

# HOW YOUNG PEOPLE COPE WITH CHRONIC KIDNEY DISEASE: LITERATURE REVIEW

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## SUMMARY

**Background:** Chronic kidney disease (CKD) is a complex, long-term condition occurring in all age groups. It has been reported that the incidence of renal replacement therapy in young people is 7–8 per million population. Notwithstanding those individuals who may receive a donor kidney, many individuals may be disenfranchised by perceptions of helplessness and feelings of powerlessness against a backdrop of diminished health outlook, consequently impacting on capacity for effective coping.

**Aim:** The aim of this review is to explore how young people cope with CKD.

**Methods:** Three hundred and thirty-seven abstracts were identified. Sixty-three papers were cross-examined using a Critical Appraisal Skills Checklist Tool.

**Results:** Young people face various demands; these may be episodic or ongoing, depending on health and circumstance. The themes this review uncovers are: 'Lack of a Coping Definition'; 'Coping Strategies in Young People'; and 'Barriers to the Understanding of Coping in Young People'.

**Conclusion:** More qualitative research is vital to retrieve 'real-life' perceptions from young people coping with kidney disease to identify how care should be made more explicit for them.

**KEY WORDS** Chronic kidney disease • Coping • Literature review • Young people

## INTRODUCTION

It has been reported that the incidence of renal replacement therapy (RRT) in young people is 7–8 per million population

(PMP) below the age of 16 years (van der Heijden *et al.* 2004). Frequencies can fluctuate around 55 and 62 PMP (van der Heijden *et al.* 2004; Lewis *et al.* 2010b). Forty years ago, young people with chronic kidney disease (CKD) died. Now, morbidity has improved by the availability of multiple treatment modalities. In majority, young people are treated with kidney replacement therapies, which remain the foremost effective methods of treatment (McDonald & Craig 2004). Paediatric renal teams endeavour to identify a suitable donor for transplantation as swift as possible, because patient survival depends upon the availability of kidneys (Watson 1996; McDonald & Craig 2004).

Young people with CKD can be challenged with attaining prime development in the mental, bodily and social spheres. Young people also require time to cope with this illness or accompanying disability (Boekaerts & Roder 1999). Coping processes in young people with chronic conditions like CKD are extremely pertinent in the arena of clinical medicine and psychology. The lasting prognosis rate among young people needing RRT is 79% in the first decade and 66% in the second decade (McDonald & Craig 2004). Despite progress in prognosis, young people with CKD and family members are still under substantial tension (Reynolds *et al.* 1986). Because young people with CKD undergo a variety of treatment and

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Coping	Renal	Challenges
Coping	Renal failure	Psychological
Mental health	Stage 5	Physiological
Well-being	Chronic	Psychosocial
Quality of life	Kidney	
Resilience	Disease	
Trauma	Paediatric	
Adapting	Nephrology	
Accepting	Renal replacement therapy	
Adversity	Transplantation	
Attitude	Medication	
	Peritoneal dialysis	
	Haemodialysis	
	Surgery	
	Healthcare	

Table 1: The grouping of terms—literature review.

care pathways, a literature review is required to explore coping and what has been documented in the young CKD population (Reynolds *et al.* 1986; Reynolds *et al.* 1988; Eiser & Morse 2001a; Heiwe *et al.* 2003).

## AIM

The aim of this review is to explore the current literature surrounding coping in young people with CKD. In addition, this review aims to explore:

- (1) The processes/ strategies and ways of coping used by young people with CKD and determine what mechanisms they adopt to cope.
- (2) To identify the main challenges young people with CKD face.
- (3) To determine and describe whether or not the coping strategies/processes adopted are helpful.
- (4) What coping with CKD actually means to young people.

