

Supporting the mental health of young people with chronic conditions

Additional evidence from Centre for Mental Health

May 2024

Introduction

The Chair of the Health and Social Care Committee wrote to us to seek our views and evidence relating to the mental health support that is offered to children and young people with chronic (physical) conditions. We have explored this as part of research into the emotional and psychological needs of people living with chronic kidney disease, in partnership with Kidney Research UK.

The evidence below is drawn from our report of that work (Wilton, 2023). References cited in this evidence paper are all available in the full report:

https://www.centreformentalhealth.org.uk/wp-content/uploads/2023/05/CentreforMHKRUK_TheCaseForChange.pdf.

While our evidence relates to kidney disease, we believe that it is applicable across long-term conditions. Every young person is different, and the challenges of living with different (and, for some, multiple) long-term conditions will differ, too, but the themes identified in this work will apply broadly.

Key points

- Having a long-term condition places especial pressure on the mental health of children and young people.
- Poor mental health can affect the physical health outcomes for young people living with a long-term condition.
- The transition from paediatric to adult care is a time when having the right psychosocial support in place is especially important. Children will also experience transitions prior to this, for example after diagnosis or when changing schools.
- Families, friends, and peers all play an important part in supporting the mental health of children and young people with long-term conditions.
- Children and young people are not just small adults. They have distinct needs, preferences and risk factors, which must be considered in their own right when developing psychosocial support for these age groups.
- The model of 'whole person care' for long-term conditions needs to be adaptable to fit the diverse needs of children and young people. Psychosocial support should not be 'just another medical appointment' on top of those they already face.

Mental health impacts of chronic conditions

Kidney disease, like many long-term conditions, has a significant negative impact on the quality of life and mental health of children and young people (Francis et al., 2019; Hamilton et al., 2019; Splinter et al., 2018; Tjaden et al., 2016; van Muilekom et al., 2021). This impact is seen across their emotional, social, physical and educational wellbeing and functioning (Kerklaan et al., 2020; Ruidiaz-Gómez & Higuaita-Gutiérrez, 2021; Rupp et al., 2021). And, as in adults, there is evidence that psychosocial issues have a negative impact on the medical outcomes of children and young people (Clementi & Zimmerman, 2020; Hamilton et al., 2018).

In a multinational interview study of 30 young adults (aged 18-36) living with kidney disease, Kerklaan and colleagues (2020) identified six themes relating to their psychosocial wellbeing:

1. Struggling with daily restrictions (from symptoms and side effects, giving up valued activities, impossible to attend school and work, trapped in a medicalised life, overprotected by supporting adults and cautious to avoid health risks)
2. Lagging and falling behind (delayed independence, failing to keep up with peers and struggling socially)
3. Defeated and hopeless (incapacitated by worry, an uncertain and bleak future, feeling unworthy of relationships, low self-esteem and shame)
4. Reorienting plans and goals (focusing on the day-to-day, planning parenthood and forward and flexible planning)
5. Immersing themselves in normal activities (refusing to miss out, finding enjoyment, determined to do what peers do and being present at social events)
6. Striving to reach potential and seizing opportunities (encouragement from others, motivated by the illness, establishing new career goals and grateful for opportunities).

While some of these themes hold true for adults living with kidney disease, others are more distinctly tied to the challenges and opportunities of young adulthood.

Transitions during childhood and adolescence, and into adulthood

Childhood, adolescence and young adulthood are life-stages full of changes. The needs of a two year old are very different from those of a ten year old which, in turn, are very different from those of a twenty year old. One of the most significant changes over these life-stages is from complete dependence on families and caregivers at the start of life to, for most young people, relative independence by their early twenties. This development is gradual and does not happen at the same pace for all.

For some of the young people and parents who spoke to us, the transition from paediatric to adult care was relatively abrupt and took place at a 'cut-off' age. About 35% of young adults lose a successfully functioning kidney transplant within 36 months of moving from paediatric to adult care (Harden et al., 2012), making this an especially high-risk time in their life.

One young person said: *"It would be nice to be introduced to the new doctors beforehand. Yeah, there was not much to it, there was not much thought behind it."*

And a mother, talking about her daughter's transition from paediatric to adult care, described it as "being thrown in at the deep end". This transition is a vulnerable stage for young people, when their condition and their psychosocial wellbeing may deteriorate (Dallimore et al., 2018).

