COPING IN YOUNG PEOPLE WITH CHRONIC KIDNEY DISEASE (CKD)

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Muhammad S., Milford D.V., Carson A., Young H., Martin C.R. (2015). Coping in young people with chronic kidney disease (CKD). *Journal of Renal Care* **xx**(xx), 1–9.

SUMMARY

Background: Chronic kidney disease (CKD) is an irreversible disease with physiological, psychological and psychosocial challenges, especially for young people.

Objectives: The objective of this phenomenological study was to identify coping strategies in two groups of young people aged 12–18 years. In one group, the young people were healthy and in the other group, the young people had stage 4–5 CKD.

Design: Young people with CKD (stages 4–5) (n = 7) (mean age = 11.5 yrs.) and young healthy people (n = 7) (mean age = 14 yrs.) were recruited from a Children's Hospital and Youth Club respectively, and were invited to take part in one face-to-face, semi-structured interview.

Findings: Data analysis showed 11 different coping themes.

Conclusion: It can be concluded from the interviews that young healthy people and those with CKD alike, utilise a range of coping strategies. The themes derived can prompt researchers to potentially develop a coping measure for a young CKD population. However, a longitudinal study would help to recognise coping strategies young people adopt over time and provide a pathway for the development of a formal coping framework.

KEY WORDS **Chronic kidney disease • Coping • Paediatric • Phenomenology • Young people**

INTRODUCTION

Chronic kidney disease (CKD) in young people impacts on educational and personal development, and many psychosocial complications continue into adult life, which reduces the chances of leading a successful work and social life (Renkema *et al*. 2011). Clinical advances allow young people to conduct modified forms of renal replacement therapy (RRT) in the home, including peritoneal dialysis (PD) and nocturnal haemodialysis (HD) (Marks 2007). In the case of CKD stages 4–5, RRT often necessitates the development of specific coping skills (Lewis & Smith 2010; Lewis *et al*. 2010). HD often challenges young people's coping strategies, and requires continual appraisal of these strategies in times of stress. Coping with CKD also means living with the risk of transplant rejection and other clinical complications (Nicholas *et al*. 2011).

LITERATURE REVIEW

The range of psychosocial concerns of young people with CKD and their families has been documented for many years (Schmidt *et al*. 2003; Judson 2004). Young people can be affected by changes to their environment, placing them at higher risk of poor psychological and psychosocial functioning (Department of Health 2006). More recent studies have associated coping strategies with the suppression of negative emotions (Janowski *et al*. 2014) and have demonstrated the positive effects of self-management (Sakraida & Robinson 2012; Reynolds *et al*. 2014). It has been shown that early intervention

BIODATA

Shahid Muhammad *is a co-founder for The Renal Patient Support Group (RPSG). He is a specialist biomedical scientist and registered scientist and has a specialist interest in Paediatric Nephrology. This study outlines the importance of understanding coping in young people with CKD for future care and practices.*

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to learn adaptive coping skills with young people suffering chronic illness has benefits (Sansom-Daly *et al*. 2012).

Increasingly young people with CKD seek personal health information about their illness, in order to acquire self-care skills (Giarelli *et al*. 2008). Their experiences include not feeling 'normal', frequent absence from school and increased reliance on family, friends and healthcare providers (Darbyshire *et al*. 2006; Nicholas *et al*. 2011). Coping strategies include confrontational coping, support and self-reliance (Harwood *et al*. 2009).

Past research involving young people with CKD has often focused on quantitative methodologies, such as scoring of quality of life (QOL) tools (Varni *et al*. 2003a, 2003b, 2004, 2006, 2007).

A number of external measures claim to provide objective information about the extent to which young people with stage 4–5 CKD succeed in coping, including their attainment in indicators such as sustaining long-term relationships, employment and further education (Fowler & Baas 2006). However, young people with CKD are also subject to feelings of helplessness, a perceived lack of control and a negative health outlook, resulting in failure of coping strategies. Personal perspectives from this population would help fill a gap in knowledge and inform future care (Muhammad *et al*. 2012a).

A variety of approaches have been used to understand the experience of coping. A study carried out by Kanzaki *et al*. (2004) in Japan involved mixed methods to collect data relating to coping strategies from patients with rheumatoid arthritis (RA). On a given day, all participants were invited to compose diary entries and an on-line blog was also created for each participant, so that they could enter their events on coping with their illness. The online blog also enabled participants to interact with and analyse records entered (Kanzaki *et al*. 2004). This team identified that using mixed methods to understand coping strategies in a population with RA was very helpful. It would, therefore, be interesting to understand coping experiences from other chronic illness populations, for example, those with diabetes and CKD.

