

**Young adults with chronic kidney disease: An exploration of their relationships and support networks**

**Emma Coyne<sup>A</sup>, Heather Langham<sup>B</sup>, , Matthew Tomlin<sup>C</sup>, Wendy Hope<sup>D</sup>,  
Catherine Johnson<sup>E</sup>, Catherine Byrne<sup>A</sup> & Charlotte Bebb<sup>A</sup>, Heather Buchanan<sup>F</sup>**

**<sup>A</sup>Nottingham University Hospitals NHS Trust**

**<sup>B</sup>South West Yorkshire Partnership NHS Foundation Trust**

**<sup>C</sup>Trent Vineyard Conference Centre**

**<sup>D</sup>Leicester City CCG**

**<sup>E</sup>Derby Hospitals Foundation NHS Trust**

**<sup>F</sup>University of Nottingham**

## **INTRODUCTION**

It is now established that young adults with chronic kidney disease (CKD) are a vulnerable group with poor treatment outcomes. For example, young people with CKD have an eight times higher risk of rejecting their kidney, compared to adults (Dobbels *et al.* 2005) and they have an increased risk of transplant graft failure compared to both children and older adults (Foster 2015; Van Arendonk *et al.* 2013). Young adulthood (sometimes referred to as ‘emerging adulthood’) brings with it complex challenges for the CKD patient. This population is seeking identity, peer recognition and independence from parents/caregivers while at the same time dealing with altered body image (due to medication effects or procedures) as well as absence from normal age-appropriate activities (Ferries *et al.* 2016). A recent systematic review and meta-analysis (Hamilton

*et al.* 2017) established that young people with kidney failure experience a number of adverse psychosocial consequences with lower quality of life and limited employment, independence, and relationships compared with healthy peers. They must also learn to manage their own health in order to achieve good health outcomes and longer survival. However, dealing with the transition from paediatric to adult care is not always managed well which can have adverse health consequences (Watson *et al.* 2011; Tong *et al.* 2013).

Bailey *et al.* (2018) have argued that we need to understand how renal failure affects all aspects of young adult's lives as this may help us to better prepare and support these young people before and during treatment, and improve outcomes. They conducted a systematic review and thematic synthesis of studies on research describing young adults' experiences of the psychosocial impact of kidney failure and renal replacement therapy (RRT). They found that young adults on RRT experience difference and liminality, even after transplantation. Within this they found that participants described renal failure as impacting on the development of their identity and their capacity to form relationships. This fits with the findings of Reynolds *et al.* (2003) who showed that young adults with CKD were less socially mature than healthy controls and more young adults with CKD lived with their parents and had fewer intimate relationships outside the family. This is perhaps not surprising considering young adulthood is a time of transition where relationships take on a different significance.

## **BACKGROUND**

Exploring further these young adults' relationships is important as social support can have a significant impact on outcomes such as improved survival, concordance and quality of life (Cohen *et al.* 2007). Where patients perceive a discrepancy between expected and received social support this has also been associated with increased mortality in both haemodialysis (HD) and peritoneal dialysis patients (Thong *et al.* 2007). Poorer social support is associated with higher mortality risk as well as being associated with lower adherence to medical care, and poorer physical quality of life in HD patients (Kimmel *et al.* 1998).

As social support is modifiable there is scope for potentially developing support interventions. Indeed, there have been reports of innovative support interventions for young people with renal failure, with promising results. For example, using mixed methods, Sattoe *et al.* (2013) evaluated a peer-to-peer support camp for young people aged 16-25 in the Netherlands with End Stage Renal Disease (ESRD). Camp Cool (CC) involved 'therapeutic camping' with buddy-to-peer support. They found that peer-to-peer support (in terms of buddy-to-attendee support) was greatly appreciated and beneficial for the attendees and participating in the camp seemed to have a positive influence on self-management of these young people with ESRD. More recently, Finderup *et al.* (2018) evaluated a youth clinic (outside the hospital context) in Denmark for young people with kidney disease based on a similar clinic in the UK. They found that the clinic had a positive influence on the young people's daily life with kidney disease and helped most of them have more faith in themselves and their own abilities to deal with a life lived with kidney disease. They concluded that their findings strengthen

the already existing evidence for the positive effects of interventions specifically focused on young patients.