## METHODS

### PUBMED

An initial PubMed search was conducted, whereby key terms from Table 1 such as coping, young people and kidney disease were inserted into the search box. Three issues were quite rapidly recognised:

- (1) There were two papers that explored coping in young people with CKD before 1978;

Coping	Renal	Challenges
Basic search	Basic search	Basic search
A combination of coping words (as listed in table 1)	A combination of renal terms inserted (as listed in table 1)	A combination of challenges terms inserted (as listed in table 1)
This retrieved 48 papers (1976–2012)	This retrieved 24 papers (1989–2012)	This retrieved 291 papers (1975–2012)
Advanced search	Advanced search	Advanced search
Inserting all the words (see Table 1)	Inserting all the words (see Table 1)	Inserting all the words (see Table 1)
Selecting, title/ abstract and OR search option	Selecting, title/ abstract and OR search option	Selecting, title/ abstract and OR search option
This retrieved 28 papers (1976–2012)	This revealed 24 papers (1989–2012)	This revealed 388 papers (1975–2012)
Refined search	Refined search	Refined search
Highlighted:	Highlighted:	Highlighted:
Child (6–12 yrs), adolescent (13–18 yrs), OR search	Child (6–12 yrs), adolescent (13–18 yrs), OR search	Child (6–12 yrs), adolescent (13–18 yrs), OR search
English	English	English
Humans	Humans	Humans
Title/abstracts	Title/abstracts	Title/abstracts
Medline and PubMed Central subsets were also marked	Medline and PubMed Central subsets were also marked	Medline and PubMed Central subsets were also marked
Retrieved 20 papers (1976–2012)	Retrieved 22 papers (1989–2012)	Retrieved 98 abstracts (1989–2012)

Table 2: Number of papers identified according to PubMed, PubMed Central and Medline Searches.

- (2) The literature surrounding coping in young people with CKD after 1978 is insubstantial; and
- (3) The young CKD population is a small one.

Three following specific PubMed searches were also conducted and these are shown in Table 2, which outlines the search strategies: (1) a *Basic search*, (2) an *Advanced search* and (3) a *Refined search*. The reason for conducting three search types was to try to identify the most specific literature surrounding this study. Table 2 also highlights the number of abstracts/papers established relating to coping, renal and challenges under search strategy.

### EBSCO HOST DATABASE

A range of databases using EBSCO Host Engine over a 34-year period year was used to conduct this search. Databases accessed using EBSCO host included CINAHL Plus with Full Text

Group	Further terms
Young people and coping	Child (6–12 years)
	Adolescence (13–18 years)
	Coping
	Mental health
Young people and renal	Quality of life
	Child (6–12 years)
	Adolescence (13–18 years)
Young people and challenges	Chronic disease
	Child (6–12 years)
	Adolescence (13–18 years)
	Psychological
	Psychosocial

Table 3: Explicit grouping of terms according to PubMed, PubMed Central and Medline Searches.

Review (1978–2012), Psychology & Behavioural Sciences Collection (1978–2009), PsyINFO (1978–2012), Health Source; Nursing/ Academic EDT (1978–2009), International Bibliography of the Social Sciences (1978–2012). Table 3 presents the keyword arrangement into three distinct categories; (1) *young people and coping*, (2) *young people and renal*, (3) *young people and challenges*. Searching also included the following options: *Smart Text searching* (smart texting option was used replacing the AND/ OR method. *Smart Texting* allows as much text to be entered for a search. A basic coding process was used to ensure that terms related to those categories outlined in Table 3. In addition, options were selected for full text, peer-reviewed journals, periodicals, child (6–12 years), adolescence (13–18 years.), abstract available, English language and population group (human).

### ANALYSIS/SYNTHESIS OF LITERATURE

In the analysis of literature, the Critical Appraisal Skills Programme (CASP) (<http://www.sph.nhs.uk/sph-files/casp-appraisal-tools/S.Reviews%20Appraisal%20Tool.pdf>) was implemented. Using this CASP, papers were initially classified on type of study, (i.e. Qualitative, Quantitative, Systematic Reviews, RCTs/ interventional, Cohort Studies, Case Controlled and Diagnostic Test Studies) and 337 abstracts went under a 10 question screening process. The CASP helped analyse in the following manner: (1) Is the study valid? (2) What are the results? (3) Will the results help locally? The CASP 10 questions screening process is designed to help think about issues systematically. A number of prompts are given after each question and these are designed to remind why the question is important.

