

ILLNESS, NORMALITY AND IDENTITY:**THE EXPERIENCE OF HEART TRANSPLANT AS A YOUNG ADULT**

Rebecca Waldron^a, Zoey Malpus^b, Vanessa Shearing^c, Melissa Sanchez,^d * Craig Murray^a,

^aFaculty of Health & Medicine, Lancaster University, Lancaster, United Kingdom; ^bUniversity Hospital of South Manchester NHS Foundation Trust, Manchester, United Kingdom; ^cPapworth Hospital NHS Foundation Trust, Cambridge, United Kingdom; ^dRoyal Brompton & Harefield NHS Foundation Trust, Harefield, United Kingdom.

***Contact detail**

Dr Craig D. Murray
Doctorate in Clinical Psychology
Division of Health Research
Faculty of Health & Medicine
Furness College
Lancaster University
Lancaster LA1 4YG
United Kingdom
Tel: +44 (0)1524 592730
Email: c.murray@lancaster.ac.uk

IMPLICATIONS FOR REHABILITATION

- Heart transplant presents specific challenges according to the recipient's life stage
- The needs of young adult recipients should be considered
- Transplant professionals should consider providing opportunities for peer support and addressing the identities and values of young adult transplant recipients during rehabilitation

ILLNESS, NORMALITY AND IDENTITY:

THE EXPERIENCE OF HEART TRANSPLANT AS A YOUNG ADULT

Purpose: End stage heart failure and transplant present great opportunities and challenges for patients of all ages. However, young adulthood may present additional specific challenges associated with the development of identify, career and romantic relationships. Despite recognition of greater mortality rates in young adults, consideration of the experience of transplant during this life stage has been largely overlooked in the literature. The aim of this study was to explore the experience of heart transplant in young adults.

Method: Interviews were conducted with nine participants across three transplant services in the United Kingdom and the data subject to interpretative phenomenological analysis.

Results: Analysis identified three themes. ‘Separating from illness’ and ‘working toward normality’ involved limiting the influence of illness on identity, as well as reengaging with typical functioning in young adulthood. ‘Integrating transplant into identity’ involved acknowledging the influence of living with a shortened life expectancy.

Conclusions: The need for support that recognises specific challenges of transplant as a young adult is discussed (e.g., the development of age specific end of life pathways, improved communication between transplant recipients, their families and teams), including consideration of the impact of societal discourses (e.g. gift of life) which provided additional challenges for patients.

Adult organ transplantation is widely recognised as presenting individuals in end stage organ failure with a ‘second chance’ or ‘gift of life’¹⁻³. This provides recipients with good physical and functional outcomes over a median survival period of 11 years post transplant⁴. A gap between physical and psychological outcomes of transplant has been reported in the literature⁵. This has been explained by the challenges of end stage heart failure being replaced by different challenges as a transplant recipient⁶, including lifelong medication and side effects⁷, lifestyle changes⁵ and uncertainty regarding future health⁸.

Increased rates of depression, anxiety and post-traumatic stress disorder^{9,10} and poor return to employment figures¹¹ have been reported in adult heart transplant recipients. Such factors have been demonstrated to impact transplant survival rates¹², and yet there is no consensus regarding support with these difficulties¹³⁻¹⁸. Guidelines for the care of heart transplant recipients recommend psychology representation in multidisciplinary teams, specifically highlighting a role in assessing and treating depression, non-adherence and providing support during pregnancy for transplant recipients¹⁹.

Heart transplantation is most common between the ages of 40 and 59⁴. Differences in survival rates depending on recipient age at transplant have been reported, with rejection rates higher among younger adults, whereas morbidities in older adults include infection, renal failure and malignancy^{4,20}. Alongside biological explanations regarding these differences (e.g. cardiac diagnosis, immune system functioning), psychological factors and adherence to medication in younger adulthood have also been suggested^{4,21}, as well as an interaction between the two¹⁵. However, these factors and how they might influence behaviours and survival rates are under explored and there is a particular absence of qualitative research exploring the lived experience of these transplant populations.

While quantitative research has focused on psychological distress associated with heart transplant⁹⁻¹⁰ and adherence in adolescence^{22,23}, there has been a lack of research on

young adults' experiences of heart transplant and ways to support these recipients.

