity:

*“I had a lot, lot more to concentrate on... didn't really need to know who I was because I just had so many things to do like my health and I didn't really have time to think about who I was or what I liked so... when I did have that time I didn't know what I like, I didn't know who I liked, I didn't know what I wanted... yeah it was complicated but... you know I needed that time to find out who I was” (P5)*

Illness demands precluded the "work" of self-exploration and finding the "real me". This is rendered particularly challenging as the "old" self was characterised by illness related paraphernalia: *“before I had [transplant] obviously everyone knew because I had a carer and wheelchair... so everybody knew sort of I was a bit different, but I suppose now... it's a bit weird” (P4)*. While this loss of “old” identity markers was unsettling for some; *“I was just like ugh what do I do yeah it was like I'd sort of just been given a pair of lungs and then been put out in the big wide world and I was just there like I don't know” (P5)* others expressed a sense of freedom from being defined by illness: *“now I am just happy with how I am” (P2)*. This contrasts with the ongoing prominence given to disease and its management; regarding hospitalisation one participant said *“I'm weird and enjoy it” (P6)*.

Participants' understanding of their past is clearly essential in identity construction. One described assembling information from various sources to construct her personal illness story: *“my parents sort of told me and doctors sort of told me, sort of got things that come in the post on my medical history” (P4)*. Parents and medics seemed prominent in providing a narrative framework, yet friends also contributed: *“as I started seeing my friends more [...] started persuading me to sort of find out who I was” (P5)*.

Some participants had refined a narrative of their experiences to share with others, yet their detached presentation made it unclear if they identified with it: *“I had a double lung transplant and I'm here you know and that's about it” (P1)*. Others seemed to have integrated their transplant

experiences into their identity: *“for me it’s just part of a conversation, normal conversation, a part of me”* (P3). Another participant described instantly integrating her *“new lungs”* into her physical sense of self, *“when I got told I got lungs that was it they were mine”* (P6).

### ***3.2. Isolation, Exclusion and (Re)connection***

Each participant felt in some way excluded due to physical restrictions and described *“staying off school”* or even at school being isolated and missing out: *“In primary school obviously I couldn’t go climb trees or whatever with my friends but now I don’t really want to do that sort of stuff”* (P4).

Friends developed, progressing through different experiences, leaving her behind. Later, even when transplantation facilitated inclusion the loss could not be fully ameliorated.

Although some participants maintained contact with peers this was challenging and *“upsetting”*, highlighting things they *“couldn’t do”*. Some participants consequently isolated themselves: *“singled myself out from everyone, I wouldn’t really communicate with a lot of people because whenever I’d make plans to do something I’d never be able to go through with it”* (P5).

Transplantation facilitated greater social inclusion which was highlighted as a benefit. However, participants also noted that socialising was initially challenging, suggesting that through previous isolation they had become socially anxious. One participant related, *“Just... really weird, you have to like learn to be social again. Which I don’t know I am still not good at now”* (P3). Being social was described as *“really weird”*, needing to be re-learned, suggesting it is a skill that does not come naturally. This extract also indicated that socialising continues to be difficult. Another participant alluded to continued isolation: *“I don’t really go out much so....”* (P4). She trails off at the end perhaps implying loneliness, which is difficult to admit. Another participant who disclosed struggling with friendships at school mentions making friends online. This could be due to electronic communication being more familiar, as it is for many adolescents, but also because it was the primary form of communication available when his illness forced isolation.

Another excluding factor was requiring treatment in isolation thus preventing interaction with other patients: *“couldn’t really talk to the other kids because I was always in isolation”* (P1). However, this did not stop some who found ways to connect with other patients by using technology. Participants described contact with the illness community as helpful: *“it was nice because they’d understand me and I’d understand them... they’re people with the same illness as you, really the only people that are going to know how you feel.”* (P6)

Others aimed to aid their illness community and themselves derived benefit: *“I managed to get like 9000 people to become organ donors [...] that helps me because I feel like I’m helping someone”* (P5).

## Discussion

This study delivers a number of novel findings relating to the adolescent lung transplant population.

Participants related the debilitating consequences of a deteriorating lung condition setting the scene for their transplant experience. The meaning ascribed to the transplant, *“the big deal”*, was particularly pertinent. Being considered for transplantation came as a shock, bringing the illness severity and imminence of death into stark relief. The initial post-transplant period held disappointment for some when expectations were unmet or additional complications had to be faced, leaving them feeling *“grumpy”* and hopeless. This is consistent with previous findings of psychosocial post-transplant adjustment difficulties (1, 27), and highlights a need to address expectations and offer support in the post-transplant period as this study showed that even positive outcomes may require preparation to adjust. It further illustrates that preparation prior to transplant could be useful because of the impact of being on the list, the increased uncertainty as well as sometimes high expectations leading to disappointment. Nevertheless, initial disappointment notwithstanding, participants described a range of gains.

