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Development of a measure of caregiver burden in paediatric chronic kidney disease: The Paediatric Renal Caregiver Burden Scale

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Abstract

To inform the development of a measure of caregiver burden for carers of children with chronic kidney disease, interviews were conducted with 16 caregivers and 10 renal healthcare professionals. A pool of 97 items generated from interviews was reduced to 60 items following review. A piloting exercise provided evidence for the usability, readability and relevance of items and informed further adaptations resulting in the 51-item Paediatric Renal Caregiver Burden Scale. Further to assessment of its psychometric properties, it is hoped that the Paediatric Renal Caregiver Burden Scale will serve as a useful measure of caregiver burden in paediatric chronic kidney disease.

- [caregiver burden](#)
- [measure development](#)
- [paediatric chronic kidney disease](#)

Introduction

‘Chronic kidney disease’ (CKD) is a term used to describe irreversible kidney damage or reduced kidney function that persists for more than 3 months. While children and adolescents¹ comprise a relatively small proportion of those with CKD (Ardissino et al., 2003; UK Renal Registry, 2009), its implications are nonetheless pervasive, not only for the child but also for his or her main family caregiver. Advances in treatment for paediatric chronic illness, including CKD, have resulted in hospital-based care being increasingly replaced by home-based care provided largely by family caregivers (Kepreotes et al., 2010; Murphy, 2008). In the context of paediatric CKD, family caregivers can assume a multitude of caregiving duties including managing medication, ensuring adherence to strict dietary and fluid requirements, transporting to hospital and providing dialysis when required,

duties which occur alongside the psychological burden of having a chronically ill child ([Aldridge, 2008](#); [Gayomali et al., 2008](#); [Tong et al., 2010](#)).

There are five stages of CKD, progressing from near normal kidney function through to end-stage renal disease (ESRD; stage 5)² where dialysis or transplantation is required to sustain life. Haemodialysis (HD) conventionally takes place in hospital on a thrice-weekly basis, while peritoneal dialysis (PD) is administered at home by trained family caregivers, usually on a nightly basis ([Tong et al., 2008](#); [Tsai et al., 2006](#)). While kidney transplantation is a desired goal, it does not signal the end of treatment. Complications can ensue post-transplant; caregivers must monitor for indicators of transplant rejection and continue to support their child in attending hospital while managing a complex medication regimen alongside strict dietary and fluid requirements. In paediatric CKD care, efforts usually focus on the medical treatment and well-being of the child. In light of research indicating links between increased parental stress and poorer outcomes for children with CKD, both medically and developmentally (e.g. [Brown-bridge and Fielding, 1994](#); [Fielding et al. 1985](#); [Furth et al., 2003](#); [Furth, 2005](#); [Gerson et al., 2004](#); [Reiss, 2005](#); [Watson, 1997](#)), it has been argued that outcomes among family caregivers should be monitored in order to provide targeted intervention where required ([Aldridge, 2008](#); [Brownbridge and Fielding, 1994](#); [Tong et al., 2008](#); [Tsai et al., 2006](#); [Weidebusch et al., 2010](#); [Zelikovsky et al., 2007](#)).