Adolescent experiences of heart transplant have been reviewed²² and, in one qualitative study which used a combined sample of adolescent and young adult recipients, it was found that those recipients who “pushed away” the transplant experience and “worried they would never be normal” were reported to demonstrate poor adherence²³ (p. 52). However, adolescence and young adulthood are associated with different life events, which may influence experience of organ transplantation.

The general lower age at which a person is considered an adult (as reflected in law and the configuration of health service provision) is 18. There is no definitive upper limit on the age of a young adult, although in relation to transplant surgical rates this has been suggested as 30²⁰. If we consider this age bracket as indicative of young adulthood, it is also possible to identify major life changes that characterise this period of life which are qualitatively different to life in adolescence: for the heart transplant population these these have been cited to include “1) leaving home for the first time, 2) pursuing education / jobs, 3) establishing significant personal relationships, and 4) beginning to manage their own healthcare needs”²⁴. Therefore, alongside their developing independence, the young adult is faced with decisions about their transplant healthcare and has much more personal responsibility for this in contrast to adolescents, where family and services will take a more active role in care planning.

The impact of transplantation on these life changes has not been reported in the literature, but diagnosis of cancer in young adulthood has been reported to present difficulties in relationships, career development, loss of independence, body image and existential difficulties²⁵. This may reflect that physical illness and facing mortality are more typically associated with later adult life and therefore that younger adults are less well equipped to be managing these challenges²⁶.

As a consequence of the above findings, there may be specific challenges related to being a young adult heart transplant recipient that require exploration. Understanding the experiences of these transplant recipients has the potential to lead to the development of interventions to support young adults through this process and to improve outcomes. Consequently, this research aimed to explore how young adults experience the transplant process and manage the challenges it presents.

Method

Design

Qualitative methodology was considered most appropriate because the aim of the research was to develop an understanding of the experience of young adult heart transplant recipients. Semi-structured interviews were used because this permitted participants to share their experiences in a flexible way, to ensure that detailed, first person accounts were obtained. IPA was chosen because it was developed for use in health psychology²⁷ and has been widely used to study experiences of physical illness²⁸. Three theoretical principles of IPA, phenomenology, hermeneutics and idiography were important in gaining the desired perspective necessary to achieve the aims of the research. The phenomenological nature of IPA allowed participant's lived experiences to be prioritised, and the idiographic nature allowed the nuances of individual experiences to be preserved alongside the development of an understanding of the collective experiences of participants. In addition, the hermeneutic nature of IPA allowed the analysis to privilege participants' meanings, as well as recognising the role of the researcher as an interpretative resource, who 'bracketed' presuppositions which might otherwise have unduly influenced the outcome of the²⁸.

Sampling and Participants

IPA involves purposive sampling to recruit a small yet well-defined group of individuals who have particular characteristics that makes the research question salient for them. Such studies are typically conducted with small samples of 4-10 participants that form a fairly homogenous sample. Homogeneity can occur on a variety of levels. At the most fundamental level, participants in an IPA study are homogenous because they are all bound by the experience of a similar phenomenon. Beyond that there are other levels of homogeneity that can apply to a given sample but these parameters will vary according to the particular research question and topic area²⁸. For this study, participants were required to have been aged between 18-30 at the time of transplant and to be a maximum of 10 years post-transplant at the time of interview.

Participants were recruited from three cardiothoracic transplant centres in England. Information packs were either given to or posted to eligible participants by transplant staff and a poster advertising the research was also displayed in transplant outpatient departments. Nine participants expressed an interest in taking part during the recruitment period and all were included. All participants had undergone their transplant in adult services, were outpatients and up to 10 years post-transplant (range 7 months to 9.5 years, mean 3.6 years). In negotiating access to our participant sample concerns were expressed regarding the possible identification of participants because of the small number of young adult heart transplant recipients. As a result, individual participant characteristics are not reported. Five men and four women, ranging in age from 19 to 29 at the time of transplant, participated in this research. Five were diagnosed with dilated cardiomyopathy, three with restrictive cardiomyopathy and one whose heart condition had been caused by previous medical treatment.

As can be seen from the above, the present sample differs on some characteristics and is more homogenous on others (people will always differ from one another in more ways than they can ever be similar). Smith et al²⁸ (p.50) contend that homogeneity in IPA work is about making the sample as uniform as possible with regards to “obvious social factors or other theoretical factors relevant to the study” rather than having a set of carbon copy, or ‘identikit’ participants. The central focus of our paper is the experiences of heart transplant for young adults and the sample was chosen accordingly; that is, the sample is homogenous according to the characteristics of research focus and our analysis is concerned with the convergences and divergences in the obtained sample.

