

# Children's and young people's experiences of chronic renal disease: a review of the literature, methodological commentary and an alternative proposal

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## Children's and young people's experiences of chronic renal disease: a review of the literature, methodological commentary and an alternative proposal

**Aim.** The aims of this paper were to review and critique existing research literature on children's and young people's experiences of chronic renal disease and to propose alternative approaches that may be more fruitful in addressing existing research shortcomings.

**Background.** Chronic renal disease, which results in approximately 1·6–4 new cases per year per million population in the 0–15 years age group, is a serious illness that causes severe and irreversible reduction in kidney function. Despite modern medical advances, its significance and implications for the lives of the children and young people concerned are profound.

**Method.** Salient literature for this review was obtained using the major health and social science electronic databases such as Medline, CINAHL, PsycLit and Sociofile. Manual searching of relevant books, journals and 'grey literature', combined with the genealogy approach, extended and strengthened the search.

**Conclusions.** Research in this area focuses mainly on two areas, namely psychological adjustment and adaptation to end-stage renal disease. This research is grounded within a framework of empirical psychology that values objectivity, measurement and quantification. This predominantly psychometric approach is critiqued for simplifying the complex experience of end-stage renal disease and for pathologizing children and young people with this disease. We identify a significant gap in the research literature, namely the lack of research that takes into account these children's and young peoples' *own* perspectives of their experiences.

**Relevance to clinical practice.** Chronic renal disease has a significant impact on children's and young people's lives. Understanding the experiences of these children is important for the provision of effective healthcare. Conducting child-centred qualitative research in this area would allow us to explore vital questions of

meaning, perception and understanding. If health and social care organizations claim to provide 'consumer-focused' services, it behoves us to develop first a clearer understanding of the lives and experiences of children and families who seek our help and to use this knowledge and understanding to plan and provide more grounded and responsive services.

**Key words:** children's experiences, children/young people, chronic renal disease, literature review, nurses, nursing

## Introduction

In this paper, we use the term chronic renal disease (CRD) as one that incorporates the full spectrum of the manifestation of the condition, including end-stage renal disease (ESRD). CRD in children and young people is a serious and debilitating condition resulting in approximately 1.6–4 new cases per year per million population in the age group 0–15 years old (Beecroft 1993). While CRD cannot match the 'numerical significance' of more common childhood conditions such as asthma or diabetes, its significance and health implications for the children concerned are profound (Balinsky 2000, p. 304).

## Aims

The aims of this paper were to review and critique existing research literature on children's and young people's experiences of CRD and to propose alternative approaches that may be more fruitful in addressing existing research shortcomings.

## Methods

We searched the research and professional literature related to CRD in children and young people, concentrating on work published in English between 1975 and 2005. The scope of the research included journal papers, books and book chapters. All major health and social science electronic databases such as Medline, CINAHL, PsycLit and Sociofile were searched, using key terms such as 'children', 'youth', 'chronic illness', 'chronic renal failure' and 'CRD' in various combinations. The genealogy approach was also used to consult cited work that may not have been uncovered by these searches.

## Results

### The emergence of CRD as a child-health issue

Chronic renal disease results from a range of conditions that cause irreversible damage to the kidneys. People with CRD

experience loss of kidney function, progressing to ESRD where there is a severe and irreversible reduction in function (Australian Institute of Health and Welfare 2002). Modern medical advances, such as dialysis and kidney transplantation, have markedly increased the chances of survival for children and young people with CRD. However, the health and well-being implications of the condition remain profound and children with CRD may experience a range of medical problems associated with the loss of kidney function that require 'lifelong treatment and management in order...to survive' (Snethen *et al.* 2001, p. 160).

