

Health care transition in paediatric liver transplantation: The perspectives of paediatric and adult health care professionals

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Running head: Staff views of health care transition

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Abbreviation

HCP – health care professional

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Abstract

Introduction

Transition from paediatric to adult services of young people with a liver transplant is an important priority due to increasing numbers of young people surviving into adulthood. There is increased incidence of graft loss and non-adherence following transfer to adult services. Although studies have considered the views and perceptions of young people who have undergone liver transplantation and their parents about transition, there is currently no qualitative research with healthcare professionals working in the field of liver transplantation. The aim of this study was to elicit the views of this group of stakeholders about barriers and facilitators of an effective transition process.

Methods

Semi-structured interviews were carried out with eleven health care professionals (HCPs) from paediatric and adult liver transplant programmes and from a range of professional backgrounds. Interviews were transcribed verbatim and analysed using thematic analysis.

Results

Four themes were identified: 'non-adherence and psychosocial issues', 'need for better psychological support', 'the role of parents' and 'the emotional impact of transition on health care professionals'. Within these themes professionals described factors which hindered or promoted an effective transition process.

Conclusions

Screening tools which address psychological and social aspects of the lives of young people should be used in routine practice to identify patients requiring psychosocial support and to identify those at risk of non-adherence. All staff involved with transition should be trained in the use of psychosocial screening strategies. The development of a formal referral pathway so that young people can access psychological support in adult services is recommended.

Background

With increasing numbers of young people with long-term conditions requiring ongoing management in adult care, establishing effective healthcare transition from paediatric to adult care is essential.¹ For young people with a liver transplant, the ongoing management of their health is vital to ensure both patient and graft survival. Adherence to medication regimens significantly decreases after transfer to adult care.² Furthermore, there is also increased incidence of graft loss following transfer to adult care³ highlighting the important need for effective facilitation of transitional care. In order for this transition to be successful, young people require assistance to develop skills of independence and self-management particularly as health transition occurs in conjunction with other major life transitions typical of those in mid to late adolescence. It is also important they receive developmentally appropriate care in order to successfully manage their health condition and adapt to changes as they enter adulthood.⁴ Despite extensive guidance regarding transition programme planning and management,^{1,5} the literature suggests many difficulties are faced by young people with a long-term condition, and their families, during transition and following transfer to adult services. Common barriers to transition include lack of preparation, difficulties ending existing relationships with paediatric clinicians and negative attitudes towards adult services.⁶⁻⁸

Research into transition has moved away from transition policy and position papers towards exploring stakeholder views in order to gain more in-depth understanding of transition experiences and variables that contribute to success or failure.⁹ The majority of these studies have been with young people and parents or caregivers^{6,10} and studies exploring health care professional (HCP) views have been relatively few and mainly in other specialties.^{6-9,11,12} One recent quantitative survey involving 236 hepatologists identified that formalised transition programmes are uncommon in adult hepatology clinics, with poor adherence and limited patient knowledge seen as barriers to optimal care.¹³ A further study identified that team climate, defined as 'a team's shared perceptions of organisational policies, practices and procedures',¹⁴ and changes in team climate predicted the

quality of transitional care to chronically ill adolescents.¹⁵ The interplay of these three groups of stakeholders - namely young people, parents and HCPs - impacts on transition and therefore it is important to understand the views of all three in order to identify practices that make transition more or less successful and highlight future service and training requirements.^{9,16}

The few qualitative studies regarding HCP views of transition have revealed that HCPs have an important role in promoting the independence of young people.^{6,9} The study by Reiss and colleagues⁶ also stressed the need for paediatric HCPs to appropriately facilitate closure of existing relationships with young people and families in order to facilitate personal responsibility and independence. Another study found paediatric HCPs were concerned about the abilities of adult staff to meet their patients' needs, which was seen as a perceived barrier to transition.¹⁷ Views of adult HCPs have been rarely captured.^{12,18} To date, there have been no studies exploring experiences of transition in professionals working specifically in liver transplantation. The current study therefore aimed to explore the views and perceptions of transition for both the paediatric and adult health professionals working with young people with liver transplants in order to identify areas for development.