Data Collection

Semi-structured interviews were used to collect data. An interview schedule was developed for use with all participants through consideration of relevant literature, IPA interview guidance²⁸ and consultation with transplant staff, and was used to prompt discussion. Phrasing of questions was modified during data collection but the schedule was not substantially changed between interviews. At the outset of each interview the purpose of the research was outlined and the participants were given the opportunity to ask questions. Participants were encouraged to tell their story and the interview schedule was used to prompt further areas of discussion. The main areas covered included life prior to transplant, waiting for transplant, experiences during the transplant surgery and recovery, and life following hospitalisation. Interviews lasted between 30 minutes and 120 minutes (all except one exceeded 1 hour) and were digitally recorded and transcribed. Interviews were stopped once all topic areas had been covered and participants did not volunteer additional information.

Data Analysis

IPA, an approach which aims to identify participants' lived experiences of a phenomenon, was conducted by the first author on each of the transcripts separately, resulting in a number of initial themes for each participant. These were then merged across transcripts and audited by a co-author to result in the final themes presented in the results section, following direction provided by Smith and colleagues²⁸. (A detailed overview of the analysis process followed can be found in Murray and Wilde²⁹.) All of the themes are evidenced by extracts from participants, exceeding Smith's 'acceptable' criteria ("extracts from at least three participants for each theme... or extracts from half the sample for each theme" p. 17)²⁷. Guidelines regarding good practice in qualitative research, including bracketing assumptions, member checking and auditing, were followed^{28, 30-31}.

Reflexivity and Credibility of Analysis

IPA requires that assumptions and preconceptions are bracketed off to prevent them from influencing the research process²⁸. The first author (who conducted the interviews and led the analysis) recorded her thoughts, reactions and experiences throughout the research and discussed with a co-author (an experienced IPA researcher). As the first author was in the same age group as participants it was recognised that assumptions about reactions to the transplant process would be made. For example, the researcher expected that having a shortened life expectancy would compromise the development of romantic relationships, which was not the case for most participants. Being able to identify and bracket such preconceptions ensured they did not drive or unduly influence the analysis.

The credibility of the analysis was checked in two main ways. First, the initial theme narratives were sent to participants to allow them to reflect on the sense that the researcher had made of their experiences. Only one of the participants contacted the researcher, and

then provided a short response indicating the accuracy of the information. Second, the research team included an experienced IPA researcher who helped ensure that the theoretical principles of IPA were being adhered to. This involved detailed discussion (and subsequent modification) of the initial theme narratives of one of the transcripts and of the merging of themes across transcripts.

Ethical Approval

The research was approved by a Research Ethics Committee and local Research and Development approval for each of the transplant hospitals was provided. Consent was achieved by providing participants with information about the research and the opportunity to opt in. Confidentiality was assured by using pseudonyms and removing other identifiable information. The main ethical concern regarding this project was the potential for distress to be caused by participants' recalling their experiences of transplant. This concern was managed by providing participants with contact details for a local clinical health psychologist, who agreed to provide support if required, though this was not taken up by any of the participants.

Results

Analysis resulted in the identification of three themes: 'separating from illness'; 'working toward normality'; and 'integrating transplant into identity'. A summary of each is presented in below.

Separating from Illness

Participants protected themselves from the impact of illness, the transplant process and the future. There were descriptions of ways to restrict the influence of illness on participants' identities and to promote coherence between themselves before and during illness:

Everybody perceives you as that sickly, ill person. And you are on the outside, but inside you're still who you were twelve months ago. You've not changed, you're not a different person; it's just that your body isn't quite what it used to be. (Jane)

Participants reported 'separating from illness' involved living in the moment to prevent illness and transplant from overwhelming them. For example:

. . .you just take each day as it comes don't you, you've got to otherwise . . . I've got a friend here and he's quite ill, but . . . he's always thinking back, and you know, no wonder you're getting ill, you're constantly thinking you're ill. You've got to get on with your life (Oliver).

This separation, or keeping illness at a distance, was aided through carrying out and managing the practical aspects of living with a transplant in routine activities that did not require too much thought - such as taking medication: "I've learnt to deal with [medications] . . . [I] just switch off, it's just automatic pilot now" (Alex).

