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REVIEW ARTICLE

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Identifying experiences of supportive care of children and young people affected by kidney failure: A qualitative systematic review

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Abstract

Background: Children and young people affected by kidney failure experience complexities in their care. Little is known about the unique needs of this young patient population group living with a long-term condition.

Objective: A meta-aggregation of all qualitative studies was conducted to identify experiences of supportive care among children and young people living with kidney failure.

Methods: A systematic review of qualitative studies was conducted following the Joanna Briggs Institute meta-aggregation method. This review has been reported according to the PRISMA statement guidelines. Six electronic databases (CINAHL, Cochrane Library, MEDLINE, Proquest, PsycINFO, and Scopus) were comprehensively searched by an expert systematic review librarian using keywords and subject headings, from inception to September 2022. All studies were accessed using a predetermined inclusion and exclusion criteria. Methodological quality assessment and data extraction performed. Qualitative findings accompanied by illustrative quotes from included studies were extracted and grouped into categories which created the overall synthesised findings.

Results: A total of 34 studies were included in this review representing a total of 613 children and young people affected by kidney failure. There was a total of 190 findings which created 13 categories representing experiences of supportive care. The meta-aggregation developed five synthesised findings namely: 'physical needs', 'information and technology', 'treatment and healthcare', 'social needs' and 'psychological impacts'.

Conclusion: This systematic review identified that children and young people affected by kidney failure can experience a range of unmet supportive care needs in routine clinical services. Kidney failure impacted children and young people's self-identify, social and peer networks, introduced daily practical needs because of

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inherent physical and psychological burden due to the failure and associated treatments. Despite improvements in the medical management of kidney failure in children and young people, further attention is needed to optimise supported self-management in this young patient group.

KEYWORDS

children, qualitative, renal failure, supportive care, systematic review, young adults

INTRODUCTION

Kidney failure is a slow-progressing kidney injury with irreversible functional deterioration (Winnicki et al., 2018). Congenital malformation and hereditary nephropathies are the main causes of kidney failure in children. Often kidney replacement therapy is possible, in the form of haemodialysis (HD), peritoneal dialysis, or kidney transplantation, however, children with severe kidney failure have a 30-fold higher risk of mortality, compared with their age-matched population (Chong et al., 2017). Furthermore, kidney failure which develops in childhood requires long-term treatment, which often continues into adult life (Wong et al., 2012).

Childhood kidney failure (Stages 3–5) is a complex long-term illness and presents the child and their family caregivers with multiple physical, psychological, social, and spiritual impacts on quality of life (Agerskov et al., 2019). Kidney supportive care is defined as a person-centred approach to the provision of necessary services to maintain quality of life, manage distressing symptoms, provide emotional support, and facilitate advanced care planning for individuals of all aged affected by kidney failure (Davison et al., 2015; Mckie et al., 2023). Children and young people have unique supportive care needs compared to older adults (Aoto et al., 2018; Mckie et al., 2023). Often children and young people grapple with emotional impact of the failure, social challenges of treatment (impact on education and friends/peers), self-management of diet, fluid restrictions and medication regimes and managing changes in self-identify (Agerskov et al., 2019; Aoto et al., 2018; Carolan et al., 2014; Coyne et al., 2019).

Previous systematic reviews have explored the lived experiences of parents of children affected by kidney failure (Ong et al., 2021; Tong et al., 2008). The findings identified that parents were the children's main caregivers and faced significant burdens of care and multiple areas of distress on a daily basis (Ong et al., 2021). These existing reviews have provided an important contribution to understanding the lived experience of parents but provides little insight into the experiences and perceived supportive care needs for the child or young person's perspective. The considered age range of a young person is debatable and in many studies as the literature includes a young adult as 18–30 years, and for this review a young adult is considered 30 years and younger (Jose et al., 2021; Kidney Health UK, 2023). More recently the introduction of transition clinics has provided young people with the specialised services they need to ensure they receive appropriate care. However, the success of these clinics lies in the availability and ongoing access to these tailored resources (Jose et al., 2021; Michaud et al., 2019). Young adult kidney clinics are largely successful in the early stages, and the challenge remains to ensure that a therapeutic relationship develops where psychological issues and can be better addressed and managed over time (Michaud et al., 2019; Tong et al., 2011).

Currently, there are limited supportive care programmes available for young people (Kreuzer et al., 2019; Wolff et al., 1998; Watson et al., 2011). Children and young people can experience problems with body image, physical appearance, difficulties with education disruption, academic underachievement, delayed career ambitions, employment difficulties, social isolation, problems with intimate relationships and experience difficulties with physical activity (Heath et al., 2017). Therefore, this timely review aims to identify experiences of supportive care among children and young people affected by kidney failure.

METHODS

Ethical approval: Human Research Ethics Approval was not required for this systematic review. This review carefully considered common forms of search biases, such as database bias, availability bias, language bias, country bias and multiple publication bias.

Design: A systematic review of qualitative studies was conducted and reported in keeping with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The presentation of findings in this review conforms to the Enhancing Transparency in Reporting of the Synthesis of Qualitative Research (ENTREQ) statement [15] (see Table S1 for completed checklist). This review also followed a registered priori systematic review protocol available from PROSPERO [CRD42021288623]. The review team included experienced researchers, kidney clinicians, and a young consumer as part of this investigator team.

Inclusion criteria

The PICo, which stands for population, phenomena of interest and context (Lockwood et al., 2015) was applied to the inclusion criteria.

All participants (≤30 years) diagnosed with kidney failure (inclusive for all treatments modalities). The classification of supportive care needs domains was the phenomena of interest included: healthcare service needs, psychological/emotional needs, information needs, social needs, spiritual needs, physical/daily living needs, interpersonal/intimacy needs and family related needs (Culp et al., 2016; Davison et al., 2015; Mckie et al., 2023) across kidney care continuum. All qualitative studies irrespective of research design, mixed methods studies with an explicit qualitative component. Studies published in the English language in peer-reviewed journals. All quantitative publications, conference abstracts, commentaries, editorials, or studies which did not present qualitative findings to address the aim of the review were excluded.

Search strategy and sources

The CINAHL, Cochrane Library (Database of Systematic Reviews and Central Register of Controlled Trials), MEDLINE, Proquest, PsycINFO, and Scopus, databases were searched on 20 September 2022 for all relevant publications. A limiter was applied to retrieve English language studies only. Relevant systematic reviews were scrutinised for potentially relevant studies for screening. The reference lists of all included studies were also checked for additional relevant studies. An expert systematic review librarian conducted the database searches, see Table S2 for the full record of database searches.

Study selection

The study selection process was conducted in Covidence systematic review software and screening was performed according to the inclusion and exclusion criteria (Babineau, 2014). All titles and abstracts, and full-text publications were screened independently by two reviewers, with any conflicts resolved by discussion. Full-text studies that did not meet the inclusion criteria were excluded, and reasons for exclusion provided. Studies that were excluded are presented in Table S3.

Assessment of methodological quality

The JBI Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015) was used to assess methodological quality of the included studies. This is a 10-item Critical Appraisal Checklist used a score assigned to each question item of (low risk of bias—2, unclear risk of bias—1 and high risk of bias—0).

Data extraction

The data extracted included a study characteristics table and findings table. According to the JBI methodology the findings were extracted directly from the included studies and a qualitative quote extracted to justify the generation of each individual finding. Specifically, the themes of the individual qualitative studies were classified as findings.

Analytical approach

All findings and supporting illustrations were assessed for congruence by using the JBI ConQual system (Lockwood et al., 2015). Individual findings were rated as 'unequivocal' (clear association between the finding and illustration), 'equivocal' (unclear association between the finding and illustration, leaving it open to challenge) or 'not supported' (findings not supported by data). All unsupported findings were excluded from the final synthesis in keeping with JBI recommendations. Two or more findings were grouped into categories and further synthesised to create a single set of comprehensive finding descriptions.

FINDINGS

A total of 34 studies were included in this review representing a total of 613 children and young people affected by CKD. Figure 1 presents the PRISMA flow diagram of the literature search and selection process. There were several countries represented in the findings including: Canada (7), United Kingdom (9), Australia (6), United States of America (2), Japan (1), Turkey (1), Brazil (1), Multiple countries (2), South Korea (1), Philippines (1), Demark (1), Kingdom of Bahrain (1) and New Zealand (1). The age ranges of the participants ranged from 8 to 27 years old, and were representative of both males and females (see Table 1). All the studies had incomplete reporting of demographic and clinical characteristics such as duration of failure, treatments, and type of kidney failure. Overall, the methodological quality of the included qualitative studies was of medium to high quality (see Table 2). The main limitations of the included studies were a lack of transparent reporting in relation the researchers influence on the research, and vice versa.

Synthesised findings

Across the included studies there were a total of 190 findings (see Table S3) and 13 categories (see Table 3). The categories were then synthesised into five synthesised findings namely: 'physical needs', 'information and technology', 'treatment and healthcare', 'social needs' and 'psychological impacts' see Table 3.

Physical needs

The symptoms of kidney failure and the physical impact of treatment were noted across many studies. Fatigue and tiredness were

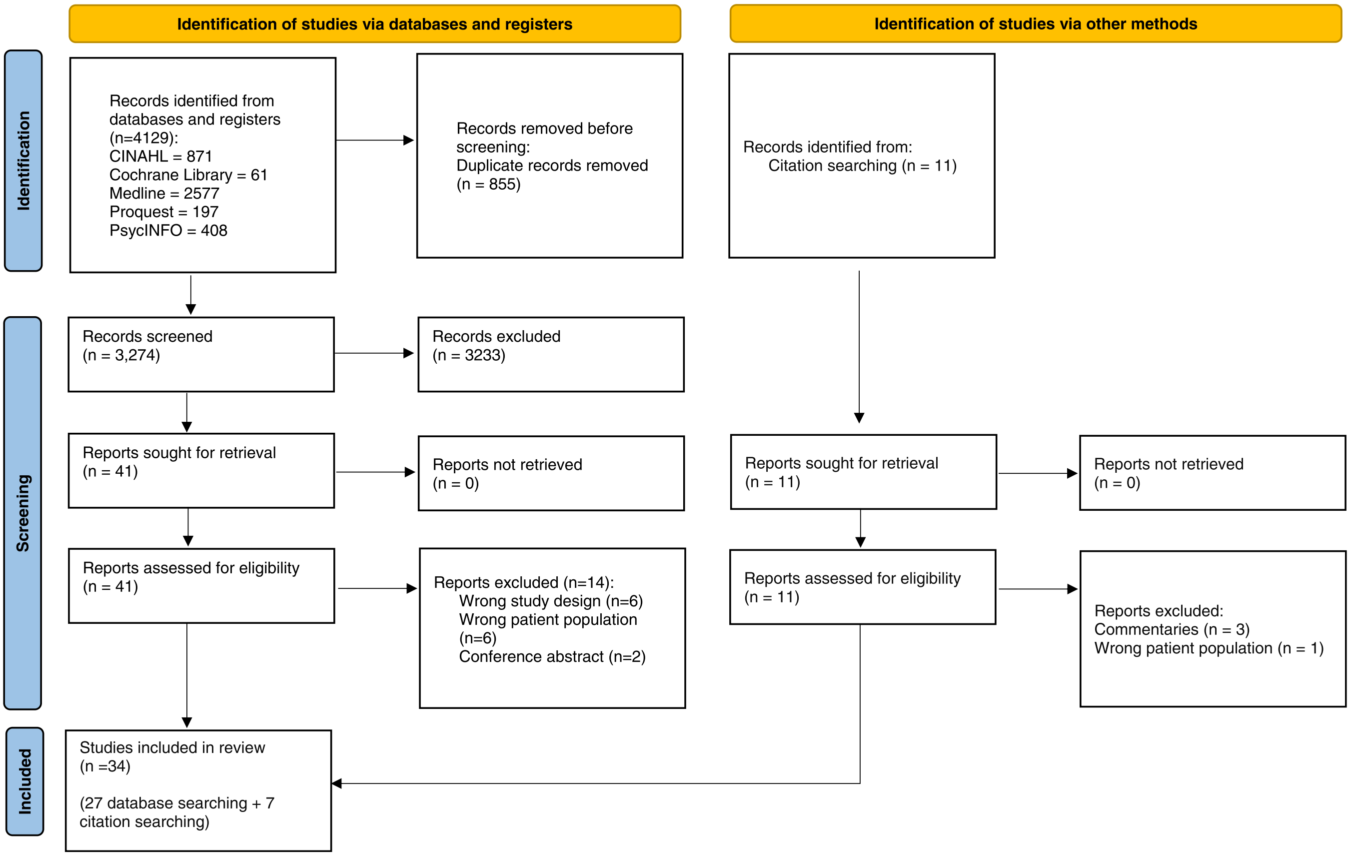

FIGURE 1 PRISMA flow diagram.

frequently experienced in young people and children which often prevented them from participating in activities and sports (Oberdhan et al., 2022; Wells et al., 2013). Other issues included joint soreness and body fluid accumulation which also reduced physical activity levels, because children and young people needed to rest to prevent or manage current symptoms (Kerklaan et al., 2020; Oberdhan et al., 2022; Waters, 2008; Wells et al., 2013). The severity of physical symptoms increased when children and young people started HD which caused extreme blood pressure changes that exacerbated symptom burden and concerns about tiredness and fatigue levels (Başkale & Başer, 2011; Oberdhan et al., 2022; Murray et al., 2014). The effects of HD were so severe that some felt dizzy frequently, required assistance to walk which impacted feelings of vulnerability, helplessness and being afraid (Başkale & Başer, 2011; Murray et al., 2019).

The experience of pain is not uncommon in people living with kidney failure and children and young people are no exception. The experience of pain was identified in many studies and was considered debilitating enough to prevent children and young people from getting out of bed (Başkale & Başer, 2011; Korus et al., 2011; Oberdhan et al., 2022; Swallow et al., 2014). Pain in the kidney area was noted in not only those with a kidney transplant but other children and young people with kidney failure. Many children and young people struggled to manage the intensity of pain associated with kidney failure and treatments. Some participants articulated that the pain left them feeling numb and emotionless while their parents watch helplessly (Başkale & Başer, 2011; Korus et al., 2011; Oberdhan et al., 2022).

Information and technology

Several studies identified information and technology was important among children and young people living with kidney failure. A lack of preparedness due to little information being provided to them from healthcare professionals and their parents, left many young people not knowing what to expect and what to do to help look after themselves (Gutman et al., 2018; Huby et al., 2017). Many children and young people expressed a lack of appropriate information about their condition and treatments that were not readily available, and found it very difficult to navigate their kidney failure (Gutman et al., 2018; Huby et al., 2017). Some young people felt a proactive desire to learn more about kidney failure and the associated medical management which included accessing websites and blogs, as often these information sources were written in words that young people could understand devoid from medical jargon (Braj et al., 1999; Gutman et al., 2018; Huby et al., 2017; Nightingale et al., 2017). However, confirming the reliability of this information was of great importance to young people because it made them feel informed and prepared (Nightingale et al., 2017).

TABLE 1 Characteristics of the included studies.

