Lost in Transition? The journey of adolescent renal patients from Paediatric To Adult Services

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Lost In Transition? The Journey Of Adolescent Renal Patients From Paediatric To Adult Services

Abstract

Background: Adolescents with chronic renal disease are a growing patient population and present some specific challenges for health services. The concept of transition between services has evolved in an effort to better support this vulnerable patient group.

Aims: To gain insight into the experiences and concerns of young people with chronic renal disease who have undergone transition in the last eight years and identify areas of services with the potential for improvement.

Methods: A qualitative study using semi-structured interviews with a purposeful sample of 10 young people between the ages of 18 and 23 years. The participants were recruited by their adult renal physician. Interviews were conducted, transcribed and analysed by the student researcher.

Results: The key issues for young people undergoing transition are i) being involved in decisions about timing of transfer, ii) feeling prepared for adult services in terms of knowledge, confidence to take on responsibility and expectations, iii) optimal communication between services, iv) the gradual handover of responsibility from parents to young person v) feeling isolated in adult services.

Conclusion: Recommendations for service provision include earlier involvement and education of the young person, co-ordination of transfer by a key worker and opportunities for peer support.

Introduction

Young people, defined by WHO as 10-24 year-olds, constitute 15% of the population in developed countries(1) and the prevalence of chronic disease in this group is 12% and growing(2) as increasing numbers of children with chronic disease, including renal disease survive into adulthood.(3) Consequently more young people are progressing from paediatric to adult healthcare services.(3) Adolescence occupies an ambiguous place between childhood and adulthood and is at risk of being neglected by both paediatric and adult services since it does not fit naturally into either.(1) Moreover it is the time when life-long health behaviour patterns are laid down and therefore could represent a key ‘window of opportunity’ for health promotion.(4)

It has been shown to be a time of vulnerability and risk. It is associated with high rates of non-compliance(3,5) and this is especially pertinent for renal transplant patients, as it can have negative consequences for their health: Among renal patients transplanted between 14 and 17 years of age, the five-year graft survival rate is poorer than both their older and younger counterparts. Non-compliance is thought to be a significant factor.(1)

Furthermore, transfer from paediatric to adult care coincides with adolescence and has been shown to contribute its own risk. Watson followed-up 20 transplanted patients transferring from paediatric to adult renal care and found that 7 out of 20 experienced unexpected graft loss within 36 months of transfer.(5)

In an attempt to address this vulnerability, the concept of ‘transition’ has evolved. Transition is defined by the National Service Framework published by the Department of Health in 2006 as ‘a
purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems’. It encompasses the event of ‘transfer’ but is, as described above, a process(6) which begins in paediatric care and extends until patients are in their early 20s.(7) Underpinning transition is the recognition that adolescence is a transition in itself; a progression from the dependence of childhood to the independence of adulthood.(8)

Several major policy documents have been published highlighting the need for improved transitional care,(1,9,10) but robust evidence of benefit was lacking until McDonagh et al showed that a structured programme of transitional care (PTC) developed specifically to meet the needs of adolescents with juvenile idiopathic arthritis confers benefit in outcomes such as health-related quality of life, knowledge and satisfaction.(9)

Aims

• To investigate the experiences of young people with chronic renal disease in Edinburgh who have transferred from paediatric to adult services within the last eight years.
• To gain insight into the ideas and concerns of young people with a chronic illness and explore how these may affect their experiences.
• To elicit young people’s perceptions of how well current services meet their needs and examine any specific problems they encountered.
• To identify areas of services with the potential for improvement.

Method

The data was collected through semi-structured interviews with the young people, in their homes wherever possible. A topic guide (see appendix i) was drawn up, prior to starting the interviews, based on background reading about transition and on the aims of the project. It outlined the topics to be addressed during the course of each interview but was used as a guide only, not as a rigid series of questions. At the start of each interview, it was explained that the questions were open-ended and the young people were encouraged to raise any issues that they wanted to. The interviews were recorded on a digital recording device.

Sampling

Purposeful sampling was used to select potential participants from adult patient list of one adult renal physician, according to the following criteria:
• Year of birth after 1984 (i.e. current age under 25)
• Transfer within the last 8 years
• Severity of disease sufficient to ensure significant involvement with renal services

Most participants were contacted either in person or by telephone by their renal physician to gain verbal consent for the student researcher to contact them and given an information sheet about the project (see appendix ii). Some participants were sent a letter and information sheet by their renal physician, notifying them that the student researcher would be in contact shortly and giving them the option to decline to be contacted. An interval of a several days was allowed to give the participants time to consider their involvement and if necessary opt out of being contacted again. Then the student researcher contacted them by telephone to gain informed consent to participate in the project, answer any questions and arrange an interview.
Ethics
Ethical approval for the project was granted by the University of Edinburgh College of Medicine with additional advice from Professor Kenneth Boyd, Professor of Medical Ethics. The participants signed consent forms (see appendix iii).

Analysis
The audio recordings of the interviews were transcribed verbatim by the interviewer. The first part of the analysis process consisted of manually annotating transcripts and developing a coding framework based on topics that emerged from the data. This framework was transferred onto computer with a separate document per topic and revised several times as throughout the analysis procedure, to produce a few broad themes, each with several sub-themes. Quotations were extracted from the transcripts and allocated to one or more themes as required. Close reference was made to the audio recordings during analysis and transcripts were repeatedly examined to ensure quotations remained in context.

Participants
Outcome of the recruitment process.
Recruited and interviewed 10
Recruited but not interviewed* 2
Declined 1
Non-responders 3
Ineligible # 1

*2 participants consented to be involved but were unable to be interviewed due to time pressures
#1 participant was admitted to hospital during the recruitment process and was therefore considered ineligible to be interviewed

Participant characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
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<tbody>
<tr>
<td>Participant Age</td>
<td>21</td>
<td>18</td>
<td>23</td>
</tr>
<tr>
<td>Transfer Age</td>
<td>16.5</td>
<td>14</td>
<td>19</td>
</tr>
<tr>
<td>Number of years in paediatric services</td>
<td>15.25</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Number of years in adult services</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

3 Parents also took part.
Results

Transition and Transfer

Transition
The young people had all transferred to adult services at different times within the last 8 years and this, together with their different clinical circumstances and personalities, meant that they had each had a unique experience of transition. These are some of their feelings about the process overall.

<table>
<thead>
<tr>
<th>Patient A</th>
<th>It was pretty simple. It’s just going to a different place and the same things being done…not much different really.</th>
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<tbody>
<tr>
<td>Patient J</td>
<td>It’s not as bad as what they make out.</td>
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<tr>
<td>Patient I</td>
<td>They did the absolute best that they could.</td>
</tr>
<tr>
<td>Patient E</td>
<td>That was a bit of a shock, it was going from…I suppose it was going from a comfort zone actually…and [I] walked into the adult world of medicine…It wasn’t the best transition.</td>
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<tr>
<td>Patient B</td>
<td>I don’t like a lot of changes, I like stuff being the same.</td>
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<tr>
<td>Patient F</td>
<td>When I was at the children’s hospital I was like, ok with it…But I had a…I had a shock moving on to the adults’ hospital</td>
</tr>
<tr>
<td>Patient C</td>
<td>My fistula wasn’t ready. And they had to put a line in my neck there and then, on the seat, so I could dialyse. So, it wasn’t a good experience for me, right starting off.</td>
</tr>
<tr>
<td>Patient H</td>
<td>Maybe it’s worse for the parents, I guess than the child. They’ve been seeing the same consultant, [then you] move onto someone else</td>
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Growing out of Children’s Services

Many young people reflected upon how their feelings about being in children’s services had changed as they had got older. Individually they had transferred at a range of ages but by the time they were transferred, the majority felt that they had outgrown the children’s hospital.