Despite participants attempting to restrict the influence of illness on their identities and finding ways to "just keep going" (Aimee) despite illness, the language they used to describe these efforts, including "fighting" (Tom) and "struggling" (Aimee), indicated the difficulty in achieving this. Participants, then, were in the paradoxical position of attempting to separate themselves from their illness but being involved in routines and activities which made these attempts psychologically difficult and physically laborious. Jane explained:

Even if it was going to take me three hours to get in the shower, wash my hair, get out and dry myself, it could be like an all day job, really. But I think once I'd done it, even though I was, I just wanted to sleep for days, for me the fact that I'd done it drove me on to do the next thing and there was always the next thing that you had to do. And I do think if I'd stopped doing it, um maybe . . . you would have stopped fighting as hard.

Participants' attempts to separate themselves from illness (illness which permeated life prior to transplant, waiting for transplant, during the transplant surgery and recovery, and life following hospitalisation) were further challenged by the engagement required of them with the transplant process. For example, for some participants receiving information about transplant was overwhelming and brought the nature of their illness and its impact on their sense of self in to sharp focus; Tom described this as "like being hit by a truck. [I] just didn't know what to think or how to take it in or anything."

Others' reactions towards them could also be problematic for participants' attempts to restrict the influence of illness on their identities as independent young adults. Prior to transplant, greater dependence upon family challenged separation from illness. This improved following recovery from transplant surgery, but participants felt that family members continued to "mollycoddle" them (Jane). For example, Oliver reported his family would say "don't forget your tablets, have you got your tablets with you?" Participants perceived these interactions as overprotective and challenging to their autonomy which sometimes resulted in conflict:

After the transplant it was very, sort of, I wanted to push them [parents] away, because I felt, I felt trapped and suffocated. . . I just fought back against it really . . . and it became a battle. (Alex)

Working Toward Normality

Participants' recounted their attempts to re-engage with typical life tasks in the context of societal expectations regarding transplant recipients. Most participants reported working toward the functioning they had experienced prior to illness, which included working, engaging in activities and living independently. For example, Ella reported: "I just expected to be able to live my life normally and that's exactly what I do." However, for two participants, illness had characterised most of their lives and they explained learning about what 'normal' was like. For example, Aimee said: "I think it was just having so much more energy. I used to say that it's like being a superhero now."

Returning to employment was important for all participants because illness or transplant surgery had stopped them from working, for example Eden commented "[I] was really keen on just being able to afford my own things. And my rent and, not only my rent ...everything... all the bills that go with all that independence". As well as employment, other activities had been restricted. Being able to take part in physically demanding activities seemed to be a benchmark of being 'normal' for a number of participants and Tom explained that he had not expected to be "chasing the football down the fields and feel[ing] great."

Maintaining or restoring 'normal' social roles was important, especially as some participants had moved back in with their parents when they were ill because they required additional support. Subsequently, being able to move out signalled a return to independence:

I had my place and then I moved back with my mum when I got ill, so I'm thinking I need to start finding my place again to live again, I don't want to be this old living with me mum. (Junior)

Socialising with friends was another aspect of returning to 'normal'. Eden explained having to renegotiate her friendships to stop them from treating her differently:

I've never expected to be treated differently and I've never expected to be, have special treatment or, like, or it's like someone saying 'Oh yeah lets all go . . . to town and go shopping' and someone going 'I'll baggy the front [of the car], oh no, Eden can go in the front cos she's had a heart transplant'. . . I'd be like 'No' that's, I don't want that in life.

Dominant societal discourses of transplant as a gift of life^{34,35} and a second chance³⁶ were prevalent in participants' accounts of their experience of heart transplant, and, to the extent that these discourses presented heart transplant as an end to participants' health difficulties, they assumed the achievement of normality rather than recognising a process of 'working towards normality' in which participants were actively and continually engaged in. For example, Matt explained,

A little bit I do [see myself as ill] and a little bit I don't. A lot of people just think everything just goes back to normal . . . But they don't realise everything like biopsies and rejection and scans.