Methods

Sampling and participants

HCPs were eligible for inclusion if they worked with young people with a liver transplant in the process of transition from paediatric to adult services. Working with the clinical teams and using a sampling matrix, HCPs were selected purposively to allow for the recruitment of participants from a range of professional groups and services (paediatric or adult) who had worked with young people in transition for at least 12 months. Twelve participants from the disciplines of hepatology, nursing and allied health (e.g. pharmacists and play specialists) in both paediatric and adult liver transplant teams were invited to participate. Eleven participants (nine females, two males) consented to take

part; six paediatric HCPs (two nurses, one doctor and three allied health professionals) and five adult HCPs (three nurses, one doctor and one allied health professional). There was no response from one participant working in adult services (a doctor).

Design and setting

A qualitative, semi-structured interview design was used to obtain in-depth insight into HCP views and experiences of transition for young people with a liver transplant.¹⁹ Interviews were conducted by the first author at two paediatric and two adult liver transplant centres providing acute, specialist care. The first author was not involved in the clinical care teams at either centre. Interviews took place in a private room independent of interruptions.

Procedure

Potential participants were invited to take part in an interview by the researcher via email. All participants were provided with an information sheet and gave informed consent prior to taking part.

Each interview began with a brief introduction to the purpose of the study, assurance of anonymity, and format of the interview. Participants were given the opportunity to ask questions. The focus of the interview was HCPs' views and experiences of transition. The interviewer adopted a minimalist, passive approach during interviews to encourage a narrative response. An interview schedule was used by the interviewer to guide question topics. The content of the interviews was developed from the generic transition literature and in consultation with the wider research team, which included professionals with extensive clinical experience of transition. Topics included participants' own definitions of transition and their experiences of the transition process with their patients. Example questions included "How would you define successful transition?", "What are the challenges faced by clinicians in delivering transitional care?", "What can make transition difficult for young people,

families or HCPs?” and “What factors promote successful transition?”. As the study was exploratory in nature, interviews were flexible and guided by the interviewee rather than the interviewer, with the interview schedule reflecting areas of interest rather than being employed prescriptively. The interviews were conducted between January 2012 and February 2013. Interviews were digitally audio-recorded and transcribed verbatim.

Data analysis

Interviews were analysed by the first and second author using an inductive approach of thematic analysis. Thematic analysis was chosen as it aims to identify and analyse patterns and themes across data and gain an understanding of participants’ direct experiences.²⁰ It is also a widely used method in health research.²¹

Qualitative analysis software was used to support the analytical process (NVivo version 9.2). Data analysis was conducted according to the processes outlined by Braun and Clarke²⁰ which describes the systematic process of identifying, interpreting and reporting patterns in data. This process began with the familiarisation of data through immersion and repeated reading of data by the first and second authors whilst searching for meanings and patterns and making notes of initial ideas. Next, interesting features of the data were coded at the semantic, explicit level using concise and descriptive coding names which reflected the overt content of the data independently by the first and second author. The authors met periodically to discuss emerging themes and a final consolidated list of master themes was produced by grouping codes into candidate themes and sub-themes using a series of mind maps to link particular topics or codes and to facilitate the systematic identification of themes. Themes were then reviewed by re-examining all data extracts included

within each theme to assess cohesion. Themes were also reviewed to assess whether they were representative across the data set.

Reflexivity

The interviews were conducted by the first author (a female research assistant) and analysed by the first and second (a female health psychologist with a background in qualitative methodology) authors. Both authors had experience of working in health settings and knowledge of the field of transition which contributed not only to the data collection but also to interpreting the data and the credibility of the research.

Ethical issues

Ethical approval was obtained from an NHS Research Ethics Committee and the research adhered to the hospitals' individual research and development protocols. The anonymity of participants was protected during transcription and analysis through the use of participant numerical codes. Informed consent was sought for the digital recording of interviews and for interview content to be used in publications. Participants were informed that they could withdraw from the study at any time.