Participants’ accounts demonstrated that lung transplantation is physically and emotionally harrowing and like participants in other studies they experienced *“ups and downs”* (10). Particular

challenges were: making sense of and coping with the experience, talking and connecting with others and identity exploration during developmental turbulence. Some participants struggled to process traumatic experiences, “chucking” painful memories and denying the severity of their condition, as did heart transplant recipients in another study (28), highlighting a potential area for intervention. Anbar and Murthy (29) noted that patients who learn helpful coping strategies show better treatment adherence, leading to improved physical and psychological wellbeing.

For most participants pre-transplant demands on time and energy appeared to impede adolescent identity development with their “old” identity centring around disability with its physical markers (oxygen, wheelchairs), so much so that the initial experience of ‘self’ following drastic transplant changes was one of loss and confusion, requiring work to frame and communicate a new identity. This is an important finding as research suggests that failure to reconcile transplantation and identity is associated with poor medical adherence, reduced independence and social isolation (30) yet transplantation dominating identity prevents recipients recognising their other unique characteristics (13). The prominence of disease and its management in participants’ sense of self was striking, even featuring in post-transplant identity where it continued to have some desirable aspects (e.g. being looked up to by peers). This contrasts with liver transplantation (31) where recipients’ identities were less grounded in illness experiences, perhaps because lung disease is a more consciously embodied experience, each breath serves as a reminder. This is consistent with Carel's (32) phenomenologically-informed account of her experiences of chronic lung disease. The presence of dramatic physical symptoms (e.g. coughing blood) further differentiates this group from other transplant groups.

A further finding unique to lung disease and transplantation related to the impact of participants’ lung conditions making it physically difficult to speak and thus challenging to maintain social relationships in the pre-transplant period. Several participants’ accounts suggested that socialising following transplant was initially challenging too, indicating an area requiring support as noted in



previous research (17, 33). However, as Kaufman and colleagues (13) emphasise, young people with few or no friends may not want to admit this, complicating assessment of social integration.

Consequently alternative methods of developing social skills and connectedness for all transplant candidates may be required. Some studies have suggested introducing peer mentoring programmes and facilitated adolescent support groups (7, 17). In spite of the physical difficulty of having conversations, many participants found talking about their experiences therapeutic and chose to do this by talking to parents, friends or other lung transplant recipients. Not all participants discussed accessing psychological support; however, those that did had distinct experiences. One participant outlined striking benefits while others either resisted or found it undermined their own resilience. Findings thus suggest if psychological support is offered it may be better to frame this as informal chat rather than being problem-focused.

Hospitals and clinicians played a central part in participants' experiences and relationships with medical staff were defining. These relationships could be developed as a useful resource; however, care is required as early negative experiences can have long-term effects. Participants described pre-transplant experiences impacting on their expectations and confidence in clinicians, e.g. having "*gathered up fear*" through "*heavy handed*" interventions. This affirms discussions of the importance of young people's relationships with clinicians (34). Evaluations of clinicians seemed to mirror the nature of the transplant experience, participants who viewed their transplant as transformational expressed admiration for the "*amazing people*" involved in their care. Participants also expressed appreciation of being involved in their own care and being spoken to directly rather than having things "*done to*" them or professionals speaking in terms they didn't understand. This demonstrates a preference for active involvement in their care, consistent with recommendations from Kennedy's review (35) of NHS services for young people.

## **Study Limitations**

### ***Generalizability***

While the sample size for the present study is admittedly small, only 78 lung transplants were conducted globally in this age group according to 2014 data (11). The participants were referred for surgery in this centre from throughout the United Kingdom and represented 60% of the recruitment population. All participants were of white European ethnicity and the majority required a lung transplant due to Cystic Fibrosis (CF) possibly limiting the generalizability of the findings to other ethnic groups or young people with other health conditions. However, the participants can be seen as representative of the population as the patients who did not participate were also of white-British origin. Furthermore, statistics show that CF is most common in people of northern and central European ancestry with 73% of adolescent lung transplant recipients in Europe requiring transplantation due to end-stage CF (36). Additionally it is recommended that IPA studies recruit a homogenous sample which was the case for this study's participants (23). As one participant was transplanted due to primary pulmonary hypertension, an effort was made to include her voice in all the themes to ensure findings were not limited to CF patients' experiences and in fact many areas of convergence were evident in this participant's account with the others.