Similarly, participants reported a sense of debt to donor families for having received a transplant but also perceived high expectations by these families that they should be better than 'normal' and achieve outcomes which they felt exceeded their capabilities and placed a heavy burden on them:

I don't want to be a disappointment to [the donor family] . . . because you get that, someone has died that you love, and they've given the gift of life, the second chance, cos 90% of people think that way, and they put you up on a pedestal and think you're going to have done something amazing with your life (Eden)

Integrating transplant into identity

Participants discussed how they integrated the transplant into their identity and the influence of this on their decisions about the future. For example, Ella explained: “. . . [Transplant] is something that happened to me and it made me who I am, but it’s not who I am, it’s just something that happened.”

Appearing to adhere to gender stereotypes, Alex and Junior reported distress regarding physical frailty, whereas Eden, Ella and Jane reported distress regarding their weight gain as a side effect of taking steroids. For example:

I didn’t [cope well] . . . because the person looking back at me in the mirror wasn’t me for a long time. Um, it was just like I say, it was just my face was just so big, I just looked so weird, so alien. (Ella)

It seemed that discourses of strength in men were challenged by frailty reported by some of the males in this research, whereas discourses of physical attractiveness were challenged by the weight gain in some of the females.

There were many aspects of difference discussed but the most prominent for these young adults was living with a shortened life expectancy. Alex explained: “I guess most people don’t really question their mortality do they. Most . . . don’t set a sort of date and time on how long they think they’ll live.” These participants also felt different from other transplant recipients, as Aimee explained:

I often don’t feel very comfortable when in a ward with older patients who look at me as if to say ‘what are you doing here?’ . . . I will often think hang on, I’m going through this now, not at their age and ‘what were you guys doing at my age?’ I’m sure living a pretty normal life, with little worries and not feeling this rubbish. (Aimee)

In the context of their acknowledged shortened life expectancy, most participants recognised that their developmentally appropriate aspirations, e.g. “a nice job, nice house, kids, girlfriend, wife maybe . . .” (Tom), were challenged. Aimee reported her concerns about her career:

If you want a career it’s a lot of work to get to a point where you think this is brilliant, this is where I want to be. It might take you 10 years. Do I waste 10 years in a really rubbish job fighting to get where I want to get? I might not get there.

Despite living with a reduced life expectancy, participants meaning making in relation to the future, in particular new romantic relationships and plans to start a family, showed some variation. With regards to developing or maintaining relationships, Tom explained that: “There’s just been no like, no point, but obviously that’s changed now [after transplant]. I’ve been with my girlfriend now like 7 weeks and it’s going really well.” In contrast, Eden reported the challenge of finding a boyfriend post-transplant:

If you have a boyfriend they’re either really frightened of you, like don’t wanna break you, like ‘Oh my god you’re coughing, are you about to die?’ . . . To the other end of the scale, where they’re just like ‘Oh I’m not getting involved.’

As well as influencing decisions about developing intimate relationships, transplant also influenced thinking about becoming a parent. Junior reported: “My life span is very short. I was thinking before, even if I had a kid, would it be unfair for the kid if I did pass away. I probably wouldn’t even get to see my grandchildren.” In contrast, Ella reported that: “I’ve spoken to the nurses and they’ve said, there’s absolutely no reason why you can’t have a baby. . . it just needs to be more planned out that’s all”.

Discussion

Separating from illness and working toward normality had similarities to themes of pushing transplant away and worrying about not returning to normal reported in previous research considering adolescent and young adult experiences^{22,23}. However, in contrast to the negative impact of these on adjustment in adolescence, these processes did not appear to have impeded adjustment in young adults post transplant. For example, these processes were not reported to relate to poor adherence, with participants reporting that medication was part of a routine and had become automatic.

It was apparent that managing the influence of illness and transplant on identity was very important to these recipients, which is likely to reflect the ongoing development of identity during young adulthood²⁴ that accompany the major life changes that characterise this period of life (e.g., as stated earlier, gaining financial and familial independence, moving in to the workplace, setting up their own home and developing longer-term romantic relationships). Integrating transplant into identity involved participants' accounts of the impact of living with a shortened life expectancy post-transplant, with these participants reporting considering future illness and end of life, which were associated with uncertainty. It is likely that these concerns were more prominent than in previous research as older transplant recipients may experience a smaller discrepancy between average and post transplant life expectancy and may have already fulfilled career, relationship and family aspirations. Further research explicitly examining the experience of living with a shortened life expectancy in older transplant populations would be useful in verifying this.