These, and other, support interventions have demonstrated positive and encouraging results of bringing together young people with kidney disease outside of the clinical environment. Across the studies a mutual understanding of what it is like to live with kidney disease appears to be important in helping facilitate social support and improve health-related outcomes. However, it has been noted that this may not always be entirely positive. For instance, Sattoe and colleagues (2013) highlight that there was a diminished sense of social inclusion of attendees after Camp Cool. This may be due to ‘over-identification’ whereby a subculture is created during the camp in which the young people perceive themselves as being different from others. This may relate to Bailey *et al*’s (2018) key review finding that young people with kidney failure experience difference. Therefore it may also be helpful to foster efforts to help these young people establish (and maintain) relationships with individuals/groups without CKD within their everyday lives.

In summary, young people with CKD have a number of key issues and life changes to manage while also possibly transitioning into adult care while managing their condition. During this time, the nature of their support networks including, social, romantic, family and health-care relationships, is changing. Therefore, our study set out to explore these young people’s experience and perceptions of their past, current and future relationships and support networks.

## **METHODS**

**Design of the study**

It has been noted that a qualitative approach is vital when tapping into the experiences of young individuals with CKD (Darbyshire, *et al.* 2006; Nicholas *et al.* 2011). Therefore, we conducted semi-structured interviews in order to gain an in-depth understanding of the experiences and needs of young adults with CKD.

**Participants**

Young adults (aged 18-26) with CKD stages 3-5 in adult renal services in two UK NHS hospital trusts were invited to participate in the study. Purposive sampling was undertaken in order to reflect the views of young adults in each treatment modality (pre-dialysis, unit-based haemodialysis, peritoneal dialysis and transplant). There were no young adults on home haemodialysis in either hospital. Potential participants were given an information sheet to help them decide whether they wanted to take part. Sixteen were approached and 14 agreed to participate.

**Ethical considerations**

The study was approved by a Proportionate Review Sub-committee of the National Research Ethics Service (REC reference 10/H0401/100). This study was part of a wider 2011-2012 study on exploring the needs of young adults with chronic kidney disease. All participants provided written informed consent before the interviews. Participants were assured that their data would remain confidential and their names would not be used in the transcript or any subsequent reports. In addition, it was stressed that declining to participate would not affect their care in any way. They could also withdraw from the study at any time leading up to (or during) the interviews and this would not affect their care.

### **Interviews with young people with CKD**

A semi-structured interview guide was developed by the authors, encouraging participants to reflect on their experiences of having CKD and how this had been influenced (if at all) on other areas of their lives (family, social life, relationships and life goals). HL showed the participants a guide diagram with examples of different aspects of their life that we encouraged them to explore (e.g., relationships including romantic relationships, family and friends, social life etc). HL then explained she would like to explore their experiences in relation to these areas and any others they would like to talk about. Further prompts including asking for any ideas they had about what might help/support them in this area. Interviews were conducted individually by the same interviewer (HL), unless the participant required a relative to attend to help with any additional support needs (one participant). HL had had no prior contact with the participants before the study commenced. After each interview the participant was informed about the option of receiving individual support from their service's Young Adult Worker. Interested participants who consented were referred directly to this service; alternatively contact details to request this input later were provided. Interviews lasted for up to 90 minutes and were audio-recorded and transcribed verbatim by a medical secretary. Dots (...) within the transcript indicate where a participant has hesitated or paused.