This was expressed in a number of different ways, often in relation to feeling different from the majority of the other patients.

<table>
<thead>
<tr>
<th>It wasn’t much of a concern until, you know, I was there one day and I realised, ‘I’m the only person here old enough to drive!’ (Patient A)</th>
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<tbody>
<tr>
<td>I was kind of a bit too old for the children’s hospital ‘cause my legs were about that far (gestures) over the bed! (Patient G)</td>
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</table>

Other aspects of children’s services were perceived as inappropriate:

- ...The play leader, she comes round and you know, asks you ‘Do you want any paper and pens to colour in?’ And you tell them ‘I’ll just lie on my bed.’ (laughs) (Patient G)
- They’re bored at the children’s hospital, they’re not interested in playing with the toys or the games. (Parent B)
- The medicine ‘was usually to children’s like, dosage so it wouldn’t really work for me’. (Patient H)
- They were always giving you these silly plasters even though they knew you were like, 15! (Patient E)

For some this was seen as an incentive to move on to adult services. However for others, the familiarity of the staff and the environment compensated and they were happy to remain there right up until transfer.

<table>
<thead>
<tr>
<th>I was in the ward with all these toddlers and I felt quite old, but it was still quite nice because I had my doctors around me that I knew really well (Patient I)</th>
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</table>
| Interviewer: Did you feel quite settled there or did you feel that perhaps it was time to move on? Patient H: Um…I quite liked it (laughs slightly embarrassed)
**Timing of transfer**

During the interviews the young people were prompted to reflect on the timing of their transfer. Many people were under the impression that they had simply reached the ‘age limit’ for remaining in children’s services, however perceptions of what this was varied considerably.

Once you hit 18 he says, *(referring to child physician)* that’s it, all notes and everything was getting changed to the adults’ hospital *(Parent D)*

I think if you’re getting too big, you have to move on *(Patient H)*

Another factor that was thought to be important in the timing was being an adult both in terms of emotional maturity and, in one individual’s opinion, ethical rights.

I wasn’t a...a child anymore, in their eyes. *(Patient B)*

*Interviewer*: What kind of factors do you think came into the decision? Or what kind of factors should come into the decision?
*Patient A*: Mostly whether the patient themselves feels that they’re ready, to move on. ‘Cause there’s no point having a set age, ‘cause everyone’s different, not everyone would be ready to move on.

*Interviewer*: By ‘ready’ what do you mean?
*Patient A*: They feel like they are up to the responsibility of...you know, taking care of things themselves.

I think they moved us to the adults’ hospital because when you’re 16 things can be confidential between you...er, between me and the doctor. *(Patient F)*

Two people identified logistical reasons for the timing of their transfer, for example the availability of haemodialysis services at the adult hospital but not at the children’s hospital and one person cited her relationship with her children’s team as a factor.

‘I’d just gotten so close to them that they didn’t want to let me go and I didn’t want to go so...’ *(Patient I)*

Some of the young people described feeling, during transition, that the timing was wrong.

I thought they had done it a bit quick...I thought they should have given me a wee bit more time. *(Patient B)*

Oh I wasn’t happy at all. Especially the fact that I knew the general age was 18, so I assumed that I wouldn’t move until I was 18. *(Patient E)*

I was at the children’s hospital for a while, you know...for probably a bit longer than I should have. *(Patient A)*
However the majority felt, at the time or on reflection, that the timing had been appropriate.

I think it was the right time ‘cause I did start to feel you know, completely out of place. *(Patient G)*  
I was ready for a change…everything was changing with me…going to uni. *(Patient I)*

I felt less awkward being there *(in adult services)* *(Patient A)*

I actually feel happy about moving to the adults’ hospital, because that way it shows you that you’re starting to grow up and that you’re being mature and going off to do your own thing. *(Patient F)*

Since going to the adults’ hospital it *has* helped me build up my confidence a little *(Patient F)*

**Concerns and expectations**

The young people also discussed their feelings prior to transfer. A minority had been ambivalent and had not given it much thought.

*Interviewer:* And what sort of thing did they say about moving on to adult services? What was said…and when did you talk about that? Can you remember?  
*Patient A:* Not really…(pause) No…It wasn’t all that interesting  

‘If you’ve got to do it, you have to do it. You just take it as you go’ *(Patient H)*

However, the majority had some concerns and admitted to feeling nervous about moving to adult services.

I was worried for the transaction, just not having people my own age or stuff like that…just because it is quite scary…just, I found it scary anyway. *(Patient C)*

I was a bit nervous going to the adult bit ‘cause I was, I was so used to going to the children’s hospital. *(Patient F)*

I was worried about it being really impersonal, I was worried about not being given the attention I needed. (Laughs) It sounds really selfish but it’s true! *(Patient I)*

You’re so used to going over so many years and seeing the same group of people and then when that stops then…um…you don’t…you don’t know…you don’t know what it’s going to be like. *(Patient B)*
Not knowing what to expect was a common source of anxiety. The following quotes illustrate the expectations people had of the adults’ services.

You just expect it to be something similar, maybe a kids’ playroom at the side or something…it’s not. *(Patient E)*

I did have a good idea that when I went there I would be treated pretty much the same as anybody else as like, a fully grown adult, whether or not I was really ready to be…to sort of grow up, just yet. *(Patient G)*

I had completely different expectations of an adult hospital *(Patient I)*

I was expecting it [to be] a lot worse from what they said, ‘cause they said that I would be stuck next to like, pensioners [that were] ill, just facing you all the time. *(Patient J)*

Some of the nurses, like, you know, [said] ‘It’s the best place to be, the children’s hospital because in the adults’ hospital, they don’t really give you…they don’t put you under for much things eh?’ *(Patient C)*

People handled their feelings differently.

You just take it as you go. *(Patient H)*

I just thought ‘Ok, well this is going to be another thing to…it’s going to be an obstacle to overcome, but it’s fine though.’ *(Patient I)*

Even when we went in for clinics (at the adults’ hospital) I still ran out of them all the time! *(Patient E)*

**Communication**

One aspect of transition that was perceived to be crucial in the success or failure of the process was communication. This was highlighted by the young people in several contexts, for example the importance of communication between the adults’ and children’s hospitals.

*(Speaking about an acute crisis)* The adult hospital didn’t have my notes yet, but the children’s hospital wouldn’t take me - I was too old…And that’s when it hit me. *(Patient H)*

*(Speaking about transfer)* I think they work quite closely together and I don’t think they would have done it if they didn’t feel that it was in her best interests *(Parent B)*
Effective communication between health services and the young person was also felt to be critical.

They were really helpful when I was getting transferred to the Royal, they introduced me to everybody that would be dealing with me and talked me through everything before it actually happened months in advance, so that I knew step by step what was going on all the time (Patient J)

(Speaking about what makes a smooth transition) Just making sure that patients…everything’s clear…everything’s explained well so they don’t get confused. (Patient A)

A couple of young people described being ‘handed over’ from consultant to consultant and the positive impact this had on their experience of transition. Another expressed a wish to have been able to say goodbye to the children’s team.