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Aoto et al. (2018) Japan	*Methodology*: Modified version of the grounded theory approach *Data collection*: Semi-structured interviews. Audio recorded.	To explore psychosocial adaptation process of Japanese children with chronic kidney disease and identifying factors that facilitated adaptation.	*Setting*: patients (children and adults) with chronic kidney disease who had attended the paediatric outpatient clinic of Tottori University Hospital, Japan between May and August 2016.	*Participants*: 10 *Gender*: Female (6), Male (4) *Age*: 17.2 (SD 4.07) years *Race*: Japanese (10) *Educational level*: Elementary school (1), Junior high school (1), High school (6), Preparing for college (1), Employed (1) *Disease*: Idiopathic nephrotic syndrome (5), IgA nephropathy (1), Purpura nephritis (2), Lupus nephritis (1), Chronic nephritis (1) *Duration of disease*: 8.4 (SD 5.9) years *Current treatment*: Oral drugs (7), only periodic hospital visits (3) *Family structure*: Parents and their children (3), father or mother and his/her children (0), extended family [with grandparent(s)] (6), live alone (1)	Category emerged related to 1: Emotional impact on being informed of disease, 2: Social challenges of treatment and resulting identity diffusion, 3: Emotional conflict on school return, 4: Resilience and related factors, and 5: Re-establishment of identity.
Başkale and Başer (2007) Turkey	*Methodology*: Qualitative approach. *Data collection*: Semi-structured interviews. Audio recorded.	To explore how adolescents receiving haemodialysis for end-stage renal disease were affected by their diagnosis and treatment.	*Setting*: Patients (adolescents) receiving haemodialysis for end stage renal disease in outpatient haemodialysis centres in two Turkish cities, Izmir and Denizli.	*Participants*: 18 *Gender*: Female (10), male (8) *Age*: 15.5 (SD 2.5) years *Race*: Not reported *Educational level*: Not reported *Disease*: End-stage renal disease (18) *Duration of disease*: 3.2 (SD 2.0) years *Current treatment*: Haemodialysis 3-times per week (15), Haemodialysis 2-times per week (3). *Family structure*: Not reported.	Category emerged related to 1: Difficulties with physiological effects of haemodialysis, 2: Issues with medication compliance, 3: Issues complying with dietary restrictions, 4: Feelings of anger, anxiety, depression, and withdrawal, 5: Feeling different/body image problems, 6: Fear of death, 7: Coping behaviours and what helps, 8: Relationships with family and friends, 9: Social isolation, 10: School problems, 11: Future expectations.
Braj et al. (1999) Canada	*Methodology*: Phenomenology *Data collection*: Semi-structured interviews. Audio recorded.	To describe the meanings adolescents attached to their renal transition to adult services experience.	*Setting*: Interviews took place at the hospital. Adolescents who were receiving haemodialysis treatments in an adult	*Participants*: 3 *Gender*: All male *Age*: Aged 18–22 years (no further information reported. *Race*: Not reported. *Educational level*: Not reported.	A major theme related to ownership, knowledge of dialysis technology and being accountable.

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
			centre following transfer from a paediatric centre within 1 year.	*Disease*: Not reported. *Duration of disease*: Not reported. *Current treatment*: Haemodialysis (no further information reported. *Family structure*: Not reported.	
Ramos et al. (2015) Brazil	*Methodology*: Clinical qualitative research. *Data collection*: Semi-structured interviews. Interviews were recorded.	To analyse the impact of kidney disease and treatment on the mental health of adolescents on haemodialysis.	*Setting*: Patients (adolescent children) with chronic kidney disease who had attended a dialysis clinic in the city of Fortaleza, Brazil between February and April 2013.	*Participants*: 8 *Gender*: Female (6), Male (2) *Age*: 10–17 years. *Race*: Not reported. *Educational level*: Varied. *Disease*: Chronic kidney disease. *Duration of disease*: 3.1 years on average. *Current treatment*: Haemodialysis 3-times per week (8) *Family structure*: Not reported.	Category emerged related to 1: Feelings of adolescents with CKD about the disease, 2: Expectations of adolescents related to coping and adapting to the illness, 3: Changes in the lifestyle of the adolescents on haemodialysis, 4: Impact of the treatment routine on the mental health of adolescents
Coyne et al. (2019) United Kingdom	*Methodology*: Qualitative *Data collection*: Semi-structured interviews. Audio recorded.	To explore young people's experience and perceptions of their past, current and future relationships and support networks.	*Setting*: Transitions to an adult centre following transfer from a paediatric centre.	*Participants*: 14 *Gender*: 8 male and 6 female *Age*: mean 22 years, SD not reported. *Race*: 10 White British, with one Indian, one Pakistani and two individuals who were of a different Asian background. *Educational level*: Not reported. *Disease*: Not reported. *Duration of disease*: Not reported. *Current treatment*: Pre-dialysis, HD, PD or transplant (no further information reported. *Family structure*: Not reported.	Four themes: 'Disclosure—To tell or not to tell?', 'Disclosure—To tell or not to tell?', 'Disclosure—To tell or not to tell?' and 'Happy ever after?'
Crawford et al. (2021) Australia	*Methodology*: Qualitative descriptive approach. *Data collection*: Semi-structured interviews. Interviews were recorded and transcribed verbatim.	To explore individual experiences of adolescents and young adults with chronic kidney disease in relation to the transition process and transfer to adult care.	*Setting*: Interviews took place either at the participants home, the hospital, or a café. Patients (adolescents and young adults) with chronic kidney disease who either were in transition (process of moving to adult care) within	*Participants*: 18 *Gender*: Female (8), Male (10) *Age*: 19.2 (SD 1.6) years. *Race*: Not reported. *Educational level*: Not reported. *Disease*: Chronic Kidney Disease stages 1–5. *Duration of disease*: 17.5 years on average. *Current treatment*: Transplant (9), dialysis (3), CKD not requiring KRT (6). *Family structure*: Not reported.	Category emerged related to 1: Leaving the comfort of paediatric care, 2: Advocacy through mothers, 3: Daunting and intimidating adult clinic, 4: Continuity of care in the adult clinic, 5: Adherence to self-care, 6: Transition to adulthood, 7: Preparing adolescents and young adults.

(Continues)

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
			paediatric setting or had transferred to adult care within the last 5 years.		
Cura (2012) Philippines	*Methodology*: Interpretive phenomenology *Data collection*: Semi-structured interviews. Interviews were recorded and transcribed verbatim.	To explore the experience of care transitions among young people.	*Setting*: Not reported. *Context*: Not reported.	*Participants*: 6 *Gender*: Female (3), Male (3) *Age*: 17–22 years old *Race*: Not reported. *Educational level*: Not reported. *Disease*: Chronic kidney disease stages *Duration of disease*: 7 months–3 years *Current treatment*: Not reported. *Family structure*: Not reported.	Three general themes were found: Living a Shorter Life; Dependence and Independence; and Struggle of Being Normal Amidst Difference.
Finderup et al. (2012) Demark	*Methodology*: Qualitative descriptive approach. *Data collection*: Semi-structured interviews, focus groups and observation. Data recorded and transcribed verbatim.	To qualitatively evaluate a new established youth clinic and to gain knowledge of the experiences of young people and their parents	*Setting*: An evaluation of a youth clinic to gain a deeper understanding of the role of a youth clinic in the life of a young person with kidney disease, and to explore which elements were found the most important	*Participants*: 12 *Gender*: Female (6), Male (6) *Age*: 16–26 years (average age was 20.5 years) *Race*: Not reported. *Educational level*: Not reported. *Disease*: Chronic kidney disease stages *Duration of disease*: Not reported. *Current treatment*: Not reported. *Family structure*: Not reported.	Eight themes were identified: (1) A meeting place; (2) a mutual understanding; (3) the young people have established a social community between themselves; (4) I feel less directed by my kidney disease; (5) I accept my life with the disease to a larger extent; (6) I am the safety net; (7) they have their life with the disease under control and they handle it and (8) the youth clinic is a gift from heaven.
Gutman et al. (2018) Australia	*Methodology*: Qualitative *Data collection*: Semi-structured interviews. Audio recorded.	To describe the child and parental perspectives on communication and decision-making in CKD	*Setting*: Three centres in Australia (*n* = 44), two centres in Canada (*n* = 16), and one centre in the United States (*n* = 36).	*Participants*: 62 parents and 34 children participated in 16 focus groups. *Gender*: 19 male, 15 female *Age*: 8–21 years *Race*: Not reported *Educational level*: Not reported. *Disease*: 12 Congenital abnormalities of kidneys/urinary tract, 4 nephrotic syndrome (cause not specified), 3 focal segmental glomerulosclerosis, 2 polycystic kidney disease, 2 cystinosis, 1 IgA nephropathy, 1 unknown	Four themes: (1) disempowered by knowledge imbalance, (2) recognising own expertise, (3) striving to assert own priorities, and (4) managing child's involvement

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
				Duration of disease: Not reported. *Current treatment*: dialysis 22, transplant 12 *Family structure*: Not reported.	
Huby et al. (2017) England	*Methodology*: Qualitative study underpinned by self-efficacy theory. *Data collection*: Semi-structured interviews, digitally recorded, transcribed verbatim, and anonymised.	To explore children and young people's views on the content of a proposed young person-appropriate application to support personal management of their condition.	*Setting*: Patient interviews conducted in a venue specified by the interviewee such as in the family home or a quiet hospital space. Children's kidney unit in the north of England.	*Participants*: 26 *Gender*: Female (12), Male (14) *Age*: 5–10 (7); 11–15 (10); 16+ (9). *Race*: White British (15), South Asian (11). *Educational level*: Not reported. *Disease*: Chronic kidney disease: Stage 3 (9); Stage 4 (6); Stage 5 (11). *Duration of disease*: Not reported. *Current treatment*: Not reported. *Family structure*: Not reported.	Category emerged related to 1: Access, 2: Information; 3: Normalcy; 4: Accessibility.
Jose et al. (2021) Australia	*Methodology*: Qualitative study informed by the EBCD framework and the consolidated criteria for reporting qualitative research. *Data collection*: Semi-structured interviews. Audio recorded, transcribed and deidentified.	To evaluate how the establishment of a transition clinic in a regional hospital had impacted the lives of young adults with severe CKD and their families and inform ongoing development of the clinic.	*Setting*: Interviews took place at either the hospital outpatient clinic or medical research institute. Young people living with a kidney transplant or stage 4–5 kidney disease, attending a hospital or medical research institute in Hobart, Tasmania, Australia.	*Participants*: 6 *Gender*: Female (3), Male (3) *Age*: 20.2 (Range 17-29 years) *Race*: Not reported *Educational level*: Not reported *Disease*: Chronic kidney disease Stage 4-5 (2), Transplant (4). *Duration of disease*: Not reported. *Current treatment*: Not reported. *Family structure*: Living at home with one or both parents (5), other (1).	Category emerged related to 1: The model of care, 2: Peer support, 3; Transition towards self-management: Building life skills.
Johnson et al. (2008) USA	*Methodology*: Modified version of the grounded theory approach (M-GTA) *Data collection*: Semi-structured interviews. Audio recorded.	To explore the following three issues: (1) inherent conceptions about the disease process, expression, and treatment; (2) barriers to access to care and treatment; and (3) reasons for potential non-adherence with treatment.	*Setting*: University of California, San Diego (UCSD) and Rady Children's Hospital and Health Center (CHHC) in San Diego, California.	*Participants*: 29 *Gender*: 19 male, 10 female Age: 1–16 years *Race*: 17 Latino and 12 patients were identified as non-Latinos (including 10 non-Latino Whites, 1 Asian and 1 African American). *Educational level*: Not reported. *Disease*: 5 Dysplasia, 4 genetic kidney disorder, 10 glomerulonephritis, 5 obstructive uropathy, 2 perinatal asphyxia, 1 vasculitis *Duration of disease*: Not reported.	Themes related to diagnosis and treatment trajectory/illness career model.

(Continues)

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
				Current treatment: Dialysis 22, transplant 12 *Family structure*: Not reported.	
Kerklaan et al. (2020) Multiple countries	*Methodology*: Not reported *Data collection*: Semi-structured interviews. Audio recorded.	To describe the perspectives of young adults with childhood-onset CKD on life participation.	*Setting*: Centres in Australia, Canada, India, United Kingdom and USA.	*Participants*: 30 *Gender*: 10 male, 20 female *Age*: (mean 23.4 years, SD 4.0) *Race*: Not reported. *Educational level*: Not reported. *Disease*: 7 Congenital abnormalities of kidney/urinary tract, 4 focal segmental glomerulosclerosis, 3 nephrotic syndrome (cause not specified), 3 polycystic kidney disease, 2 haemolytic uraemic syndrome, 2 lupus nephritis, 2 reflux nephropathy, 1 granulomatosis with polyangiitis, 1 Henoch–Schönlein purpura, 1 diabetic, 1 unknown *Duration of disease*: Diagnosis was 7.7 years (SD 5.3) *Current treatment*: 7 Not on kidney replacement therapy, 2 5D, haemodialysis, 5 5 T, deceased donor kidney transplant, 5 5 T, living donor kidney transplant Family structure: Living with parents 19, housemates, 2, partner 7, alone 2	Six major themes: struggling with daily restrictions, lagging and falling behind, defeated and hopeless, reorienting plans and goals, immersing oneself in normal activities and striving to reach potential and seizing opportunities.
Kim and Choi (2016) South Korea	*Methodology*: Qualitative study using qualitative content analysis. *Data collection*: Semi structured individual and group interviews, audio-recorded and transcribed.	To explore the experiences of Korean adolescents who have undergone a renal transplant.	*Setting*: Interviews conducted in adolescents' homes, counselling office in a hospital, or researcher's office according to participant convenience. Adolescents who had received a renal transplant, more than 6 months before the study, at a general hospital in Seoul, South Korea.	*Participants*: 9 *Gender*: Female (7), male (2) *Age*: 16.2 (Range 12-18 years) *Race*: Korean. *Educational level*: Not reported. *Disease*: Chronic renal failure: congenital renal failure (2), acute renal failure (7). *Duration of disease*: Not reported. *Current treatment*: Transplant recipients. Received transplant at least 6 months before the study. *Family structure*: Not reported.	Category emerged related to 1: Being different from others, 2: Not being involved as a decision maker, 3: Becoming one of them, 4: Still being different form others, 5: Having mixed feelings towards mothers, 6: Coping with new circumstances.

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Korus et al. (2011) Canada	*Methodology*: Qualitative *Data collection*: Semi-structured interviews. Audio recorded.	To explore information needs of adolescents who have undergone kidney transplantation	*Setting*: Canadian tertiary care paediatric center	*Participants*: 8 *Gender*: 4 Male, 4 female *Age*: Mean age 15 years (SD not reported) *Race*: Not reported. Educational level: Not reported. *Disease*: Not reported. *Duration of disease*: Not reported. *Current treatment*: 1 Teen was pretransplant, 1 was within the first year after transplant, 1 teen was between 1 and 3 years after transplant, 3 had received their transplant between 3 and 5 years earlier, and 2 teens had received their transplant more than 5 years earlier. *Family structure*: Not reported	Adolescents described the transplant process as very stressful and articulated four major subthemes of stressors.
Michaud et al. (2019) Canada	*Methodology*: Mixed methods design using complementary approach and a concurrent triangulation strategy. *Data collection*: Survey questionnaires. Biomedical markers (tacrolimus blood levels). Clinic attendance rates and rejection episode data. Semi-structured interviews.	To explore experiences of kidney transplant patients attending young adult clinic (YAC) as compared to attending a regular adult clinic (RAC).	*Setting*: Centre Hospitaler de l'Universite de Montreal. Kidney transplant patients who had attended the young adult	*Participants*: Surveys conducted with *n* = 17 (YAC), *n* = 16 (RAC). Interviews conducted with subset of total sample comprised of *n* = 10 (YAC) and *n* = 8 (RAC). *Gender*: 11 (64.7%) male at YAC, 10 (71.4)% male at RAC. *Age*: 26.5 ± 4 YAC. 26.6 ± 3.8 RAC. *Race*: Mixed *Educational level*: Not reported *Pretransplant diagnosis*: YAC: Glomerulonephritis: 2 (11.8%), IgA glomerulonephritis: 1 (5.9%), reflux nephropathy: 2 (11.8%), renal hypoplasia: 2 (11.8%), renal dysplasia: 1 (5.9%) Haemolytic uraemic syndrome: 1 (5.9%), Uropathy: 3 (17.6%), Lupus: 1 (5.9%) Other: 4 (23.5%), *Duration of disease*: Not reported. *Current treatment*: Post-transplant clinic attendance. *Family structure*: Mixed.	Four themes emerged: (1) resilience, (2) relational needs and the therapeutic alliance, (3) the quest for balance and (4) the quest for normalcy.