Prior to the advent of dialysis, in the early 1960s, there was no effective treatment for CRD. As Bevan (2000) noted, early selection criteria for dialysis treatment specifically excluded children and young people ('except for research purposes') as they were deemed to be 'not potentially self-supporting' (p. 438). Yet in recent years, when more children and young people have been treated for CRD, there remains a surprising lack of research exploring their health, illness and treatment-related experiences, perceptions and understandings. Children's experiences of CRD and treatment are a potentially potent intersection of embodiment, technology, dependence-independence, children's rights, identity and ultimately survival. Despite this, research approaches to understanding the lives and worlds of children and young people with CRD rarely seem to extend beyond a 'medical' and 'psychological' bifurcation.

Most research in this area is grounded within a framework of empirical psychology that values objectivity, measurement and quantification (Hoffart 1995). This is not the broad and inclusive understanding of empirical, meaning based on data, but rather an approach dedicated to 'systematically observing and measuring quantifiable objects or phenomenon that affect objects' (Indick 2002, p. 22). There are two predominant areas of psychosocial functioning that form the focus of this body of literature, namely psychological adjustment and adaptation. We present some central research findings in these areas and suggest a critique of this body of literature. We then draw upon the growing bodies of scholarship on children's rights (Woodhouse 2004), children's participation and involvement (de Winter *et al.* 1999, Francis & Lorenz

2002, Lightfoot & Sloper 2002) and participatory research with children (Scott 2000, Alderson 2001, Morgan *et al.* 2002, Clark 2004), to propose alternative approaches that may be fruitful in addressing existing research shortcomings.

### The 'adjustment' and 'adaptation' of children and young people with CRD

Adjustment and adaptation are understandably popular foci in the psychological literature, given the implications of CRD for a child's health and everyday patterns of living. The most common approach to understanding these phenomena is based on assumptions that these are essentially linear processes whose locus lies within the child or young person and which can be assessed and measured by a range of standardized and non-standardized survey tools. We do not suggest that these assumptions have no value, but do propose that critique can open up other valuable approaches to understanding the lives of children and young people living with CRD.

#### *Children and young people's psychological adjustment to CRD*

Systematic psychological research into children's adjustment and adaptation to CRD began in the 1970s (Korsch *et al.* 1973) and continues today (Madden *et al.* 2002, 2003). The psychological literature often claims that children with chronic illness 'are typically found to be at increased risk for psychological maladjustment compared with their healthy peers' (Madden *et al.* 2002, p. 323). Chronic illness in childhood also has a perceived social cost, particularly as a result of treatment regimes limiting these children's 'activities, socialization and school involvement' (Snethen *et al.* 2001, p. 160). Children with CRD are often reported to experience difficulties with psychosocial adjustment (see e.g. Marland 1995), yet the research results are inconclusive.

In one of the earliest studies, Korsch *et al.* (1973) explored the psychosocial adjustment of children following kidney transplantation, expressing concern that 'some of the gross failures in rehabilitation of patients with end-stage kidney disease are partly or wholly rooted in psychosocial malfunction' (Korsch *et al.* 1973, pp. 399–400). This was one of the first systematic studies in this area using standardized measures of psychological and social functioning. The authors found that their post-kidney transplant sample demonstrated normal patterns of personal, family and social functioning. They did, however, demonstrate high levels of anxiety and damage to self-esteem.

A later study exploring similar variables in adolescent transplant recipients, albeit using different tests, directly

contradicted those of Korsch *et al.* (1973). In this study, Melzer *et al.* (1989) examined adolescents' body image, self-esteem and social networks using a combination of structured interview and rating scales. The 16 adolescents with ESRD were compared on these measures with 16 healthy adolescents. The authors found that family members 'provided a greater proportion of transplant patients' (social) networks compared with the controls' (Melzer *et al.* 1989, p. 311). In addition, the transplant recipients had 'significantly fewer individuals in their total social networks, particularly unrelated and opposite sex peers' (Melzer *et al.* 1989, p. 311). However, the transplant recipients did not score significantly lower on the self-esteem measure than the controls and nor did they demonstrate problems with body image that were found in previous research.