Results

Four themes representing HCPs' perceptions and experiences of transition were identified: 'Non-adherence and psychosocial issues', 'need for better psychological support', 'the role of parents' and 'the emotional impact of transition on health care professionals'.

Non-adherence and psychosocial issues

HCPs recognised that psychosocial or mental health issues were prevalent in their adolescent and young adult patients. HCPs discussed the link between psychosocial issues and nonadherence, with

it being noted that perhaps the psychosocial context of certain behaviours was not always considered by health professionals.

'There are a lot of young people with issues; body image type things, because they feel down, depressed and I think that when they rebel or do risky behaviours, it's because they've got something on their mind that they need to deal with and they can't talk about it. But we as health professionals, because we're not looking at the mental health side of things, we miss all of that, and we put it down to non-compliance or put it down to them being a stroppy teenager. But maybe, what they're doing is crying out for help.' Adult HCP (nurse)

Non-adherence to medications was discussed by all the HCPs in the study as this was an issue encountered frequently in many of their patients. HCPs seemed unanimous when discussing the reasons for non-adherent behaviour, believing it to be a means of the young person taking back control and also to help diminish any feelings of being different as a result of their long-term condition.

'They don't like being different from their mates.'" Well my mates don't take medicine, they don't have to think about when their bloods are due, and they don't have to think about coming to clinic.'" It's just about rebelling against it all.' Paediatric HCP (nurse)

For many of the HCPs, treating young people who were non-adherent was often frustrating as they felt powerless to help change their behaviour. Often the only tool they felt they had was to educate young people in why they should take their medications, but they felt that warning young people of the consequences seemed to make little or no difference as young people were not necessarily concerned about the consequences of not doing so.

'It's frustrating. It is just really hard to get that bit through. I think that it's this feeling that gives them some control for now and hang the consequences because my feeling is that when you're young, you don't really think about consequences. You're only really living for today and

today, you don't want to take your medicines because you don't want to be different from your mates. That's all that matters. You feel immortal when you're a young person, you can do anything because you're going to live forever.' Paediatric HCP (Allied health professional)

Need for better psychological support

HCPs reported that developmentally appropriate care was not always delivered and some concerns of the young people remained unaddressed, whether that be as a result of time constraints or not feeling confident to discuss such matters with young people. However, many of the HCPs felt that it would be beneficial to allow some extra time in consultations to discuss relevant psychosocial factors and that this may have an impact on clinical outcomes in the long term.

'Taking that little bit of extra time, even if it's ten fifteen minutes just to listen to what the patient's trying to say because that's when they get frustrated and do sometimes tend to become non-compliant because they feel like nobody's listening to them.' Paediatric HCP (Allied health professional)

HCPs felt that there was a lack of psychological support in general for young people. While input from psychologists was more commonplace in paediatric care, HCPs commented that continuity of care during transition in both paediatric and adult care settings in terms of support from psychologists or other mental health practitioners would be beneficial.

'We've had quite a lot of psychologists with our team over the years and they are often limited to how much time they can give but if you don't have that continuity, I think it's difficult for young people to engage with new people, coming in at various stages into their life. If you haven't built up that rapport very early on, I think the psychologists do struggle to get in there and give that support.' Paediatric HCP (nurse)

Adult HCPs were particularly vocal with regards to the need for more regular psychological support for young people. They were keen for their service to include providing support from a trained mental health professional in order to help young people to manage their health and wellbeing.

‘We lack really good psychological support and counselling in particular. I think if we had a couple of trained professionals who are used to working with young people, it might make a huge difference because I think there probably is an opportunity that if you can engage earlier on, to actually intervene and make a difference before patterns of behaviour are too set.’

Adult HCP (doctor)

The role of parents

HCPs discussed the difficulties faced by parents during transition due to the change in culture as their child transferred to adult services and the sudden shift of their own role in their child’s health.