### **Data Analysis**

Transcripts were checked against the original recording by HL to ensure accuracy and to increase familiarity with their content. Thematic analysis was then commenced by HL

and one of the co-authors (EC) using Braun & Clarke's (2006) guidelines. Both HL and EC had specific training in conducting thematic analysis at undergraduate degree and Doctorate level. An inductive approach was used with initial codes generated from the interviews, and quotes with similar coding extracted and listed together. These were organised into themes; these were reviewed and the theme names and structures were altered as further coded quotes were extracted. Themes were then integrated to develop more substantial and interpretative themes, with exemplar quotes identified. These were then organised into four over-arching themes (and sub-themes) which were reviewed against the quotes supporting earlier themes. Final themes were reviewed by the research team, who also had qualitative research training and experience, for a further credibility check.

## **FINDINGS**

Fourteen young adults aged 18-26 years and accessing adult renal services (8 male, mean age 22 years) were recruited. All participants were aged 17 - 25 years when they entered adult renal services. Half of the participants had entered adult renal services directly while the other half had transferred from paediatric renal services, with each of the main treatment modalities (pre-dialysis, haemodialysis, peritoneal dialysis or transplant) reflected equally at time of entry to the service. The majority of participants (ten) were white British, with one Indian, one Pakistani and two individuals who were of a different Asian background.

We identified four over-arching themes (along with sub-themes; see Table 1). These are discussed below.

Disclosure – to tell or not to tell?

This theme highlighted the difficulties the young adults felt in disclosing their CKD to new people in their lives, developing friendships and potential partners.

(a) Disclosure challenges – how and when?

Participants found it hard to know how to bring up their CKD in conversation with new people. They also found it difficult to know when to disclose it; some wanted to disclose early in a relationship while others wanted to let a relationship develop before they disclosed the information:

*How do you tell a person you've got a pipe sticking out of you, stuff like that, it's not kind of er the first thing you tell them about? I dunno (Participant 9).*

(b) Coping with reactions

The participants were anxious about disclosing their health condition in case they were met with a negative reaction:

*Yeah, erm I was quite petrified at first, cos obviously you don't tell them...you don't want to scare them off (Participant 4).*

Unfortunately this anxiety appeared to be based on previous negative reactions from others following disclosure of their CKD:

*Erm, and I've had...I've had two instances where I've explained it and they just walked away (Participant 1).*

### Managing support networks

This theme highlighted the challenges the young adults faced in managing the network of support around them.

#### (a) Normal versus ill friends

The young adults really valued maintaining their ‘normal’ friendships outside of the renal world. They didn’t want to talk about, or be reminded of, their condition all of the time. However they also appreciated the relationships with other young people who could understand and identify with their experiences:

*Every now and then when you are ill and you do want someone to rant at, you want someone who knows what you’ve been through (Participant 12).*

#### (b) Support versus Over-involvement

There were clear differences in how support was perceived and received and the varying outcomes of this within the young adults’ accounts. The participants reported how support is often highly valued, including simply being with the other person when they are in hospital:

*My sister’s always been there as well.. and my brother, erm I remember I was ill, when I was younger and he was doing his ‘A’ Levels but he had like study leave. But instead of studying at home, he came into hospital, and was doing his revision here just to be with me and stuff so they’re the best (Participant 12).*

However, some participants discussed the problem of individuals in their social network, predominantly parents, being too involved in their care, which had an adverse effect on

the individual and the relationship. They discussed how parents often had a problem relinquishing the role of caregiver at a time when they needed to assert their independence and achieve separation from the parental unit:

*I don't really speak to my mum anymore because she couldn't cut the apron strings. Erm she wanted to care for me and as I grew, sort of 15 or 16, I wanted to be a bit more independent with it and my Mum could never let go (Participant 1).*

#### Relationship strains and carer needs

In this theme participants described how their health condition could put a strain on their relationships with family, friends and partners, as well as impacting adversely on their family caregivers' lives.