In a more recent study, Madden *et al.* (2003) explored the cognitive and psychosocial outcome of infants dialyzed in infancy. Sixteen children, aged between 1.6 and 12.1 years, who had survived peritoneal dialysis begun in the first year of life, were assessed in relation to their mental development, IQ and psychological adjustment using standardized measures. While the IQ scores were predominantly within the normal range, the authors noted that over half of the participants demonstrated behavioural and emotional difficulties. Penkower *et al.* (2003) found similar psychological difficulties in their study of adolescent renal transplant recipients.

Disparities and contradictions among psychological studies of children and young people with CRD have been attributed to a range of methodological problems within this body of research (Osberg *et al.* 1980, Molzahn 1993, Shaben 1993). These include inadequate consideration of subject selection, the description of subjects, the measures used, the assessment procedures, the conditions of testing, the use of comparison groups and the use and inclusion of appropriate data analysis measures (Osberg *et al.* 1980).

It is possible that these variations in research findings can be at least partially accounted for by considering the number of variables that are usually subsumed under the shorthand of 'adjustment'. These include the effects of maternal stress (Madden *et al.* 2002), the visibility of a child's 'physical differences' (Beck *et al.* 1986, Reynolds *et al.* 1993), treatment modality (Reynolds *et al.* 1991) and the severity of the child's CRD (Fielding & Brownbridge 1999, Crocker *et al.* 2002).

#### *Children and young people adapting to life with CRD*

The psychological approach to adaptation proposes that children and young people with CRD may need to adapt and change both cognitive and social aspects of their lives to meet the challenges of living with CRD. Research in this field tends

to focus on areas such as the development of effective coping skills and strategies (Brem *et al.* 1988, Snethen *et al.* 2004) and the achievement of markers of adaptation such as marriage, children, jobs and education. Once again this body of research draws on the assumptions and tools of empirical psychology, in particular, standardized and non-standardized survey tools.

Given the potential long-term impact of chronic illness on the physical and emotional well-being of children and young people, the development of coping skills and strategies is of great significance in children with CRD. As Schmidt *et al.* (2003) point out:

...early adopted strategies of coping with chronic disease may serve as a buffer against these disease-related consequences (p. 63).

One of the early studies of children's coping skills in relation to CRD was that of Brem *et al.* (1988). In this study, the psychosocial characteristics and coping skills in 12 children maintained on dialysis were assessed using standardized and non-standardized psychological measures. The authors found that, while the incidence of psychosocial problems was no higher than in a population of healthy adolescents, the study group developed different types of coping skills depending on the mode of dialysis treatment. In particular, patients treated with home peritoneal dialysis drew on self-reliance more often than did those receiving haemodialysis, perhaps because the self-management required of peritoneal dialysis might encourage this, whereas, haemodialysis patients rely more on health-care staff for treatment.

In a more recent study of coping, Snethen *et al.* (2004) explored the coping strategies of 22 adolescents with ESRD and suggested that the type of coping reported by the participants was related to treatment modality, with transplant recipients using more physically and cognitively demanding activities to cope with their illness than those receiving dialysis. This may be because transplantation corrects the anaemia and bone problems of ESRD, thus increasing energy and mobility in this group. For adolescents receiving dialysis, time on dialysis had an impact on the coping strategies used, with those receiving this treatment for a longer period tending to talk to adults or counsellors to help them cope. Finally, age influenced coping strategies, with older participants using a broader range of coping strategies than did younger adolescents.

While the exploration of coping skills and strategies focuses more on intrapsychic features of adaptation, some researchers have explored more external, social indicators of adaptation. A number of external measures are claimed to provide objective information about the extent to which children have adapted to life with CRD. These include the

attainment of a range of 'markers' of successful adaptation in late adolescents or adulthood, namely living away from parents, being married or in a long-term relationship, having children and being either employed or undertaking further schooling or vocational education.