‘I think the parents find it a really hard and emotional time. Adult services are very much focused on the patient and the extended family isn’t really as involved. I think for a parent, to give your child independence and let them move on is hard when you’ve looked after them, when you’ve cared for them every day. To give that control up must be incredibly hard. I think it’s just a different ethos, it’s a different culture in paediatrics as it is in adults.’ Paediatric HCP (nurse)

HCPs in adult services found the level of parental involvement challenging at times. While they understood the integral role they played in paediatrics, and still continued to play in their child’s life, the nature of adult services required a different approach. HCPs reported feeling frustrated when parents would answer questions directed to the patient. HCPs also expressed concern that having family members present in consultations may impact on patient disclosure.

‘I think they do try and take over. You can talk to one of the patients and instead of them replying, their relatives are answering for them rather than letting them get out what they

want to say. And they're always with them in the blood room or they're in with the doctors, so if they did want to speak to you on a one to one basis, that would be difficult. So I think sometimes, they don't tell you the full picture.' Adult HCP (nurse)

Paediatric HCPs also highlighted the issue of over-protective parenting behaviours and felt that perhaps at times their level of involvement may hinder the patient developing independence and self-management skills. HCPs discussed how this might be addressed while in paediatric services so that young people might become acclimatised to the different structure of adult services and parents may feel more confident that their child can cope in that environment and more comfortable with a slightly diminished role.

'I could list quite a number of parents who I know for a fact will struggle with letting go because they can't even let go now. It's something that we can flag up, do the team need to be working with the parents about letting go and giving patients that little bit [of] extra responsibility.' Paediatric HCP (doctor)

The emotional impact of transition on HCPs

HCPs described the emotional impact that transition had upon them personally. For HCPs in paediatric services, relationships with young people and their families were often long-standing and young people had been treated when very ill. There was a sense of attachment conveyed by paediatric HCPs resulting in feeling anxious about transition. Anxieties about handover were not just about the loss of the relationship, but were also about how potentially vulnerable young people who were receiving support from the paediatric team would cope in the new environment without the same support system.

'It is hugely worrying. Inevitably, we get quite attached because we've known them so long. You can't help it. So it's quite hard and it worries us a lot. There are some [young people] who we think 'they'll be fine' and we're quite happy to transfer them, they're mature, they're

sensible, they've been really compliant, they understand everything. And then there are others that we've hung onto because we just don't think that they are going to cope. You know, these are the ones we're worried about and we need to do this but there isn't always the facility for the adult side to do the same things. But we know that some of these [young people] are really going to struggle, and they do.' Paediatric HCP (Allied Health Professional)

When a young person died or lost their graft, HCPs expressed the impact this had on them personally and on the team as a whole. For both paediatric and adult teams, this was very difficult and highly emotive. One HCP reflected on a recent death of a young person.

'It's devastating. It was only last week that we heard that one of our patients had passed away which is very, very sad and it does have a very big effect on our team.' Paediatric HCP (nurse)

Death or poor outcomes for patients were incredibly emotional for the HCPs, particularly as many of the young people died through non-adherence and re-transplantation was not possible. HCPs discussed how frustrating this was and how powerless they felt to change the outcome for those young people.

'It's frustrating and very upsetting. When you're watching someone do that to themselves [non-adhering] and you warn them what will happen but they don't – they can't...and then it's too late and there's nothing we can do. And they're so young, which makes it even more tragic.' Adult HCP (nurse)

Discussion

This study adds to a small body of qualitative research into HCP views of transition^{6,9,17,22} and an even smaller body of work regarding adult HCP views of transition.^{11,18,23} This current study is, as far as we are aware, the first study to explore HCP views of those working in a liver transplant

service and a further strength is the inclusion of professionals from a range of different disciplines working in both paediatric and adult services.