(Continues)

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Murray et al. (2014) United Kingdom	*Methodology*: Mixed methods. *Data collection*: Semi-structured interviews	To assess the impact of ESKD on education and employment outcomes in young adults	*Setting*: United Kingdom with paediatric and adult services	*Participants*: 14 *Gender*: 71.4% Male *Age*: Median age of 23.5 years *Race*: Not reported. *Educational level*: Median school-leaving age was 16 years. Of our sample, 21.4% were studying for a degree, 28.6% were in full-time work, 21.4% were in part-time work, and 28.6% were unemployed. *Disease*: 71.4% Transplanted, 28.6% HD. *Duration of disease*: time since graft receipt was a median 29 (1–56) months, having received dialysis for a median 20 (0–43) months before transplantation. Seven of the 10 transplanted patients previously received HD, three received PD. *Current treatment*: Posttreatment. *Family structure*: Not reported.	Themes impacting on education and employment included low energy levels, time missed, loss of self-esteem, and feelings of loneliness and isolation, which may progress to depression and recreational drug use. Lack of understanding from educators and employers resulting in lost work, and career ambitions changed or limited because of dialysis.
Murray et al. (2019) United Kingdom	*Methodology*: Mixed methods. *Data collection*: Semi-structured interviews	To explore how ESKD impacts education and employment attainment in a matched UK and USA patient cohort.	*Setting*: Young people with ESKD aged 18–30 years (27), attending single-centre follow-up in Oxford, UK were matched with 27 comparable young people aged 19–30 years, under follow-up in Denver, USA	*Participants*: 12 *Gender*: 9 Males (75%) *Age*: Not reported *Educational level*: Not reported *Disease*: Not reported *Duration of disease*: Not reported *Current treatment*: Dialysis (2), transplant (10) *Family structure*: Not reported	Themes included fatigue, self-esteem loss, social isolation and low mood. The impact of dialysis and poor understanding from educators/employers resulted in lost work time, and/or limited educational attainment.
Nguyen et al. (2020) Canada	*Methodology*: User-centred design. *Data collection*: 9 Focus group meetings with semi-structured focus group scripts, self-report questionnaire.	To explore barriers to and facilitators of medication adherence in adolescent and young adult kidney transplant recipients	*Setting*: Montreal Children's Hospital of the McGill University Health Centre, Centre Hospitalier Universitaire Ste. Justine, The Hospital for sick Children, and British Columbia	*Participants*: 32 *Gender*: 14 (43.8%) Female AYA across all age groups. *Age*: Mean 17.6 (SD 3.6), 13.0–24.8 *Race*: Non-Hispanic White/European 26 (81.3%), Black/African 1 (3.1%), Hispanic/White 1 (3.1%), Asian or Native Hawaiian/Pacific Islander 1 (3.1%), Mixed 3 (9.4%)	Themes such as: difficulty remembering to take medication on time and learning the steps required for medication management were identified.

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
			Children's Hospital, and in US UPMC/UPMC Children's Hospital of Pittsburgh, St. Louis Children's Hospital and Seattle Children's Hospital	*Educational level*: 9th grade or lower 13 (40.6%), 10th–12th grade 12 (37.5%), >high school 7 (21.9%) *Disease*: Congenital anomalies of kidney/urinary tract 11 (34.4%), nephronophthisis 6 (18.8%), acquired disorders including focal segmental glomerulosclerosis, glomerulonephritis 5 (15.6%), other 6 (18.7%), unknown 4 (12.5%) *Duration of disease*: Not reported *Current treatment*: Post-transplant *Family structure*: Not reported	
Nicholas et al. (2009) Canada	*Methodology*: Mixed methods. *Data collection*: Online dialogue transcripts (of online support intervention) and post-intervention qualitative interviews.	To evaluate the experiences of adolescents with chronic kidney disease using an online social support network intervention	*Setting*: Three paediatric health sites in central Ontario, Canada. Participants were drawn from databases of adolescents with CKD at	*Participants*: 24 *Gender*: Not reported *Age*: Mean age of 15 years *Race*: Not reported *Educational level*: Not reported *Disease*: Not reported *Duration of disease*: Not reported *Current treatment*: 16 Had received a kidney transplant, 4 received peritoneal dialysis, 2 were on haemodialysis, and 2 were receiving prerenal replacement therapy *Family structure*: Not reported	Four themes were evident, and included (1) conveying sympathy, offering advice, and venting feelings, (2) the desire to share own stories, (3) little support from health peers and (4) balancing safety/anonymity and connecting with others.
Nicholas et al. (2011) Canada	*Methodology*: Ethnographic. *Data collection*: Semi structured interviews. *Data analysis*: Content analysis/'long interview'	To explore how children undergoing RRT perceive and manage ESRD in daily life	Setting: Interviews conducted in the 'family home or treatment facility' (not specified). The healthcare provider alerted potential participants and their families about the study.	*Participants*: 25 *Gender*: 15 Female and 14 males *Age*: 6–18 years *Race*: 17 North American, 4 Asian, 2 Caribbean, 1 Middle Eastern *Education level*: Not reported *Duration of disease*: Not reported *Current treatment*: Receiving RRT including live/deceased transplantation, and heamo- and peritoneal dialysis *Family structure*: Not reported	Seven themes emerged: (1) not feeling normal, (2) knowledge about ESRD and involvement in treatment, (3) transitioning responsibility for self-care, (4) absence from school, (5) the challenge of truth telling: peer relationships and revealing ESRD, (6) social support: family, friends, and healthcare providers, (7) adjustment despite challenge.

(Continues)

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Nicholas et al. (2018) Canada	*Methodology*: exploratory *Data collection*: Long interview method, open ended interviews	To explore the experiences of youth with CKD of transition from paediatric to adult renal care	*Setting*: interviews took place in the clinic or at the participant's home, depending on participant preference. Participant caregivers were present at interviews when requested by participants. Sample was recruited from Canadian paediatric nephrology programmes in three large multicultural cities—further details not reported.	*Participants*: 28 *Gender*: 12 Female and 16 males *Age*: 12–25 years *Race*: Not reported *Educational level*: Not reported *Disease*: CKD *Duration of disease*: Not reported *Current treatment*: 8 CKD without dialysis or transplant, 2 peritoneal dialysis, 1 haemodialysis, 17 with a kidney transplant *Family structure*: Not reported	Themes included: incremental shifts to care independence and a 'gentler' transfer to adult care.
Nightingale et al. (2017) United Kingdom	*Methodology*: Medical Research Council (MRC) complex intervention development and evaluation framework. *Data collection*: Semi structured interviews and focus group interviews.	To explore the views of children with CKD, their parents, and health professionals to inform the development of a child focused care app.	*Setting*: Children were interviewed with their parents present. Participants were identified by the researcher who worked with children with CKD and their families.	*Participants*: 17 *Gender*: 8 Female and 9 males. *Ages*: 5–10 years of age, 11–14 years of age, 15–18 years of age *Race*: Caucasian *Education level*: Not reported *Disease*: Chronic kidney disease (stage not stated) *Duration of disease*: Not stated *Current treatment*: Not stated *Family structure*: Not stated	Three key themes emerged 1: Gaps in current online information and support, 2: Difficulties experienced by children with a long-term condition and 3: Suggestions for digital care management app.
Nightingale et al. (2022) United Kingdom	*Methodology*: Grounded theory *Data collection*: Semi-structured interviews	To explore self-management experience in young people affected by kidney disease.	*Setting*: Face to face in the hospital setting or family home, or by telephone. Young people and their parents were offered the opportunity to be interviewed together or separately.	*Participants*: 16 *Gender*: 9 Female and 7 males. *Age*: 13–17 *Race*: Caucasian 7, South Asian 5, Black 3, other 1 *Education level*: Not reported *Disease*: Chronic kidney disease (stage not stated) *Duration of disease*: Not stated *Current treatment*: Pre-emptive transplant 7, dialysis 9 *Family structure*: Not stated	The theory is comprised of a core category (shifting responsibilities) and two interrelated subcategories (developing independence and making changes).

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Oberdhan et al. (2022) Multiple countries	*Methodology*: Qualitative study *Data collection*: Semi-structured interviews	To explore issues from the adolescent patient's perspective affected by CKD.	*Setting*: Telephone interviews in different countries. Participant's native language.	*Participants*: 33 *Gender*: Not reported *Age*: 12–17 *Race*: Not reported. *Education level*: Not reported *Disease*: Autosomal dominant polycystic kidney disease *Duration of disease*: Not stated *Current treatment*: Not reported *Family structure*: Not reported	DPKD experience physical, social and emotional impacts from their disease.
Poursanidou et al. (2003) United Kingdom	*Methodology*: Multi perspective. *Data collection*: Semi-structured interviews	To identify the difficulties relating to school in children with a kidney transplant and explore the support needs in relation to schooling.	*Setting*: The study took place within the participants home and at school	*Participants*: 18 *Gender*: 8 Female and 10 males *Age*: 13.68 mean age (range 9.66–17.80 years of age). *Race*: not stated *Education level*: 13 children were at secondary school, 1 at a school for special educational needs and 4 other (including home schooling). *Disease*: Not stated *Duration of disease*: Not stated *Current treatment*: Post-transplant (2 years) *Family structure*: Not stated	Four themes were identified relating to children 1: Peer relations difficulties at school, 2: Concerns related to school absence, 3: Lowered motivation for schoolwork and poor school performance linked to posttransplant health condition, 4: The importance of hospital school liaison
Rupp et al. (2021) USA	*Methodology*: Grounded theory *Data collection*: Semi-structured interviews	To explore and investigate the relationship between social support in education and employment setting and transition readiness for young people with end stage kidney disease.	*Setting*: Hospital clinic. The participants were obtained through a list of paediatric nephrology patients who received care at a large teaching hospital.	*Participants*: 19 *Gender*: 9 Female and 10 males. *Age*: 24 years of age mean (range 19–28 years of age) *Race*: 9 African American, 6 Caucasian, Latino 3, American Indian 1. *Educational level*: 12 had college/vocational schooling, 6 secondary school, 1 undergraduate degree. *Disease*: ESKD *Duration of disease*: Not stated *Current treatment*: 10 HD, 3 PD, TX 6 *Family structure*: 8 lived with parents, 6 lived with a partner and 5 lived independently.	1: Willingness to attend school/work, 2: Barriers to school/work attendance, 3: Overcoming barriers through social support, 4: Barriers to establishing social support

(Continues)

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Swallow et al. (2014) United Kingdom	*Methodology*: qualitative description *Data collection*: Face-to-face interviews.	To explore their views on content of the proposed online parent information and support (OPIS) web-application	*Setting*: Children's kidney unit in the North of England, part of a network of 13 units in the United Kingdom.	*Participants*: 26 *Age*: 5–16 years *Race*: White British (12), South Asian (14) *Education level*: Not reported *Disease*: CKD 3 (9), CKD 4 (6), CKD 5 (11) *Duration of disease*: Not reported *Current treatment*: Not reported *Family structure*: Not reported	The web application should enable clinical caregiving, with condition-specific, continuously available, reliable, accessible material and a closed communication system to enable contact between families living with CKD.
Tong et al. (2011) Australia	*Methodology*: Grounded theory. *Data collection*: Face-to-face interviews.	To explore adolescent perspectives following kidney transplantation.	*Setting*: Hospital and home. Participants were recruited through five transplant units across Australia. Interviews took place in hospital and home setting.	*Participants*: 22 *Gender*: 10 Female and 10 males *Age*: 12–19 years of age *Race*: 16 Caucasian, 6 other. *Educational level*: Not stated *Disease*: Not stated *Duration of disease*: Not stated *Current treatment*: In receipt of a kidney transplant. *Family structure*: Not stated	Two main themes that included: (1) Barriers and (2) enablers.
Tong et al. (2013) Australia	*Methodology*: Grounded theory. *Data collection*: Semi structured interviews.	To elicit the experiences and perspectives of young people waiting for a kidney transplant.	*Setting*: Mixture of hospital clinic, hospital meeting room, home and telephone. Interviews took place over the telephone, in the home and at the hospital.	*Participants*: 27 *Gender*: 16 Female and 11 males. *Age*: 12–24 years of age. *Race*: 9 Caucasian, 14 other. *Educational level*: Not stated *Disease*: CKD *Duration of disease*: Not stated *Current treatment*: 10 HD, 4 PD, 13 awaiting to start dialysis treatment. *Family structure*: Not stated	Five major themes emerged that included: (1) inferiority, (2) insecurity, (3) injustice, (4) resilience, (5) adjustment mentality
Tong et al. (2015) Australia	*Methodology*: Mixed methods. *Data collection*: Semi-structured interviews	To evaluate a young adult renal clinic (YAC) intervention that included a multidisciplinary clinic and social programme	*Setting*: New YAC in Adelaide, Australia	*Participants*: 15 *Gender*: Male 7 (47%) *Age*: <21 years (8), >21 years (7) *Race*: Not reported *Educational level*: Tertiary degree (4), High school year 12 (9), High school year 11 (2) *Disease*: CKD 1–5 *Duration of disease*: Not reported *Current treatment*: Haemodialysis (1), transplantation (7), non-dialysis (7) *Family structure*: Not reported.	Six themes: gaining confidence (encouraging self expression, exchanging experiential knowledge, helping others, positive reflection and optimism); social connectedness; appreciating a welcoming environment; competing priorities; avoiding the sick identity; and relational boundaries.

TABLE 1 (Continued)

Study and country	Methodology, methods for data collection and analysis	Phenomena of interest	Setting	Participants characteristics	Description of main results
Walker et al. (2019) New Zealand	*Methodology*: Exploratory *Data collection*: Face-face semi-structured interviews	To understand the experiences and expectations of children during the process of kidney transplantation to inform clinical care.	*Setting*: Tertiary children's hospital. Children's health setting including regional health services in NZ and all interviews were conducted with a parent present.	*Participants*: 13 *Gender*: 6 Female and 7 males. *Age*: 7 and 17 years *Race*: 10 NZ European, 1 Māori, 1 Pacific Islander and 1 Asian. *Educational level*: Not stated *Disease*: Not stated *Duration of disease*: Not stated *Current treatment*: Post-kidney transplant *Family structure*: Not stated	Three main themes that included: (1) transplant as the goal, (2) dealing with negative emotions and (3) enhancing and understanding knowledge.
Waters (2008) Kingdom of Bahrain	*Methodology*: Ethnography *Data collection*: Data were also derived from: children's stories and drawings, document analysis, informal inter Views and semi-structured interviews	To explore the experience of long-term renal illness, including issues concerning compliance with treatment, from the perspectives of children and young people	*Setting*: Renal unit was situated in a UK inner city NHS children's hospital, closely connected to the main hospital wards and departments.	*Participants*: 13 *Gender*: 6 Males *Age*: 5–8 years (2), 9–12 years (5), 13–16 years (6) *Race*: Not reported *Educational level*: Not reported *Disease*: Not reported *Duration of disease*: Not reported *Current treatment*: Not reported *Family structure*: Not reported	Conceptualisation of life with long-term renal illness that highlights children's management of 'illness labour', their inhabitation 'renal geographical space', 'a renal body' and a 'renal social world'.
Wells et al. (2013) United Kingdom	*Methodology*: Exploratory *Data collection*: Photo elicitation interviewing	To explore the lived experiences of adolescents with kidney failure (receiving dialysis) and identify barriers to effective treatment.	*Setting*: Large urban teaching hospital. Young people meeting the criteria were identified by a known renal nurse specialist.	*Participants*: 10 *Gender*: 6 Females and 4 males. *Age*: 13–17 years *Race*: Not stated *Educational level*: Not stated *Disease*: ERF *Duration of disease*: Not stated *Current treatment*: 5 receiving haemodialysis and 5 receiving peritoneal dialysis. *Family structure*: Not stated	Four themes emerged: (1) understanding and acceptance of treatment, (2) living in a nonfunctioning body, (3) impact upon daily life, (4) sources of support.