The concept of 'caregiver burden' is common in the caregiving literature ([Chou, 2000](#)). While initially viewed as a unidimensional concept defined as 'any cost' to the individual's family, caregiver burden was subsequently dichotomised into its objective dimensions (e.g. tangible disruptions to the caregiver's life) and subjective dimensions (e.g. the caregiver's emotional response to caregiving) ([Montgomery et al., 1985](#)). A more recent trend is to view caregiver burden as a multidimensional construct, defined by [Chou \(2000\)](#) as 'an individual's subjective perception of overload in one or more of four perspectives: physical, psychological, social and financial through the caregiving process' (p. 405). Indeed, research exploring the experiences of caregivers of children with CKD has identified a multitude of stressors with reported difficulties including poor physical health, restlessness, helplessness, uncertainty, preoccupation with the future, concern about their child's growth and development, reduced family income, disruptions to family activities and relationships, loss of social contacts and difficulties associated with the complexities of the CKD treatment regimen ([Aldridge, 2008](#); [Fedewa and Oberst, 1996](#); [Hasegawa et al., 2005](#); [Hulstijn-Dirkmaat and Damhuis, 1994](#); [Reynolds et al., 1988](#); [Tsai et al., 2006](#); [Weidebusch et al., 2010](#); [Wolters et al., 1980](#); [Zelikovsky et al., 2007](#)). The findings of a review of qualitative studies exploring the experiences of caregivers of children with CKD were categorised into three clusters spanning intrapersonal issues (e.g. uncertainty, fatigue), interpersonal issues (e.g. disruptions to family life, difficulties with relationships with medical staff) and external issues (e.g. caregiving demands of the CKD treatment regimen) ([Tong et al., 2008](#)). A recent qualitative study concluded that being a parent of a child with CKD was 'consistently reported as being a pervasive and profoundly negative experience' ([Tong et al., 2010](#): 555). As treatment increasingly moves from the hospital setting to the home, there is potential for a further increase in burden on CKD caregivers. Recent research has found that parents of children receiving PD (typically a home-based treatment) rated their quality of life, physical functioning and emotional functioning lower than that of their child ([Kiliš-Pstrusińska et al., 2013](#)).

Despite the recognised demands faced by caregivers of children with CKD and the emphasised need to monitor outcomes, there is no specific tool available to meet this aim. Existing measures of caregiver burden have been largely developed for family caregivers of adults post-stroke or with dementia, and 'proxy' generic measures of stress, anxiety and depression that have been used to assess the experiences of the paediatric CKD caregiver population to date (which have not been adapted to capture caregiver-specific sources of stress, anxiety or depression that may exist) may not fully capture all of the aspects relevant to caregivers of children with CKD ([Aldridge, 2008](#)). The impetus for this research was the lack of a measure of caregiver burden specifically developed for caregivers of children with CKD, with measures of caregiver burden in existence largely developed for caregivers of older adults or those with mental health diagnoses ([Robinson, 1983](#); [Schene et al., 1994](#); [Visser-Meily et al., 2004](#)). Of the existing measures developed to assess the experiences of caregivers of children with chronic illness, that is, the Pediatric Inventory for Parents (PIP) ([Streisand et al., 2001](#)) and the Parent Experience of Child Illness (PECI) ([Bonner et al., 2006](#)), these have not been developed for a paediatric CKD population.

It has been argued that the application of nonspecific burden measures to different populations of caregivers has hindered progress in caregiver burden research ([Chou, 2000](#)), and researchers have highlighted the importance of creating instruments that measure the unique aspects of kidney disease ([Bradley, 1997](#); [Goldstein et al., 2006](#)). CKD produces unique demands for caregivers; it is a chronic condition characterised by a complex treatment regimen which can include the need for dialysis and strict dietary and fluid restrictions. [Aldridge \(2008\)](#) notes that a measure of carer burden in this population would allow clinicians to qualify areas of stress among carers and to monitor response to targeted intervention. A measure developed specifically in this context could serve to support multidisciplinary teams working with children with CKD and their primary caregivers in tailoring a treatment regimen that may best serve not only the child with CKD and their main caregiver but the family as a whole. Research from several caregiver populations suggests that a range of psycho-social support and interventions may be beneficial in reducing caregiver burden. Caregivers of children with high functioning autism who perceived themselves to be well supported by the institution involved in the care of their child were shown to have lower levels of somatic symptoms and a higher cortisol awakening response (a biomarker indicating lower levels of stress) than those who reported feeling unsupported by the institution ([Ruiz Robledillo et al., 2013](#)). Similarly, caregivers of children with leukaemia who perceived a high level of social support and felt able to complete daily activities to meet their own basic needs reported less psychological symptoms ([Demirtepe-Saygılı and Bozo, 2011](#)). In CKD specifically, home-based education interventions have been shown to reduce burden in caregivers of adult HD patients ([Mollaoğlu et al., 2013](#)).