AIM OF STUDY

The objective of this qualitative study was to identify coping strategies in two groups of young people aged 12–18 years. In group one, the young people had stage 4–5 CKD and in the second group, young people were healthy. The research question was: *What coping strategies do young people adopt to enable them to cope?*

THEORETICAL FRAMEWORK

The theoretical basis for this study involved a phenomenological approach, where the investigators essentially sought to understand coping strategies in young people, and to begin from a perspective free from hypotheses or pre-conceptions. Phenomenological methods are particularly effective to help bring forth the experiences and real perspectives from individuals, thus, challenging assumptions. Phenomenological studies relating to young people with CKD and other conditions have been carried out (Castle *et al*. 2007; Cura 2012; Heath *et al*. 2015). Using an interpretive dimension to phenomenological research allows the investigative team to inform, support or challenge policy and action (Husserl 1970; Measor 1985; Moustakas 1994).

METHODS

This study collected qualitative data from two participant groups during semi-structured interviews. Young people with CKD in group 1 were identified by a paediatric nephrology clinic nurse who later acted as a point of contact for participants. Prior to participants attending their appointments, their parents/guardians were contacted and provided with an introductory letter, information sheet and consent form asking their permission for their dependants to participate. Young healthy people in group 2 who had received written parental consent were recruited by a youth club over a one-month period and then contacted to confirm their intention to participate. All participants were informed of the purpose of this study, and that their interview data would be anonymised.

INTERVIEW GUIDE AND SEMI-STRUCTURED QUESTIONS

The interview guide was developed from previously published literature (Muhammad *et al*. 2012a, 2012b), and included questions on living and coping, family and friends, plus coping and planning. Supplemental Table S1 outlines the interview guide and the semi-structured questions.

ETHICAL APPROVAL

Ethical approval for interviewing young people in Group 1 was given by The National Research Ethics Service (NRES) in the UK, South West Committee, Frenchay and the Birmingham Children's Hospital Research & Development Department (ref: 11/SW/

Phases	Description of the processes
• Becoming familiar with the Insights	Recording information, appraising insights and putting them down in a constructive manner
• Generating initial cyphered context	Encrypting stimulating structures of the information in a systematic manner across the insights collected, gathering information relevant to cyphered context
• Identifying themes relating to key subject area	Gathering cyphered context into potential subject areas, gathering all information relevant to each potential area
• Studying subject areas carefully	Establishing if important information relates back to cyphered context (1) and the all information collected (2), composing a thematic 'map' of the inquiry
• Placing subject areas in an ordered manner/relevant to importance	Ongoing inquiry to polish specifics insights relating to subject area, and in relating to overall analysis; composing transparent descriptions and names for each theme.
• Composing a full account	Composing a final account providing detail and persuasive instances, relating to key subject area of research question, creating a report of the data collected ready for presentation

Table 1: Phases involved in thematic analysis.
Table adapted from Braun & Clarke (2006).

0247) in June 2012. Ethical approval for Group 2 participants, comprising healthy young people received ethical approval in April 2011 from the University of the West of Scotland Research Ethics Committee (ref: EC051010/44).

THEMATIC ANALYSIS

Thematic analysis provides a flexible and useful analysis tool, which can potentially provide a rich and detailed, yet complex account of data (Boyatzis 1998; Attride-Stirling 2001; Tuckett 2005). Table 1 summarises the phases involved in the thematic analysis (Braun & Clarke 2006). QSR NViVo-9 qualitative research software was used to analyse data.

FINDINGS

Table 2 summarises the demographic data of the participants in the two groups. Eleven themes emerged following thematic analysis.

ANTICIPATING A CHALLENGING SCENARIO

Young people tried to anticipate a challenging scenario by implementing different strategies. One young person stated they tried '*to find out everything before anticipating a challenging scenario'* (Participant 2/5). Another young person said '*I like going for a big/ long walk ....This helps me anticipate a challenging scenario*' (Participant 2/6). One participant informs '*yoga helps calm the mind'* (Participant 2/4). Another young participant said '*If I couldn't do something I'd probably just try a different way of doing it and then if I still couldn't do it I'd just ask someone to help me'* (Participant 1/3). One young person mentioned '*I just speak to parents, but like if it's a problem at school I'll go and see the teachers there*' (Participant 1/2). Anticipating is important. One young person mentioned '*I think as long as I've got somebody to tell me that it's going to be alright'* (Participant 1:6); another young person said '*I just cope really'* (Participant 1/5).