In the current study, HCPs reported concerns about non-adherence in adolescent and young adult patients. As there is increased morbidity and mortality in non-adherent liver transplant patients compared to young people who are adherent,²⁴ this was a particular concern. The feeling of being different was attributed to be one of the likely causes of non-adherent behaviour by all the HCPs in the study which is in line with other studies exploring young people's experiences of life with a liver transplant.^{25,26} Understanding barriers to adherence from the perspective of the young person is imperative for all professionals caring for this age group^{27,28} In a rheumatology study of decision-making regarding biologic therapies for arthritis, young adults expressed the need for professionals to address the wider psychosocial impact of medication regimens and not just consider them in the context of disease control and the consequences of nonadherence.²⁹ Approaching adherence in a developmentally appropriate manner is imperative for success and yet is not always acknowledged by health care professionals.³⁰ Furthermore, communication strategies such as motivational interviewing which address ambivalence and emphasise self-responsibility in changing one's behaviour have potential within this age group and are worthy of further study. Whilst empowering and encouraging young people to assume more responsibility is important, indiscriminate promotion of self-management by adolescents may result in poorer clinical outcomes,³¹ highlighting the importance of a shared management strategy with parents. Symptoms of emotional distress in caregivers may also provide insight into family barriers to adherence, with recent evidence that higher levels of caregiver distress are associated with poorer adherence in adolescent and young adult transplant recipients.³²

HCPs working in liver transplant services stated that those who tended not to adhere with their medication regimens were also those who tended to have psychological, social or behavioural difficulties, suggesting these aspects are particular risk factors for non-adherence. This has been

reported by other authors,^{33,34} as has non-engagement in adult services which was associated with substance use.³⁵ It would therefore be beneficial for young people with risk-factors for non-adherence to be identified earlier, so that appropriate support can be delivered.³⁶ Consequently, it is also important that HCPs have a greater awareness of the psychosocial context for young people in order to provide care which is more holistic, personalised and promotes positive long-term management.

It is recommended that HCPs providing regular follow-up implement the use of routine psychosocial screening tools in clinical practice to identify additional support needs, personalise care, and engage with young people.^{37,38} Such tools also provide a framework with which to discuss psychological, social and behavioural concerns (for example, HEADSSS³⁹ and the transition-specific version, THRxEADSS⁴⁰) and they provide a way to identify and support protective resilient behaviours as well as address problematic behaviours, and in so doing ensure good long-term outcomes. When one such tool was evaluated in adolescents in a general surgical setting, unforeseen mental health issues were identified and addressed.⁴¹ However how such tools are used in clinical practice requires training. In a Danish study of the use of the HEADSSS approach, although staff reported discussing the topics encompassed by this approach, young people did not recall the discussions (particularly of the more sensitive issues).⁴² Whilst unmet adolescent health training needs amongst health professionals continue to be reported both in paediatric and adult settings,^{43,44} the potential of these tools in specialty clinics is increasingly recognised.⁴⁵ Furthermore, it is also evident that developmentally in-tune professionals are more likely to provide transitional care and support youth autonomy.⁴⁶

A need for better psychological support was highlighted in the current study as HCPs felt that some young people required input from health professionals with mental health training. Support was more readily available in paediatric services although HCPs felt that at times the continuity of care

was poor which hindered the progress of patients. In adult services it was felt that psychological support was not easily accessible and, when available, professionals were not specially trained in adolescent health issues and more regularly dealt with more common adult mental health issues, such as drug and alcohol misuse. Establishing a formal referral pathway for adult HCPs to refer young adults to access and/or signpost psychological support is essential for transplantation programmes. It is also vital that young people are assisted in navigating the system when accessing mental health and other appropriate services, as this can sometimes be problematic.⁴⁷

HCPs acknowledged that transition was a difficult time for parents but at times they found the relationship challenging with some parents who struggled to let go and potentially hindered the process of the young person becoming independent. These findings draw parallels with the literature about parents in transition who report finding transition a difficult time and handing over responsibility to their child anxiety provoking.^{8,10,48} Supporting young people to become increasingly independent and effectively self-manage is one of the most important skills we can equip young people with a long-term condition with and is an essential component of providing high quality care to people with long-term conditions.⁴⁹ It is important that HCPs and parents work together to support young people in the gradual acquisition of autonomy and to build the confidence of the young person so that they can manage their condition in adult care and beyond.³¹