While measures specific to the kidney disease caregiver population are emerging (e.g. [Horsburgh et al., 2008](#); [Schneider, 2010](#); [Teixidó et al., 2006](#)), these have been developed for caregivers of adults with renal disease and have tended to operationalise the objective dimension of caregiver burden, or the objective and subjective dimensions simultaneously. [Gerritsen and Van der Ende \(1994\)](#) argue, however, that ‘to increase the specificity of the concept, only the subjective dimension should be operationalized, because distress is regarded as the core of agreement on what constitutes burden, i.e. “worry, anxiety, frustration, depression, fatigue, poor health, guilt and resentment”’ (p. 483); a number of caregiver burden researchers concur (e.g. [Chou, 2000](#); [Poulshock and Deimling, 1984](#); [Stommel et al., 1990](#)). The development of a measure of caregiver burden specific to caregivers of children with CKD could serve to support multidisciplinary teams working with these caregivers to identify those who are in need, and to plan targeted support and tailored intervention where possible.

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Methods

Design

The study design followed recommended steps of measure development ([DeVellis, 1991](#); [Oppenheim, 1996](#); [Ratray and Jones, 2007](#)), that is, determination of the construct to be measured, item generation, item reduction, determination of the measurement format and preliminary piloting.

Materials

To facilitate the generation of an item pool for the measure, two semi-structured interview schedules were developed for use with caregivers of children with CKD and renal healthcare professionals. (It should be noted that in the context of paediatric CKD, healthcare professionals work intensively with children and their families and gain an in-depth understanding of the experiences of the demands placed upon family caregivers; their exclusion from the study was therefore deemed to be a potential oversight.) The interview schedule content was informed by existing research with this population and comprised open-ended questions to explore the main perceived difficulties of caring for a child with CKD including those which were broader (e.g. ‘Can you tell me about the main difficulties of caring for your child?’) and those developed to gain more detailed insight inclusive of the perceived physical, social, financial and emotional impacts of caregiving and questions to elicit issues relating to the impact of CKD and caregiving upon the child and family life, caregiver CKD treatment responsibilities and interactions between caregivers and medical staff (e.g. ‘Can you tell me about how caring for your

child affects family life?', with prompts provided in relation to more specific details such as impact on relationship with partner, impact on relationship with other siblings if any etc). The interview concluded with the interviewer querying if there were any issues that had not been discussed or required further exploration. All interviews were conducted by one researcher (Rhian Parham (R.P.), who had 5 years' experience of working in healthcare research, conducting research interviews).

Participants

Primary family caregivers of children aged 18 years or younger receiving treatment for CKD and renal healthcare professionals were eligible for inclusion in this study. Interviews were conducted with 16 caregivers and 10 healthcare professionals; interviews ranged in duration from 20 to 65 minutes. Characteristics of the caregiver interview sample (and their children) are shown in [Table 1](#). The renal healthcare professional interview sample included two consultant paediatric nephrologists; six nurse specialists in PD, HD and transplant; and two members of the psycho-social team.

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Table 1.

Caregiver interview sample characteristics.

Ethics

Ethical approval for this study was granted by the National Research Ethics Service for the United Kingdom, in addition to local research governance approval.

Procedure

Interview recruitment

Interviews were completed with family caregivers and renal healthcare professionals. Caregivers were invited to participate via a poster, through information sheets and in person at relevant waiting rooms and wards. Renal healthcare professionals were invited to participate via email. Interviews were conducted in an isolated room or on the telephone, further to obtaining informed consent, and were recorded and transcribed verbatim. Interviews continued until item pool saturation was deemed to have been achieved. Caregivers with experiences of caring for a child across the CKD trajectory were included in the sample; of the 16 caregiver interviews conducted, a range of treatment modalities and CKD stages were discussed as follows: pre-dialysis ($n = 8$), PD ($n = 9$), HD ($n = 10$) and kidney transplantation ($n = 7$).