In a study of the long-term outcome of treatment of ESRD, 32 adult survivors from a dialysis and treatment program were assessed on a range of measures of adaptation (Henning *et al.* 1988). These included education, employment, marital state, psychiatric problems and dissatisfaction with personal and social life. The renal patients were compared with adults with juvenile onset diabetes on these measures. The results indicate that adults treated for ESRD as children and adolescents find it more difficult to form a lasting relationship with the opposite sex, experience a restricted social life and are more likely to live with their parents.

Researchers have also noted difficulties with schooling in children and young people with CRD or postkidney transplant (Lawry *et al.* 1994, Fukunishi & Honda 1995, Poursanidou *et al.* 2003a,b). Rosenkranz *et al.* (1992), for example, examined the school attendance, vocational training, occupation, marital status and caregiver dependence among 479 children and adolescents with CRD. They found that, while early school education was well-maintained, the later years of education are frequently disrupted or inadequate. They also noted low levels of independence, measured as living away from home and being economically independent.

Treatment modality may also have an impact on children's ability to adapt to life with CRD. In a study of medical and social outcome in 118 adolescents with ESRD, Roscoe *et al.* (1991) found that adolescents with ESRD who were successfully transplanted achieved a better quality of life compared with those receiving dialysis. Similar positive results were found by Morel *et al.* (1991).

## Discussion

### Critiques of the psychological literature

Psychology's interest in health and illness began in earnest around 30 years ago (Terborg 1998) and increasingly dominates our understanding of the illness experience. The predominance of the psychological framework to research and understand children's and young people's experiences of CRD is a case in point. The psychological research on children with CRD has been critiqued by a number of authors (Osberg *et al.* 1980, Molzahn 1993, Reynolds *et al.* 1993, Shaben 1993, Madden *et al.* 2002). In addition to the previously mentioned methodological critiques, the

fundamental assumptions, philosophies and theories underpinning much of the psychological research have also been questioned.

Contemporary critiques are often based on a resistance to what is termed 'positivism' as a dominant philosophical framework in psychology (Duffy *et al.* 2002). Care, however, is required here. Paley (2001) has rightly pointed to the tendency to use 'positivism' as a kind of codified abuse, detached from its genuine philosophical meaning, to denigrate those who share a different philosophical orientation. What we highlight here is the critique of psychology and its (possibly 'positivist') approach founded on 'a belief in an independent, external reality that can be apprehended either directly or indirectly through the application of a systematic way of knowing, primarily the scientific method' (Duffy *et al.* 2002, p. 364). This approach often involved breaking down the whole of the experience of health and illness into its parts, which could then be observed in isolation from the supposedly contaminating influence of contextual factors.

Terborg (1998) has criticized the dominance of this 'reductionist' approach in his review of health psychology in the United States, arguing that:

Unfortunately, the majority of health psychology research in the US has been reductionist in theory, clinical in focus and directed at studying the individual with minimal attention to context (p. 201).

Arthur Frank (1992) offers a compelling critique of psychological research with the ill, using psycho-oncology as an example. His central critique is that psycho-oncology fails to engage properly with the ill, a critique that is surely applicable to psychological research on children and young people with CRD. He outlines what he terms the 'first-person problem' (Frank 1992, p. 470) as central to this lack of engagement, where researchers themselves are absent from their reports. This absence results from a reliance on objectivity in attempting to establish an authority within the social sciences that is deemed comparable with physical sciences. Frank also critiques the psychological approach to the ill for the aggregation of individual experiences into broad categories in the pursuit of generalizability. This aggregation, he argues, simplifies the interrelated parts of life and fails to take into account the contingency of what happens to individuals.

The reliance on coping scales in research into the adaptation of children with CRD shows how reductionist approaches can simplify what is undoubtedly a complex experience by overlooking important contextual factors in the experience of illness. Danoff-Burg *et al.* (2000) have explored the (mis?) match between researchers' and participants' understandings of coping, arguing that:

Research using coping checklists, for the most part, has used reductionist data analytic methods to separate out the influences of different types of coping on adjustment. To adequately get a sense of the complex, a researcher must consider the temporal, interpersonal, situational and sociocultural dimensions of coping (p. 192).