Theme	Papers
Theme 1 Lack of a coping definition in CKD	(Lazarus <i>et al.</i> 1957; Lazarus 1985, 1992, 1993a, 1993b, 2000; Ryan 1988, 1989; Aymanns <i>et al.</i> 1995; Watson 1996; Eiser 1997; Jacelon 1997; Schwarzer 1998; Eiser <i>et al.</i> 1999; Sartain <i>et al.</i> 2000; Melnyk <i>et al.</i> 2001; Glazebrook <i>et al.</i> 2003; Schmidt <i>et al.</i> 2003; Judson 2004; Snethen <i>et al.</i> 2004; Upton <i>et al.</i> 2005; McAlinden & Oei 2006; Burgermeister 2007; Eiser & Jenney 2007; Folkman 2008; Lee <i>et al.</i> 2008; Filler 2011)
Theme 2 Coping strategies in young people with CKD	(Korsch <i>et al.</i> 1971, 1973; Raimbault 1973; Bouras <i>et al.</i> 1976; Poznanski <i>et al.</i> 1978; Reynolds <i>et al.</i> 1986, 1991; Brem <i>et al.</i> 1988; Rosenkranz <i>et al.</i> 1992; Douglas <i>et al.</i> 1998; Molzahn & Kikuchi 1998; Boekaerts & Roder 1999; Gordon 1999; Dowling 2002; Lamontagne <i>et al.</i> 2003; Truman <i>et al.</i> 2003; Upton <i>et al.</i> 2005; McAlinden & Oei 2006; Piazza-Waggoner <i>et al.</i> 2006; Littleton <i>et al.</i> 2007; Lee <i>et al.</i> 2008; Halpern <i>et al.</i> 2010; Lewis <i>et al.</i> 2010a)
Theme 3 Barriers to the understanding of coping in young people with CKD	(Fine <i>et al.</i> 1973; Fine 1975; Gayton <i>et al.</i> 1977; Cairns <i>et al.</i> 1979; Kellerman <i>et al.</i> 1980; Zeltzer <i>et al.</i> 1980; Cameron 1985; Patterson & McCubbin 1987; Brem <i>et al.</i> 1988; Davis <i>et al.</i> 1996; Corsini <i>et al.</i> 1998; Eiser & Morse 2001a, 2001b; Schmidt <i>et al.</i> 2003; Truman <i>et al.</i> 2003; Folkman & Moskowitz 2004; Petersen <i>et al.</i> 2004; Snethen <i>et al.</i> 2004; Amr <i>et al.</i> 2009; Heath <i>et al.</i> 2011)

Table 4: Themes identified from literature review.

### DECISION FOLLOWING SEARCHES

Overall, a total of 141 abstracts through the PubMed search engine and 196 through the EBSCO host databases. After removal of duplicates, 274 abstracts were subjected to inclusion and exclusion criteria as highlighted in Table 3. In synthesis, of the 274 abstracts, 63 papers were evaluated, which helped to derive themes. Table 4 shows how themes were identified.

### THEMES DERIVED

Three themes were identified:

- (1) Lack of a coping definition in young people
- (2) Coping strategies in young people with CKD
- (3) Barriers to the understanding of coping in young people with CKD

### THEME 1: LACK OF A COPING DEFINITION IN CKD

Coping is not a stand-alone phenomenon; it encompasses all changes as they occur during continued exposure to a challenge. Coping is an influential intermediary of expressive consequences; encouraging outcomes are related to particular coping processes, and undesirable outcomes are related to negative coping (Lazarus 1993b). Folkman claimed that optimistic feelings are a normal element of the coping process and

these support psychological coping, so people who are well, proficient and positive are capable and, so, less exposed towards the stresses in time. If someone underrates prospective action, no coping strategies will develop (Folkman 2008). This has been emphasized by Schwarzer 1998).