Another comment was '*Yeah, I'd probably ask the teacher for more time, where school work can be an issue'* (Participant 1/1). Another comment '*She communicates with me, my husband or nanny or grand-dad'* (Participant 1/4) and '*I talk to the nurse or my consultant or just talk to my mum'* (Participant 1/5).

Group 1 Young people with CKD (stages 4–5)			Group 2 Healthy young people		
ID	Gender	Age	ID	Gender	Age
Group 1:1	Male	16	Group 2:1	Male	14
Group 1:2	Male	14	Group 2:2	Female	15
Group 1:3	Female	13	Group 2:3	Male	16
Group 1:4	Female	12	Group 2:4	Female	16
Group 1:5	Male	14	Group 2:5	Male	14
Group 1:6	Female	12	Group 2:6	Male	13
Group 1:7	Male	14	Group 2:7	Male	13

Table 2: Data on recruited participants.

CLOSE RELATIONSHIPS

All subjects had someone close with whom to communicate when coping was difficult. One young person said *'probably just my parents really'* (Participant 1/3), whilst another said *'Parents...Mum. She'll show me her sympathy* (Participant 1/2)*'*. One young person said *'Erm, I often like call them round here* (*referring to dialysis nursing staff)'* (Participant 1/7). One mentioned that, *'I talk to my Mum or my Nan'*, (Participant 1/6), and '*Yeah, I normally talk to my Mum about it or sometimes my Dad*' (Participant 1/1). Young people from Participant 2 had similar insights on communication; one mentions *'close friends, sister and brother* (Participant 2/2)*'* and *'My Mum'* (Participant 2/4). Another said '*She's like best friends with the Receptionist'* (Participant 1/4).

COPING STRATEGIES

Some of the key coping strategies identified from responses provided in interviews with participants with CKD included *'lying down'*, (Participant 1/4), *'computers'* (Participant 1/6) and *'sleep'* (Participant 1/1). One young person said '*Yeah, I don't tend to get annoyed at stuff; I just accept that I can't do it and ask someone for help'* (Participant 1/3). Another said *'I kept calm about it'* (Participant 1/2), whilst another said *'I just tend to try and relax, I usually try and listen to some music; lying down and listen to music* (Participant 1/5). Another participant said '*I just forget it and just … urgh! Yeah, I put it to the side and don't think about it because it just worries me'* (Participant 1/6) . One young person mentioned that *'sometimes if I am bad enough, I will just go to sleep and then feel better when I wake up'*.

In comparison with participants in Group 2, these young people appeared to implement a combination of both Problem-Focused Coping and Emotion-Focused Coping. One comment was *'put it to the side'* (Participant 2:7), another young person spoke of *'Walking long distances'* (Participant 2:1) and another mentioned *'squeezing stress balls'* (Participant 2:6). More comments from young people in Group 2 included '*I'll smoke'* (Participant 2:2), *'Get angry at everybody'* (Participant 2:7) and *'Go for a jog'* (Participant 2:5). The young people in both groups displayed a range of coping strategies that surround Emotion-Focused and Active Style approaches.

DEMONSTRATING RESILIENCE

Resilience seems to play a large role in young lives. One young person said *'If it's a problem at school I'll go and see the teachers there'* (Participant 1:2), whilst another highlighted a very important point and said '*Still got to do it (homework and take appropriate treatments) because you're not ill enough to say, 'I can't do it', but you're not well enough to be able to do it properly'* (Participant 1:5). Another participant also provided a school/ homework example, saying '*Yeah, I'd probably ask the teacher for more time'* (Participant 1:6) and another was *'She hardly ever complains of pain does she? 'That's when we know when she is in pain and it's bad when she says she's in pain, because she never complains usually; she has a very high pain threshold'* (Participant 1:/P4/P5 on behalf of Participant 1:4).

EXERCISE

Demonstrating involvement in physical activity is an important strategy. One young person says '*I'm not great at sport but I enjoy doing it'* (Participant 1:3). Another said *'I'm not that much of a sporty person'* (Participant 1:2), another comment was '*She's done abseiling, canoeing – everything'* (Participant 1:4). *Being active is important. One young person said 'I just play football with friends and stuff* (Participant 1:1)*'*. Another comment was *'I think any activities can sort-of takes my mind off it (health related concerns); football, running'* (Participant 1:5) and *'I like swimming as well but I can't go swimming'* (Participant 1:6).