Young adults have worse outcomes following a kidney transplant than any other age group (Hamilton et al., 2020; Pankhurst et al., 2020). This is likely to have an impact on overall life-expectancy, as well as reducing health, quality of life and ability to work (Pankhurst et al., 2020). Providing the right support during this complex period in a young person's life is, therefore, crucial. Such support needs to focus on the young person's wellbeing, not solely on using psychological interventions as a means to increase adherence to treatment.

Families and carers

Families and other unpaid carers play an essential role in the psychosocial support of people living with chronic conditions. This is especially true for children and young people (Clementi & Zimmerman, 2020). Research has shown that, when a child has kidney disease, it has an impact on family dynamics and the relationships between all family members and that, to quote from one study, "the whole family constitutes a unit of care" (Agerskov et al., 2020).

Families caring for children and young people with kidney disease face many sources of distress and they have a range of psychosocial needs. Family members often experience overwhelming challenges, and there are gaps in the resources available to help them to cope (Wee et al., 2022). The psychosocial needs of these families, identified in a focus group study with 21 parents, include information, emotional support and practical support (Geense et al., 2017). A suggestion is that the psychosocial needs of the whole family should be taken into consideration (Abrão et al., 2021; Zhang et al., 2023).

Friends and peers

Two themes that stood out in our conversations with children and young people were the importance of play and of peers. Children and young people with kidney disease often spend a lot of time in medical environments. This comes at the expense of the time spent with friends and at school, meaning they have fewer opportunities for social interaction and for activities appropriate to their stage of life. One mother, whose young son is living with kidney disease, spoke to us about the struggle of balancing all his medical appointments against "mak[ing] time for him to be a kid".

Children and young people also spoke about the effect of kidney disease on their relationships. Their symptoms and treatments may make it harder for them to form friendships. They described living with kidney disease as "kind of isolating" and "[a] very lonely place". It could be especially difficult when their friends had little knowledge or experience of kidney disease. One of the children and young people who spoke to us said:

"Most dialysis units have patients who are over 50. But if you're a 16, 17, 18 year old, that's a fairly shocking place to spend three days of your week. Because not only are you around older people and it doesn't feel like it's your kind of thing, it's also that you can see, potentially, the trajectory of your life. I don't think we pay enough attention to that."

Because kidney disease is relatively rare among children and young people, those with a diagnosis are unlikely to meet others with a diagnosis outside of a clinical setting. This may mean they have fewer opportunities for conversations about their experiences with people their age who 'get it', compared to adults living with kidney disease.

In our interviews and focus groups with children and young people, much more so than in those with adults, the importance of being able to talk to peers came up. One young person told us, "I have met someone [my age] with kidney disease before and I found that talking to them is really helpful." This is echoed by Agerskov and colleagues (2020) who found, "Getting together with peer children with [kidney disease] resulted in a positive sense of belonging."

It may be important – even more so than for adults – to avoid psychosocial support taking the form of yet another intervention that takes place in a formal clinical setting, and to provide children and young people with opportunities to interact with people their own age who are living with kidney disease.

Psychosocial support for children and young people

Children and young people face increased and different barriers than adults to being proactive in finding psychosocial support. They often lack the knowledge and the resources to be able to search for help independently. As a result, it's especially important that this information is visible in clinics (e.g. in the form of posters) and communicated to them by health care professionals.

"Kidney health isn't something that I see talked about a lot or in the same way as other conditions might be [...] and that just adds to the lack of understanding and the scariness of that, I guess."

"Once you are able to access the support, it's amazing... but it's just being able to find out about the support."

"I've never seen any kidney leaflets about kidney disease at GPs or anything... I'm in my early 20s and I'm suddenly told that having a child might not be an option for me, or I might die younger [...] and there is no support afterwards, they kind of go 'here is all the stuff' and there is no real support network."

Research has noted the importance of designing clinical pathways for children and young people living with kidney disease that suit their lifestyles (Harden et al., 2012). The barriers faced by older young people may be connected to the way care is delivered. Many move frequently, if they are studying for qualifications or pursuing work experience. Some may spend part of their year in one location, another part somewhere else (on a university

campus and at their family home, for example). They sometimes face a trade-off between continuity of care and convenience of location. Place-based support may be less appropriate to the needs of this age group.

Centre for Mental Health and Kidney Research UK produced the following model of 'whole person care'. It is crucial that this model is responsive to all age groups, with adaptations to make it suitable at any age and to respond to the diversity of the children and young people who have long-term conditions.