Item pool generation

In lieu of guidelines for generation of an item pool for a new measure from interview transcripts, the use of thematic analysis (TA; [Braun and Clarke, 2006](#)) to provide a framework for the organisation of the interview data into a pool of potential measure items (codes) was deemed suitable for the aims of this research. Furthermore, to familiarise with the interview data, statements deemed relevant to the subjective experience of caregiver burden were identified, and potential measure items were then generated alongside the identified statements; see [Table 2](#) for an example. This process was completed for each interview transcript and a list of potential measure items was extracted and collated (completed by author R.P.).

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Table 2.

Sample section of transcript with potential measure item.

Item pool reduction

The generated item pool was reviewed by two authors (R.P. and Daljit Hothi (D.H.)) and reduced according to suggested criteria ([DeVellis, 1991](#)), that is, lack of clarity, questionable relevance or undesirable similarity to other items.

Determination of measurement format

The phrasing of measure items was informed by the aim of operationalising the *subjective* dimension of caregiver burden in order to elicit the subjective appraisals of caregivers (e.g. asking how caregivers *feel* about socialising less due to their caregiving role) as opposed to eliciting objective facts (e.g. asking if caregivers socialise less due to their caregiving role). A response scale to correspond with measure items was also constructed. Guidance outlining the desired traits of measurement items and response scales was adhered to during the process of determining the measurement format ([DeVellis, 1991](#); [Oppenheim, 1996](#)).

Piloting

A provisional version of the measure was piloted as a further check of the face and content validity of measure items and to serve as a preliminary evaluation of the usability and readability of the newly developed measure; feedback was sought in relation to the usability and readability of the measure and relevance of measure items.

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Results

Item pool generation

The full list of potential measure items was extracted from each interview transcript and collated into an item pool of 97 items. The items spanned a range of domains including the caregivers' subjective appraisals of the physical, financial, social and emotional impact of caring for a child with CKD, the perceived impact upon the family and child and the caregivers' identity/role as well as the caregivers' subjective appraisals of managing CKD treatment responsibilities and contact with the hospital/medical staff.

Item pool reduction

The item pool was reduced from 97 to 60 items further to review (by R.P. and D.H.); items were either retained as stand-alone items or a number of items were merged due to overlap.

Determination of measurement format

During the item reduction phase, items were reworded to correspond with the measure instructions and response scale (see top section of [Table 3](#)). A time window of 1 month was chosen as a sufficient time frame to encompass the range of issues contained within the measure (e.g. hospital attendance, organisation of family leisure activities).

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Table 3.

Version of Paediatric Renal Caregiver Burden Scale (PR-CBS) adapted further to piloting ($n = 51$ items).

Below is a list of things that parents of children with kidney disease have said can cause difficulty. Please read each item and *circle the number* that best describes how much of a problem this has been for you over the last month.

Piloting exercise

Piloting sample

The measure was piloted with 18 caregivers and 5 healthcare professionals. However, 10 of the caregivers and all 5 of the healthcare professionals had participated in the interview phase of the research.

Readability, usability and item relevance

Participants completing the pilot exercise were asked to comment on the wording of the measure and its ease of completion. No difficulties in understanding items or completing the measure were reported by participants; written and verbal feedback endorsed the ease of completing the measure and the relevance of the measure items to the experience of caring for a child with CKD.

Additional item reduction and item addition

Adaptations were made to the measure according to feedback from the piloting exercise. A total of 11 items were deleted or merged with other items due to negligible endorsement of relevance and/or perceived overlap with other items. Two additional items were generated due to feedback that the measure would benefit from additional coverage of the experience of caregiver burden associated with interpersonal issues (i.e. impact upon spousal relationships, impact upon siblings). The resulting 51 items form the 'Paediatric Renal Caregiver Burden Scale' (PR-CBS) are shown in [Table 3](#).