### ***Interviews***

Interviews are inevitably constrained in various ways and may be influenced by context (such as home vs hospital), ambient noise and distractions and the presence of others. In this study two participants asked for their parents to be present which, while it appeared to put them at ease, may have made it more difficult to speak about some issues. In addition, young people may have less developed verbal skills and be less adept at expressing abstract ideas (37).

## *Method*

IPA was selected as the method of analysis most suited to this study but, like all methods, it has shortcomings. Willig (21) outlines a number of conceptual and practical issues including IPA's reliance on the representational validity of language.

## **Conclusion**

Understanding subjective experiences of adolescent lung transplant recipients is crucial for service development and future studies examining the biopsychosocial impact of transplantation. There remains a need for prospective longitudinal studies examining expectations and their impact on post-transplant adjustment as well as research into particular concerns such as identity development and social integration. This study provides a starting point for future research and contributes to an evidence base for improving care and enhancing services offered to young lung transplant recipients.

Specific recommendations for clinical practice arising from this study include establishing an online community for young people in the waiting and initial post-transplant stages as connecting with peers may support social skills some participants reported having to re-learn, thus easing reintegration. Transplant clinics should further provide information outlining how psychological support can be accessed and address assumptions and inhibitions young people may have in addition to signposting to other resources. One possible approach could be supporting patients in creating a video detailing their experience of transplantation and accessing psychological support. This could be an invaluable resource for future patients while at the same time the young people creating such resources may derive benefit from telling their story and helping others, as findings showed that participants were keen to help others and experienced opportunities to help as therapeutic. A similar project with paediatric cancer patients was well received (38). Individual work with young people may also assist them in integrating their post-transplant identities. Narrative approaches (39) seem especially suited to helping transplant recipients integrate their transplant experiences into who they want to be. Clinicians should consider the timing, location and nature of

therapeutic talking and be responsive to individual preferences as participants desired a person-centred approach that accounts for individual preferences. A final clear practice implication is to view young people as key stakeholders in transplant services and to develop a culture of participation, enabling young people to shape services that play such a crucial role in their lives.

## **Authors Contributions**

Anderson, S M: Concept/Design, Data collection, Data analysis/interpretation & Drafting article

Wray, J: Data analysis/interpretation, Critical revision of article, Approval of article

Ralph, A: Data collection, Approval of article

Spencer, H: Concept/design, Approval of article

Lunnon-Wood, T: Concept/design, Approval of article

Gannon, K: Concept/design, Data analysis/interpretation, Critical revision of article, Approval of article

## **Acknowledgements**

We thank the nurses who assisted with the recruitment of participants and most importantly the young people who shared their stories; without whom this study would not have been possible.

## Figure Legends

**Table 1: Participant Demographics**

Participant	Gender	Age at interview	Years post-transplant	Condition
P1	Male	15	3	Cystic Fibrosis
P2	Male	15	0.5	Cystic Fibrosis
P3	Male	16	6	Cystic Fibrosis
P4	Female	16	4	Primary Pulmonary Hypertension
P5	Female	18	3	Cystic Fibrosis
P6	Female	17	2	Cystic Fibrosis

**Table 2: Example Interview Questions**

<b>Interview Guide</b>
<p>As the interviews were semi-structured the following provides examples of areas covered in the interviews. The precise way in which the interviews unfolded was influenced by the participant's responses.</p> <p><b>Ice breaker questions:</b></p> <ul style="list-style-type: none"> <li>• How do you feel about being here today? What lead you to agree to take part in the interview?</li> <li>• What would you normally be doing if you weren't doing this interview today?</li> </ul> <p><b>Introductory questions:</b></p> <ul style="list-style-type: none"> <li>• I am interested to hear what you have to say about lung transplantation, in as much detail as you can give me (there are no right or wrong answers, I just want to hear about your experiences and thoughts about it)</li> <li>• Can you tell me about life with a transplant?</li> <li>• What is it like having a transplant?</li> </ul> <p><b>... I'd like to ask some more questions about what you said, is that okay?</b></p> <p><b>Prior to transplantation:</b></p> <ul style="list-style-type: none"> <li>• When did you first find out that you may need a lung transplant? How did you find out? Can you described to me what you remember thinking at the time? Do you remember how you felt?</li> <li>• Can you tell me about when you were waiting to find out if you could have a transplant? How was the waiting period for you?</li> <li>• Do you remember finding out that a donor had been found for you? Can you tell me about it? How did you feel about the news?</li> </ul>

**The actual transplant:**

- What was the actual operation like? How did you recover initially? How did you cope? Were there any complications?