Separating from illness, working toward normality and integrating transplant into identity describe the experiences of heart transplant by a group of self-selected young adult recipients. These were not discussed as discrete processes but there appeared to be a trajectory through them from separating from illness to integrating transplant into identity,

however this would require prospective longitudinal research following recipients from illness through to graft failure (not represented in this sample) to determine how robust this pattern is.

These results highlight two important considerations regarding clinical practice and further research for heart transplant recipients. Firstly, heart transplant presents specific challenges depending on recipients' life stage and therefore in both research and clinical practice young adults' needs should be considered in the context of their differences from adolescents and older adults. Secondly, although further work is needed to support our suggestion of different meaning-making regarding living with a shortened life-expectancy in younger and older transplant populations, these results contribute to a debate regarding the discrepancy in outcomes for young and older adults^{4,20,21}.

Clinical Implications

Current psychological difficulties were not reported by participants, but reference was made to being overwhelmed after transplant, which appeared to reflect the transplant process as traumatic. Young adult heart transplant recipients were faced with issues surrounding their mortality much earlier than would be typical for their age group. In the present study, these issues were mostly managed by avoidance, which has been reported to leave transplant recipients unprepared for future illness and end of life issues³². Therefore, young adults might require additional support in managing these issues, perhaps through the development of age specific end of life pathways. Participants' accounts were permeated by expectations of having a shortened life expectancy, which appeared to be difficult for participants to adjust to and was managed focusing on the present.

Acceptance and Commitment Therapy (ACT) might be appropriate in supporting these difficulties in young adult transplant recipients³³. A key concern of the ACT model is

to encourage acceptance of a range of experiences, including those which are distressing. In relation to the practice of ACT, clinical interventions focus on the functions of problematic thoughts rather than on their content. ACT encourages the use of exercises which aid the identification of personal values which are in turn used to identify particular behavioural goals, along with the design and implementation of behavioural change strategies to achieve those goals. Mindfulness is a core component of ACT and involves cultivating the ability to stay focused on the present moment³⁴. This seems consistent with participants' attempts to keep illness at a distance, but would afford the opportunity to be focused on the present while also engaging in behaviours consistent with their personal values.

Some of the difficulties reported by participants related to interpersonal challenges. Interpersonal therapy might be appropriate in supporting role adjustment of transplant recipients and their significant others during the transplant process³⁵. Systemic principles could also be useful in supporting transplant recipients, their families and transplant teams³⁶. Promoting communication between transplant recipients, their families and teams regarding coping mechanisms would aid understanding of aspects of the transplant process that might be most difficult for transplant recipients to manage. For example, information regarding transplant conflicted with 'keeping illness at a distance' and forced participants to face the reality of the transplant process. Negotiating how and when information about transplant is shared could help to avoid situations such as one participant completely blocking out information about the transplant process.

Although support groups for transplant recipients are widely used in transplant services³⁶ (and have been demonstrated to reduce anger in heart transplant candidates³⁷, the present research suggests opportunities for extending the role and remit of such groups. Being younger than many other transplant recipients, these participants reported feeling isolated on wards and in clinics. This could be addressed by providing the opportunity for

young adult heart transplant recipients to meet. The context of this could be determined through consultation with young adults, but could potentially include young adult outpatient clinics or support or intervention groups. These would help to normalise some of the difficulties young adult transplant recipients might experience, which might seem quite alien within their peer groups. Geography might limit opportunities for face to face support and therefore these could be supplemented with online support. Young adult heart transplant recipients could be supported to develop an online transplant information package, which could include videos of young adult experiences and advice regarding navigating the transplant process. This might also allow young adults the opportunity to pace their understanding of the transplant process.

Societal expectations based on discourses of transplant being a gift of life and providing a second chance presented difficulties for some of these participants. For participants, the gift of life discourse did not acknowledge difference and challenges of post-transplant life. Interventions to develop a more realistic understanding of both the opportunities and challenges presented by organ transplantation in the general public might assist future transplant recipients in understanding the transplant process and therefore having realistic expectations. However, care would need to be taken to ensure that this did not damage to organ donation campaigns.

