

Title of Paper: _Psychosocial treatment of CKD: What are we doing right?
What could we be doing better?_____

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Abstract: Please type in Times New Roman 11 point font

Introduction

Much of the research on adaptation to childhood chronic illness has focused on parents' perceptions and feelings about their children's illness, and has failed to include children's own perceptions about the illness. Here we asked three young people to tell us about their quality of life (QoL) and what biopsychosocial factors impacted, both positively and negatively, upon it. Simultaneously, we also asked their parents for their views on what influences their child's QoL.

Method

Children who had participated in our previous quantitative research were invited to attend a focus group to express their opinions about our results that children with CKD have a QoL that is at least comparable with that of children in the general population. Their parents were invited to comment on the same topic. The groups were recorded and transcribed, and thematic analysis identified themes in the young people's and parent's comments.

Results

The young people predominately discussed factors that negatively impacted on their QoL. Feeling unwell, tired, or in pain were recognised by both parents and young people as factors which had a negative impact, excluding them from participating fully with their peers. Young people also found school teachers (due to their lack of understanding) and attending hospital appointments impacted negatively on their QoL (but not the treatment itself). Parents, on the other hand, focused on their lack of personal knowledge of what it feels like to live with CKD and tended to discuss factors that would positively impact on their children's QoL. Both young people and parents recognised the beneficial impact of positive family support. Whilst parents also felt that supportive friends were beneficial, the young people found that sometimes they had a negative impact, again due to a lack of understanding. Both parents and young people agreed that it was important for medical teams to ask about their QoL and provided their opinions on measures used previously.

Conclusion

Attendance at the focus group was perceived as positive by the young people as they were able to share their experiences and learn that they were not alone in them. The positive attitude of the young people, and their mature understanding that any unpleasant treatments are necessary for their health, suggest that the psychosocial support provided at Nottingham is effective. Children with CKD are able to access therapeutic residential holidays, especially those moving towards their transition to an adult kidney unit. It may be beneficial for more interactive interventions to involve the whole family, friends, and schools. This may alleviate parental worry about discrepancies in opportunities provided to their children without illness and enable young people with CKD to better educate friends and teachers about their condition and their needs.

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