MAKING DECISIONS

Young people had various people whom can support them in decision making. One young person said '*I can usually talk to my mates'* (Participant 1:1), another mentioned *'My parents about most things'* (Participant 1:3). Depending on the type of decision to be made, one said *'probably just my parents really, a group of three friends'* (Participant 1:6), *'We are in the process of getting her moved to a Special Needs school because there's just no understanding on her learning disability side of things or on the renal failure'* (Participant 1:/P4/P5 on behalf of Participant 1:4) and '*Talk to the nurse or my consultant or just talk to my mum'* (Participant 1:2).

PASTIMES

One young person from group 2 said '*Attending the youth club allows me to change my group of friends'* (Participant 2:5). This is quite important because this can help gain more perspectives. One young person said '*Attending the youth club helps to communicate with someone when making decisions and something is difficult'* (Participant 2:2). On pastimes, young

people from group one had varied comments including *'I like kind-of drawing and reading', 'I like model building actually, Astronomy'* (Participant 1:2), '*Football and FIFA'* (Participant 1:5), '*I like playing football; I like doing lots of sports and stuff'* (Participant 1:7), *'I did like running but I can't do it now'*. (Participant 1:6), *'When it's sunny and the kids come round, we've got a trampoline in our back garden'* (Participant 1:/P4/P5 on behalf of Participant 1:4) and *'I like playing football'* (Participant 1:1).

PEER PRESSURE

As for group 2, young people from the CKD group 1 did not really report experience of peer pressure. All young people reported having a tight group of friends they can talk to and enjoy time with, for example, '*I can usually talk to my mates'* (Participant 1:1), 'probably *just my parents really, a group of three friends'* (Participant 1:6) and '*talk to the nurse or my consultant or just talk to my mum'* (Participant 1:2).

RELAXATION-RELIEF

A range of comments related to relaxation-relief; one young person says '*The youth club as a place where young people are able to relax and relieve any tensions*' (Participant 2:4). Another said '*the youth club is where young people are very much welcomed, empathising with our direct situation/circumstances*' (Participant 2:2). One young person said '*If I think of a story and I write it down—just write whatever comes out—it usually helps me*' (Participant 1:3). To relax, young people said '*I usually try and listen to some music; lying down and listen to music*' (Participant 1:5) and '*being calm and just lying down*' and also '*counting to 10 or breathing*' (Participant 1:1). Another comment was '*she is independent so she'll quite happily just go off and play in her room*' (Participant 1:/P4/P5 on behalf of Participant 1:4).

STRESS TRIGGERS

All participants spoke about different stress triggers. Some comments include '*Exams are a cause a trigger for stresses'* (Participant 2:1–4). Other comments include '*arguing with my mum a lot'* (Participant 2:6) and '*people telling me what to do'* (Participant 2:7). The young people here indicated there were a variety of causes of their stress. One participant identified that *'If I have difficulty doing certain tasks (e.g. homework, some home chores), I find that this can cause me stress'* (Participant 1:6). Relating to a clinical scenario, one young person said *'well if my creatinine goes up—it can be kind-of like stressful then'* (Participant 1:2). School work is an obvious stressor, one young person said *'keeping on revision is hard—it's just another thing that you've got to deal with on top of everything else'* (Participant 1:5) and *'I was like in hospital a load of the time so I missed loads of education'*. (Participant 1:3). One participant explained '*I think mixing with her learning disabilities as well; she does have time off school and she's in a mainstream school at present and sometimes she's not aware of different things; she's not aware of the full consequences'* (Participant 1:/P4/P5 on behalf of Participant 1:4). *'I've missed quite a bit of school', so when I first got diagnosed I missed nearly all of Year 3'*. This young person elaborated '*I've missed days and weeks with my illness coming into hospital and just that builds-up because then I had my GCSEs'* (Participant 1:1).

WORST CASE SCENARIO—ON THE EXTREME

A number of participants in both groups spoke of escaping from the situation when it became too extreme, for example, '*Be the big man and walk away'* (Participant 2:3), *'I just try and distract myself I suppose'* (Participant 2:4) and one said *'I just leave the situation'* (Participant 2:5). The healthy young people talked about removing themselves from the situation. However, many of the young people in group one used strategies to emotionally remove themselves. As examples, *'Erm, I often like call them round here (referring to dialysis staff on the unit)'* (Participant 1:7), another says *'I just forget it and just … urgh!* (Participant 1:6) and *'Erm, I manage well in difficult situations but then, when it does build-up, I get upset about it'* (Participant 1:1).