##### (a) Relationship strains

Participants reported the negative effect their CKD has had on their relationships, including both friends and romantic partners. This took different forms but it was often because CKD was seen to be too difficult for the partner to deal with. This often included the restrictive nature of what one can do when living with CKD, the present and future health implications and all that comes with that. Often the young adults were resigned to this, noting that it was difficult enough for them to handle, so they did not expect partners to. There were poignant accounts of the ending of romantic relationships after diagnosis:

*I had a boyfriend when all this happened, erm but when it did all happen he, it was too much for him. Erm, which I completely understand, cos it was too much for me, let alone someone who is just watching. Erm, so he left (Participant 4)*

However, some of the young adults registered their disappointment that friendships were not maintained after a diagnosis of CKD, and highlighted the lack of reciprocity when it came to dealing with difficult circumstances:

*Like I realised who my real friends were actually, because there were some people I was there for a lot, during their times and the ones I expected to be there weren't there (Participant 14)*

(b) 'Carer' needs

Many participants noted with regret the burden CKD has had on their family caregivers, also the lack of support available to family and friends. They often reported that their carers' needs had been neglected, due to their caring role:

*Sometimes I think their life's on hold as well. I mean me dad he hardly sleeps, bless him, because he worries and sometimes I get poorly through the night and erm he's always up with me through the night and stuff like that and I think, 'well he's not getting any younger and he's not fit and healthy himself' So I worry that I'm putting too much stress on them (Participant 10).*

Happy ever after?

Within this theme the young adult participants discussed their future in terms of relationships and starting a family.

(a) 'It's a lot to take on'

What was evident from the participants' accounts was that they felt it would be more difficult to meet someone and start a new relationship because they had CKD. There was

some cross-over with how participants reflected on their current and past relationships; that is the psychosocial implications of having CKD make them feel that ‘*It’s a lot to take on*’. They highlighted the ‘*baggage*’ they carry and what potential partners would need to be prepared to take on:

*Because of what I’ve got, but I’ve got a lot of baggage, do you know what I mean? (Participant 14).*

At the same time, some of the participants made clear that they do not want a relationship where the partner takes a carer role, that a relationship is still distinct from this:

*Obviously [the] relationship side of it. It is gonna be hard for somebody to want to...so I think well if I get with somebody...they’re gonna think that they’re gonna have to come and see me in hospital and they’re gonna have to look after me and stuff. I don’t want anybody to look after me, I just want someone to be there for me (Participant 10).*

#### (b) Children

A real concern for the participants was a possible future without children. As one participant describes, this is her primary concern and it would be a devastating blow if realised:

*The only thing erm I worry about was having children.....and I’ve said I’ll be really disappointed and heartbroken if I can’t have children (Participant 3).*

The participants talked about how often they think about having children, even if they don’t discuss it directly with health-care practitioners. They highlighted the different avenues that they have gone down to search for information on this topic such as looking

on the Internet. The young adults highlighted trying to fit in other commitments, such as their career plans, around fertility advice and the pressures that this holds.

## **DISCUSSION**

This qualitative research study aimed to explore young people's experience and perceptions of their past, current and future relationships and support networks while living with CKD. Participants conveyed a wide range of perceptions and experiences in relation to their relationships and social networks. Although there were some positive accounts, there were many instances where they perceived themselves as different, and discussed the complications and challenges of initiating and maintaining relationships as a young adult with CKD.

Participants described the dilemma of when, or even if, to disclose their condition within new relationships. This corroborates some of the interview findings from Nicholas and colleagues (2011) who considered the lived experience of children and adolescents with End Stage Renal Disease (ESRD). Indeed, the authors described the '*Challenge of truth telling: Peer relationships and revealing ESRD*' as one of their themes, and their participants described some similar dilemmas and challenges to our sample. Our young adults described how it can be difficult to find the right time to disclose their condition, with several participants recounting negative experiences. It may be that young adults with CKD need help with managing disclosure of their condition to others. This could involve specific social skills and communication skills development e.g. different ways to disclose a condition and how to manage different types of reaction from other people.