Study limitations

There are three main limitations of this research. The first of these relates to the retrospective nature of participant's accounts, which might have been influenced by subsequent experience and the palliative stage of the transplant process not being represented in participants experiences. This limitation could be addressed in future research by following young adult heart transplant recipients longitudinally through the transplant process; for example, to

ascertain how processes of avoidance and adjustment are used. The second limitation is that we are unable to report individual demographic information for each participant due to concerns regarding ensuring anonymity. Although our sample is relatively homogenous, we recognise that some of the demographic variation across our participants would have been useful for fully contextualising the findings presented for each of them. The third limitation concerns the sample size. Although appropriate for an IPA study, this study is relatively exploratory and therefore broad claims about the generalizability of the results to the young adult transplant population are not made. However, we have identified in depth the experience and meanings of a heart transplant for young adults and conducting similar investigations with other samples would therefore be beneficial and contribute to potential generalizability.

Conclusion

The young adult heart transplant recipients interviewed reported navigating the transplant process by separating from illness and working towards normality. Alongside this, they had and continued to face challenges of integrating transplant into their identities and the discrepancy between this and societal discourses about transplant (e.g. the gift of life). Despite predictions in the literature, difficulties with adherence were not a prominent feature of the experiences reported by these self-selected recipients. Further research is needed to understand the differing outcomes for heart transplant recipients based on age at transplant, and appropriate support that recognises the specific challenges associated with transplant at different life stages. It is hoped that the experiences shared by these transplant recipients will help professionals to support young adults to live in line with their identities and values in the context of the opportunities and challenges of post-transplant life.

Declaration of interest

The authors report no conflicts of interest

References

1. NHSBT. My life, my gift, n.d. available from http://www.organdonation.nhs.uk/ukt/campaigns/other_campaigns/detail.asp?id=2016 (accessed May 04, 2012)
2. Rauch JB, Kneen KK. Accepting the gift of life: Heart transplant recipients' post-operative adaptive tasks. *Soc Work Health Care* 1989;14:47-59.
3. Pals JL. Authoring a second chance in life: Emotion and transformational processing within narrative identity. *Research in Human Development* 2006;3:101-120.
4. Lund LH, Edwards LB, Kucheryavaya AY, et al. The Registry of the International Society for Heart and Lung Transplantation: Twenty-eighth adult heart transplant report - 2013. *J Heart Lung Transplant* 2013;32:951-964.
5. Bunzel B, Laederach-Hofmann K. Long-term effects of heart transplantation: the gap between physical performance and emotional well-being. *Scand J Rehabil Med* 1999; 31:214-222.
6. Baumann LJ, Young CJ, Egan JJ. Living with a heart transplant: long-term adjustment. *Transplant Int* 1992;5:1-8.
7. Kugler C, Geyer S, Gottlieb J, Simon A, Haverich A, Dracup K. Symptom experience after solid organ transplantation. *J Psychosom Res* 2009;66:101-110.
8. Achille, MA, Ouellette, A, Fournier, S, Hébert MJ, Girardin C, Pâquet M. Impact of transplant-related stressors and feelings of indebtedness on psychosocial adjustment following kidney transplantation. *J Clin Psychol Med S* 2004;11:63-73.

9. Dew M, Myaskovsky L, Switzer, GE, et al. Profiles and predictors of the course of psychological distress across four years after heart transplantation. *Psychol Med* 2005;35:1215-1227.
10. Stukas AA, Dew MA, Switzer GE, DiMartini A, Kormos RL, Griffith BP. PTSD in heart transplant recipients and their primary family caregivers. *Psychosomatics* 1999;40:212-221.
11. Stehlik J, Edwards LB, Kucheryavay AM, et al. The Registry of the International Society for Heart and Lung Transplantation: 29th official adult heart transplant report—2012. *J Heart Lung Transplant* 2012;31:1052-1064.
12. Spaderna H, Mendell NR, Zahn D, et al. Social isolation and depression predict 12-month outcomes in the "waiting for a new heart study". *J Heart Lung Transplant* 2010;29:247-254.
13. Rainer JP, Thompson CH, Lambros H. Psychological and psychosocial aspects of the solid organ transplant experience—A practice review. *Psychotherapy* 2010;47:403-412.
14. Baines LS, Joseph JT, Jindal RM. Prospective randomized study of individual and group psychotherapy versus controls in recipients of renal transplants. *Kidney Int* 2004;65:1937-1942.
15. Engle D. Psychosocial aspects of the organ transplant experience: what has been established and what we need for the future. *J Clin Psychol* 2001;57:521-549.
16. Gross CR, Kreitzer MJ, Thomas W, et al. Mindfulness-based stress reduction for solid organ transplant recipients: a randomized controlled trial. *Altern Ther Health M* 2010;16:30-38.
17. Konstam V. Anger: A neglected group treatment issue with cardiac transplantation recipients and their families. *Journal for Specialists in Group Work* 1995;20:189-194.