Of particular interest, and previously undocumented for this population, was the emotional accounts of HCPs about transition. The fear of the greater risk of mortality and morbidity following transfer resulted in significant anxiety for some HCPs, particularly in paediatric services, and some expressed how distressed they had become on hearing about the death of a patient who had transferred to adult services. In previous research it has been identified that stronger emotional reactions to the death of a patient occur the longer a patient has been cared for, making paediatric HCPs potentially more vulnerable to feelings of loss.⁵⁰ The psychological impact of death and dying on members of

staff is under-researched. However, it has been found that experiencing patient death can have a moderate to profound emotional impact on staff⁵¹ which can affect both their work and home environment. Seeking peer support, debriefing, and taking the time to reflect in order to develop emotional intelligence and resilience are thought to be helpful strategies following the death of a patient^{51,52} but it is likely that paediatric staff are less well supported when the death occurs post-transfer. Appropriate support and supervision for staff involved with young people has been recognised as a core quality criterion for youth friendly health services⁵³ and this should also apply to staff involved in the transfer of long-term patients to adult services. Likewise, training of both paediatric and adult staff in adolescent and young adult health care is important and has been identified as an important area for future research.^{54,45}

This manuscript completes a trilogy of papers exploring the views and perceptions of transition in liver transplantation, with the previous two publications exploring patient and parent experiences.^{55,56} This body of work provides important insight into the transition process from multiple key stakeholder perspectives, a greater understanding of the impact of transition on stakeholders and important recommendations for future transition planning. Drawing together the findings from the three groups of participants, two over-arching themes of 'roles and relationships' and 'impact of transplant and transition' can be identified (Figure 1), together with the importance of continuity of care and the need for better psychological support across both paediatric and adult services.

Study limitations

Although the relatively small sample might be considered to be a limitation, the sampling strategy enabled us to recruit HCPs from both adult and paediatric services and from a range of professional backgrounds, which is a strength of our approach. Furthermore, different HCPs from different centres were consistent in what they perceived to be the barriers and facilitators of effective transition. Whilst the diversity of the sample potentially made intergroup differences difficult to

establish, it was evident that HCPs from all centres had remarkably similar perceptions of transition. Where differences did exist this was primarily between participants from adult and paediatric centres and was related to the provision of psychological support (which was identified by participants in adult centres as being less frequently available) and the emotional impact of transition on HCPs, and in particular those in paediatric care who had a long-standing relationship with families. Participants were assured that all data would be anonymised but some HCPs may have found it difficult to be open with regards to negative aspects of the service they worked in, particularly as only a small number of centres were included in the study. This, however, needs to be considered in the context of the fact that there are only three paediatric liver transplant units in the UK, two of which participated in the current study, and the majority of paediatric patients undergoing liver transplantation transition to one of the two adult units included in this study. Finally, in order to protect the identity of participants it was necessary to exclude certain excerpts from interviews which illustrated particular themes in the manuscript. While this did not affect analysis of the data, it limited the presentation of some of the results but this was an essential step in order to uphold anonymity.

Conclusion

Young people with a liver transplant must have a successful transition from paediatric to adult care in order to ensure patient and graft survival and good health related quality of life. The views expressed by HCPs interestingly converge with those of young people and parents in terms of the factors which hinder or promote successful transition. There is strength in working with all stakeholders involved in transition to plan and manage services effectively and ensure good long-term health and quality of life for young people with a liver transplant. Recommendations include the routine use of psychosocial screening tools in clinical practice to identify young people with psychological, social or behavioural difficulties and to identify those at risk of non-adherence. It is also recommended that all staff involved with this age group are trained in psychosocial screening

strategies. Finally, it is recommended that a formal referral pathway is developed by HCPs to refer young people for appropriate psychosocial support.

Author contributions

Jessica Wright

Led obtaining ethical approval for the study. Conducted interviews and data collection. Contributed towards regular project meetings. Management of the project. Coded and analysed transcripts. Significant role in the drafting, critical revision, and approval of the article

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Contributed towards regular project meetings. Coded and analysed transcripts. Significant role in the critical revision and approval of the article.

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Developed the concept and design and contributed towards obtaining funding. Contributed towards obtaining ethical approval for the study. Contributed towards regular project meetings. Consulted on and supervised data analysis and interpretation. Significant role in the critical revision and approval of the article.