This is especially pertinent at a time where patients are considering developing new romantic relationships, as well as meeting new potential friends. This in tandem with the myriad of other changes going on in their lives, possibly including transition to adult care.

It was clear from the interviews that the friendships young adults have with individuals who do not have CKD often serve a different support function from their friends who do. The 'normal' friends helped the young adults engage in everyday chat and activities with little reference to health issues, whereas friends with CKD could provide support by knowing what the challenges are like first-hand. Finderup *et al.* (2018) and Sattoe *et al.* (2013) report positive evaluations of interventions where they brought together young people with CKD outside of the hospital environment. Like our participants, they found that young people appreciated being with other young people who know what it is like to live with the challenges of CKD. Sattoe and colleagues did note, however, that participants felt a weakened sense of social inclusion after participating in the peer-to-peer support camp for CKD young people, which they recommend should be addressed in the group. Therefore, support interventions bringing together groups of CKD young people should address this potential issue in the group. In addition, improving social support for young adults is not just about providing opportunities for them to meet and interact with other renal patients (although this was perceived as very helpful) but also supporting them to maintain and manage relationships with non-CKD individuals, as these support networks are also vital for young adults.

The challenges of establishing and maintaining romantic relationships was evident in the accounts of the participants. Bailey *et al.* (2018) in their review, also found that renal failure was highlighted as having a significant impact on young people's confidence in pursuing, establishing and maintaining intimate relationships. Similar to our findings, they report that participants across several studies reported rejection by a partner because of their renal disease. Bailey *et al.* (2018) highlight the role that social media, dating apps and online resources may have for those individuals who might want to establish a relationship before meeting in person which may be a fruitful avenue for young people who may often use online resources regularly anyway.

There may also be a need to support those in a caring role, as highlighted by the 'burden' the young adults feel these carers have taken on, sometimes at the neglect of the carers' needs. It has been documented that informally caring for a family member or friend with a chronic condition can have deleterious effects in terms of the carer's health (e.g. Legg *et al.* 2013). Support services should also be directed towards carers, to help support them, and in turn the young adult. This has also been highlighted as an area which requires further work (NHS Kidney Care, 2013). However, it is clear from the findings that in order to do this the concept of 'carers' (or perhaps a patient support network) for young adults needs to be extended from parents to include siblings, friends and partners.

It was encouraging that there were accounts of positive relationships and support from families. However, there were also instances of fractious relationships -- in particular with parents not allowing the young adults to be independent; as one participant

described ‘*refusing to cut the apron strings*’ and causing relationship strains. It is well established that the transition from paediatric to adult care (which occurred for half of our participants) is not always managed by young people which can increase the possibility of non-adherence and kidney rejection (Watson *et al.* 2011; Tong *et al.* 2013). This may be compounded by a parent who wants involvement in their child’s care beyond the child’s wishes. Support may be needed for young adults who are trying to manage this separation from parents, while trying to maintain a good relationship with them and manage their care. As previously discussed, there have been efforts to put in place support interventions for young people with CKD. Finderup *et al.* (2018) contend that collaboration with parents involving the young patient should not be overlooked.

It was clear that participants were aware of future, as well as existing, challenges in terms of family life. Fertility and future reproduction were highlighted by participants as key challenges. Bailey *et al.* (2018) also found the themes of fertility and parenthood within studies included in their review, with an associated myriad of concerns. All of our young adults, and particularly young women, had information needs in relation to this topic with few reports of asking health professionals for advice and support. Sexual and reproductive health are areas which have been recognised as requiring more research (NHS Kidney Care, 2013) and our findings clearly echo this sentiment. More research is needed on how to support young adults to engage in conversations with health professionals regarding this sensitive, yet clearly important, area of their lives.