These researchers found that, while research participants generally understood the definitions of coping derived by researchers, 'some checklist items, particularly those reflecting cognitive or affective coping constructs may be less likely to be interpreted in the manner intended by researchers' (p. 192). An important finding here was that of while questionnaires attempt to research coping's 'definable parts', such as its behavioural, affective and cognitive aspects, these aspects 'may occur simultaneously or in rapid succession' (p. 192). Thus a 'checklists approach' can easily miss the complexity of coping.

The psychological approach is also critiqued for the normative nature of its understanding of illness. By this we mean psychology's tendency to award itself the power to determine what is a normal and appropriate response to chronic illness and to define the 'normal life' following diagnosis and treatment. A central feature of psychology is the classification of feelings and actions as normal or abnormal through the use of psychometric tests and statistical analyses. Once assessed in this way, children with CRD may find themselves deemed to be 'maladjusted', 'non-compliant' or otherwise outside the psychometric and possibly moral, norm.

More detailed critiques of the social sciences in general and of psychology in particular, have been mounted by Foucault (1970) and Rose (1998), among others. Rose (1998), for example, argues that the discipline of psychology is an intellectual technology through which individuals are governed. Using a Foucauldian approach, Polaschek's (2003) study of adult men on dialysis, critiques this linear, illness career model that sees 'normality' as a kind of 'end point' to be achieved and suggests instead that the 'normality' is part of the struggle of 'ongoingness of life on dialysis' (p. 48). Frank (1992), too, has argued that social science is a 'moral discourse, presenting claims about the nature of suffering and the proper response to suffering' (p. 467). He criticises the tendency of psychology to research and treat ill individuals in terms of 'binary notions of normal and pathological' (Frank 1992, p. 476). Frank notes how the aggregation of individuals pathologizes the eccentricity of the ill individual's behaviour, rather than viewing it as a means to singularity in a homogenizing environment.

The normalizing tendency of psychology is evident in the attempt to define children with CRD as normal, or almost by definition 'abnormal', through psychometric assessment. Such research often uses standardized measures of functioning,

such as examining whether or not children with CRD are more depressed than the 'normal' population. Yet, as Frank (1992) points out:

...the 'craziness' of the ill is not 'psychopathology', though it may be diagnosable as such. Rather the eccentricity of the ill is a normal human response to an inhuman existence: being kept alive by artificial means, in artificial environments, with infantilizing demands, at enormous loss to the rest of your own life and the lives of your loved ones and then having nobody want to listen to what is happening to you except to note your 'responses' in a chart (p. 476).

This issue of 'who defines what is normal?' in the experience of chronic illness can be seen clearly in the research on adaptation discussed above. As we noted, adaptation is generally defined in relation to whether or not children with CRD achieve a number of markers of a 'normal' life following diagnosis and treatment. These include living away from parents, being married or in a long-term relationship, having children and being either employed or undertaking schooling or vocational education. Marked societal changes have, however, made such previously vaunted norms far from normative, or at least problematic.

In addition, as Reynolds *et al.* (1993) point out, it 'cannot be assumed that people who are delayed or atypical socially necessarily experience more suffering' (p. 104). This was evident in their study of both 'objective' and 'subjective' measures of adjustment. Objective measures included employment, marital status and living arrangement, which were related to '*subjective* indicators of stress and support in these areas of social life and relationships' (Reynolds *et al.* 1993, p. 49: 105, italics in original). Thorne *et al.* (2002), however, sound a note of much-needed analytic caution here when they highlight how the interpretive framing, if not the nature of chronic illness, can change and thus privilege 'the aspects of illness experience that reflect transformation, courage and spirituality, where in earlier years, such experiences might have been characterized as loss, burden and sorrow' (p. 441).