Lazarus was one of the fathers of coping research who provided a first definition of coping relating to (1) *Harm*, (2) *Threat* and (3) *Challenge* (Lazarus *et al.* 1957; Lazarus 1985, 1992, 1993a, 2000). *Harm/loss* refers to injury or damage or loss of physical function, self-esteem. *Threat* can mean the same injuries refer, but yet to happen or anticipated. *Challenge* can mean the opportunity for development, strength and ingenuity. The distinctions between these three concepts are not only important in coping specifically, but they have a crucial role to play in health and disease. A second definition developed in joint effort by Lazarus and Folkman, who asserted coping, can be problem-focused coping or emotion focused coping (Lazarus 1993b).

Problem-focused coping involves strategies that attempt to ease or eradicate challenging circumstances by gaining hegemony and balancing advantages and disadvantages; crucially, personalities who adopt this approach also subdue feelings i.e. evading or procrastination (for example, exam revision replaced by talk on Facebook).

Emotion-focused coping involves approaches to smooth emotive or possibly challenging events. Coping also depends upon appraising whether whatever can be carried through to modify a state. If a challenging situation can be approached to ease circumstance, problem-focused coping dominates, otherwise in challenging situations, emotion-focused coping predominates (Lazarus 1993b).

Following some of the work by Lazarus, a research team conducted a series of basic surveys where three questions set out to be answered surrounding young people with cancer: (1) How might cognitive and behavioural methods of coping with chronic illness impact on perceived support of one's family? (2) Are coping approaches of relevance and importance in determining and explaining differences in support? (3) Are quintessentially distinct domains of family support and coping identifiable in this group? Based on survey data from 169 patients with cancer, results suggest that problem-focused strategies for coping are more effective. Five coping strategies

had been further identified from this study: (1) Seeking Social Mixing, (2) Reflection, (3) Threat Minimization, (4) Turning to Religion, and (5) Seeking Information (Aymanns *et al.* 1995).

Whilst several papers discuss coping in young people (Eiser 1997; Compton 1998; Eiser *et al.* 1999; Eiser & Morse 2001a; Upton *et al.* 2005; McAlinden & Oei 2006; Burgermeister 2007; Eiser & Jenney 2007; Lee *et al.* 2008), exploring literature more deeply has highlighted a lack of a coping definition of young people who have CKD and youngsters who have this chronic disease face long-term challenges, which means there needs to be more support systems in place for them. Further, young people who have positive coping strategies could potentially make strides to self-care allowing better transition into adult care later. Strides have increasingly been made to assess coping in young people with chronic illnesses such as CKD because youngster have their own understanding to challenge this illness (Schmidt *et al.* 2003). A definition of coping with CKD is important because evidence suggests that there is a beneficial association in coping and how well youngsters manage this disease (Snethen *et al.* 2004). Also, characteristics such as resilience may be inherent in some individuals (Jacelon 1997).

## THEME 2: COPING STRATEGIES IN YOUNG PEOPLE WITH CKD

Several studies inform coping strategies in young people (Bouras *et al.* 1976; Poznanski *et al.* 1978; Brem *et al.* 1988; Douglas *et al.* 1998; Molzahn & Kikuchi 1998; Dowling 2002; Lamontagne *et al.* 2003; Truman *et al.* 2003; Upton *et al.* 2005; McAlinden & Oei 2006; Littleton *et al.* 2007; Lee *et al.* 2008). Citing the literature, an important point to be made is that youngsters with CKD may cope differently from their healthy peers, because they may have experienced diverse coping strategies because of their greater experience with coping and trauma, (Boekaerts & Roder 1999).