## **IMPLICATIONS FOR PRACTICE**

Exploring further young adults’ relationships is important as social support can have a significant impact on a number of pertinent outcomes (Cohen *et al.* 2007). Our findings

strengthen the growing evidence that initiating and maintaining relationships can be challenging for young people with CKD. Although there were many common themes and issues arising from the participants' accounts, it should also be noted that young adults with CKD are not a homogenous group (NHS Kidney Care, 2013). Not all of the participants described challenges in relationships, or were in need of the same type of support. The development of young adult clinics may allow support to be tailored to the individual's own emotional and social needs. Our findings also indicate that the support needs of young adults extend beyond the patient to those who support them; support services should reflect this.

## **CONCLUSION**

In conclusion, our exploratory study demonstrates that young adults with CKD may need support in helping them manage new and existing relationships, at a time where relationships are taking on different forms and significance. As social support is modifiable there is scope for developing support interventions. Future research is needed to explore how providing these support services to both young people with CKD, and their extended carer networks, can impact on key psychosocial and medical outcomes.

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Table 1 Themes and Sub-Themes

Theme	Quote
<b>I. Disclosure- to tell or not to tell</b>	

<p><b>Disclosure challenges – when and how</b></p>	<p>But in the beginning it was hard to tell, tell someone that you like, that, you, you keep it to yourself really. I did, like I didn't really tell the guy that I was dating when I was on dialysis, he didn't come round to my house just in case he saw the machine (<i>Participant 4</i>).</p>
<p><b>Coping with reactions</b></p>	<p>I mean its hard meeting people cos obviously I don't go out much and then if I do start talking to people as soon as I mention, like me being poorly and dialysis and the fact of a transplant they're gone (<i>Participant 10</i>).</p>
<p><b>II. Managing support networks</b></p>	
<p><b>Normal versus ill friends</b></p>	<p>Erm.. I think they gave me the chance [to meet other young adults on PD] but I didn't really want to meet someone anyway. I just wanted to get on with my life and see my normal friends (<i>Participant 5</i>).</p> <p>I was talking to a friend who went to the Transplant Games who's a few years younger than me, and erm we both are very, in our normal lives...we can live normal lives...we don't tell everyone...about our illness. But it is nice to know people and just like know, because then someone else understands (<i>Participant 12</i>).</p>

<p><b>Support versus over-involvement</b></p>	<p>I was fine, I got on well with my dad but we weren't like really close, kind of thing, and but then I think it brought us closer, that was one thing, yeah definitely brought us closer. <i>(Participant 14)</i>.</p> <p>Erm, my mum's always been dead protective of me and when this happened I was very, quite independent with it. Like I used to come to hospital on my own, So my mum felt very, like quite outsided <i>(Participant 4)</i>.</p>
<p><b>III. Relationship strains and carer needs</b></p>	
<p><b>Relationship strains</b></p>	<p>But I do think it affected me, my relationship..., I'm sure it did, cos being you know ill all the time, being ill and, just not having any energy sometimes, it's just like I'd get home from work and I'd be absolutely shattered and I'd go to sleep <i>(Participant 9)</i>.</p>
<p><b>Carer needs</b></p>	<p>You know, and...with there not being much patient support, I doubt very much there's...even...that there will be even less of...other support [for friends /partners] <i>(Participant 1)</i>.</p>
<p><b>IV. Happy ever after?</b></p>	
<p><b>It's a lot to take on</b></p>	<p>Obviously people don't want to take the responsibility on. I do think it'll be hard for me to find somebody while I'm poorly <i>(Participant 12)</i>.</p>

<b>Children?</b>	<b>Erm, when I first started they obviously mentioned that I can't have kids while I'm on dialysis and obviously there was only a small chance after but I've never really said anything again after that, which probably I should speak to somebody about cos like I say it does go round in my head (<i>Participant 10</i>).</b>
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