Such research questions the assumption in the psychological literature that these children and young people and anyone with a chronic illness, will inevitably experience diminished quality of life and psychosocial functioning. This has been described as a 'hidden negative assumption' (McKnight 1994, p. 422), as many people with 'chronically limiting conditions' (Koch 2000, p. 422) experience a good quality of life. As Koch (2000) has pointed out:

Where surveys and questionnaires begin with the assumption of 'disease burden' and a medical model of life quality, the assumptions of those positions – not the individual's state – is often what is typically measured (p. 423).

Furthermore, Koch notes that it is often prejudice and stigma that causes diminished quality of life. Madden *et al.* (2002) have also noted that research with children with CRD tends to focus on behavioural and emotional deficits, with less of a focus on positive dimensions, such as pro-social behaviour. Once again, however, we note Thorne *et al.*'s (2002) caution about the privileging of certain interpretations of the illness experience based on changes in interpretive framing.

The concerns raised about the privileging of the views of the researcher are particularly salient in research with chronically ill children and young people, for such research often fails to take into account these children's and young peoples' *own* perspectives of their experiences. In fact, as Madden *et al.* (2002) have noted, it is common to seek parent or teacher reports of adjustment rather than asking children themselves. Paterson and Thorne (2000) also note this tendency among researchers in relation to chronic illness self-management in children, where the issue is scarcely raised as a serious research issue 'because the underlying assumption of many researchers is that children simply follow the directives of their parents' (p. 403). As if to underscore the need for specific 'children's perspectives' research, studies that includes both children's and parents/teachers' ratings of psychosocial adjustment to chronic illness often show how poorly these perspectives align. For example, Madden *et al.* asked both mothers and their children to rate the psychological adjustment of children to ESRD. They found that:

Compared with normative data...mothers reported their children to be at increased risk of psychological problems. However, the children themselves reported no more problems than a normative sample (Madden *et al.* 2002, p. 323).

Similarly, Penkower *et al.* (2003) discovered 'disparity in agreement between parents and adolescents' (p.1422) in their study of post-transplant medical compliance. There is clearly a danger in assuming that proxy measures of children's experiences are sufficient for adequate research-based understanding of children's health and illness experiences. Considering parents' or professionals' responses or views as being synonymous with, or representative of, children's experiences effectively negates children's voices. Rendering children 'invisible' in this way can lead to the erroneous understanding that they are simply 'mini adults' and can be treated thus.

### Seeking children's and young people's views and perspectives

Current research and scholarship within 'childhood studies' in general, demonstrates the value of gaining a deeper

understanding of children's views and experiences from the child's perspective. The 'new sociology of childhood' programme of research in the UK provided a significant research impetus (Prout & James 1997) here. The 1989 UN Convention on the Rights of the Child established children's rights to participation, to express 'views freely in all matters' and to have their views given 'due weight' (Alderson 2001). However, directly researching the perceptions and experiences of young children has often been deemed 'too hard' and so they have been 'consulted' tokenistically (Curtis *et al.* 2004) or overlooked. Recent work, however, demonstrates researchers' direct engagement with children, not as passive respondents but as social actors in their own right, by ascertaining children's understandings, experiences and views across a range of health and social issues (Mauthner 1997, Morgan *et al.* 2002, Lewis *et al.* 2004).

Over a decade ago, however, reviews of renal research noted the lack of qualitative and interpretive studies in the field and especially in relation to children (Molzahn 1993, Shaben 1993). Qualitative research with children respects the child's perspective and presents this within a scholarly research framework. This does not mean that children are 'always right' (in the same way that adults rarely are), but that their articulated experiences are sought and valued as a vital perspective in the overall health-care picture (Lightfoot & Sloper 2003, Young *et al.* 2003).

The importance of understanding the perspectives of children and young people with CRD has been recognized and supported even within psychometric studies. In Reynolds *et al.*'s (1991) study of children's psychosocial adjustment after renal transplantation, the authors expressed surprise at the participants' lack of concern regarding their appearance, particularly given that previous studies reported serious concerns in this area. They note:

it may be that interviews with the children themselves would have been necessary to assess fully the degree of these concerns (Reynolds *et al.* 1991, p. 512).