Stages 4–5 CKD potentially leads to the requirement of a form of RRT and extensive changes projected to be challenging, thus, requiring diverse coping processes (Lewis *et al.* 2010a). For young people with CKD, coping can mean a lifetime of ill health. The range of psychosocial concerns that young people with CKD and their families contend with has been documented (Korsch *et al.* 1971, 1973; Reynolds *et al.* 1986, 1991). Young people with CKD differ from young people with other illnesses, such as brain or spinal cord tumours, high blood

pressure, leukaemia and diabetes (Freeman *et al.* 2003; Andrade *et al.* 2010; Collins *et al.* 2010; Halpern *et al.* 2010) in that this illness requires a lifetime of medical interventions, even after kidney transplantation (Rosenkranz *et al.* 1992).

Early literature exploring coping in young people with CKD has highlighted that their reactions are a continuum, which ranges from acceptance of their illness to rejection and denial. Coping may take either a positive or negative form. When a disease is intricate like CKD, denial has also been identified as a typical attitude. Anxiety is also common (Raimbault 1973). It has been noted that young people's overall adaptation to haemodialysis (HD) can be fairly good (Raimbault 1973); their progressive, sometimes spectacular, physical healing, contrasting with previous morbidity seems to brush aside psychological problems (Raimbault 1973).

In an early mixed method study, *Rorschach tests* (psychological assessing the perceptions of ink blots and analysis of interpretation) were carried out on 24 young people with CKD during the time they were on undergoing HD and one-year post-transplant. Investigators also conducted interviews with young people with CKD and their families, gathering drawings and commentaries (Bouras *et al.* 1976). Coping processes/strategies adopted appear to be related to traumatic experiences and their lack of support in mastering them through verbalisation expression, for example letting members of the healthcare team know what is specifically difficult for them. The authors conclude major difficulties manifest themselves in coping with personal concerns (Bouras *et al.* 1976).

Humour has been found to be quite an important positive coping strategy in young people with chronic illness (Dowling 2002). Young people's use of humour during interaction should be investigated as an intervention, because when young people use humour, this could mean something distinct (Dowling 2002). This author's work gives examples of interaction, ultimately suggesting there is need for further research to evaluate humour as an effective intervention coping strategy (Dowling 2002). Individual traits such as humour, autonomy and enthusiasm should be examined for their significance in relation to coping strategies and resilience (Jacelon 1997). Research should focus on ways to identify the presence of such traits (Jacelon 1997; Dowling 2002). See other sources (Gordon 1999; Dowling 2002; Snethen *et al.* 2004) for further content on humour as a coping strategy.

Young people with CKD were recruited to examine coping strategies to manage their chronic illness (Snethen *et al.* 2004). In this study, the *A-Cope* survey was undertaken in 24 young people with CKD during the time they were haemodialysed, and one-year following a kidney transplant. Findings in this study highlighted that transplant status (i.e. anxiety with respect to transplant rejection) and religion were related to the coping strategies (Snethen *et al.* 2004).

A variety of measures were implemented to record family running, coping processes and behaviour in youngsters across disease groups (*McMaster Family Assessment Device (FAD; Epstein et al. 1983); (Brief COPE, Carver 1997); (Kidcope, Spirito 1988) and the (Behavioral Assessment Scale for Children BASC; Reynolds & Kamphaus 1992)*). Groups included young people with kidney disease, who have similar clinical backgrounds (e.g. RRT vs. immune system-based treatments and regular medical techniques) to young people with primary immune disease disorders and a healthy comparison group (Piazza-Waggoner *et al.* 2006). One of the important findings related to school absences in both the primary immune disease disorders and kidney disease cohorts skipped, on average, two weeks of schooling days per year owing to ill health compared to seven days conveyed for young people in the healthy contrast group. The team also highlight that this may be directly related to the youngster's lack of coping strategies/processes and amount of hospital appointments documented and by families in the ill-health cohorts (Piazza-Waggoner *et al.* 2006).