The consultant at the children’s hospital was telling me about him [the adult physician] for a few years as well before …probably about a year before. So I mean it wasn’t sudden. (Patient H)

I was really, really nervous but Dr X (adult physician) knows my old consultant Dr Y and Dr X told him to take good care of me and stuff…but a lot of other people don’t have that and so it might be a bit more scary for them. (Patient I)

I didn’t get a chance to really say goodbye and like, they were quite a big part of my child years. (Patient G)

**It’s all old people!**

One major difference about the adults’ hospital upon which all the young people commented, was the older age of the other patients in comparison to themselves. This was perceived by the majority as a negative aspect of the adults’ hospital.

Well, it smelt of old people, that was the main difference! (Patient E)

It sometimes feels a bit weird when you go and it’s all like old, old men and you feel a bit like you’re not meant to be there…because you’re half the age of everybody there. (Patient G)

I’ve never seen anyone that was under 50 in the kidney section. I can see them kind of looking at me sometimes thinking ‘What are you doing here?’ But it’s fine, well, I don’t know, it’s kind of weird. (Patient I)

Bit daunting when there’s older folk (Parent D)
In addition to feeling out of place, the other patients were perceived as more sick and a significant minority of young people found this threatening and intimidating.

They were golden oldies, there were people that had to get helped in and out of the toilet (Patient E)

I was quite scared because I don’t really like the look of people being ill and having stuff coming out of their arms or something like that…But with the children’s hospital they kept it hidden. (Patient F)

Seeing people that are adults, that are like in their 30s or older…is really freaky ‘cause you know that they’re starting to get close to the age when they’re going to die and that. (Patient F)

You’re around loads of adult sick people it’s…that’s what I found when I came here, just…wow. (Patient C)

The difference in patient population contributed to a different environment at the adults’ hospital.

They’re all there for serious illnesses not to have a good time (Patient E)

It’s just [a] different atmosphere kinda, I would say…in the wards here, nothing happens. (Patient C)

There wasn’t any toys scattered about the place, there wasn’t any children sitting about or that. (Patient B)

**Relationship with Staff**

Many of the young people described children’s services as ‘personal’. They all had a sense of knowing the children’s team and being known by them.

I became friends with loads of nurses and stuff…because I was in there for so long, maybe that’s why it was…I got to know them. (Patient C)

I knew the phlebotomists by name and they knew me…you start building up a rapport. (Patient E)

The consultant at the children’s hospital basically knew me inside and out. (Patient H)

They were amazing. They were like family to me and I still keep in touch with them…Obviously, I saw them so often and stuff that I’m really attached to them (Patient I)
They contrasted this with meeting an unfamiliar adults’ team after transfer.

You don’t even know anybody (Patient B)

I think they probably just see a lot more patients and stuff like that, so they can’t know every single person…I’ve only been in as an outpatient every six months, they’re hardly going to remember me. But they are really nice to me. (Patient I)

Dr X (adult physician) has basically got to start from scratch again (getting to know him) (Patient H)

Several acknowledged that with time this had changed.

(Speaking about adult physician) Now, since I see him about every six months anyway, we know each other quite well. (Patient H)

Now…they all know my face…they do remember you…which is nice. (Patient E)

I see them a lot and I’m getting along with them and having a laugh. (Patient C)

Perceptions of staff overall were overwhelmingly positive.

(Speaking about an invasive procedure at the adults’ hospital) I get really anxious and nervous with stuff like that and I start to panic. And after I told them that they were really helpful…they’re really understanding. (Patient C)

(Speaking about adults’ staff) I had a list of questions to ask and he didn’t make me feel stupid (Parent E)

(Speaking about adults’ staff) They’re really quick to tell you what’s going on, like they’ll phone your house if they don’t catch you on the ward and stuff. So, that’s good, I like that – really thorough (Patient C)

(Speaking about adults’ staff) He’s really realistic about things, really down to earth and that’s what I need (Patient I)

(Speaking about children’s staff) At the children’s hospital, they would always have time to talk to you and stuff (Patient C)

(Speaking about children’s services) They were really attentive…[there were] loads of nursing staff ‘cause it was a children’s hospital (Patient H)

(Speaking about children’s staff) There was this one male nurse…I kind of thought ‘Yeah, he actually made me feel quite…quite good today, just by like being there, talking, just being nice really’ (Patient G)
Any negative comments were directed equally at a small proportion of staff in both adults’ children’s services.

(Speaking about adults’ staff) Some of the nurses, they’re not really good with younger people. It’s like, no problem now, but when I first went it was a bit kind of daunting, a bit…’cause it’s like ‘Whoa, these nurses aren’t as nice as the child ones!’ (Patient G)

(Speaking about adults’ staff) I know nurses are busy and stuff, but it would be good if – I know in the dialysis unit they take time to ask you about your day and all that stuff, but maybe in the wards they could be a wee bit more like that, like, a wee bit more open to you and stuff like that because most of them are just in and out ‘There’s your tablets, right, take them, bye.’ …’cause like, you can go mad not talking all day! (Patient C)

(Speaking about children’s staff) He made you feel about two feet tall (Patient E)

(Speaking about children’s staff) They’re probably good at their job but they’re quite insensitive like that one that said ‘Oh this one fits everywhere’. (Patient E)

Roles and Responsibilities

Being Treated Like a Child vs. Being Treated Like an Adult

All the young people talked about the way that their role in the management of their condition had evolved as they grew older and especially during the transition period. Many alluded to the difference in the way they were treated by staff in adults’ services compared to children’s services. Several young people felt that ‘being treated like an adult’ required some adjustment.

You tend to go from one extreme to another; you’re treated like a child, then you’re treated like an adult. (Patient E)

It took a while to get used to like, how the, sort of, nurses treated you…Not that they treat you wrong at all it’s just that, I think it’s because now you’re classed as, like, a ‘proper adult’ they’re kind of a little more…a little more professional (Patient G)

It can be a bit of a shock at first, ‘cause like when you first go, you are still a kid really, but, you’re not treated as a kid…you’re suddenly having to grow up. (Patient G)

When you’re younger you’re wanting a lot of sympathy for your condition and the hospital give that to you… But I think as you get older, you accept the fact that you’re just like any other patient and in fact there’s a lot of people who have worse than you do. So you can’t expect to have special treatment at an adult hospital because there’s just so many more people who really need it. Um, I think you have to be prepared for that. (Patient I)
For others, it was a welcome change.

[At] the children’s hospital you get a wee bit fed up, ‘cause everybody treats you like a wee child. But when you go over to the adult side, you get treated like an adult. *(Patient B)*

They treat you more like an adult here which is good because…[at the children’s hospital] they focus more on the young kids than they do on teenagers. *(Patient C)*

*(Speaking about a kidney biopsy)* If I’d been an adult and said ‘look my back ain’t numb enough, you’re not putting any needle in’, they’d be like ‘Fine, we’ll do it again.’ Um, but because I was a child, I think sometimes they think you’re acting up eh? Or you’ll just say ‘Yeah that’s fine’ even though it isn’t because you think that’s the right thing to say. *(Patient E)*

‘Do You Know What the Medicines Are For?’