Abbreviations: CKD, chronic kidney disease; ERF, established renal failure; ESKD, end stage kidney disease; ESRD, end stage renal disease; NZ, New Zealand; RAC, regular adult clinic; RRT, renal replacement therapies; YAC, young adult clinic.

Children and young people living with kidney failure had many suggestions about the effective use of technology in the management of their condition. The introduction of an app designed for young people as opposed to a website was suggested because it would facilitate easier usage, accessibility, and would be more interactive with other young people living with kidney failure (Nightingale et al., 2017). Some felt conventional methods such as Facebook were not secure enough while existing websites were not always accessible when using an iPad for example (Huby et al., 2017). The distinction between children and young people was highlighted as children with kidney failure needed specialised language and games designed to help them learn about their condition (Huby et al., 2017). Whereas, for young people the use of technology assisted more to reduce social isolation and allowed young people to view and review clips again about their failure and treatment modalities to keep them well informed (Huby et al., 2017; Nightingale et al., 2017).

TABLE 2 Results of quality assessment.

Study	1	2	3	4	5	6	7	8	9	10
Aoto et al. (2018)	Y	Y	U	U	Y	N	N	Y	Y	Y
Başkale and Başer (2007)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Braj et al. (1999)	Y	Y	U	U	U	N	N	N	Y	U
Ramos et al. (2015)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Coyne et al. (2019)	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Crawford et al. (2021)	Y	Y	Y	U	Y	N	N	Y	Y	Y
Cura (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Finderup et al. (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Gutman et al. (2018)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Huby et al. (2017)	Y	Y	Y	U	Y	N	Y	U	Y	Y
Johnson et al. (2008)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Jose et al. (2021)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Kerklaan et al. (2020)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Kim and Choi (2016)	Y	Y	Y	U	Y	Y	N	Y	Y	Y
Korus et al. (2011)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Michaud et al. (2019)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Murray et al. (2014)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Murray et al. (2019)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Nguyen et al. (2020)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Nicholas et al. (2009)	U	Y	Y	Y	Y	N	N	Y	N	Y
Nicholas et al. (2011)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Nicholas et al. (2018)	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Nightingale et al. (2017)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Nightingale et al. 2022	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Oberdhan et al. (2022)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Poursanidou et al. (2003)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Rupp et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Swallow et al. (2014)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Tong et al. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tong et al. (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tong et al. (2015)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Walker et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Waters (2008)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wells et al. (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Quality assessment Key	
Y	Yes
N	No
U	Unclear

Note: Item number checklist key*: 1—Is there congruity between the stated philosophical perspective and the research methodology?; 2—Is there congruity between the research methodology and the research question or objectives?; 3—Is there congruity between the research methodology and the methods used to collect data?; 4—Is there congruity between the research methodology and the representation and analysis of data?; 5—Is there congruity between the research methodology and the interpretation of results?; 6—Is there a statement locating the researcher culturally or theoretically?; 7—Is the influence of the researcher on the research, and vice versa, addressed?; 8—Are participants, and their voices, adequately represented?; 9—Is the research ethical according to current criteria for recent studies, and is there evidence of ethical approval by an appropriate body?; 10—Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Treatment and healthcare

Many children and young people felt a strong sense of connection with their healthcare providers, and some stated they felt included and part of the decision-making process within management of their kidney failure (Crawford et al., 2022; Finderup et al., 2018). Working in partnership with healthcare professionals allowed young people to learn how to manage and cope with their failure such as effective medication management (Johnson et al., 2008; Nicholas et al., 2011). Conversely, some young people had decisions made for them by their parents due to their young age but this resulted in children and young people feeling helpless within the healthcare system, and without a voice (Gutman et al., 2018; Kim & Choi, 2016). Although some children and young people objected to their parents' decisions regarding their treatment, many still felt they had no choice and had to trust that their parents were making the best decision on their behalf (Crawford et al., 2022; Gutman et al., 2018).

In some instances, there was also a lack of information and reassurance provided by healthcare professionals to young people

TABLE 3 Synthesised findings.

Findings	Categories	Synthesised finding
F6, F57, F83, F118, F119, F120, F121, F122, F148, F159, F165, F166, F169, F187, F189	Symptoms of kidney disease and treatment	Physical The symptoms of kidney disease are distressing and debilitating in severity and significantly impacts the young person's ability to engage in physical activity. Tiredness and fatigue impacted many children and young people while pain and discomfort are also associated with kidney disease and treatment.
F7, F8, F26, F28, F29, F30, F31, F32, F33, F34, F37, F38, F39, F40, F42, F51, F52, F53, F54, F60, F72, F84, F85, F88, F104, F97, F98, F105, F110, F111, F125, F126, F142, F149, F170, F171	Knowledge of kidney disease and treatment Technology	Information and technology A lack of appropriate and timely information resulted in many young people and children feeling unprepared and not knowing what to expect. Using technology in an effective manner was crucial as it that allows them to feel informed, educated, and part of their care.
F7, F8, F26, F28, F29, F30, F31, F32, F33, F34, F37, F38, F39, F40, F42, F51, F52, F53, F54, F60, F72, F84, F85, F88, F104, F97, F98, F105, F110, F111, F125, F126, F142, F149, F154, F163, F168, F169, F174, F175, F181, F186, F188	Treatment collaboration Lifestyle changes Transition of care	Treatment and healthcare Feeling part of their treatment process and being involved was important as many faced difficult challenges when transitioning from paediatric to adult care services. Some people were left to struggle with social and lifestyle alterations from treatment and/or kidney disease management.
F3, F4, F13, F14, F15, F20, F21, F22, F55, F58, F59, F64, F65, F68, F76, F77, F79, F86, F91, F94, F99, F100, F101, F102, F106, F107, F108, F123, F124, F129, F130, F131, F132, F133, F134, F135, F136, F137, F150, F152, F155, F156, F160, F161, F162, F172, F176, F177, F178, F180, F182, F184, F190	Support networks Occupational impacts	Social Young people and children require specialised services to help support and cope in living with kidney disease. Occupational activities such as attending school, sport and potentially engaging in employment were all significantly impacted.
F1, F2, F5, F9, F10, F11, F12, F16, F17, F19, F23, F24, F25, F27, F41, F56, F61, F62, F63, F66, F67, F69, F70, F71, F73, F74, F75, F78, F80, F81, F82, F87, F89, F90, F92, F93, F95, F96, F103, F109, F115, F116, F117, F127, F128, F138, F139, F140, F141, F143, F144, F145, F147, F151, F153, F157, F158, F164, F167, F173, F179, F183, F185	Emotional impact Coping and adapting Identity Future expectations	**Psychological** Living with kidney disease as a young person or child had a significant emotional impact on not only themselves but on caregivers as well. A person's sense of self was impacted as many struggled to predict what their future health condition may look like.

and children. Children and young people expressed that doctors and nurses did not properly inform or prepare them adequately or communicate in a lay language they could understand regarding treatments and procedures (Murray et al., 2014). Poor communication and a lack of reassurance left many feeling scared, with uncertainty in not knowing was happening, or going to happen next in their care (Gutman et al., 2018; Korus et al., 2011; Murray et al., 2014). The underestimation of pain and discomfort during treatment and procedures was evident as healthcare professionals did not clearly articulate and prepare the children and young people for what they may expect to feel during treatment and procedures (Gutman et al., 2018; Korus et al., 2011).

The impact that kidney failure had on the young person's lifestyle was notable in many studies. The strict and continual daily administration of medications became problematic as young people and children disliked the taste, struggled to swallow medication, had issues with scheduled timely administration of their medications, and many struggled with the negative side-effects of their medications (Başkale & Başer, 2011; Gutman et al., 2018; Johnson et al., 2008; Nguyen et al., 2020; Nicholas et al., 2018; Swallow et al., 2014). The social impact of medication administration was very difficult for young people and they avoided taking their medications in front to their friends because this made them look and feel different to everyone else (Gutman et al., 2018; Johnson et al., 2008). Due to the negative social impact and the need for social desirability some young people simply did not take their medications (Swallow et al., 2014).

Over time, remembering to take multiple medications at different times became easier as other patients and health professionals provided useful strategies to assist in regular medication administration (Crawford et al., 2022; Nguyen et al., 2020; Swallow et al., 2014). Self-medication administration was also considered not so bad in comparison to HD treatment, as some children and young people referred to HD as the most unpleasant of all treatment experiences (Ramos et al., 2015; Swallow et al., 2014; Waters, 2008). Dietary restrictions caused great stress and social inconvenience in many situations as young people and children killed their normal dietary routine so they could enjoy food and drinks in peer situations such as parties (Gutman et al., 2018; Kerklaan et al., 2020) while others struggled to reduce salt as it made food tasteless (Başkale & Başer, 2011). Avoiding certain foods and making healthy choices was hard for most young people and children (Ramos et al., 2015).

The kidney clinic became a constant and steady environment for many children and young people that provided resources and services to assist to them in treatment management (Jose et al., 2021). However, the transition from paediatric to adult care was distressing and daunting as many studies indicated that young people were poorly, if at all, prepared for the transition in to adult services (Crawford et al., 2022; Gutman et al., 2018; Nicholas et al., 2018). The support and familiarity within the paediatric services was lacking within the adult kidney services, because young people were then automatically expected to be independent and do a lot more for themselves (Crawford et al., 2021; Gutman et al., 2018). Parental inclusion and involvement were frowned upon in adult services as young people were considered independent adults and expected to make decisions about their own health and failure management (Crawford et al., 2022; Gutman et al., 2018). Furthermore, the very clinical and seemingly more sterile environment of the adult kidney services made some young people feel uncomfortable, and they expressed they were being treated like another number and not a person (Crawford et al., 2022).

Social needs

Several studies emphasised the need for meaningful support networks to cope with illness and treatment and to provide practical support and advocacy for young people and children (Aoto et al., 2018; Korus et al., 2011; Michaud et al., 2019; Nicholas et al., 2011; Poursanidou et al., 2003; Rupp et al., 2021; Wells et al., 2013). Children and young people described their support networks largely being immediate family, partner, friends, health professionals and other professionals (Aoto et al., 2018; Cura, 2012; Kim & Choi, 2016; Michaud et al., 2019; Nicholas et al., 2011; Poursanidou et al., 2003; Wells et al., 2013). Although children and young people needed support, they outlined the significant impact and strain that kidney failure had on their existing support networks (Başkale & Başer, 2011; Coyne et al., 2019; Kerklaan et al., 2020) and described experiences of social isolation and a sense of burden on those around them (Başkale & Başer, 2011; Coyne et al., 2019; Kerklaan et al., 2020; Tong et al., 2011). Three studies described a challenging dynamic of the young person and their caregiver—particularly their mother (Gutman et al., 2018; Kerklaan et al., 2020; Kim & Choi, 2016). Young people described their relationship as complex because of feeling over-protected, restricted, and smothered whilst simultaneously being pushed to be independent and autonomous (Gutman et al., 2018; Kerklaan et al., 2020; Kim & Choi, 2016). This complex relationship was further complicated among those who had received a kidney transplant from their caregiver, and felt obliged to accept the involvement in their care regardless of how they felt about it (Gutman et al., 2018; Kim & Choi, 2016).

Several studies identified the challenges to existing social connections and engaging with peers (Kerklaan et al., 2020; Rupp et al., 2021). A major challenge was disclosing their illness and worrying about the impact of revealing their diagnosis and potential change or loss of relationship consequently (Coyne et al., 2019; Nicholas et al., 2011; Rupp et al., 2021). A balance between general friends and kidney friends was described as important to allow for connection between like-minded peers but also a connection to the world outside of their illness (Coyne et al., 2019; Jose et al., 2021; Kerklaan et al., 2020; Nicholas et al., 2009).

Several studies described the impact of managing kidney failure on occupational activities, such as the burden of clinic and treatment appointments making it difficult to attend activities such as work and school (Başkale & Başer, 2011; Kerklaan et al., 2020; Murray et al., 2019, 2014; Nicholas et al., 2011; Oberdhan et al., 2022). These impacts to occupational activities had associated short- and long-term effects. Young people and children reported feeling fatigued after treatment, with long absences associated with reduced motivation to attend school and consequently having to work harder to catch up on missed work (Başkale & Başer, 2011; Nicholas et al., 2011; Poursanidou et al., 2003; Rupp et al., 2021). These factors led to poorer school performance which negatively impacted their confidence and they articulated their felt less capable than their peers (Kerklaan et al., 2020; Poursanidou et al., 2003). In addition to missing school, young people also described a loss of valued activities such as sports and social activities which was associated with feelings of frustration and loss (Aoto et al., 2018; Kerklaan et al., 2020; Nicholas et al., 2011; Oberdhan et al., 2022).

Three studies described the significant life impacts of managing kidney failure including delayed psychosocial development and delayed independence. In many cases young people of working age felt dependent on others due to their inability to be financially independent (Kerklaan et al., 2020; Michaud et al., 2019; Rupp et al., 2021). Even after achieving transplant, young people describe the unique challenges of building their lives alongside kidney failure management (Kerklaan et al., 2020; Michaud et al., 2019). Young people needed to reframe their career goals and find occupations that could accommodate their physical needs (Kerklaan et al., 2020). Despite the significant negative impacts of managing their kidney failure, young people want to attend school and work to try and gain a sense of normalcy and to contribute to the world around them (Kerklaan et al., 2020; Michaud et al., 2019; Rupp et al., 2021).

Psychological impacts

Children and young people experienced negative psychological and emotional impacts due to living with kidney failure (Aoto et al., 2018;

Başkale & Başer, 2011; Kerklaan et al., 2020; Nicholas et al., 2011; Oberdhan et al., 2022; Ramos et al., 2015; Tong et al., 2013). Understanding the diagnosis and prognosis of kidney failure was associated with significant emotional impacts to the young person and their family (Aoto et al., 2018; Başkale & Başer, 2011; Cura, 2012; Johnson et al., 2008; Kerklaan et al., 2020). Many young people describing feelings of shame, low self-esteem and being a burden due to their diagnosis (Kerklaan et al., 2020; Ramos et al., 2015; Tong et al., 2013). Young people described ongoing fear which was exacerbated by the worry of potential adverse outcomes to treatments (Ramos et al., 2015; Tong et al., 2013; Oberdhan et al., 2022).