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Discussion

This article outlines the development of a measure of paediatric CKD caregiver burden (PR-CBS) further to the established need for such a measure. The research was guided by the conceptualisation of caregiver burden as a multidimensional construct, primarily relating to the subjective appraisals of caregivers (rather than objective circumstances). An extensive phase of the research comprised interviews with caregivers of children with CKD and renal healthcare professionals, in order to generate a comprehensive pool of measure items relevant to a measure for this population. In line with

the conceptualisation of caregiver burden as a multidimensional phenomenon, generated items were reflective of caregivers' subjective appraisals across a number of domains including impact upon the family (e.g. guilt in relation to sibling neglect), CKD and its treatment (e.g. helplessness when the child is in pain), caregiver treatment responsibilities (e.g. worry about fluid intake), issues arising from contact with the hospital/medical staff (e.g. frustration from the amount of time spent at hospital) and subjective appraisals of changes in identity associated with the caregiver role (e.g. sadness about loss of employment). It has been argued that instruments developed to measure the subjective dimensions of caregiver burden should reflect both distress in providing care as well as distress resulting from the effects of caregiving on one's life ([Braithwaite, 1992](#)), which the current developed measure does. Moreover according to [Chou et al. \(2003\)](#), 'multidimensional measures of caregiver burden give a sensitive reading of caregivers' feelings and a sophisticated picture of caregivers' response to the demands of care' (p. 80).

Consultation with relevant professionals is a common component of the item generation phase of measure development, and it indeed proved to be a valuable source of information in this study. Much research in this field has, however, tended to rely solely on the input of relevant professionals to generate an initial item pool. [Weitzner et al. \(1999\)](#) suggest that the development of caregiver burden scales developed to date largely lack the direct input of caregivers during item pool generation. This research benefits from the intensive input of caregivers throughout the development of the PR-CBS, thus aiding attempts to ensure high face and content validity of the measure. The firsthand accounts of caregivers of children with CKD informed the generation of a comprehensive item pool; caregivers also participated in a piloting exercise, with feedback on the usability, readability and content of measure items accordingly incorporated into the measure.

The impetus for this research was the absence of a measure of caregiver burden specifically developed for caregivers of children with CKD in light of arguments that the use of nonspecific burden measures has hindered progress in caregiver burden research ([Chou, 2000](#)) and thus calls for the development of measures that address the unique aspects of kidney disease ([Bradley, 1997](#); [Goldstein et al., 2006](#)). It is encouraging that disease-specific measures of the impact of caregiving are increasingly being developed (e.g. [Sepúlveda et al., 2008](#)), and it is hoped that the PR-CBS will serve to enhance an understanding of caregiver burden specifically in the context of paediatric CKD.

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Limitations

While this study benefits from the inclusion of caregivers of children across the entire trajectory of CKD, it should be acknowledged that the interview sample contained fewer caregivers of children currently on pre-dialysis treatment or receiving PD, relative to those currently on HD or post-transplant; however, as many caregivers discussed their experiences both past and present, this was not deemed to have compromised the generation of items reflective of the experiences of caregivers across the entire CKD trajectory. Moreover, interviews were conducted with renal healthcare professionals specialising in the care of children across the CKD trajectory, and saturation of items relevant to treatment modality specific issues was deemed to have been achieved.

It should be noted that the caregiver sample was predominantly comprised of mothers, with just two fathers included in the caregiver sample. While male caregivers are largely under-represented in CKD caregiver research ([Aldridge, 2008](#)), it is much more common for mothers to assume the role of primary caregiver of a chronically ill child ([Brown et al., 2008](#); [Coffey, 2006](#)). Single-parent caregivers of children with chronic illness are also under-represented in the caregiver literature, and it must be acknowledged that these caregivers may be those who are most at risk of caregiver burden ([Brown et al., 2008](#)). While single-parent caregivers were included in the study sample (two single mothers), there may be issues pertinent to the experience of caregiver burden among single parents that were not adequately captured in this research.