One aspect of adult care that the majority of young people identified as very different and that many associated with ‘being treated as an adult’ was being more informed about their conditions and their medications.

Dr X *(adult physician)* asked, ‘Do you know what the medicines are for?* I didn’t know, because I’d never actually asked really. Or, I remember one of the consultants [at the children’s hospital] said ‘Just don’t look into it’…It had never actually crossed my mind before, what I was taking. I was just taking the medicine, going into hospital, coming out. *(Patient H)*

He *(adult physician)* tells me more than when I was at the children’s hospital. I think it’s because…[at the children’s hospital] they don’t want to upset you because you’re a kid…But Dr X one time says ‘Oh you’re quite lucky to be here.’ And it’s a bit kind of like ‘Wow, my last doctor wouldn’t have ever said that!’ *(Patient G)*

In the children’s hospital, they were like ‘You’re a child, you can’t know’ *(Patient I)*

*(Speaking about experiences in children’s hospital)* Well I didn’t really understand it, but I knew it was kind of serious ‘cause they started…they said ‘Do you want a CD player?’ *(Patient E)*

At the appointments at the children’s hospital and that, I was just sat there, I didn’t have a clue what was going on. *(Patient J)*

Most people spoke knowledgeably about their conditions and medications during the interviews. Some found the expectation to know more, daunting or resisted it.

Er, it was a bit scary at first because it was like *(sounding alarmed)* ‘Oh, I didn’t know that. Oh.’ *(Patient G)*

Some of it’s good to know and some stuff isn’t *(Patient B)*

*(Speaking about diagnosis)* It’s er…some nephropathy or something like that. IgA nephropathy…or…I don’t know. *(Patient A)*
Many embraced the change in attitude.

<table>
<thead>
<tr>
<th>It feels good to know what’s actually going on (Patient H)</th>
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<tr>
<td>I did say to him, ‘Look just tell me, ‘cause I’m willing to hear it…I’d much rather that he was honest with me. It was nice at the children’s hospital because it was comforting but I think I’m old enough now to know what the long term effects of this condition are. (Patient I)</td>
</tr>
<tr>
<td>I think at the children’s hospital they could do a lot more work with helping you understand what’s going on. It’s not really until you get to the adults’ hospital that you understand what’s happening. (Patient J)</td>
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People described the benefits of being more informed.

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<tr>
<th>At the adult hospital, pretty much any question you have, he’ll give you [an answer]… it might not be a good answer, it might be a bit scary, but he’ll tell you what the truth is. (Patient G)</th>
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<tbody>
<tr>
<td>One thing my mum’s actually said was that she can ask questions and like, she gets a proper answer while before, before it was kind of like ‘Oh well, you don’t need to worry about that’…And I feel like I can ask questions that like…might be quite difficult to answer’ (Patient G)</td>
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<tr>
<td>I’d been wanting to know for a while but it had got…the relationship I had with my doctors I was just this wee…the wee one who they used to just poke fun at and stuff, I couldn’t really sit down and say, ‘What are the difficulties about pregnancy?’ ‘cause I think they probably would have gotten really embarrassed! (Patient I)</td>
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**The Weight of Responsibility**

Another feature of the young person’s role in adult services that differed from children’s services was taking on more responsibility for booking appointments, changing medications, even getting to and from appointments etc. Some young people described not feeling ready for this.

<table>
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<tr>
<th>It’s probably not a good idea to start that too early you know, because some, most kids might not be ready for the responsibility of dealing with it. ‘Cause I know I wasn’t all that…(Patient A)</th>
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<td>(Speaking about taking phone calls from the hospital) Sometimes, um, if they’re going too fast, like…I have to say, ‘Look could you try and slow down so I can listen to what you’re saying?’ (Patient B – has a learning disability)</td>
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<tr>
<td>I think what they’re doing, is giving B total responsibility and um…she doesn’t, she can’t quite manage…that level of responsibility. (Parent B)</td>
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<td>They put all the responsibility on the child when you get swapped over and they’re like ‘Wait a minute!’ (Patient E)</td>
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<td>(Speaking about monitoring blood pressure) Weren’t bothered, was I? (Patient E)</td>
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One young person described feeling particularly vulnerable in the care of services elsewhere.

That was quite frightening, that you could obviously take this downward spiral and nobody would say anything to you, nobody would even bother to care, to phone you or whatever. (Patient E)

On the whole, they accepted the responsibility.

I’m starting to do these things myself, you know, ‘cause I need to stop relying on my parents to do that sort of stuff for me (Patient A)

I just got told the other day that my potassium’s a wee bit high, so I’ll have to get on that and lower it as quickly as possible (Patient C)

I just thought ‘Well I’m an adult, so I’ll have to start behaving like one’ (Patient I)

**Parents**

The young people reflected on how their parents’ role, in the consultation especially, had evolved over time. The majority had always seen the doctor with their parents in children’s services.

(Speaking about physicians at children’s hospital) They might give you the odd smile and a glance but they’re there to speak to your parents and they’re hoping that they’ll explain it to you! (Patient E)

I was, like, okay with it. I had my Mum there that could help me cope with the doctors and that (Patient F)

At the children’s hospital it was more like ‘Oh he’s only a wee baby, he’s only like, 9. He doesn’t know what he’s talking about. (Patient G)

The majority reported that they still go into the consultation with their parents. Some wanted the support of having a parent there, while for others it was driven by their parents’ wish to know what was going on. Many people perceived that their parents’ greater knowledge of their past medical history was important.

It’s probably not all that necessary…I like…sort of having a back-up in case I forget something, which is quite likely. (Patient A)

I would prefer to have my mum there with me. (Patient D)

If my mum’s here she’ll come in too…she likes to know what’s going on as well eh?...I dinnae want to keep her worried like, so I’m just ‘Aye, everything’s fine.’ So sometimes she comes in to make sure everything is fine!…But yeah I dinnae mind my mum coming in really, she’s been a part of it for as long as I have so… (Patient C)

It’s quite useful, like ‘cause if like she’s talking to Dr X about stuff that happened when I was a baby, she does know more than me, ‘cause I don’t remember much. (Patient G)
A significant minority saw the doctor alone.

I generally sit quiet when she’s (referring to mother) there and let her answer all the questions… I do find it easier to talk to Dr X when she’s not there to be honest. (Patient E)

I decided that I had to grow up, be brave and strong, do things on my own, because when I get older I’ll have to do them on my own. (Patient F)

She (referring to mother) just kind of lets me get on with it ‘cause there isn’t really anything she can do. I’m an adult living on my own and she’s off doing her own thing as well. (Patient I)

The young people and their parents described how the dynamics of the consultation changed throughout the transition.

They just, sort of, gradually started asking me, sort of, things about…at the appointments, you know, instead of my parents. And anything they couldn’t answer they’d then ask my parents about it so…it wasn’t too much pressure on me to know things. But at the same time they were giving me the opportunity to…you know, sort of, learn more about it – sort of, take care of things myself. (Patient A)

They address things more to B than previously, which is understandable because she’s the adult, she’s the person being treated (Parent B)

We’ve changed roles in a way. I would sit back and if there was something that she didn’t understand I would answer. But um, mostly we just let them ask her questions. You’re just a chaperone really. (Parent D)

Overall, the young people felt positively about the difference in their role, although some admitted that at first it had been daunting.