Despite challenging experiences, children and young people described the need to learn new ways to cope with their illness and find joy in their lives (Kerklaan et al., 2020; Kim & Choi, 2016; Michaud et al., 2019; Tong et al., 2013; Wells et al., 2013; Finderup et al., 2018). Many children and young people expressed a sense of determination to overcome the challenges and limitations of living with kidney failure and do normal things alongside their peers (Başkale & Başer, 2011; Kerklaan et al., 2020; Korus et al., 2011; Michaud et al., 2019; Nicholas et al., 2011; Ramos et al., 2015). Many children and young people sought positive coping strategies, they describe having constant reminders that they have an illness and needed to be cautious to avoid further negative impacts on their health (Kerklaan et al., 2020; Michaud et al., 2019).

The experience of kidney failure had a significant impacts on the identity of the young person because they needed to re-establish themselves alongside their kidney failure (Aoto et al., 2018; Kerklaan et al., 2020; Kim & Choi, 2016; Korus et al., 2011; Poursanidou et al., 2003) and some described this as a catalyst for growth and self-discovery (Braj et al., 1999; Nicholas et al., 2011; Tong et al., 2015). However, for many young people the experience of kidney failure left lasting emotional scars which affected the way they seen themselves (Kim & Choi, 2016; Korus et al., 2011; Waters, 2008). Body image was described as ostracization and some were bullied for the way they looked and moved their bodies (Başkale & Başer, 2011; Kim & Choi, 2016; Korus et al., 2011; Poursanidou et al., 2003).

Several studies described that children and young people had fears of death and dying (Başkale & Başer, 2011; Coyne et al., 2019; Oberdhan et al., 2022; Tong et al., 2013; Walker et al., 2019). Young people on HD viewed this as end to life and were distressed due to the uncertainty of whether they could find a donor (Başkale & Başer, 2011; Kim & Choi, 2016; Walker et al., 2019). The concept of living forever with HD or that their graft might fail impacted the young persons' outlook on their existence and their future (Başkale & Başer, 2011; Kerklaan et al., 2020; Murray et al., 2019, 2014; Tong et al., 2013; Walker et al., 2019).

DISCUSSION

This systematic review set out to understand the experiences and perceived supportive care needs among children and young people affected by kidney failure which has several important considerations for future research and clinical practice. What is clear from this evidence synthesis research work is that the impact of kidney failure and associated treatments are debilitating which affected multiple aspects of young people and children's lives. The experiences and voices of children and young people represented in this review identify that many experience unmet supportive care needs despite contact with healthcare professionals and their primary caregivers. Children and young people living with kidney failure have complex requirements for care related to physical, informational, social, psychological and healthcare professional needs. This review has provided important key areas that require urgent attention within existing healthcare services for young people and children living with this long-term condition.

Emotional and psychological needs were identified and underscores fundamental short-comings in care which were cross-cutting over other areas of care need domains. Children and young people reported a lack of informational support and available resources to help them understand their condition and treatment in a manner that was understandable to them. Kidney care for children and young people should take a holistic approach to tailor care at an individual level for all aspects of a young person's life. Over the past decade, there has been an important landscape shift by healthcare services to enable family centred models of care (Institute for Patient and Family Centered Care, 2020; Lloyd et al., 2018). Importantly, Patient and Family Centred Care (Institute for Patient and Family Centered Care, 2020) clearly identifies that the young person or child and their family/primary caregiver are central and both bring separate and unique entities, both individuals will require communication and collaboration, but most importantly, care is delivered in partnership with their trained healthcare professional team.

One important aspect illuminated in this review was that many children and young people grappled with significant pain and fatigue levels because of the failure and treatment, and importantly expressed that they were ill prepared for clinical procedures which inflicted more pain on them. Providing timely access to expert members of the multidisciplinary team, for example, specialist nurses, exercise physiologists, psychologist, dieticians and healthcare professionals such as nurses who are expert in pain management is central in optimising supported self-management in this young patient population. Self-management is a term used to describe a person's confidence and ability to manage the physical and psychological impacts of a condition and associated symptoms and side-effects of treatment to optimise overall quality of life and recovery (Barlow et al., 2002). This review has identified that many children and young people are not being adequately supported to develop optimal self-management skills and healthy lifestyle behaviours because of a lack of partnership with their primary caregivers and their kidney healthcare professionals. Future research should consider a codesign approach and the use of technology in supporting self-management in this young patient population, given young people and children expressed that they valued technologies.

Strengths and limitations

This systematic review was conducted using a transparent process throughout the review stages. However, were several shortcomings to point out. First, this review is representative of studies published in the English language only, and therefore experiences among other ethnic groups or countries may not be represented in this review. Second, the findings of this review are confined to the evidence presented across the included qualitative studies. Furthermore, we were not able to discern different experiences of supportive care across different demographics (age, gender) or clinical factors (time since diagnosis, stage, treatments) across the 506 participants represented in this review. This review has identified that this area is an emerging focus for research and clinical practice but may not represent all experiences of supportive care in children and young people but has enable a critical synthesis of all available existing research to inform future research directions. A strength to this review was that it illuminated experiences of supportive care through the voices of young people and children themselves, and our research team also included a young consumer affected by kidney failure.

Implications for clinical practice

This systematic review has provided insight into the unique supportive care experiences among children and young people living with kidney failure. All members of the multidisciplinary team should reflect on these findings and use them to inform individualised care within a Patient and Family Centred Kidney Care Model. Healthcare professionals should take an increasing active approach to optimise communication, informational support and provide timely reassurance to deliver supported self-management for this young vulnerable population. The importance of access to experienced healthcare professionals including kidney nurses can assist in advising the most appropriate care pathway given the negative impacts that living with kidney failure has on individuals' physical and psychological health.

CONCLUSION

This systematic review has identified that many children and young people affected by kidney failure can experience of supportive care needs not being met within existing services. Kidney failure impacted children and young people's self-identify, social and peer networks, introduced daily practical needs because of inherent physical and psychological burden due to the failure and associated treatments. Despite improvements in the medical management of kidney failure in young people and children, further attention is needed to optimise supported-self-management in this young patient group.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

C. Paterson: Conceptualization, methodology, validation, formal analysis, interpretation, writing—original draft, writing—reviewing and editing, supervision. **M. Turner:** Literature search, formal analysis, writing—original draft, writing—reviewing and editing. **A. Mckie:** Methodology, validation, formal analysis, interpretation, writing—original draft, writing—reviewing and editing. **M.-E. Hooper:** Validation, formal analysis, interpretation, writing—original draft, writing—reviewing and editing. **E. Ladbrook:** Validation, writing—reviewing and editing. **L. Macauley:** Validation, writing—reviewing and editing, expert representative consumer advice.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Supplementary Table 1. ENTREQ checklist (Enhancing transparency in reporting the synthesis of qualitative research)

No. Item	Guide Questions/Description	Reported on Page
1. Aim	A meta-aggregation was conducted to identify the experience of supportive care needs of children and young people affected by kidney disease .	4
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	6
3. Approach to searching	The search was pre-planned. Comprehensive search strategies were undertaken to seek all available studies.	5
4. Inclusion criteria	Inclusion criteria All published studies exploring experiences of supportive care needs of children and young people affected by kidney disease. Only original qualitative studies published in English in peer-reviewed journals were assessed. Exclusion criteria This review excluded case reports, reviews, commentaries, editorials, or studies with no clear data on unmet supportive care needs.	4
5. Data sources	The CINAHL, MEDLINE, PsychINFO, Scopus, and Cochrane (CCTR and CDSR) controlled trials databases and clinicaltrials.gov were searched for all relevant publications (from January 1990 – September 2022, English and non-English language studies).	5
6. Electronic search strategy	The search architecture was designed by an expert systematic review librarian and the management of citations was conducted using Endnotex9 (Clarivate Analytics, PA, USA). The search used a wide range of keywords and free text items to increase the sensitivity and inclusiveness of the searches, see Supplementary Table 2.	5, Supplementary Table 2
7. Study screening methods	Overview of the study screening methods	5
8. Study characteristics	Table 1 presents the characteristics of the included studies (author(s), year of publication, country, population, number of participants, data collection, methodology, analysis and limitation of the studies).	Table 1
9. Study selection results	A flow diagram using PRISMA guidelines for reporting of systematic reviews is presented in Figure 1 in reporting of the selection process and results.	Figure 1
10. Rational for appraisal	All studies meeting the PICo (participant, phenomenon of interest, context) inclusion criteria were assessed using the JBI Critical Appraisal Checklist for Qualitative Research. The 10-item,	5

	Critical Appraisal Checklist instrument assesses congruity between the philosophical/theoretical position adopted in the study, study methodology, study methods, the research question, the representation of the data, and the interpretation of the findings of each of the selected studies. The item ratings of each appraisal were consolidated and represented in a final quality appraisal table as agreed by two reviewers.	
11. Appraisal Items	Appraisal Checklist for Qualitative Research. The 10-item, Critical Appraisal Checklist instrument assesses congruity between the philosophical/theoretical position adopted in the study, study methodology, study methods, the research question, the representation of the data, and the interpretation of the findings of each of the selected studies.	Table 2
12. Appraisal Process	Appraisal was conducted independently by two independent reviewers. The two reviewers discussed if consensus was required.	5
13. Appraisal Results	Appraisal Results presented in Table 2.	Table 2
14. Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies.	5
15. Software	State the software used.	5
16. Number of reviewers	Identify who was involved in coding and analysis.	5
17. Coding	Describe the process for coding of data	5
18. Study comparison	Describe how were comparisons made within and across studies	5
19. Derivation of themes	Explain whether the process of deriving the themes	6
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	Supplementary Table 2
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies	Table 3

Supplementary Material

Supplement 2 - Database searches for systematic review on unmet supportive care needs of children affected by renal disease.

Cumulative Index of Nursing and Allied Health Literature (CINAHL)			
Date of search: 20/09/2022			
Symbols used in this document:			
MH = CINAHL Subject Heading			
+ = Explodes the CINAHL Subject Heading			
“ ” finds a phrase			
Asterisk * = Truncates the stem of a word to find all endings			
N5 = finds words that are 5 words or less away from each other			
Search	**Concept**	**Search Terms/Strategy**	**# of Results**
#1	Children and young people	((MH "Adolescence+") OR (MH "Child+") OR (MH "Young Adult")) OR adolescent* OR child* OR teen* OR young OR youth*	1,551,799
#2	Renal diseases	((MH "Kidney Diseases+") OR (MH "Kidney, Cystic+") OR (MH "Polycystic Kidney, Autosomal Recessive") OR (MH "Polycystic Kidney, Autosomal Dominant") OR (MH "Kidney Failure, Chronic+") OR (MH "Renal Insufficiency+") OR (MH "Diabetic Nephropathies") OR (MH "Renal Replacement Therapy+")) OR kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD	152,071
#3	Supportive care needs	((MH "Health Services Needs and Demand+") OR (MH "Needs Assessment")) OR ((physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) N5 (need* OR support*))	878,814
#4	Qualitative research	(MH "Qualitative Studies+") OR attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured	1,628,311
#5		#1 AND #2 AND #3 AND #4	922
	English language	Limiter applied	871

Cochrane Library (Database of Systematic Reviews and Central Register of Controlled Trials)			
Date of search: 20/09/2022			
Symbols used in this document:			
“ ” finds a phrase			
Asterisk * = Truncates the stem of a word to find all endings			
NEAR = finds words that are 6 words or less away from each other			
Search	**Concept**	**Search Terms/Strategy**	**# of Results**
#1		MeSH descriptor: [Adolescent] explode all trees	110,535
#2		MeSH descriptor: [Child] explode all trees	61,855
#3		MeSH descriptor: [Young Adult] explode all trees	72,786
#4		(adolescent* OR child* OR teen* OR young OR youth*):ti,ab,kw	341,421
#5	Children and young people	#1 OR #2 OR #3 OR #4	341,421
#6		MeSH descriptor: [Polycystic Kidney, Autosomal Dominant] explode all trees	182
#7		MeSH descriptor: [Polycystic Kidney Diseases] explode all trees	206
#8		MeSH descriptor: [Kidney Diseases, Cystic] explode all trees	5
#9		MeSH descriptor: [Polycystic Kidney, Autosomal Recessive] explode all trees	0
#10		MeSH descriptor: [Kidney Diseases] explode all trees	383
#11		MeSH descriptor: [Renal Insufficiency, Chronic] explode all trees	165
#12		MeSH descriptor: [Kidney Failure, Chronic] explode all trees	66
#13		MeSH descriptor: [Diabetic Nephropathies] explode all trees	1,564
#14		MeSH descriptor: [Renal Replacement Therapy] explode all trees	9,702
#15		(kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency” OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD):ab	54,980
#16	Renal diseases	#6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15	56,129
#17		MeSH descriptor: [Health Services Needs and Demand] explode all trees	493
#18		MeSH descriptor: [Needs Assessment] explode all trees	376
#19		((physical OR psychological OR psychosocial OR social OR emotion* OR interperson* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) NEAR (need* OR support*)):ab	56,080
#20	Supportive care needs	#17 OR #18 OR #19	56,621
#21		MeSH descriptor: [Qualitative Research] explode all trees	1,337
#22		(attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR	408,211

		observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured) OR AB (attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured):ti,ab,kw	
#23	Qualitative research	#21 OR #22	385,523
#24		#5 AND #16 AND #20 AND #23	61
• 61 includes 9 Systematic Reviews and 52 Trials			

MEDLINE			
Date of search: 20/09/2022			
Symbols used in this document:			
MH = Medical Subject Heading (MeSH)			
+ = Explodes the “MeSH”			
“ ” finds a phrase			
Asterisk * = Truncates the stem of a word to find all endings			
N5 = finds words that are 5 words or less away from each other			
Search	**Concept**	**Search Terms/Strategy**	**# of Results**
#1	Children and young people	((MH "Adolescent") OR (MH "Child+") OR (MH "Young Adult")) OR adolescent* OR child* OR teen* OR young OR youth*	5,033,324
#2	Renal diseases	((MH "Polycystic Kidney, Autosomal Dominant") OR (MH "Polycystic Kidney Diseases+") OR (MH "Kidney Diseases, Cystic+") OR (MH "Polycystic Kidney, Autosomal Recessive") OR (MH "Kidney Diseases+") OR (MH "Renal Insufficiency, Chronic+") OR (MH "Kidney Failure, Chronic+") OR (MH "Diabetic Nephropathies") OR (MH "Renal Replacement Therapy+")) OR kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD	873,922
#3	Supportive care needs	((MH "Health Services Needs and Demand+") OR (MH "Needs Assessment")) OR ((physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) N5 (need* OR support*))	2,125,203

#4	Qualitative research	(MH "Qualitative Research+") OR attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured	3,734,684
#5		#1 AND #2 AND #3 AND #4	2,799
	English language	Limiter applied	2,577

Proquest (Health & Medical Collection and Nursing & Allied Health Database)			
Date of search: 20/09/2022			
Symbols used in this document:			
“ ” finds a phrase			
Asterisk * = Truncates the stem of a word to find all endings			
N/5 = finds words that are 6 words or less away from each other			
Search	**Concept**	**Search Terms/Strategy**	**# of Results**
#1		mesh(adolescent)	155,217
#2		mesh(child)	141,045
#3		mesh(Young Adult)	71,542
#4		ti(adolescent* OR child* OR teen* OR young OR youth*) OR ab(adolescent* OR child* OR teen* OR young OR youth*)	1,135,091
#5	Children and young people	#1 OR #2 OR #3 OR #4	1,281,410
#6		mesh(Polycystic Kidney, Autosomal Dominant)	403
#7		mesh(Polycystic Kidney Diseases)	454
#8		mesh(Kidney Diseases, Cystic)	276
#9		mesh(Polycystic Kidney, Autosomal Recessive)	86
#10		mesh(Kidney Diseases)	11,969
#11		mesh(Renal Insufficiency, Chronic)	1,550
#12		mesh(Kidney Failure, Chronic)	8,449
#13		mesh(Diabetic Nephropathies)	2,923
#14		mesh(Renal Replacement Therapy)	548
#15		ti(kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD) OR ab(kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD)	149,071
#16	Renal diseases	#6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15	157,774
#17		mesh(Health Services Needs and Demand)	7,605
#18		mesh(Needs Assessment)	6,035