A further potential limitation of this study is that the caregiver sample was predominantly White, and it is thus possible that the generated item pool may not be fully generalisable to caregivers of children with CKD from minority ethnic groups. Furthermore, just 2 of the 16 caregivers interviewed in this

study did not speak English as a first language. While the PR-CBS contains an item reflecting worry related to poor understanding of medical staff, it should be acknowledged that issues arising from communication difficulties are likely to be exacerbated among those caregivers with a limited command of English, particularly in the context of a medicalised setting and a complex treatment regimen.

While it could be argued that the initial phases of the development of this measure took a great deal of time, it has been suggested that some researchers who have developed measures of caregiver burden have not always invested the care required during the item generation phase, which is arguably the most critical phase of measure development ([Hinkin, 1995](#)). Indeed, establishing the content validity of a new measure is the minimum psychometric requirement for measurement adequacy ([Schriesheim et al., 1993](#)).

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Future directions

It is essential that newly developed measures can demonstrate reliability, validity and acceptability for use among its target population. A subsequent programme of research has been completed to evaluate the psychometric properties of the PR-CBS. It is hoped that the PR-CBS will enhance an understanding of the experience of caregiver burden in this population and serve as a tool to aid the identification of caregivers who may benefit most from support intervention; assessment is after all a prerequisite for intervention ([Cousins et al., 2002](#)). The identification of caregivers who may be most in need of additional support, and thus potentially compromised in their caregiving duties, may be particularly important in light of advances in treatments which increasingly shift care into the family home ([Gayomali, 2008](#)). There is currently limited research exploring support interventions for caregivers of individuals affected by CKD ([Tong et al., 2008](#)), and it is hoped that the PR-CBS will be a useful tool in future studies which aim to explore the development and evaluation of support interventions in this caregiver population.

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Conclusion

It has been argued that family caregivers of children with CKD should be considered as a target of intervention with a view to improving outcomes for these caregivers, and ultimately their children ([Tong et al., 2008](#)). In the United Kingdom, the National Health Service (NHS) views the experiences and support needs of caregivers as a priority ([Department of Health, 2004](#)). This is the first study which has sought to develop a measure of caregiver burden specific to caregivers of children with CKD in order to provide a tool which addresses those issues unique to paediatric CKD, and benefits from the direct input of family caregivers and renal healthcare professionals to inform the measure content. It is hoped that the PR-CBS will enhance an understanding of caregiver burden in the paediatric CKD caregiver population and ultimately serve as a tool in efforts to improve outcomes for caregivers of children with CKD, as well as their children.³

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Article Notes

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Notes

- ↵1. For the remainder of this article, ‘children’ is used to denote children and adolescents aged 0–18 years.
- ↵2. For the remainder of this article, ‘CKD’ is used to denote all stages of chronic kidney disease (CKD; stage 1–5, inclusive of end-stage renal disease (ESRD))
- ↵3. Following development of the Paediatric Renal Caregiver Burden Scale (PR-CBS), preliminary steps were taken to begin assessment of the validity and reliability of the measure. Using a sample of 107 CKD caregivers recruited from two national specialist sites, caregivers completed the PR-CBS along with the Hospital Anxiety Depression Scale (HADS) (Zigmond and Snaith, 1983) and Caregiver Strain Questionnaire (CGSQ) (Brannan et al., 1997). Exploratory factor analysis was undertaken to assess the internal structure of the 51 item PR-CBS, which indicated retention of 20 items, representing five factors. These were labelled as follows: ‘Illness worries’, ‘Impact on self’, ‘Impact on child’, ‘Responsibility’ and ‘Institutional burden’ and together explained 53 per cent of the variance. Cronbach’s α was used to assess internal reliability which was acceptable (< 0.7) for each of the five factors as well as the full scale. Convergent validity of the PR-CBS with the HADS and CGSQ was demonstrated through significant positive correlations between the PR-CBS and both measures. Preliminary findings suggest the PR-CBS has the potential to be a valid and reliable measure of caregiver burden in a paediatric CKD population. However, a larger sample size, to enable further exploratory analysis and confirmatory factor analysis, would be necessary to provide more definitive conclusion on the properties of this new scale.