**Post transplantation:**

- Can you tell me about how things have been in the time since the operation? You must have to take a lot of medication, how is that?
- What things are different about your life now compared to before you had the transplant? What has changed for you or about you? Are there things you can do now that you couldn't do before? How did it impact on the things you do at school?

**Relationships:**

- What effect has this experience had on your family and your relationship with your parents? Does your family talk about the transplant? How? Has your relationship with your parents/siblings changed since the transplant? What sort of relationship do you have with the care providers?
- Has your illness and your transplant had any effect on your friendships and other relationships? Did you manage to stay in touch with friends when you were ill? How did you stay in touch? What is different now?

**Appearance/Disclosure:**

- How do you feel about your new lungs? How do you feel about your body and the way you look in general? Do you feel this has changed since your transplant?
- Do you tell people that you had a lung transplant? What is it like telling people? What do your friends know about your transplant?

**Future/Transition:**

- What do you think about the future? Have you got hopes, plans, goals and dreams for the future? What are your expectations? Can you tell me about them? How do you feel about moving to adult services?
- Is there anything else you would like to share with me about your experience? Or anything else you think would be important for me to know?

**Debriefing:**

- How do you feel about the conversations we've just had? If there were one thing that you feel is important to tell me about today or one most important thing that you have already told me, what would that be? Is there anything that bothered you about the interview? Is there anything that you'd like me not to transcribe? Do you have any questions for me? You can contact me if you have any other questions.

**Prompts:** Please, tell me more. What do you mean? What was that like for you? How does that make you feel? How do you think about that? Can you give me an example?

## References

1. Mintzer LL, Stuber ML, Seacord D, Castaneda M, Mesrkhani V, Glover D. Traumatic Stress Symptoms in Adolescent Organ Transplant Recipients. *Pediatrics*. 2005;115(6):1640-4.
2. Olausson B, Utbult Y, Hansson S, Krantz M, Brydolf M, Lindström B, et al. Transplanted children's experiences of daily living: Children's narratives about their lives following transplantation. *Pediatric Transplantation*. 2006;10:575-85.
3. Annunziato RA, Jerson B, Seidel J, Glenwick DS. The psychosocial challenges of solid organ transplant recipients during childhood. *Pediatric Transplantation*. 2012;16(7):803-11.
4. Tong A, Morton R, Howard K, Craig JC. Adolescent Experiences Following Organ Transplantation: A Systematic Review of Qualitative Studies. *The Journal of Pediatrics*. 2009;155(4):542-9.
5. Wright J, Elwell L, McDonagh JE, Kelly D, Wray J. 'It's hard but you've just gotta get on with it'--The experiences of growing-up with a liver transplant. *Psychology & health*. 2015;30(10):1129-45.
6. Taylor RM, Franck LS, Gibson F, Donaldson N, Dhawan A. Study of the factors affecting health-related quality of life in adolescents after liver transplantation. *American journal of transplantation*. 2009;9(5):1179-88.
7. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatric Transplantation*. 2011;15:285-93.
8. Benden C, Goldfarb SB, Edwards LB, Kucheryavaya AY, Christie JD, Dipchand AI, et al. The Registry of the International Society for Heart and Lung Transplantation: Seventeenth Official Pediatric Lung and Heart–Lung Transplantation Report—2014; Focus Theme: Retransplantation. *The Journal of Heart and Lung Transplantation*. 2014;33(10):1025-33.
9. Todd L, Anthony S, Dipchand AI, Kaufman M, Solomon M, Stein M, et al. Body image and eating attitudes and behaviours among adolescent heart and lung transplant recipients: a brief report. *Progress in Transplantation*. 2012;22(3):259-63.
10. Green A, Meaux J, Huett A, Ainley A. "It has its ups and downs": adolescents' quality of life after heart transplantation. *Progress in Transplantation*. 2011;21(2):115-20.
11. ISHLT Transplant Registry Quarterly Reports for Lung [database on the Internet]. The International Society for Heart and Lung Transplantation. 2016 [cited 25/9/2016]. Available from: <http://www.ishlt.org/registries/quarterlyDataReportResults.asp?organ=LU&rptType=all&continent=3>.
12. Benden C. Specific aspects of children and adolescents undergoing lung transplantation. *Current Opinion Organ Transplant*. 2012;17(5):509-14.