#19		ti(((physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) N/5 (need* OR support*))) OR ab(((physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) N/5 (need* OR support*)))	257,127
#20	Supportive care needs	#17 OR #18 OR #19	267,467
#21		mesh(qualitative research)	4,793
#22		ti(attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured) OR ab(attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured)	1,491,587
#23		#21 OR #22	1,492,029
#24	Qualitative research	#5 AND #16 AND #20 AND #23	210
#25	English language	Limiter applied	197

<table>
<tr><td colspan="4">PsycINFO</td></tr>
<tr><td colspan="4">Date of search: 2022/09/22</td></tr>
<tr><td colspan="4">Symbols used in this document:</td></tr>
<tr><td colspan="4">“   ” finds a phrase</td></tr>
<tr><td colspan="4">Asterisk * = Truncates the stem of a word to find all endings</td></tr>
<tr><td colspan="4">N5 = finds words that are 5 words or less away from each other</td></tr>
<tr><td>Search</td><td>Concept</td><td>Search Terms/Strategy</td><td># of Results</td></tr>
<tr><td>#1</td><td>Children and young people</td><td>adolescent* OR child* OR teen* OR young OR youth*</td><td>1,422,124</td></tr>
<tr><td>#2</td><td>Renal diseases</td><td>kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD</td><td>13,763</td></tr>
</table>

#3	Supportive care needs	(physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) N5 (need* OR support*)	1,076,300
#4	Qualitative research	attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured	2,050,746
#5		#1 AND #2 AND #3 AND #4	431
	English language	Limiter applied	408

Scopus			
Date of search: 2022/09/22			
Symbols used in this document:			
“ ” finds a phrase			
Asterisk * = Truncates the stem of a word to find all endings			
W/5 = finds words that are 5 words or less away from each other			
Search	**Concept**	**Search Terms/Strategy**	**# of Results**
#1	Children and young people	adolescent* OR child* OR teen* OR young OR youth*	6,268,401
#2	Renal diseases	kidney-disease OR renal-disease OR renal-failure OR kidney-failure OR renal-insufficiency OR dialysis OR pre-dialysis OR predialysis OR hemodialysis OR haemodialysis OR peritoneal-dialysis OR kidney-transplant* OR renal-transplant* OR ESRF OR ESKF OR ESRD OR ESD OR CKF OR CKD ORCRF OR CRD OR CAPD OR CCPD OR APD	8,664
#3	Supportive care needs	(physical OR psychological OR psychosocial OR social OR emotion* OR inter-person* OR family OR caregiver* OR partner OR spous* OR intima* OR practical OR financial OR employment OR daily-living OR housekeeping OR nutrition* OR diet* OR exercise OR spiritual OR existential OR end-of-life OR bereavement OR decision* OR cognitive OR patient-clinician OR health-care OR sadness OR fear OR pain OR isolat* OR lonel* OR information* OR transition*) W/5 (need* OR support*)	1,126,805
#4	Qualitative research	attitude* OR content-analysis OR discourse-analysis OR experience* OR face-to-face OR focus-group OR interview* OR observation* OR phenomenology OR qualitative OR questionnaire* OR themes OR semi-structured OR structured OR unstructured	8,763,728
#5		#1 AND #2 AND #3 AND #4	17
	English language	Limiter applied	15

Supplementary Table 3: Excluded studies

Author	**Title**	**Reason for exclusion**
Abed et al. 2020	Functional health literacy and caregiving burden among family caregivers of patients with end-stage renal disease	Wrong patient population
Agerskov et al. 2019	Parents' experiences of donation to their child before kidney transplantation: A qualitative study	Wrong patient population
Agerskov et al. 2020	The significance of relationships and dynamics in families with a child with end-stage kidney disease: A qualitative study	Wrong patient population
Bailey et al. 2018	Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies	Wrong study design
Beanlands et al. 2020	Through the Lens of Chronic Kidney Disease: A Qualitative Study of the Experiences of Young Women Living With CKD	Wrong patient population
Dallimore et al. 2018	Why is transition between child and adult services a dangerous time for young people with chronic kidney disease? A mixed-method systematic review	Wrong study design
Gafton et al. 2019	G228 Understanding the experience of young people undergoing maintenance haemodialysis therapy in an adult unit	Wrong study design
Gallo et al, 1991	Description of the illness experiences by adolescents with chronic renal disease.	Editorial
Massengill, & Ferris 2014	Chronic kidney disease in children and adolescents. Pediatrics in Review	Editorial
McCaffery Sweeney et al. 2021	Self-management in healthcare transition for adolescents with renal transplants and their caregivers	Wrong study design
Mitchell, et al. 2009	Patients' experience of transition onto haemodialysis: A qualitative study	Wrong patient population
Molzahn et al. 1998	Children and adolescents of parents undergoing dialysis therapy: their reported quality of life	Wrong patient population
Nicholas et al. 2013	Examining transitions from adolescent to adult care for youth with chronic kidney disease	Wrong publication type – conference abstract
Nightingale et al. 2019	P18 Supporting young people to develop independence in managing their long-term condition	Wrong study design
Nightingale et al. 2014	Using focused ethnography in paediatric settings to explore professionals' and parents' attitudes towards expertise in managing chronic kidney disease stage 3-5	Wrong patient population
Shaw et al, 2010	Transition of adolescents to young adulthood for vulnerable populations	Editorial
Snethen et al. 2001	Adolescents' perception of living with end stage renal disease	Wrong study design
Woodland 2012	Giving young people with chronic kidney disease a voice in planning healthcare services	Wrong publication type – conference abstract

Supplementary Table 4. Study findings and illustrations

Study	Evidence	Unequivocal	Credible	Not supported	Finding Number
Study	**Aoto et al. 2018**				
Finding	**Emotional impact on being informed of disease**				
Illustration	"My doctor suddenly told me that I have a disease, but it is difficult to conceive, and I don't believe that I have a disease" p169	X			F1
Finding	**Social challenges of treatment and resulting identity diffusion**				
Illustration	"I wish that I did not have the disease. If I did not have it, I could do what I wanted" p169	X			F2
Finding	**Emotional conflict on school return**				
Illustration	"I wondered whether I should tell my friends about the disease" p170	X			F3
Finding	**Resilience and related factors**				
Illustration	"My teacher encouraged me when I was worried because I could not keep up with studies" p170	X			F4
Finding	**Re-establishment of identity**				
Illustration	"I am different from everyone else so it is no use comparing myself with others" p171	X			F5
Study	**Baskale & Baser 2007**				
Finding	**Difficulties with physiological effects of haemodialysis**				
Illustration	"The machine is too bad. I have a headache after dialysis sessions. My blood pressure sometimes drops. I feel exhausted and I can't walk. Also, I'm afraid" p421	X			F6
Finding	**Issues with medication compliance**				
Illustration	"I'm bored with taking medications. I'm taking them by force. I don't want to take them" p423	X			F7
Finding	**Issues complying with dietary restrictions**				
Illustration	"Eating without salt is too difficult. I don't adhere to my diet. Because I can't eat unsalted meals. I feel as if it is tasteless" p423	X			F8
Finding	**Feelings of anger, anxiety, depression, and withdrawal**				
Illustration	"They (people) pity me. This affects me badly. I don't want them to pity me. I'm a person too. Being ill isn't a crime. I'm angry" p423	X			F9
Finding	**Feeling different/body image problems**				
Illustration	"I have the same height since (I was) 6 years. Everybody looks at me as if I'm a little child" p423	X			F10
Finding	**Fear of death**				
Illustration	"I'm afraid of the machine (HD). Because of this I didn't have the dialysis treatment for 6 months. Nobody knew this. I'm afraid of dying" p424	X			F11
Finding	**Coping behaviours and what helps**				
Illustration	"They are like my family. Because I celebrated Mother's Day and Father's Day in dialysis centre. Doctors are like my brother and father, nurses are like my mother" p424	X			F12
Finding	**Relationships with family and friends**				
Illustration	"My mother and father often began to argue. It affected both economics and morale. My father worried a lot, my mother had stomach problems. It is difficult economically to travel to the haemodialysis centre. I feel as if I'm a burden on my family members' shoulder" p424	X			F13
Finding	**Social isolation**				

Illustration	“I rarely go outside. Also, nobody comes my home. Because I’m ill. I have so few friends” p425	X			F14
Finding	**School problems**				
Illustration	“I miss lessons and examinations. This means I have to study harder than my friends. And studying hard causes tiring and losing weight” p425	X			F15
Finding	**Future expectations**				
Illustration	“I hope to go to school in the future. Also, I think about transplantation. And I worry about what will happen in the future if I can’t have a transplantation” p426	X			F16
Study	**Braj et al. 1999**				
Finding	**Ownership**				
Illustration	“Its your dialysis and nobody else’s” p4	X			F17
Finding	**Knowledge of dialysis**				
Illustration	It kept pushing me because I had to lean all of these things and when I got it right, I’d feel good. It makes you think a lot. It feels kinda good; real good”.p4	X			F18
Finding	**Being accountable**				
Illustration	“I do everything myself. Very mature and responsible” p4	X			F19
Study	**Coyne et al. 2019**				
Finding	**Disclosure challenges—how and when?**				
	‘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 ’p23	X			F20
Finding	**Managing support networks**				
Illustration	‘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’ p24	X			F21
Finding	**Relationship strains and carer needs**				
Illustration	‘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 ’ p24	**x**			F22
Finding	**Happy ever after**				
	‘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’ p25	**x**			F23
Study	**Costa Ramos et al. 2015**				
Finding	**Feelings of adolescents with CKD about the disease: fear sadness and anger**				
Illustration	“it’s good for our health, because we get better, but it’s bad for the head. We think nonsense, get ashamed and sometimes have to be hospitalized […] I’m afraid of dying, afraid of suffering without access to dialysis, because I have seen many people like that.’ p1431	**X**			F24
Finding	**Expectations of adolescents related to coping and adapting to the illness: Desire to overcome the limitations of the illness, especially hemodialysis**				
Illustration	“There are days when I get sad, but then it’s over, because I still want to study hard and have a good job, because I dream of better days” p1431	**X**			F25
Finding	**Changes in the lifestyle of the adolescents on haemodialysis: Negative impact**				
Illustration	“The disease itself is not so bad, because you only have to go to the consultation and take the medication.	**X**			F26

	The worst is that over time I had to start dialyzing. Then things got really worse. But eventually we got used to it" p1431				
Finding	**Impact of the treatment routine on the mental health of adolescents**				
Illustration	"Haemodialysis is boring and tiring. […] Those who make this treatment are always anxious and worried, willing to know if something will happen, because we so many sad things" p1432	**X**			F27
Study	**Crawford et al. 2021**				
Finding	**Leaving the comfort of paediatric care**				
Illustration	"I guess I was quite a bit – a little sad because, the paediatric team I knew very well and worked with them, that they worked with me for a long time and they knew me" p6	**X**			F28
Finding	**Advocacy through mothers**				
Illustration	"I am used to like looking at mum, and then she just answers" p7	**X**			F29
Finding	**Daunting and intimidating adult clinic**				
Illustration	"Kind of daunting when I went and I just see old people waiting and there's me, young, and I feel like they're all just looking at me" p8	**X**			F30
Finding	**Continuity of care in the adult clinic**				
Illustration	"I just went to my new appointment, like nothing. It was just like going to another appointment" p9	**X**			F31
Finding	**Adherence to self-care (medications)**				
Illustration	"Pay attention and stay on top of them" p10	**X**			F32
Finding	**Transition to adulthood**				
Illustration	"Try and actually understand what's going on" p12	**X**			F33
Finding	**Preparing adolescents and young adults**				
Illustration	"They always made me feel like it was my choice and my decision, with the things that I wanted to do. If they had just continued talking to my parents as if I wasn't there, or wasn't making decisions, then I would have felt really left out of the whole process, with my transplant, and things like that. But they didn't do that, they made sure that I was always included" p13	**X**			F34
Study	**Gutman et al 2018**				
Finding	**Unprepared and ill-informed**				
Illustration	"I wanted to know if I would get better, but the answer she said didn't actually make any sense. Something printed out in words that I could understand [would be useful]" p552	x			F35
Finding	**Suspicion of censorship**				
Illustration	"My mom was crying about it, and I was like, "Why are you crying, what's going on?" And she was like, "You might have a transplant". And I was like, "What's that?" And she wouldn't tell me because I was young" p552	x			F36
Finding	**Identifying opportunities for control and inclusion**				
Illustration	"I started doing all my medications, I want it to get to the point where I don't need them to do anything. Not depend on my parents, or fixing the medications I need to take, or the dosages" p553	x			F37
Finding	**Empowering participation in children**				
Illustration	"I'm just worried 'cause you're like, at the moment it's in your mum and dad's hands, when you get older you've got to take it into your own hands, got to know about	x			F38

	the medications and stuff” p553				
Finding	**Negotiating broader life impacts**				
Illustration	“Sometimes we want to hang out with friends, go out, have fun, be normal kids. We really can’t with medications, we have restrictions. Like, You can’t do this, you might get sick. You can’t do this, you might get sick. We have so much we can’t” p553	x			F39
Finding	**Choosing to defer decisional burden**				
Illustration	“Doctors should have that reassurance, like “it’ll be okay” p554	x			F40
Finding	**Overprotected and overruled**				
Illustration	“I feel like that can be stressful at home, because your parents are protective - “Hey, have you taken your medication?” “Are you sure?” p554	x			F41
Finding	**Struggling to voice own preference2**				
Illustrations	“had to do something like this for my psychologist because I didn’t take my tablets because they made me sick. We had to write a whole list down of what was important and what was not. ..I didn’t take my tablets because they made me sick… Oh they are disgusting! I took a sip and I threw up. They said if I didn’t drink it I wouldn’t be able to eat. I still ate. But I didn’t drink it….” p554	x			F42
Study	**Huby et al. 2017**				
Finding	**Access to the application on all platforms and devices**				
Illustrations	“…I’d find it good if I could use it on my iPad if I can find it accessible… Yeah because some websites that I can’t access because they’ve got Flash Player which is really frustrating …” p129	X			F43
Finding	**Access: Presence of Wi-Fi signal in the hospital**				
Illustrations	“It would jut be really good because I Skype with my friends…so I don’t feel that I can’t see any of my friends or talk to them” p129	X			F44
Finding	**Information clarity: Quick access to key information**				
Illustrations	“…Having useful information. Not just everything there, just the main stuff….” p129	X			F45
Finding	**Information accuracy: Trustworthy, checked by health professionals. Contrasted with uncertainty of accuracy of information from certain websites**				
Illustrations	“…they might not be the right thing, they might just be about – I don’t know – someone who’s done a blog or something like that” p129	X			F46
Finding	**Normalcy: Would not access the information when not in hospital**				
Illustrations	“No, because when I’m not in the hospital, I, just, have a normal life” p130	X			F47
Finding	**Accessibility: Information needs to be age appropriate**				
Illustrations	“…a section for younger kids, which is more games and stuff to help them learn, and then a part for older people, more my age, that would obviously read a bit more…” p129	X			F48
Finding	**Accessibility: Videos may reduce travelling for treatment**				
Illustrations	“Yeah, had to come over quite a lot of times and it’s quite far as well…so if we did have videos it would be much better” p130	X			F49
Finding	**Accessibility: Security**				
Illustrations	“I don’t really like the idea of it being on Facebook…I mean people can hack into you to see what you’ve been writing and people can, without hacking into you; see what you’ve written…” p130	X			F50
Study	**Johnston et al. 2008**				