### **THEME 3: BARRIERS TO THE UNDERSTANDING OF COPING IN YOUNG PEOPLE WITH CKD**

The majority of measures aimed at assessing how young people cope do allow young people to complete the surveys unaided, whereas some may require additional aid by parent(s)/next-of-kin. Assessment of coping poses unique problems in young people with CKD. Young people may interpret questions differently to adults, and have dissimilar perspectives regarding the course of their disease (Schmidt *et al.* 2003). In addition, their aptitudes to inform using measures, understand terminology and routinely complete measures as within adult studies, may be affected by development (Eiser & Morse 2001a). Traditionally, in both clinical and research work, the assumption that adults can answer for young people has gone unchallenged. However, young people may have their an exclusive viewpoint on coping, which may be influenced on existing life, earlier familiarities, dreams, plus aspirations (Eiser & Morse 2001a).

The *Adolescent Coping Orientation for Problem Experiences (A-Cope)* is a 54-item, self-reporting measure. In one particular study, the *A-Cope* survey was used to identify coping strategies utilized by 35 youngsters with kidney disease (aged 13–18); 9 of whom were 13–14 years, 10 were 15–16 years of age and 16 were 17–18 years of age. There were 20 males and 15 females. The bulk of participants were post-kidney transplant patients (Snethen *et al.* 2004). Findings indicated that young people with CKD face specific demands which may be episodic or ongoing, depending on their health and circumstances, ultimately coping processes in young people with CKD.

Acquiring information from young people continues to be challenging in clinical work; youngsters may not understand a question, or only provide answers adults want to hear. An IT-version of the Strengths and Difficulties Questionnaire has been established implementing similar vernacular as the paper version, but it has visuals exemplifying individual questions (Truman *et al.* 2003). Youngsters who finished the IT-style considerably conveyed the questionnaire was easy to complete than those young people completing the paper version. The computer-based edition is therefore an improvement on the current paper-based tool (Truman *et al.* 2003).

A study by Cairns assessed coping using a series of measures in youngsters with CKD (Cairns *et al.* 1979). Twelve young people with CKD (six of the young people were on HD and six were on a form of peritoneal dialysis) were recruited. The age range was from 10 to 19 years and the investigators implemented a variety of measures including the *Nowicki-Strickland Children's Locus of Control Scale* (Kellerman *et al.* 1980), *Piers-Harris Self-Concept Scale* (Gayton *et al.* 1977; Cairns *et al.* 1979; Orr *et al.* 1984), and *Adolescent Coping Orientation Problem Experiences* (Patterson & McCubbin 1987). This study highlighted that young people on peritoneal dialysis were more likely to show self-reliance and further probable to cultivate bonds than those on HD and this may be because there is less restriction on this form of RRT (Brem *et al.* 1988). These authors highlight that denial of challenges have been found in young people with such as CKD and summarise structured interview techniques are also required in a larger number of youngsters in this population, which is also a finding in a study by Zeltzer *et al.* (1980).

Young people are perceived as unpredictable respondents, who may lack the verbal and perceptive ability required to comprehend to measures. In many cases, it may well be that young

people are too poorly to end measures. Ironically, it is especially in these cases that evidence on youngsters' health-related quality of life (QOL) is most critical (Eiser & Morse 2001b).

A recently developed measure is the *Generic Children's QOL Measure (GCQ)*, which is used to assess perceived QOL in young people between 6 and 14 years (Heath *et al.* 2011). The *GCQ* is not disease-specific, but it has been implemented in a young renal population (Heath *et al.* 2011). The *GCQ* has an inviting layout and can be used to compare young people across age groups or in follow-up studies (Heath *et al.* 2011).

## DISCUSSION

A chronic illness not only affects the youngster, but his or her family members also. Each chronic ailment encompasses diverse challenges, and it is probable that different measures are required to effectively assess various aspects of a disease (Boekaerts & Roder 1999) to draw more concrete conclusions about how young people with CKD cope (Brem *et al.* 1988). There are several publications that give further insight on measures and assessing QOL of youngsters (Eiser 1997; Eiser & Jenney 2007; Heath *et al.* 2011). Unfortunately, the information surrounding coping to support youngsters with CKD pre- and post-transplant has not been explored in detail. Coping for youngsters can include managing symptoms, undergoing invasive RRTs, tolerating every day medicine, dealing with fluid-intake and eating restrictions and attending hospital for appointments (Boekaerts & Roder 1999).