That was quite a good thing. You know, people feel like they’re…being patronised less a bit I suppose. (Patient A)

I think it’s fair because at least…they know what I think about all these things (Patient B)

You’ve been used to seeing…having your mum and dad in there with you, you’re not used to saying a word and then all of a sudden you’re plonked in this office and you’re expected to talk. (Patient E)

It was a bit scary because it was like ‘Oh right, suddenly I have to know all these things’…but it’s better…your voice is more heard. (Patient G)
They also reflected on their parents’ perspective.

I think they approved that I was starting to take care of things myself more… They start to feel a bit less necessary…That’s a good thing I suppose but… (Patient A)

They gave me a lot of space to do what I want, ‘cause they said that that would be quite good, for me to actually try and learn to go up there by myself and that. (Patient F)

They like the children’s hospital more, because they’re more informed. (Patient H)

One of the parents interviewed, articulated a parent’s conflicted feelings about sending their son or daughter into the consultation alone.

I didn’t want to, she was my baby, I wanted to hold onto her…but she was getting older…she had to deal with this herself…And to be honest she’s more than capable and kids are more than capable…after the first time she was fine and I just sat reading magazines going ‘I wonder what the hell’s going on in there?!’

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Chronic Illness Experience

During the interviews, a variety of issues were raised that were specific not just to young renal patients but to young people with any chronic illness. Clearly adolescence, much like transition, is not a defined time period. The first section presents those issues that the participants themselves related specifically to adolescence. The following sections will cover the young people’s feelings about having a chronic illness, taking medication and about interventions. Evidently this is an artificial distinction since there is some overlap. However, it is based, as much as possible, upon the perceptions of the participants as to which issues were ‘adolescent’ however young people did not always articulate this and some interpretation on the part of the researcher was necessary.

What is Different about Looking After Adolescents?
Many young people expressed a common sentiment about the information needs of adolescents.

When you’re about my age and you know, something traumatic happens you basically want to know what’s going on. (Patient H)

I think an adolescent wants to know a bit more about what you’re planning to do to them for a start!...It’s probably slightly more frightening because they can understand what’s going on. Em, I mean, if you say, say for instance ‘cancer’ to a child, they’re going to think ‘Well I’m obviously ill.’ If you say ‘cancer’ to an adolescent, they’re probably going to be worse than an adult with…with fear and whatever. (Patient E)

They’d probably need to be talked to a bit more than, like, kids but not as much as an adult ‘cause they might…’cause they still get upset a bit (Patient G)
Several people appreciated that some allowance for their age was already given by staff.

There’s a couple of nurses that call me ‘son’ and stuff just ‘cause I’m the young one in there…which is good, like, ‘cause they make me feel at ease and they always make sure I’m alright and stuff. (Patient C)

I think the doctors and nurses at the adult hospital, they still, even though I’m in an adult hospital, treat me, not like a kid, but they still respect that I’m quite young and they still explain everything clearly to me as well. (Patient H)

Issues around schoolwork and absence for illness were mentioned by many people.

When you’re in high school, you’ve got more work to deal with…you’re doing exams and when you’re relapsing or you’re sick, you get really tired. (Patient I)

I had teachers [at the children’s hospital]…but ‘cause I wasn’t well, I just wasn’t interested (Patient J)

(Speaking about going back to school after absence) It was quite hard, because you kind of feel stupid. Because they’ve all done things… and I’m like ‘What’s that?’ ‘Cause I remember I had to go to the…sort of, special class for a wee while…So like I was learning the alphabet when people were doing times tables and stuff, because of all the time I was missing. (Patient G)

It was hard going back to school though, that was one of the, probably, the hardest things I’ve ever had to do…it was totally different, it wasnae like when I left. Obviously being away for that long friends had moved on, friends had left… I lost a lot of confidence… I remember the first day I went back…and nobody noticed who I was eh? They were asking, so are you new here? And I was like ‘It’s me.’ It was quite sad, knowing that. (Patient C)

People spoke about feeling isolated.

Because like…people don’t really know what it’s like and to go through it when you’re a teenager is probably…makes it a bit more difficult because you’re kind of growing up, like, all around children really. And it’s kind of like, you know, you kind of feel a bit out of place. (Patient G)

(Speaking about other patients at adult hospital) They were very old, it wasn’t just…well, I suppose everybody’s very old when you’re 15! (Patient E)

Obviously when you’re adolescent you’re thinking ‘The whole world’s against me, nobody understands!’ but then when you’re relapsing, you look like a gerbil, people are maybe picking on you a bit for that, you think ‘Ok, really people don’t understand! (Patient I)
The physical effects of illness and/or medication had a significant impact.

A few people observed that a teenager’s lifestyle and attitudes did not always mix well with a chronic illness.

Feelings and Attitudes about Illness

This section aims to portray young people’s feelings about having a chronic illness. Although this was not a topic that was addressed directly, everybody spoke about it in one context or another. People’s attitudes varied considerably. Some were unconcerned.

Some still got nervous about going to outpatient appointments.
Many young people demonstrated an attitude of resilience and acceptance.

<table>
<thead>
<tr>
<th>It’s quite frustrating if you are disabled, getting …um, getting help. But you just have to get on with your life…There’s people on dialysis and I’m just grateful that I’m one of the lucky ones. (Patient B)</th>
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<tr>
<td>I always see it as ‘You can’t get out of it, you may as well get on with it’ eh? So, get on with it and get it over and done with. (Patient C)</td>
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<tr>
<td>Positive thinking is the way to go…just have to get on with it. (Patient I)</td>
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Many felt conscious of their vulnerability and some observed that this awareness had emerged as they had got older.

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<tr>
<th>Seeing some of the kids walking about that aren’t even in double digits yet, it’s quite…sad and all the parents there as well, it’s like, quite daunting…when you’re older you know what’s going on and it’s harder I suppose. (Patient C)</th>
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<td>When I was younger I didn’t really care about my illness or anything like that, but as I got older I wondered how it was going to affect me. Er, in the future if I have kids, will it affect them too?... But I still kind of like worry about my condition sometimes, if it’s life-threatening or something like that. (Patient F)</td>
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<td>I am really grateful to the children’s hospital…It could have been quite a different life that I had (Patient G)</td>
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<td>I remember as a kid, they always used to say, like, ‘Oh you’re a lucky one’ or whatnot, but that’s just a comforting phrase. But I looked into it and it is quite… (Patient H)</td>
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<td>You go to the hospital and somebody my age should be a healthy individual and then you go and you’re surrounded by a lot of people who are older and it does…it’s a bit of a wake-up call, the fact that I am so young. (Patient I)</td>
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Several people alluded to their feelings about how their illness or medication affected their self-image.

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<th>I have this thing, that I always keep – or kept – my hair long, ‘cause when I relapse, I like to have hair to hide behind. I relapsed in first year of uni, twice. And that meant that I walked around looking like a hamster and it was really difficult to get to know people and stuff like that. (Patient I)</th>
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<td>I can’t have short hair now ‘cause it just reminds me too much…it just puts me back in that phase where I was like…dunno, having long hair is like a cover for me, it’s like a screen. Keeps me…it gives me a wee bit more confidence. I can hide dialysis which is good, for confidence and stuff, unless people see my arm and then I’ll tell them. But if I’m wearing a long top then I’m a well boy, nobody knows. (Patient C)</td>
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Medication

Nearly all of the young people had to take medication regularly. Every young person (except one who was physically unable) managed their medication independently. Several described how their parents’ involvement had changed as they got older.