Finding	**Circuitous route to appropriate care.**				
Illustration	“I didn’t go to the doctor, or anything. But I felt very bad . . . at that time they didn’t know that I had a kidney disease . . . you know, over there [in rural Mexico] many believe in witchcraft. And they thought that a woman was harming me.]” p95	x			F51
Finding	**Working with doctors**				
Illustration	“I . . . I am a planner. I would try, as much as I could, to ask about whatever they said. So they would offer some literature, and I’d read it . . . If there was something I thought was important that I didn’t understand, I’d ask about it” p96	x			F52
Finding	**Medication adherence**				
Illustration	“. . . it [medication] tastes like cement . . . like cement with onion and . . . since I hate onion, it’s . . . I don’t know I just hate it.” p96	X			F53
Study	**Jose et al. 2019**				
Finding	**The model of care: young adults liked the clinic**				
Illustration	“It’s just that the clinic runs from 9 to 12, and if you just show up whenever, you can talk to the doctor, go get some food or something, and then play some games, and there’s not a set…it’s not like a set timetable. It’s not like a schedule. It’s just whatever you want to do” p87	X			F54
Finding	**Peer support valued by the young adults**				
Illustration	“The main purpose is to obviously talk to [specialist] about my health and what’s going on but as well as to see the others…The thing I like most about the clinic is being able to do stuff with the others” p87	X			F55
Finding	**Transition towards self-management: building life skills**				
Illustration	“I think my social interactions. I’m more confident to talk to people about what happened and what I’m going through” p87	X			F56
Study:	**Kerklaan et al., 2020**				
Finding	**Debilitating symptoms and side effects**				
Illustration	“couldn’t move because of my swollen ankles” p5	X			F57
Finding	**Giving up valued activities**				
Illustration	“I hated that I wasn't well enough to go to my dance school and I pretty much gave up dancing” p5	X			F58
Finding	**Impossible to attend school and work**				
Illustration	“”I was physically uncomfortable, because of tubes sticking out of my stomach and chest. I just wanted to be home all the time” p5	X			F59
Finding	**Trapped in a medicalised life**				
Illustration	“I am always going to have to be tied to the hospital because that’s my lifeline, for medications, blood tests, doctor appointments, checkups. It’s always going to be at the forefront of my life” p5	X			F60
Finding	**Overprotected by adults**				
Illustration	“Be cause they (my parents) were protective of me, I became a bit fearful, I became scared of a lot of things” p5	X			F61
Finding	**Cautious to avoid health risks**				
Illustration	‘”s this going to affect my kidney?” p5	X			F62
Finding	**Delayed independence**				
Illustration	“I’d like to move out, but if anything serious happens and I can’t work, I can’t pay for the place anymore” p5	X			F63

Finding	**Failing to keep up with peers**				
Illustration	“I was studying engineering and I watched a lot of my friends go on and graduate from that programme” p6	X			F64
Finding	**Socially inept**				
Illustrations	“social anxiety’—‘I've missed out on like the social side to life as a kid… I have social anxiety. I struggle with big crowds and the work Christmas party I don't go to” p6	X			F65
Finding	**Incapacitated by worry**				
Illustration	“I feel like I’m definitely going to die younger than a lot of my family” p6	X			F66
Finding	**An uncertain and bleak future**				
Illustration	“My life participation is going to decline and that I won’t be able to do things” p6	X			F67
Finding	**Unworthy of relationships**				
Illustration	“if you have to buy an apple, you will take a fresh one, not the one that has a hole in the middle. They will choose the healthy one (for an arranged marriage)’ p6	X			F68
Finding	**Low self-esteem and shame**				
Illustration	I am still not fully confident about myself, and this would not have happened (if I didn’t have CKD as a child)’.	X			F69
Finding	**Focussing on the day-to-day**				
Illustration	“doing a day at a time” p6	X			F70
Finding	**Planning parenthood**				
Illustration	“I will never have my own kids, because I don’t know how I got the disease. Because if he or she ends up having a problem, I will be blaming myself” p7	X			F71
Finding	**Forward and flexible planning**				
Illustration	“I will not eat potassium foods and I’ll be careful today with water, so when I get to the party, I can actually have a soft drink” p7.	X			F72
Finding	**Refusing to miss out**				
Illustration	“We did five-a-side football, which I was able to do because they made like a special shield that went over the kidney” p7	X			F73
Finding	**Finding enjoyment**				
Illustration	“appreciate the little things’ because of the kidney disease, making every effort to ‘enjoy every day and have fun” p7	X			F74
Finding	**Determined to do what peers can do**				
Illustration	‘”be able to do everything everyone else did,’ which also included drinking—‘I still went out and drank, because I wanted to be normal” p7	X			F75
Finding	**Being present at social events**				
Illustration	“hang out’ with friends and family was important—‘(kidney disease) doesn’t impact me that it stops me from going out and having a social life” p7	X			F76
Finding	**Encouragement from others**				
Illustration	“not being treated differently or as if they couldn’t do things’ helped them stay motivated and not to feel like a patient. Some found it helpful to meet others with kidney disease, ‘people that understood’—‘that was the point where my whole attitude towards everything changed, because I realised that I wasn’t alone and I realised that actually people were coping with it” p7	X			F77

Finding	**Motivated by the illness**				
Illustration	“I’m there for the new generation, to help them cope and be that inspiration” p8	X			F78
Finding	**Establishing new career goals**				
Illustration	“I’d probably go into something with childcare. But because of infection and stuff, that’s probably not a good idea” p8	X			F79
Finding	**Grateful for opportunities**				
Illustration	“when I go on a hike or to the gym, I’m like, I am so lucky. I’m so grateful that I can do these things because I wasn’t able to do it before” p8	X			F80
Study	**Korus et al., 2011**				
Finding	**Body Image.**				
Illustration	“I really disliked the bloating after prednisone. I got teased a lot too and it really bothered me” p56	x			F81
Finding	**Wanting to Be Normal.**				
Illustration	“Oh, well you don’t look like me so, like the popular kids. They’ll be like, ‘Oh you don’t look like me so, why are you coming near me?’ or ‘Why are you hanging out with me?’” p56	X			F82
Finding	**Pain and Discomfort**				
Illustration	“It was just painful. . . . It’s just painful right after: I’m having bladder spasms, as my dad puts it, he’s never seen someone in so much agony” p56	X			F83
Finding	**Breakdown in Communication**				
Illustration	“I felt they didn’t prepare me enough. They said it wouldn’t hurt, but it did. They said I would be knocked out and I wasn’t” p56	X			F84
Finding	**Gaining Knowledge.**				
Illustration	“Well if they’re at a young age, like when I got it at 5, like they probably—10 years old. He deserves to know something that he’s gone through. So, they should tell you slowly, bit by bit, what’s going on, why you’re in hospital, why—why it’s going on” p57	X			F85
Finding	**Developing Meaningful Social Support**				
Illustration	“Uh, I basically forget about everything. Like now, I just, live my life. Like wake up in the morning, go to school, and come home, and sit around. And on the weekends, hang out with my friends” p58	X			F86
Study	**Kim & Choi 2016**				
Finding	**Being different from others**				
Illustration	“While on peritoneal dialysis, I was frequently hospitalized because of peritonitis. When I went through the dialysis at first, I was a paunchy boy. I’ve had a hard time making and keeping friends.” p160	X			F87
Finding	**Not being involved as a decision maker**				
Illustration	“When the transplant was determined, nobody asked me about whether I wanted it or not. My parents and the medical staff assumed I had no ideas about the transplant.” p160	X			F88
Finding	**Becoming one of them**				
Illustration	“While being on dialysis I couldn’t soak in water. When I went to a water park after the transplant, it was quite wonderful as I didn’t need to attach a bandage to my body anymore, could get along with friends, and was not different from others.” p161	X			F89
Finding	**Still being different form others**				

Illustration	“During gym class, I gave water to a girl who complained of thirst. But she refused to take it, because she feared my disease could be transmitted through the water.” p 161	X			F90
Finding	**Having mixed feelings toward mothers**				
Illustration	“I still can’t understand my mom, who says riding water slides can cause the transplanted kidney to detach. I still can’t believe it. Even though the stitches are already absorbed after the transplant, I think mom overreacts. Also, she seems to know that would not happen. However. she seems to worry about a little chance.” p161	X			F91
Finding	**Coping with new circumstances**				
Illustration	“I don’t want to rely on my parents when I get older. I want to do what I want, support my parents, and have my own place to live. I have no idea whether it is possible though.” p162	X			F92
Study	**Michaud et al., 2019**				
Finding	**Resilience**				
Illustration	“Pain gives wisdom. When you’ve suffered so much you can endure a great deal, you no longer react to little problems.” p7	X			F93
Finding	**Relational needs and the therapeutic alliance**				
Illustration	“She has this quality, a calming presence, it helps a lot even when everyone is panicking, as soon as she walks into a room everything becomes calm and slows down.” p8	X			F94
Finding	**Quest for balance**				
Illustration	“The difference between older adults and us is that when they get sick, they already have a job, a family. Once they are transplanted they can go on with their life. When you’re young and sick, you have to build all that.” p8			X	F95
Finding	**Quest for normalcy**				
Illustration	“I’ve always lived as if I wasn’t sick and coming back here reminds me of it. I know I’m well, but it’s confronting.” p9	X			F96
Study	**Nguyen et al. 2020**				
Finding	**Difficulty remembering to take medications on time**				
Illustration	“I have to take my medications four times a day. When I am on my own I have a hard time remembering, so my mom reminds me to do it” p6	X			F97
Finding	**Learning the steps required for medication management**				
Illustration	“To begin with, [my coordinator] helped me learn my pills by color, by name, by dose and when they are due. I can tell I’m getting better at remembering these details which makes me feel good” p6	X			F98
Study	**Nicholas et al., 2009**				
Finding	**Conveying sympathy, offering advice, and venting feelings over online forum (asynchronous)**				
Illustration	“I was so scared when I first found out that my kidney was starting to fail and found out that I was going to be needing a transplant. Now I have been though a lot of different things, but this was the scariest thing that I had to ever face. If u would like any help with wanting to know what to expect then u can leave me a message, let’s hope u know how.” p28	X			F99
Finding	**Desire to share own stories, experiences, and wisdom over online forum (asynchronous)**				
Illustration	“Because I’m doing fine with my experiences, I’d love to give advice to a younger girl or guy who’s just like, going to have a transplant. Like, I’d find that cool. . . . Just give them more advice. . . . Like, with my personal life because I find it’s affected a lot too. . . .” p28-29	X			F100

Finding	**Little support from healthy peers and seeking support from peers with CKD (post-intervention interview)**				
Illustration	“It would be cool to talk to the kids who are on dialysis and they’re waiting for their kidney—it would be good if we give them information about what happens when you receive a kidney transplant, what are the side effects and whatever experiences that we should share with them, and when we were on dialysis how did we suffer and other stuff like that” p29-30			X	F101
Finding	**Balancing safety/anonymity and connecting with others (post-intervention interview)**				
Illustration	“Just make [the network] more personal. [Having personal bios] would be so much easier because then you will get those little things about people such as where they live, how old they are, if they’ve had a transplant or even just want kind of music they listen to. If you find someone who listens to the same music you can have an hour conversation just from that. You just have to find one little thing that is similar. Even like, age—just finding out their age because if they’re in the same age group then you can talk about school.” p30			X	F102
Study	**Nicholas, Picone and Selkirk, 2011**				
Finding	**Not Feeling Normal**				
Illustration	“[Without kidney disease], I would have more energy. I wouldn’t have to go to the hospital at all and I would have a normal life. I wouldn’t have to come to hospital every three weeks.” p165	X			F103
Finding	**Knowledge about ESRD and Involvement in Treatment**				
Illustration	“Because I’m sick so much, I’ve learned so much in the hospital—hands on, experiencing it myself” p167	X			F104
Finding	**Transitioning Responsibility for Self-Care**				
Illustration	“I can take care of myself. But my parents are still like, ‘Oh, have your meds. Did you take them?’ Just checking in, even though I am self-sufficient to take them for myself” p167	X			F105
Finding	**Absence From School**				
Illustration	“The bad thing about hospital dialysis is that you miss hanging out with your friends. It’s better to [miss school] in the morning, but there’s two different dialysis times… Kids in the morning [dialysis] miss the morning. After they’re done they go back to school, but they don’t feel like doing nothing so…” p168	X			F106
Finding	**The Challenge of Truth Telling: Peer Relationships and Revealing ESRD**				
Illustration	“[Peers] want me to take gym [class]. They wonder why I’m not there. So I just make up something like, “[I’ll take it] next semester or [I took it] last semester,” because with high school, we all have our own courses. They just think I’m in a different course” p168			X	F107
Finding	**Social Support: Family, Friends, and Health Care Providers**				
Illustration	“I listen to music sometimes just to get my frustration out. I might go out . . . to volunteer to get away from the atmosphere I’m always surrounded by. I might talk to my one of my close friends, maybe even a family member. It depends on what is bugging me” p169	X			F108
Finding	**Adjustment Despite Challenge**				
Illustration	“I think the kidney disease . . . helped me to see who I really am . . . like what I can really be and what I can really do and what anyone can really do” p169	X			F109
Study	**Nicholas et al., 2018**				
Finding	**Incremental Shifts to Care Independence: An Aim and a Challenge**				
Illustration	“remembering to take my meds all the time (and having) medication as part of my daily routine” was akin to “growing up” p555			X	F110
Finding	**A ‘Gentler’ Transfer to Adult Care**				

Illustration	“You’re a child here; yet there, you’re an adult” p557			X	F111
Study	**Nightingale et al. 2017**				
Finding	**Gaps in current online information and support**				
Illustration	“Most of the sites regarding stuff like diet are like forums, so anyone can post, so there’s not really that reliability…the Kidney Foundation or something, that’s pretty reliable obviously’ cause it’s a government website, so I use that mostly” p5	X			F112
Finding	**Difficulties experienced by children with a long-term condition**				
Illustration	“I don’t really like looking at the websites…because it reminds me of how much I’m different from all the rest of my friend” p6	X			F113
	Suggestions for digital care management app				
	“I think an app would probably be better, rather than going on a website to do it, because apps are more convenient. You don’t have to type anything up and you can just click on it “ p6	X			F114
Study	**Nightingale et al. 2022**				
Finding	**Shifting responsibilities**				
Illustration	“For me, when you say, independent, I think I'm taking my tablets by myself. That's just a habit I got into. We'd tell them [HCPs], ‘She's started taking her tablets by herself’, but I don't remember them having much input. It was a transition that happened at home. I don't know if the doctors have much to do with that really” p1922	X			F115
Finding	**Developing independence**				
Illustration	“I've always had to do it. I've always had the help, but as I've got older, I've had to be aware of what I can and can't do. I'm OK with it because I know that it's something that I have to do. I don't have a choice” p1923	X			F116
Finding	**Making changes**				
Illustration	“She'll help me do it on my own. Like, when I have to change my PEG, she'll show me how I take it out, and the process of putting it back in. Then the next time I have to do it while she watches” p1925	X			F117
Study	**Oberdhan et al. 2022**				
Finding	**Pain**				
Illustration	“They [kidneys] hurt so bad I could not get out of bed” p6	X			F118
Finding	**Hypertension**				
Illustration	“Like if like you stand up you get like really dizzy and see a bunch of different colors for a couple of seconds” p6	X			F119
Finding	**Pain characteristics**				
Illustration	“I can’t stand straight anymore; my lower back hurts a lot” p6	X			F120
Finding	**Pain impact on daily activities**				
Illustration	“I can’t practice sports; I am not allowed at all, if I do my knees hurt a lot, I can’t feel my legs, and I start to tremble. I get chills and so on, and that’s that, and my kidneys hurt” p6	X			F121
Finding	**Urinary urgency and frequency**				
Illustration	“I go to the bathroom and maybe 10 or 15 minutes later I have to go again” p6	X			F122
Finding	**General impact on daily activities**				
Illustration	“If I go by what physicians say I wouldn’t be allowed to do anything. I do sometime. I also need to have fun” p6	X			F123