DISCUSSION

In this research the investigators identified, depending on situation, young people with CKD were able to apply relevant coping strategies, ranging from problem-focussed and emotion-focussed coping to more passive strategies such as avoidant-focussed or style strategies. Subjects in this group as in the healthy group adopted anticipation, developing resilience and communication as counteractive approaches where possible. In many cases there was evidence of steps being taken to enhance coping through exercise, relaxation and pastimes. Exercise was a positive coping strategy to relieve stress and anxiety, and potentially helps to enhance control of challenging issues (Heiwe *et al*. 2003). Being involved in physical activity can also be a positive relaxation strategy for young people and this also enabled some to cope. Young people in 'negative' environments may be left them feeling resentment or 'trapped'. Resilience, created by physical activity can also be powerful 'tool' in coping (Jacelon 1997; Ahern *et al*. 2008).

Data here only describes some of the insights from parents/guardians. The data collected from youth club workers and health professionals has not been included. The results indicated harmony between comments made by subjects and their parents/guardians. Data from the Healthy cohort revealed that young people in times of challenge found attending the youth club positive and a place where they could go to help relieve any particular stresses. It became apparent that emotion based coping and physical/active-based coping are used by healthy young people. These forms of coping have been described by (Folkman & Lazarus 1988).

Under the decision-making theme the results indicated a good support system is likely to help young people cope with specific challenges and preclude stress triggers (Cameron 1985; Swallow *et al*. 2008). A 'buddy or mentoring' system, whereby young people in CKD (stages 4–5) can communicate with CKD peers or mentors who have been in similar circumstances would be advantageous. Where coping can be difficult, there perhaps needs to be more communication pathways set up for young people with CKD. This would be consistent with research by (Harden *et al*. 2012) and (Harden & Nadine 2006). Some young people used a variety of coping strategies perhaps just because of the time in being a long term patient with CKD (stages 4–5), whilst others require more formal support. This is consistent with research (Snethen *et al*. 2004).

On the stress theme, the experiences of the two subject groups were not clearly distinguishable (there were common stress triggers, experiences of frustration and lack of ability to express feelings). In view of the data collected it appears that getting involved in activities and talking about issues/ concerns are forms of positive coping which can apply equally to CKD sufferers as to healthy young people – this is consistent with work by (Snethen *et al*. 2004), (Ahern *et al*. 2008) and (Webb *et al*. 2010).

STUDY LIMITATIONS

This research involved a small sample size, so the findings are not generalisable. Young people with CKD were particularly challenging to recruit, with only one young person undergoing HD. There were differences in ages across both groups which may bring about different findings, since the coping strategies of a 12-year old may differ from those of a 16-year old.

IMPLICATIONS FOR PRACTICE

Young people with stage 4–5 CKD may not cope as well as those with earlier stage CKD due to limitations associated with disease progression, for example, physical exercise. The psychological approach to coping proposes that young people with CKD may need to adjust both cognitive and social aspects of their lives to meet the challenges of living with chronic illness, (Royal College of Paediatrics and Child Health 2011).

The themes derived can prompt researchers to potentially develop a coping measure for a young CKD population. Additionally, it would be advantageous to look at how young people with CKD have developed their own coping strategies through a longitudinal study to provide a pathway for the development of a formal coping framework.

This study highlights some of the insights and experiences of young people with CKD. The findings could allow professionals in paediatric nephrology to develop a guideline to complement clinical practice and strengthen coping strategies for young people with CKD. Future studies on coping should focus on the perceptions of coping from parents (Folkman & Moskowitz 2000).

CONCLUSION

For young people with CKD, coping strategies can be impaired by normal daily living activities. This, in turn, can reduce physical activity, the enjoyment of close friendships, contentment with family and performance in school or work. If young people with CKD have support to adopt more positive coping-based strategies, this may also enable a smoother transition from paediatric renal care to adult renal services where they are required to become more autonomous. Prospective studies should, thus, adopt a similar qualitative methodology approach, but seek wider opportunities to encourage greater participation from this population.

ACKNOWLEDGEMENTS

The lead author would like to acknowledge and thank Professor Pauline Banks, Faculty of Health, Nursing and Midwifery for her time co- supervising. The primary author would also like to thank the paediatric nephrology teams whom he visited during the course of this research period, especially the Birmingham Childrens Hospital, UK.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

SM: Principal Project Leader, conceived study, participated in design and coordination, undertook interviews and analysed the data. DM: Participated in coordination, read amd approved final manuscript. AC: Participated in design and coordination, supported in data analysis. HY: Participated in coordination. CM: Participated in design and coordination, read and approved the final manuscript.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site.

Table S1: Interview Guide and Semi-Structured Questions.