(Speaking about filling pill box) My mum did it at first, then I started filling them up and she would obviously have a sneaky peek to see if I’d been taking them and stuff and now I obviously just take them out of the packets. (Patient E)

I think Mum put me on it by myself almost, since I was about 9…Reminding me and then she gradually stopped reminding me and I took it by myself. (Patient H)

They (parents) make a point of asking me, you know, pretty much every time they phone up. (Patient A)

Some people spoke about difficulties in learning to physically swallow tablets, especially at a younger age.

It took you a while to take tablets eh? …Afraid to swallow them eh? (Parent D)

I was convinced they were going to make me sick and then as soon as I put it in my mouth I was sick. It was totally psychological, but I had it in my head…It took about two weeks for me to get it down eventually. I couldn’t even take a tablet before I’d gone into hospital. (Patient E)

I took my pills and then I started having a panic attack and I think it was nothing to do with my pills at all, but I stopped breathing and I thought I was going to die…but ever since then I’ve had this kind of psychological thing about taking my pills and like even now, when I take my pills in the morning I think ‘Oh this might send me mad again’ but I know it’s not them, I know they’re doing good… (Patient I)

Many said that they were usually good at remembering to take them since they were used to doing so.

I’ve been taking them all my life so it’s just second nature really (Patient J)

It’s just routine (Patient H)

Forgetting to take medication was perceived as more likely during busy periods and change of routine.

It is more difficult as I grow up ‘cause you kind of feel…you’ve got like your uni, or a job, or you’ve got friends. But with like, uni and with placement it’s a bit difficult. I have to take it with me and like, it can be quite hard, when like, it’s busy and like you have to go and… (Patient G)

There have been periods when I have forgotten…not forgotten all of them but like maybe only taken then once or twice a day, especially during exam time (Patient H)

I don’t find it difficult taking any of them um…it’s just that if I’m going to my aunty’s and that, I have to remember to take them with me. (Patient B)
One person attributed previous non-compliance to alcohol.

It was mostly just forgetting – too drunk to remember! *(Patient E)*

A significant minority felt self-conscious taking medications in front of other people.

I don’t really like taking them in front of people that don’t know me, ‘cause you sometimes get funny looks like ‘Oh, what’s that?’ kind of thing. *(Patient G)*

There were some times I didn’t take them because I didn’t want to take them in front of other people, ‘cause then it’s just a case of…they want to know exactly what’s wrong with you…And then if you say it’s, sort of an immune disorder…they automatically assume it’s something like AIDS and you have to explain the whole thing and it’s just…well it was just an absolute nightmare…especially when you’re a certain age as well um, you don’t want to have to go into detail. *(Patient E)*

Some young people reflected on whether there were consequences to non-compliance.

The relapse after that was naturally pretty bad. *(Patient A)*

It generally bites you in the back. *(Patient H)*

I’d forgotten to take it quite a few times actually and then I did relapse so maybe that had something to do with it, but I don’t know…sometimes I forget doses and it doesn’t make a difference and I think well, you know, I could just stop taking them and see what happens. But I wouldn’t want to take that risk. Too scary. *(Patient I)*

I missed them once at night…took double the next morning and I didn’t feel any different. *(Patient J)*

People’s feelings about having to take medications varied greatly.

It’s fine. I’ve had to take it like, since I was a wee boy so it’s just a normal part of my life now really *(Patient G)*

It doesn’t worry me too much…it’s not much of an issue *(Patient A)*

I didn’t mind at all when I was young really, it was just part of life, but I hate it now. I don’t know why it’s changed, it’s just since I’ve come to uni, I absolutely hate having to fill my pill box every week and having to remember to take my medicine. I feel like I’m living an independent life but I’m being dragged down by these drugs. *(Patient I)*

I’m still going to go on it just in case…he said it doesn’t do much harm so I might as well. *(Patient H)*
**Interventions**
The young people had varied experience of invasive procedures. Many expressed feeling anxious about having blood taken and several young people perceived that as children this was understandable but that as young adults they ought to be able to cope with it. This was conveyed in a common pattern of people describing feeling nervous but then immediately contradicting their previous statement with an assurance that they it was not an issue now.

> And blood tests occasionally, which I always dread. I’m alright with them now though. *(Patient A)*

> I’ve never been great with needles, ever. I’m alright now, funnily enough. *(Patient E)*

> I do get quite nervous, you know, when I’m getting it done even though still. I’m calmer [now]. *(Patient D)*

The source of most people’s apprehension was pain and people managed their fear in different ways.

> I have to watch, I’m still the same, I can’t help it…it’s obviously one way I deal with it. *(Patient E)*

> It just hurts a little bit when I get it done but, but I just kind of look away and hold onto something really tight. *(Patient F)*

> *(Speaking about having local anaesthetic cream applied first)* So it means I dinnae feel the – well, I feel the needle going in – but I dinnae feel any pain. *(Patient D)*

Some young people had undergone more invasive procedures. They observed that the experience was different at the children’s and at the adult’s hospital.

> And basically any little operation you would get…sedated for. So, that was good but when I first came here…um, it wasn’t like that at all. *(Patient C)*

> I remember one major thing was that I used to get anaesthetic as a kid when I was in the children’s hospital. That was quite painful the first time I had the procedure [without anaesthetic in the adults’ hospital]! *(Patient H)*

**Dialysis**
There’s been times in here with dialysis I’ve found it really hard and like…just, there’s some times you just…I dinnae even want to be in here because I know it’s bad, but you see the same people, the same things, they ask you the same things…you just…(sighs) it just gets on top of you sometimes. Like, if you’re in here three times a week, you can’t get out of it… And like if your friends are away doing stuff…birthdays as well, things like that its kind of…it you never get away from it eh? *(Patient C)*
Service Provision for Young People

The young people were prompted to reflect on various aspects of services that have been proposed in guidelines regarding transition and adolescent healthcare.

Transition Clinics

The majority of young people had attended a transition clinic at the children’s hospital where they met the adult physician before their first appointment at the adults’ hospital. Many of these people commented on the benefit conferred by doing so.

They didn’t just say ‘Right off you go B, you’re going there’ I mean they did have her meeting Dr X (adult physician) a few times. (Parent B)

*Patient F:* Really the only person who was a familiar face at the adults’ hospital was my doctor.
*Interviewer:* And did that help, having met him before?
*Patient F:* Yes because I’m not too keen on meeting, er, knowing new people. I prefer getting to know somebody before I actually move on.

I went for about two or three appointments before I went to the adults’ hospital, so I got to know him (adult physician) then. *(Patient H)*

Those who had not, expressed their feelings about the idea.

It’s kind of…less kind of like, just cut and then straight to the adult’s hospital *(Patient G)*

I suppose if we’d got to meet him in between it would’ve been…maybe it would have helped her better. But um, she was ok. *(Parent D)*
Key Worker

The term ‘key worker’ describes a health professional who would meet a young person before transfer, while he/she was in children’s services and then attend the first few appointments at the adult hospital with them. Two people felt they had had this in the form of a transplant nurse co-ordinator and a dialysis nurse specialist respectively. Others had used a trusted health professional informally for support, for example a support worker from children’s services or a nurse. Others felt that the adult physician fulfilled this role.