A similar suggestion was also made by Snethen *et al.* (2004). Madden *et al.* (2002) also reflected that:

Many authors have emphasized the importance of multiple perspectives in research on children's adjustment. The present results support this conclusion and identify the significance of obtaining the child's perspective of their adjustment (p. 328).

The response to this call for qualitative research with children and young people with CRD has, however, been disappointing. Qualitative approaches to understanding CRD have focused more on adult patients' and families' perceptions, meanings and experiences (Rittman *et al.* 1993, Gregory *et al.*

1998, White & Grenyer 1999) and have also been conducted with parents and carers of children with CRD (Obrecht *et al.* 1992, MacDonald 1995, Middleton 1996, Knafl 2000). The few qualitative studies undertaken in this area tend to focus on adolescents' experiences (Gallo *et al.* 1992, Snethen *et al.* 2001).

A recent study asking adolescents about their experiences with CRD (Snethen *et al.* 2001) used a mixed qualitative and quantitative approach. In this study, a pool of statements about life with ESRD were developed from interviews with adolescents with ESRD and rated by 35 adolescents. Statistical analyses produced four factors under which a significant number of participants loaded, namely 'normalization', 'illness intrusion: barrier to normalcy', 'illness management: parent-focused' and 'illness management: self-focused'. While this study did ask adolescents directly about their experiences, the essentially quantitative approach to data collection and analysis suggests that an opportunity to engage young people in a deeper dialogue and discussion about their lives may have been missed.

In the only study found where younger children were asked to describe their treatment, this was performed as part of a study on short stature related to renal failure (Reynolds *et al.* 1995). Here, children aged between four and 18 years were interviewed briefly as part of a psychometric assessment. Unfortunately, there was no systematic qualitative approach taken and so no interpretive themes or direct quotes from the children are presented. In a glimpse of what is possible when children are involved in more open, conversational, qualitative interviewing, the researchers noted that these 'small children understood and readily expressed their feelings about treatments (...) and hospital visits' (Reynolds *et al.* 1995, p. 40). Given the ability of young children to discuss and describe important aspects of their lives (Clark 2004, Darbyshire *et al.* 2005) and evidence from the growing body of research genuinely involving young children (Bricher 1999, Scott 2000, Lightfoot & Sloper 2002), the absence of such studies involving children with CRD constitutes a significant gap in research knowledge.

## Conclusion

Chronic renal disease is a serious chronic condition that has a significant impact on children's and young people's lives. Understanding the experiences of these children is important for the provision of effective healthcare. In this paper, we have presented a critical overview of the existing literature exploring the experiences of children and young people with CRD, suggesting that the pervasive psychometric research approach leaves many questions unasked and unanswered

and continues to leave children and young people essentially voiceless regarding their experiences.

This review shares the common limitation of incorporating only studies in English and thus has overlooked potentially important work in this area published in other languages. Despite this shortcoming, this review has highlighted a significant gap in research knowledge concerning the lives of children and young people with CRD, namely research that asks these children *directly* about what life is like for them. Conducting child-centred qualitative research in this area would allow us to explore vital questions of children's and young people's meanings, perceptions and understandings that could inform and enrich the practices and policies of renal nursing and paediatric nephrology. If health and social care services claim to provide 'consumer-focused' services, it behoves us first to develop a clearer understanding of the lives and experiences of those children and families who seek our help and to use this knowledge and understanding to plan and provide more grounded and responsive services. Qualitative approaches can enable researchers to uncover and interpret the many ways in which children with CRD can articulate and make sense of their experiences and to discover 'how potently they (children) express themselves through their words and behaviour and how much they need to be listened to and respected' (Alderson 1995, p. 67).

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## Contributions

Study design: PD, PH; data collection: PD; data analysis: PD, CO, PH; manuscript preparation: PD, CO, PH.

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