With regard to the aims, this literature review has highlighted that young people with CKD live with the actual or threatened loss or impairment of body functioning such as weight loss, weakness, lack of energy and impaired cognition. Youngsters with CKD can experience a loss of social interaction, loss of membership in groups, frustrations in their plans for the future, difficulties in school and academia as well as marked changes in their relationships to members of their family (Sand *et al.* 1966; Scharer *et al.* 1994; Watson 1996; Wong *et al.* 2007; Murphy *et al.* 2008a, 2008b; Watson *et al.* 2010). Living with CKD (in particular stages 4 and 5), therefore, has consequences for young people in a number of dimensions, which transcend pathophysiological abnormalities, making coping with this chronic illness challenging (Heiwe *et al.* 2003).

There has been research exploring coping in other chronic illnesses and these have highlighted positive coping behaviour

is related to better physical outcomes among those with chronic diseases (Grey *et al.* 1999, 2000; Doering *et al.* 2004). At present, there is a perception that CKD only occurs in the older population, when clearly this is not the case. More research needs to concentrate on young people's ability to cope at different ages and cognitive development; for example strategies for a 3-year old will have different requirements than a 15-year old.

The coping processes/strategies utilised by youngsters with CKD have not been established. It could be that detailed methods of deducing encouraging and undesirable trials relate to a youngster's lifestyle (Goodwin 2006). For example, it may be that emotion-focused coping relating to injury ultimately increases the likelihood of depressive feelings because a youngster may be less emotionally 'equipped' to interact, and this often leads to social development, and feelings of despair (Goodwin 2006). *QOL is a broad concept encompassing a variety of dimensions, whereas coping is thought to be more specific.* It is important to stress that current research involving young people with CKD (especially stages 4 and 5) has been limited or insubstantial. Searching through abstracts and papers over a 34-year period has highlighted that coping-based research in young people has been insubstantial. What is most needed is to describe what a young person with CKD is thinking and doing in the effort to cope with stressful encounters. Much of the research conducted surrounding young people with CKD involves assessing QOL and collecting quantitative data. Any evaluation of current approaches in understanding how a young person copes needs to consider the provision for them to rate their health and care (Eiser & Morse 2001a).

### IMPLICATIONS FOR PRACTICE

With regards to specific renal nursing practice and research, more qualitative research is vital to understand actual perspectives from a young CKD population for future interventions and to identify how care should be made more explicit for them. With evolving clinical practice and research, there needs to be tighter research collaborations and a much needed

reform is an original coping service framework catered explicit to young people who suffer with CKD. This document should be an inherent part of the patient's care plan.

### CONCLUSION

The findings from this review indicate that in the wider literature (and referring back to the aim of this review), there have not been enough data collected using qualitative methodologies to understand whether or not the coping strategies/processes adopted are helpful and what coping actually means to young people with CKD. Although some references cited in this work may be quite dated, this really emphasises that research surrounding coping in young people with CKD has been a very under-researched area with only one single paper exploring transition to adult services for children with renal failure (Lewis & Smith 2010).

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

### AUTHORS' CONTRIBUTIONS

SM designed the literature review, and conducted the main analysis in the review and drafted the paper. HN had informed discussions with SM to help with focus and what how the paper could should be put together more formally and informing of specific citations. PB reviewed the manuscript at various stages. PB also helped to bring focus on the psychological aspects of health care. AC helped to compare specific practices in mainstream nephrology and how it is quite different to paediatric nephrology through discussions and also informing of citations/papers. CM reviewed and revised the manuscript at all stages of drafting and supported written contribution to bring more focus and further on the importance of psychological and psychosocial aspects of health care.

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