It’s a lot easier, just to ease you into it, ‘cause you’re just going in and it’s just strangers. Not knowing what to expect, not knowing who they are… (Patient J – had dialysis nurse specialist as a key worker)

I mean if you’ve known them before, they’re more likely to open you up as well…Even if they go into your first appointment with you, they can talk through your questions beforehand and then they’d obviously prompt you to ask the things that you wanted to ask. I mean you can say obviously that a parent can do that but maybe…an adolescent’s more likely to think ‘I don’t want to worry my parents either’ so… (Patient E – met adult physician before transfer but had no formal key worker)

A nurse in there…he’s seen me down one time and he was like, ‘If you ever want to talk, come and find me and I’ll talk to you and stuff…’ (Patient C – no formal keyworker)

I think probably your consultant’s more important (Patient H – no formal keyworker)

Mentor

A mentor would be a young person who had already transferred who could talk to patients before they transferred about his or her experience of transition. Most people expressed interest in this idea, a couple had already used a mentor informally in other situations, before starting dialysis and in pregnancy respectively.

When you’re about 15, 16 now or something like that and you’re not going to be ready I don’t think at that age. So it would be really handy I think to have someone to speak to when you’re that young, I think, just to say ‘Its ok, they’re friendly’. (Patient I)

It probably would have helped just to, kind of, if you had any questions… just so that when you first go you know what to expect. (Patient G)

A few people felt it would not be worthwhile.

Probably not, it doesn’t really seem necessary. It’s…fairly easy, the whole process, so I don’t think it would have been worth it to have that available. (Patient A)
Young Person’s Unit

The participants were asked about their opinions on a Young Person’s Unit. The responses were overwhelmingly positive. Having other young people to talk to was seen as the most significant advantage.

If there was a unit here with just teenagers, you’d be able to meet people and…yeah. ‘Cause then you’d be able to plan days out with them and stuff. Whereas here with a lot of the older people, they’re maybe too ill to do stuff. *(Patient C)*

That’d be much…easier I think, having people to talk to and stuff because you can’t always talk to…some people don’t like…like I know I found it hard to talk to my Mum and stuff about stuff because I didn’t want to worry her *(Patient C)*

I think it would give people – well, teenagers – a lot more confidence…it wouldn’t be daunting then…I definitely think it would help out in an inpatient situation…I think people would be more open as well. *(Patient E)*

But with kids probably about my age, it would make you feel better, just you’d get to like, talk to them. *(Patient F)*

That would be a really good idea…I think, yeah, that would be just brilliant...Obviously there are a lot of teenagers with kidney problems and it was quite difficult to get to know them…I don’t know anybody, I feel like I’ve kind of missed out on that ‘cause it would have been really nice to have someone to speak to. *(Patient I)*

That would be a lot better like, even if you talk to people roughly the same age, going through the same thing, just see what they think. See each other’s different views. *(Patient J)*

A couple had experience of meeting other young people with renal conditions.

I actually met a boy…that was on dialysis at the same time… I’m guessing there’s people not been as lucky. *(Patient J)*

There was a couple of other lads in the unit so I spoke to them. So it was good to talk to somebody that’s on the same wavelength and really knows what you’re going through *(Patient C)*

A few people felt a more teenager-friendly environment would be an improvement.

I think it would actually be much better by putting in a television…to watch like neighbours or hollyoaks, something like that to that would actually calm my nerves. Or like having a computer there that you could have a go on, and just do something while you wait. *(Patient F)*

With kids…teenagers being in hospital they should maybe try and get a bit more into their things, what they like and stuff. Like, I don’t know…computers, get computers in and stuff. Just to make it feel a wee bit more of a teenage place. *(Patient C)*
Support Group

They were also asked to consider the idea of a support group for young renal patients. Some people felt they would not use a support group now or would not have used it in the past.

Could be interesting, yeah, but again I’m not really sure it would be worth it…it (referring to transition) wouldn’t especially worry most people. (Patient A)

(Speaking about previous experience of a support group) I was trying to keep my mind off things like that and it was quite intense and that. I did enjoy it, it was still good, but I probably wouldn’t go back. (Patient C)

I probably wouldn’t use it. Basically I just get on with my life. (Patient H)

I don’t think I would have needed it, but you can never tell until you try it. (Patient J)

Others expressed enthusiasm about the idea.

I would actually love to meet other people with the same condition I have. (Patient F)

I think that would be quite good. ‘Cause right now, I don’t know anyone else that is even close to my age, that has to take medicine or go to hospital so it’s a bit kind of…no-one really knows what it’s like really. (Patient G)

I would be a bit shy but yeah I think I would [use it]. (Patient D)

I know you can get like forums and stuff like that, like websites, which I’ve thought about joining, but it would have been really good…I would expect that I would probably have quite a lot to talk to them about and yeah, it would have been nice actually…‘cause you have so much support from the staff but you don’t really have support form other people with kidney problems. (Patient I)
Discussion

Methods - Advantages and Limitations

Richards and Morse say ‘Qualitative research does not, and should not, use a rigid prior conceptual framework that dictates the nature of the variables to be collected and the relationships among those variables.’(12) Given the exploratory aims of the project a qualitative method was deemed most appropriate. It was felt that semi-structured interviews would allow the young people to broach topics of importance to them and not simply the topics that the researchers assumed would be relevant.(13) The topic guide enabled some consistency between interviews to be retained.

In addition it was anticipated that a focus group format might exclude an important subgroup of young people - those with poor attendance at clinics – as they would be unlikely to attend. It would also preclude extraction of individual narratives from the participants(14).

The ‘purposeful sampling’ technique (selecting patients on the basis of characteristics perceived by the researcher to have some relevance on their perceptions and experiences(15)) was used in order to elicit the views of a variety of young people, with a variety of clinical conditions. This was important given the relatively small number of participants, however not every young person had experience of being an inpatient for example, which restricted comparison.

Using a combined approach to recruitment (i.e. approaching patients in clinic and also phoning them or writing to them) was intended to encompass young people who frequently did not attend at clinic, a patient group whose views were deemed important to include. However telephoning and writing did not always achieve this aim as it was not possible to contact some people.

Being a medical student and therefore neither part of the paediatric or the adult renal team afforded the interviewer the benefit of a ‘neutral’ stance in the eyes of the young people and permitted them to be frank in their appraisal of current services. This may have been slightly compromised since the participants were initially contacted by their adult renal physician; however this was unavoidable in the interest of data protection.

The decision about having a parent present at the interview was left to the young person, with the intention of creating a setting that would be comfortable for each individual. A parent was present at three out of ten interviews and this may have inhibited or altered some young people’s responses.

Time restrictions limited the amount of interviews carried out, as the transcription and analysis stages were both time- and labour-intensive.
Conclusions

The Royal College of Physicians of Edinburgh guidelines on transition recommend asking young people what would help them (1) and there is recognised inconsistency between health professionals’ ideas about the healthcare needs of adolescents and young people’s actual health concerns.(16)

From this study, it can be concluded that the salient aspects of transition for young people span across paediatric services, ‘transfer’ and adult services, reflecting the current philosophy transfer is one event that occurs during the period of transition.