18. Soos JG. Psychotherapy and counselling with transplant patients. In: Craven J, Rodin, G, editors. *Psychiatric aspects of organ transplantation*. New York: Oxford University Press; 1992. p.89-107
19. Costanzo MR, Dipchand A, Starling R, et al. The International Society of Heart and Lung Transplantation Guidelines for the care of heart transplant recipients. *J Heart Lung Transplant* 2010;29:914-956.
20. George JF, Taylor DO, Blume ED, et al. Minimizing infection and rejection death: Clues acquired from 19 years of multi-institutional cardiac transplantation data. *J Heart Lung Transplant* 2011;30:151-157.
21. Canter CE. Outcomes of heart transplantation in young adults—more than a pediatric concern. *J Heart Lung Transplant* 2011;30:139-140.
22. Tong A, Morton R, Howard K, Craig JC. Adolescent Experiences Following Organ Transplantation: A Systematic Review of Qualitative Studies. *J Pediatr* 2009;155:542-549.
23. Lawrence K, Stillely CS, Olshansky E, Bender A, Webber SA. Further exploration: maturity and adherence in adolescent and young adult heart transplant recipients. *Progress in Transplantation* 2008;18:50-54.
24. Pahl E, Grady KL. 2012. Pediatric heart transplantation: transitioning to adult care. *ISHLTLinks* 3(11): unpaginated.
http://www.ishlt.org/ContentDocuments/2012AprLinks_Pahl-Grady.html Accessed 2016 July 05
25. Rowland JH. Developmental stage and adaptation: Adult model. In Holland JC & Rowland JH, editors. *Handbook of Psychooncology*. New York: Oxford University Press; 1990. p 25-43
26. Olbrisch ME, Benedict SM, Ashe K, Levenson JL. Psychological assessment and care of organ transplant patients. *J Consult Clin Psy* 2002;70:771-783.

27. Smith J. Evaluating the contribution of interpretative phenomenological analysis. *Health Psychol Rev* 2011;5:9-27.
28. Smith J, Flowers, P., & Larkin, M. *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications Ltd; 2009.
29. Murray CD, Wilde DJ. *Phenomenology and Interpretative Phenomenological Analysis*. In: Cartwright S, Walshe C, Brearley S, editors. *Handbook of Theory and Methods in Applied Health Research*. Cheltenham: Edward Elgar; forthcoming.
30. Elliott R, Fischer CT, Rennie DL. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *Brit J Clin Psychol* 1999;38:215-229.
31. Spencer L, Ritchie J. In Pursuit of Quality. In Harper, D, Thompson, AR, editors. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. Oxford: Wiley-Blackwell; 2011. p 225-242.
32. Gill, P, Lowes, L. The kidney transplant failure experience: a longitudinal case study. *Progress in Transplantation* 2009; 19(2): 114-121.
33. Hayes SC, Luoma JB, Bond FW, Masuda A, Lillis J. Acceptance and commitment therapy: Model, processes and outcomes. *Behav Res Ther* 2006;44:1-25.
34. Flaxman, P., Blackledge, J., Bond, F. W. *Acceptance and commitment therapy: The CBT distinctive features series*. East Sussex: Routledge; 2011.
35. Rauch, J. B., Kneen, K. K. Accepting the gift of life: Heart transplant recipients' post-operative adaptive tasks. *Social Work in Health Care* 1989; 14(1): 47-59.
36. Baines, L. S., Joseph, J. T., Jindal, R. M. Prospective randomized study of individual and group psychotherapy versus controls in recipients of renal transplants. *Kidney International* 2004; 65(5): 1937-1942.

37. Engle, D. Psychosocial aspects of the organ transplant experience: what has been established and what we need for the future. *Journal of Clinical Psychology* 2001; 57(4): 521-549.
38. Konstam, V. Anger: A neglected group treatment issue with cardiac transplantation recipients and their families. *Journal for Specialists in Group Work* 1995; 20(3): 189-194.