13. Kaufman M, Shemesh E, Benton T. The Adolescent Transplant Recipient. *Pediatric Clinics of North America*. 2010;57:575-92.
14. Overview of Pediatric Lung Transplantation [database on the Internet]. Medscape. 2013 [cited 01.09.2015]. Available from: <http://emedicine.medscape.com/article/1013065-overview>.
15. Dew MA, Switzer GE, Goycoolea JM, Allen AS, DiMartini A, Kormos RL, et al. Does transplantation produce quality of life benefits? A quantitative analysis of the literature. *Transplantation*. 1997;64(9):1261-73.
16. Radley-Smith R, Aurora P. Transplantation as a treatment for end-stage pulmonary hypertension in childhood. *Paediatric Respiratory Reviews*. 2006;7(2):117-22.
17. Lochridge J, Wolff J, Oliva M, O'Sullivan-Oliveira J. Perceptions of Solid Organ Transplant Recipients Regarding Self-Care Management and Transitioning. *Pediatric Nursing*. 2013;39(2):81-9.
18. Burch M, Aurora P. Current status of paediatric heart, lung and heart-lung transplantation. *Archives of Disease in Childhood*. 2004;89:386-9.
19. Fredericks E, Zelikovsky N, Aujoulat I, Hames A, Wray J. Post-transplant adjustment--the later years. *Pediatric transplantation*. 2014;18(7):675-88.
20. Carel HH. Breathless: Philosophical Lessons from Respiratory Illness. *Hektoen International, A Journal of Medical Humanities* 2014;6(1).
21. Willig C. *Introducing Qualitative Research in Psychology*. 3rd ed. Maidenhead: Open University Press; 2013.
22. Fiese BH, Bickham NL. Qualitative inquiry: An overview for pediatric psychology. *Journal of Pediatric Psychology*. 1998;23(2):79-86.
23. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage; 2009.
24. Smith JA. Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*. 1996;11(2):261-71.
25. Reid K, Flowers P, Larkin M. Exploring lived experience: An introduction to interpretative phenomenological analysis *The Psychologist*. 2005;18(1):20-3.
26. Smith JA, Jarman M, Osborn M. Doing Interpretative Phenomenological Analysis. In: Murray M, Chamberlain K, editors. *Qualitative Health Psychology Theories & Methods*. London: Sage; 1999.
27. Yorke J, Parle M, James M, Gay T, Harkess M, Glanville A. Lung transplantation in adolescents and young adults with cystic fibrosis. *Progress in Transplantation*. 2006;16(4):343-9.
28. Kaba E, Thompson DR, Burnard P. Coping after heart transplantation: a descriptive study of heart transplant recipients' methods of coping. *Journal of Advanced Nursing*. 2000;32(4):930-6.

29. Anbar RD, Murthy VV. Reestablishment of hope as an intervention for a patient with cystic fibrosis awaiting lung transplantation. *Journal of Alternative & Complementary Medicine*. 2010;16(9):1007-10.
30. Lawrence K, Stillely CS, Olshansky E, Bender A, Webber S. Further exploration: maturity and adherence in adolescent and young adult heart transplant recipients. *Progress in Transplantation*. 2008;18(1):50-4.
31. Taylor RM, Franck LS, Dhawan A, Gibson F. The Stories of Young People Living With a Liver Transplant. *Qualitative Health Research*. 2010;20(8):1076-90.
32. Carel H. *Illness*. Stocksfield: Acumen; 2008.
33. Wray J, Lunnon-Wood T. Psychosocial Outcomes: Growth and Development. In: Goldfarb S, Benden C, Sweet S, Kirklin JK, editors. *ISHLT Monograph Series: Pediatric Lung Transplantation: The International Society for Heart & Lung Transplantation*; 2013.
34. Lerret SM, Stendahl G. Working together as a team: adolescent transplant recipients and nurse practitioners. *Progress in Transplantation*. 2011;21(4):288-93.
35. Kennedy IA. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. Department of Health 2010.
36. Benden C, Edwards LB, Kucheryavaya AY, Christie JD, Dipchand AI, Dobbels F, et al. The Registry of the International Society for Heart and Lung Transplantation: Fifteenth Pediatric Lung and Heart-Lung Transplantation Report—2012. *The Journal of Heart and Lung Transplantation*. 2012;31(10):1087-95.
37. Hill M. Ethical considerations in researching children's experiences. In: Greene S, Hogan D, editors. *Researching Children's Experience: Approach and Methods*. London: Sage; 2005.
38. Moxley-Haegert L. Hopework: Survival stories from the C.O.U.R.A.G.E. program - Families with children who have cancer Dulwich Centre; 2013; Available from: <http://narrativetherapyonline.com/moodle/mod/resource/view.php?id=577>.
39. White M, D. E. *Narrative means to therapeutic ends*. New York: Norton; 1990.