The following recommendations are proposed, many of which are supported by the RCPE guidelines:

• Greater involvement of young people with respect to decisions about timing of transfer
• Better and more advanced preparation of young people for the different expectations and ethos of adults’ services, including the implementation of a ‘mentor’ scheme, involving young people already in adults’ services.
• Optimise co-ordination between services and identify a key worker who acts as a ‘familiar face’ in adult services, a point of contact and a source of support for the young people and their parents.
• Encourage the young people to be seen independently of their parents. Support for parents is especially important in facilitating this change.
• Improve peer support for young renal patients through the establishment of adolescent outpatient clinics, adolescent inpatient bays and support groups.
• Greater appreciation and awareness of the specific challenges faced by young people with chronic illness with respect to education, employment, self-image and peers. A multi-disciplinary approach is required.
• Earlier and more significant involvement of young people in consultations and earlier education about their condition and medication may have benefits for compliance, coping ability, adjustment to adult services and relationship with staff.

Future Study

This study presents an important insight into the experience of transition from the perspective of the young people undergoing it. A greater sample size is required to expand on and validate the conclusions drawn.

It may be beneficial to investigate the views of younger patients who are still in paediatric services, at the other ‘end’ of the transition process from the young people in this study.

This study indicates that the parents of young people undergo transition along with their children and therefore probably have unique needs and concerns. Further exploration of their perspectives and experiences would be valuable.

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Acknowledgements

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(11) McDonagh JE, Southwood TR, Shaw KL. The impact of a co-ordinated transitional care programme on adolescents with juvenile idiopathic arthritis. Rheumatology 2007;46(1):161-8
(12) Richards L, Morse JM. On getting it right and knowing if it’s wrong: Ensuring rigor in the design phase. In: Richards L, Morse JM, authors. User’s guide to qualitative methods. 2nd ed: Sage Publications Inc; 2007. p190-194
Appendix i) Topic Guide

- YOUR views and thoughts
- Qu’s open-ended, feel free to bring up anything at all you think is important
- You don’t have to talk about anything you don’t want to

General

- Age
- How long have you been seeing a renal team? Age of diagnosis
- Do you mind telling me a bit about how things have been over that time?
- How much have you been involved with health services? In what ways?
- How do your appointments work now? Who do you go with? When did that change?
- What do you think about the health services you’ve used?
- Is that based on any experiences in particular that you’ve had?
- Does anything particularly, either positive or negative stick out in your mind thinking back on your experiences?

Children’s Services

- What do you remember it being like?
- hospital
- staff
- appointments
- in-patient stays
- other patients
- How did you feel about things in general?
- Did you feel any differently about things as you got older?

Transition and Transfer - YOU

- How did the switch to adult services work for you?
- What do you think about the way it went?
- Do you remember the idea of moving on to adult services being brought up? What was said?
- Age?
- How did you feel about it all?
- What did you expect it to be like?
• What about your parents? How did they feel?
• Looking back, how do you think the team came to this decision? How involved were you? What do you think about that?

Adult services
• What was it like? Different in any way? First impressions
• How did you feel about it at first? Has that changed as you got older?
• Good things? Bad things?
• Staff – treatment of you, expectations, attitude – what were they like?
• Hospital
• Appointments – who do you go with now? When did this change happen?
• In-patient stays
• Other patients?
• How did you feel about it generally in comparison to children’s services?
• Parents - Was their role in things different to before? In what way?
• How did you feel about that? How did they feel?
• Has your attitude about your health changed in any way over time? How?
• Medications – issue for you? For others?

Transition for other patients
• What advice would you give to other patients going through transition?
• What advice would you give to the doctors and nurses? And the people planning transition?
• What was done well? What could be improved?
• Did you get to talk to someone who had done it before? How would you feel about that?
• Would you think about ‘mentoring’ someone younger who was in the process of changing to adult services?
• Support groups - What do you think of the idea?
• Youth worker – what do you think?
• YAs/adolescents vs. children – how is looking after them different?
• YAs/adolescents vs adults
• Adolescent medicine dept – what do you think?
• What are your general feelings about your experience now, looking back?
What was it like moving from children's healthcare services to adult's healthcare services? Having done it, you know more about what works and what doesn't than anyone else. What was your experience like?

My name is Karina Hannigan. I am a medical student due to qualify as a doctor in 2010. I am doing a project as part of my 4th year studies, looking at what Renal patients in Edinburgh think of their healthcare.

What would being involved mean?
It would mean talking to me about your experience for an hour or so. The interview will be informal and I can organize a time and place to suit you. I would like to record the interview so that I can type it up later, if you don't mind. If you wish I will send you a short report in June, at the end of the project. All the information will be treated confidentially - your name won't be attached to any comments in my report.

Professor Neil Turner is supervising the project, but your comments will remain anonymous - only I will know who they are from. Whether or not you choose to become involved will not affect your medical care in any way. You can change your mind about helping at any time. If you have any questions you can e-mail me at k.l.hannigan@sms.ed.ac.uk or ask the member of staff who gave you this leaflet.

Thanks for reading this. I hope you will get involved.
Professor Kenneth Boyd,
Professor Medical Ethics, Medical Teaching Organisation,
Doorway 3, Teviot Place
Edinburgh EH8 9AG
Email k.boyd@ed.ac.uk

Who will advise as to whether a full submission to the Lothian Health Ethics of Research Committee is required.

- Supervisors should be aware that as Student Options have a large educational component, the ethical criteria to be used differ slightly from those for pure research projects. However, if your project scores YES on any of QUESTIONS 3-6 and your Supervisor is sure that a submission to the Lothian Research Ethics Committee (LREC) is required, you should use the National Research Ethics Service (NRES) form, the standard form for ethics applications across the UK. When you specify this is a student project, with a major educational component, many of the questions do not require to be completed, simplifying the procedure.

- The NRES form is available at: [http://www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk) and can be completed online or using readily available dedicated software.

- Further guidance on applying for ethical approval and electronic copies of this preliminary form can be found on the 'Student Research – Ethics and Regulation' page of EEMcC (in the Medical Ethics & Legal and Professional Responsibilities Vertical Theme, within CSPPD), or obtained from the Student Records Section, College of Medicine Office (0131 242 6533). Submissions for ethical approval using the NRES form must be submitted according to the explicit instructions detailed on the NRES site and form, at least 8 weeks in advance of the project starting.

- If you intend to use student volunteers as subjects AND answer YES to questions 4, 5 or 6, when you receive your ethical approval from LREC, you must lodge a copy of your NRES form and protocol, with this statement from LREC advising of ethical approval at the College of Medicine Office, Chancellor's Building, for transmission on to the University of Edinburgh Committee on the use of Student Volunteers.

Student: Name
KARINA HANNIGAN
Signed
KARINA HANNIGAN
Date 21/02/01
Email
KARINA.HANNIGAN@yaho0.co.uk

Supervisor: Name
NEIL TURNER
Signed
Date 21/02/01
Email neil.turner@ed.ac.uk

NHS status of Supervisor: Kim James (Hon Candidate)

If full submission made to the Lothian Health Ethics of Research Committee, tick here

If submission made to the University of Edinburgh Committee on the use of Student Volunteers, tick here

Please return this completed form to Lisa Ketchion, SSC4 Administrator, College of Medicine Office, Chancellor's Building, 49 Little France Crescent, Edinburgh, EH16 4SB and upload to your electronic portfolio.