Finding	**Impacts on school**				
Illustration	"It takes a lot out on a kid and like, I don't know basic because none of the teachers wanted to teach me after I got back... And it has a really big effect on children because their learning is really affected by it and that's probably my biggest concern" p6	X			F124
Finding	**Dietary impacts**				
Illustration	"I have to watch my salt intake. I have to avoid chips, those things that are really salty. ... all my friends are eating chips and popcorn and I'm just like eating an apple" p6	X			F125
Finding	**Impacts on social activities**				
Illustration	"I have to stop and think, I cannot do this right now because of this or because I have this condition p6	X			F126
Finding	**Emotional impacts**				
Illustration	"You can't really talk about it with anybody" p6	X			F127
Finding	**Impact on life plans**				
Illustration	"I want to have children, and pregnancy can be a problem and I know it's a hereditary disease, so I will have to think about my children, whether I want to take the risk" p6	X			F128
Study	**Poursanidou et al. 2003**				
Finding	**Peer relations difficulties at school**				
Illustration	"Last year, I also had a problem with a boy called Adrian…He said that I'd killed somebody cause I took their kidney! I think if anybody calls you that, you do feel upset, don't you? Especially when its something to do with you and if you've had problems like…had a transplant and then people go saying things like that…So I felt really upset" p169	X			F129
Finding	**Concerns related to school absence**				
Illustration	"I don't get any help from my school to catch up with lessons I have missed! The school does not send work home! I have to catch up by myself with nobody else to help me! p170	X			F130
Finding	**Lowered motivation for schoolwork and poor school performance**				
Illustration	"If I lose this transplant due to the rejection episode that I am having, and I'll have catheters in, I won't be able to do PE, I wont be able to play games…I wont be able to do much" p172	X			F131
Finding	**The importance of hospital school liaison**				
Illustration	"People from the hospital going into school are helpful…they can explain things about my transplant a lot better than I can! Cause I don't know as much about it as they do!" p175	X			F132
Study	**Rupp et al. 2021**				
Finding	**Willingness to attend school/work**				
Illustration	**"**He pays for most of the stuff, and it takes away your independence when you're relying on someone else. We rent a house together. We have cars and just the basic necessities of house, the energy, and all that stuff. When he pays all that, it makes me feel like I'm just sitting here. I'm not helping. I'm not contributing" p5	X			F133
Finding	**Barriers to school/work attendance**				
Illustration	"Its hard to be out of school for a little bit and then try to go back sometimes. If you stay out too long, when you come back you wont be motivated" p6	X			F134
Finding	**Overcoming barriers through social support**				
Illustration	"People will either feel really sorry for you or kind of just think, "you're about to die anyway". People are really mean that way" p7	X			F135

Finding	**Barriers to establishing social support**				
Illustration	“To be honest, its none of their business because then they ‘re going to ask a thousand more questions, and I’m not going to feel like answering” p9	X			F136
Study	**Tong et al. 2011**				
Finding	**Facilitators**				
Illustration	“I know who my friends are, the ones that stayed with me through it” p288	X			F137
Finding	**Enablers**				
Illustration	“I always worry about if I fall will it affect my kidney” p288	X			F138
Study	**Tong et al. 2013**				
Finding	**Inferiority**				
Illustration	“But I just feel like such a failure. I know my family won’t say it straight to my face, but I know they’re thinking it” p378	X			F139
Finding	Insecurity				
Illustration	“When I was little I thought I had perfect health, like, yeah, that’s why, I grow up suddenly I have this problem, I can’t handle it” p378	X			F140
Finding	**Injustice**				
Illustration	“I always wonder how different my life would be if I didn’t have chronic kidney disease” p378	X			F141
Finding	**Resilience**				
Illustration	“I have to sort of base my lifestyle around my dialysis times as opposed to [home haemodialysis] being able to base my dialysis times around my lifestyle” p379	X			F142
Finding	**Adjustment mentality**				
Illustration	“I don’t deserve another one [kidney transplant]” p379	X			F143
Study	**Walker et al. 2019**				
Finding	**Transplant as the goal**				
Illustration	“100% I would rather have a transplant than be on dialysis. Once I had the transplant, things very much went back to normal” p649	X			F144
Finding	**Dealing with negative emotions**				
Illustration	“I remember being really concerned and remember a lot of anxiety, and fear about not finding a donor” p649	X			F145
Finding	**Enhancing understanding and knowledge**				
Illustration	“I didn’t really know what to expect” p650	X			F146
Study	**Wells, Ritchie and McPherson 2012**				
Finding	**Understanding acceptance of treatment**				
Illustration	“No its just one of those things…I cant imagine my life unless I was here now, so either way I have just learnt to accept what has happened” p606	X			F147
Finding	**Living in a non-functioning body**				
Illustration	“I used to do a lot of sport before but I seem not to do as much because I am really tired all the time and I just don’t seem to do as much” p606	X			F148
Finding	**Impact upon daily life**				
Illustration	“Imagine that each one of those DVD’s is a day I have spent on dialysis- they would pretty much take away the same amount of time from your life” p607	X			F149

Finding	**Sources of support**				
Illustration	"Here every staff member I know inside out and they are very friendly…I talk to them and they talk to me if something happens in my family life they will keep it confidential and they will speak to me, and I will speak to them because I trust them" p608	X			F150
Included articles from citation searching					
Study	**Cura et al. 2012**				
Finding	**Living a Shorter Life**				
Illustration	"How will this end? I hope one day, all these pains would just be gone" page 121	X			F151
Finding	**Dependence and Independence**				
Illustration	"It seemed like they need to help you even on easy, simple things…Sometimes you feel ashamed" page 121 "Sometimes I would just keep [it] (cries)…to myself" page 121	X			F152
Finding	**Struggle of Being Normal Amidst Difference**				
Illustration	"He [child] looks at me…You could not hear him… He said I have something here (points to neck)" page 122 "They feel 'different', yet they want to be treated 'normally' and feel 'normal' as if without illness" page 122 "To look at me just like before, when I did not have the illness. Treat me normally" page 122	X			F153
Study	**Finderup et al. 2012**				
Finding	**A meeting place. The odd setting gives value.**				
Illustration	"More fun to meet outside the hospital, to arrange the youth clinical this way" page 213 "I feel incredibly ill in the hospital and have to get the rests of my tests. I don't feel the same here" page 213	X			F154
Finding	**A mutual understanding. The others understand me and I am able to identify with the others**				
Illustration	" … when I am at school I feel alone in the world because the others at school are not able to relate to the way I feel" page 213	X			F155
Finding	**The young people have established a social community between themselves**				
Illustration	"New friends who have been through the same, having fun and meeting outside the hospital … and meet and have a good time and drive somewhere and have something to eat and just be together" page 213	X			F156
Finding	**I feel less directed by my disease**				
Illustration	"Meeting others with kidney disease just makes it possible to see things in a whole new light and you know that you are not the only one … you can always comfort yourself to know others (with kidney disease) and if they can life with it so can you" page 213	X			F157
Finding	**I accept to live with the disease to a larger extent**				
Illustration	"It has been easier for me to accept that it's the way I am because there are so many others just like me … and that's actually OK." Page 213	X			F158
Study	**Murray et al. 2014**				
Finding	**Low energy levels or tiredness**				
Illustration	"Before my transplant, it was quite hard to focus in school. The fact I was very tired affected my A-level work and afterwards I was having a hard time recovering from the operation." Page 508	X			F159
Finding	**Education or career ambitions negatively changed or were limited because of dialysis**				
Illustration	"Quite often I got frustrated and felt down. I hate being out of work, I've always prided myself on being in work." Page 508	X			F160
Finding	**Unpredictability of health and well-being on dialysis and inability to plan ahead**				

Illustration	“I was fortunate it could be planned so it minimised disruption to my exams, it’s harder to revise and there’s a lot more disruption.” Page 508	X			F161
Finding	**Felt disadvantaged when seeking work**				
Illustration	“If you [kidney patient] put your CV in and you [employer] get a ‘normal’ CV in; ‘I can work full time, there’s nothing wrong with me.’ Well, who would you choose?” Page 508	X			F162
Finding	**A lack of understanding (welfare providers), regarding how dialysis truly affected patient’s lives and health**				
Illustration	“I was disgraced at the way they [welfare office] were treating me, absolutely disgraced. It’s not like I’d just ‘cut my finger’, I’ve lost the use of my organs!” Page 508	X			F163
Finding	**Recreational drug use as a coping strategy**				
Illustration	“It was something that could take my mind off things. Maybe for a while it helped, but it became a problem for me” Page 508	X			F164
Study	**Murray et al. 2019**				
Finding	**Dialysis profoundly limits quality of life**				
Illustration	“I couldn’t work full-time . . . You’re on dialysis 5 hours a day and when you aren’t, you can’t do anything else.” Page 34	X			F165
Finding	**dialysis-related fatigue**				
Illustration	“It sucks the life out of you, you feel worthless, like you’ll never do anything” Page 34	X			F166
Finding	**unpredictability of health**				
Illustration	“I didn’t have time or energy for a social life, also it’s a lot to ‘tell’ [explain to] people ...” Page 34	X			F167
Study	**Swallow et al. 2014**				
Finding	**Non-compliance is a considerable problem**				
Illustration	“I understood what to eat and not to eat. Sometimes I follow [the advice], sometimes I don’t!” Page 5	X			F168
Finding	**Significance of certain symptoms**				
Illustration	“…the fistula [vascular access for dialysis] is one [procedure] I would like to see [on OPIS]. …it was quite scary to think that it would look like that…it would just be massive in your arm… and possibly how the tube [gastrostomy] would look - the tube that goes into your stomach.” Page 5	X			F169
Finding	**Cartoon about having a transplant to help**				
Illustration	“Introduce characters that help to explain the disease e.g. Karl the Kidney” Page 5	X			F170
Finding	**Recommended a Q&A area**				
Illustration	“… some parents may prefer a phone call or face to face communication.” Page 5	X			F171
Finding	**Communicate with a wider circle of like-minded peers**				
Illustration	“I think it’s nice as well if you can talk to someone who’s actually been through it. Page 5	X			F172
Finding	**Managing stress**				
Illustration	“It will be really important to describe the process of going through a transplant, the checks and Procedures” Page 6	X			F173
Finding	**Appointment reminder system**				
Illustration	“Remembering appointments is very difficult; a reminder would be helpful.” Page 7	X			F174
Finding	**Bright, colourful and interactive**				
Illustration	“OPIS should be eye catching and colourful for kids and informative.” Page 7	X			F175
Study	**Tong et al. 2015**				

Finding	**Encouraging self-expression**				
Illustration	“You can talk to your friends and your family but they don’t really understand, they are not going through it themselves, so it’s hard for them to understand what’s happening. You kind of try and explain, but they don’t really get it.” Page 5	X			F176
Finding	**Experiential knowledge**				
Illustration	“When they have their transplant, because we didn’t realize how long the pain would last. It would be good to just to give them the heads up that it might take some people quite a while.” Page 5	X			F177
Finding	**Helping others**				
Illustration	“I feel like I’ve helped other people which is good . . . just to sort of show people that you can actually just have a normal life if you want to.” Page 5	X			F178
Finding	**Reflection and optimism**				
Illustration	“I have a career and I work full time and I go out and do things and I might not necessarily be as sick as some of them are, and I’m lucky for that, and I realize that I’m lucky that I’m not quite as unwell as some of the other.” Page 5	X			F179
Finding	**Connectedness**				
Illustration	“Sometimes you might feel alone. You’re like the only person in your age and everyone else is fit and healthy, so just meeting new people and talking to them about it, like this is good.” Page 5	X			F180
Finding	**Welcoming environment**				
Illustration	“It looks like I’m the only person under 50 there. It’s not that comfortable to sit there in front of people, maybe looking around and thinking ‘I’m going to be here and end up like them.” Page 5	X			F181
Finding	**Competing priorities**				
Illustration	“I just haven’t found the time to break away from TAFE and homework.“ Page 5	X			F182
Finding	**Avoiding the sick identity**				
Illustration	“Thinking about what I went through makes me go insane . . . I want to just look forward and not look back. Just every time these things, it reminds me about [dialysis]. I don’t really like to socialize too much with this type. It just brings back bad memories.” Page 5	X			F183
Finding	**Wary of relational boundaries**				
Illustration	“There wasn’t much interaction with the others cause everyone is quiet and shy. You can’t just jump in – They say ‘Hi’ and that’s it but you don’t want to get right into their cultural [personal] life.” Page 5	X			F184
Study	**Waters, 2008**				
Finding	**Illness labour**				
Illustration	Children often said they were: ‘waiting for a kidney’. This was an ambiguous experience: children often looked forward to and badly wanted a kidney, yet the process was sometimes associated with tension, emotional pain and distress. Page 3108		X		F185
Finding	**Renal space: the renal world**				
Illustration	‘My life is going to hospital every Monday, Wednesday and Friday and trying to get better but before that I had a normal life going to school trying to get good work playing with friends and having fun but now I can’t do that. I cannot do anything without my mum and dad looking over me but I am on the list now to get a kidney. I will be back to the same thing I did before that. And that is my life.’ Page 3109	X			F186
Finding	**Living in a renal body**				
Illustration	“ … 16-year-old boy said he hid drinks and he stole drinks: when I am choking thirsty.” Page 3109	X			F187

Finding	**Medicines**				
Illustration	‘they’re too big’; ‘I forget’; ‘I am too tired to remember’; ‘I keep forgetting again and again’; ‘my mum forgets’ ‘there’s too many’; ‘they go down and then they come back up again’; ‘when they come back up I can’t get them down again. I just can’t’ and ‘they taste disgusting’. Page 3110	X			F188
Finding	**Scarring**				
Illustration	One child described herself as ‘full of holes’. Page 3110	X			F189
Finding	**A renal social world**				
Illustration	I need salt. Get Louise quick. (10-year-old boy who knew all the nurses in the haemodialysis unit, one day when he suddenly felt breathless having haemodialysis, bypassed the specialist nurse looking after him.	X			F190

Evidence is allocated to a category based on quality level of finding: **Unequivocal** (findings accompanied by an illustration that is beyond reasonable doubt and; therefore not open to challenge), **credible** (findings accompanied by an illustration lacking clear association with it and therefore open to challenge) and **not supported** (findings are not supported by the data)