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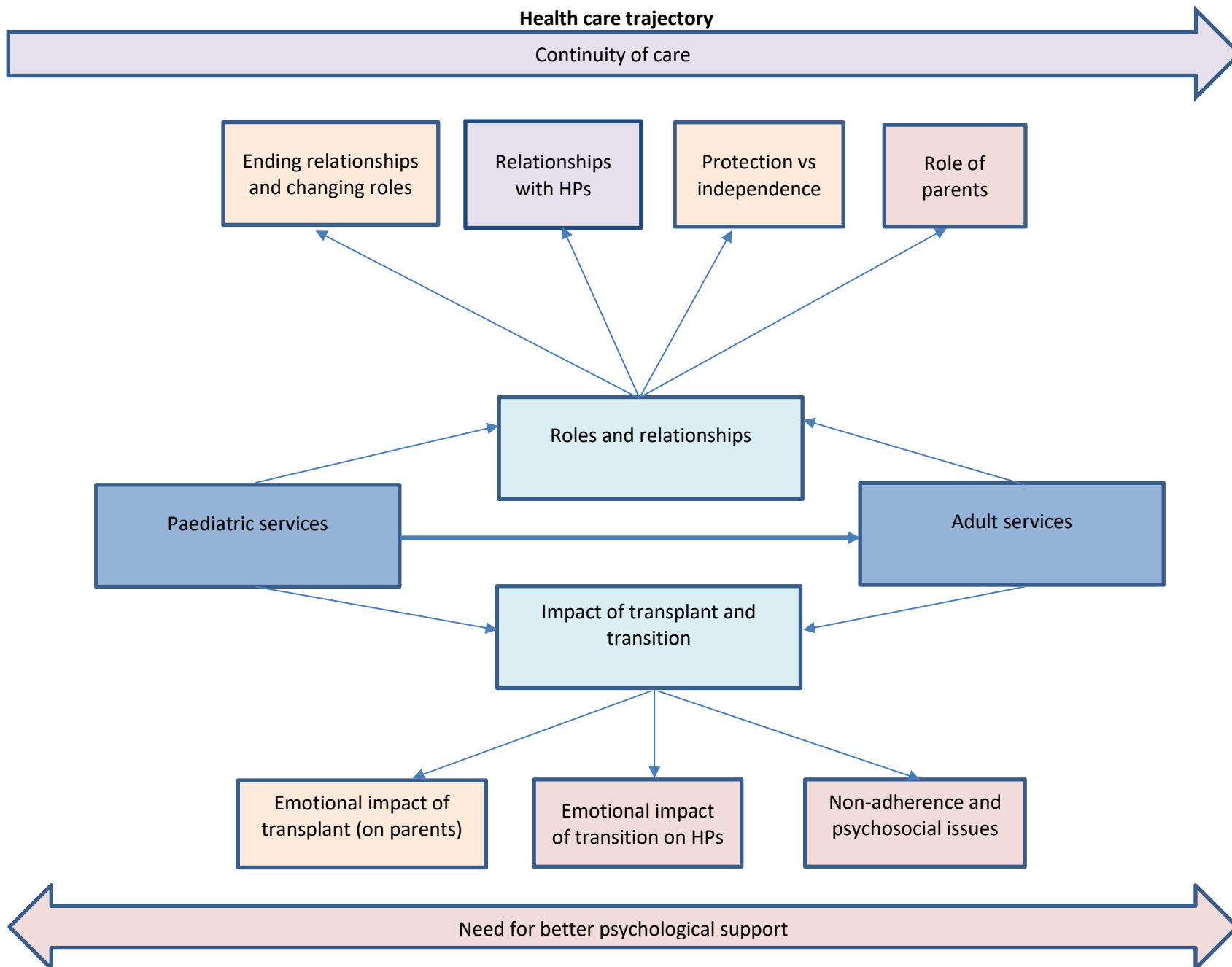


Figure 1: Themes identified from interviews with young people⁵⁴ and parents⁵⁵ together with those identified from interviews with health professionals