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References

1. ↵
 1. Aldridge MD

(2008) *How do families adjust to having a child with chronic kidney failure? A systematic review.* *Nephrology Nursing Journal* 35(2): 157–162.

[Find it @ CCCUMedlineOrder article via InfotrieveGoogle Scholar](#)
2. ↵
 1. Ardissino G,
 2. Daccò V,
 3. Testa S,
 4. et al
(2003) *Epidemiology of chronic renal failure in children: Data from the ItalKid Project.* *Pediatrics* 111: e382–e387.

[Abstract/FREE Full Text](#)
3. ↵
 1. Bonner MJ,
 2. Hardy KK,
 3. Guill AB,
 4. et al

. (2006) *Development and validation of the parent experience of a child illness. Journal of Pediatric Psychology 31(3): 310–320.*

Abstract/FREE Full Text

4. ↵
1. Bradley C

(1997) *Design of a renal-dependent individualised quality of life questionnaire: RDQoL. Advances in Peritoneal Dialysis 13: 116–120. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/9360663>*

Find it @ CCCUMedlineOrder article via Infotrieve

5. ↵
1. Braithwaite V

(1992) *Caregiving burden: making the concept scientifically useful and policy relevant. Research on Aging 14: 3–27.*

Abstract

6. ↵
1. Brannan AM,
2. Heflinger CA,
3. Bickman L

(1997) *The caregiver strain questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. Journal of Emotional and Behavioral Disorders 5(4): 202–222.*

Find it @ CCCUGoogle Scholar

7. ↵
1. Braun V,
2. Clarke V

(2006) *Using thematic analysis in psychology. Qualitative Research in Psychology 3: 77–101.*

Find it @ CCCUCrossRefGoogle Scholar

8. ↵
1. Brownbridge G,
2. Fielding DM

(1994) *Psychosocial adjustment and adherence to dialysis treatment regimes. Pediatric Nephrology 8(6): 744–749.*

Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar

9. ↵
1. Brown RT,
2. Wiener L,
3. Kupst MJ,
4. et al

. (2008) *Single parenting and children with chronic illness: An understudied phenomenon*. *Journal of Pediatric Psychology* 33(4): 408–421.

[Abstract/FREE Full Text](#)

10. ↵

1. Chou KR

(2000) *Caregiver burden: A concept analysis*. *Journal of Pediatric Nursing* 15(6): 398–407.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveGoogle Scholar](#)

11. ↵

1. Chou KR,
2. Chu H,
3. Tseng C,
4. et al

. (2003) *The measurement of caregiver burden*. *Journal of Medical Sciences* 23(2): 73–82.

[Find it @ CCCUGoogle Scholar](#)

12. ↵

1. Coffey JS

(2006) *Parenting a child with chronic illness: A metasynthesis*. *Pediatric Nursing* 32(1): 51–59.

[Find it @ CCCUMedlineOrder article via InfotrieveGoogle Scholar](#)

13. ↵

1. Cousins R,
2. Davies ADM,
3. Turnbull CJ,
4. et al

. (2002) *Assessing caregiving distress: A conceptual analysis and a brief scale*. *The British Journal of Clinical Psychology* 41: 387–403.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

14. ↵

1. Demirtepe-Saygılı D,
2. Bozo O

(2011) *Perceived social support as a moderator of the relationship between caregiver well-being indicators and psychological symptoms*. *Journal of Health Psychology* 16(7): 1091–1100.

[Abstract/FREE Full Text](#)

15. ↵

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs*. London: The Stationary Office.

16. ↵

1. DeVellis RF

(1991) *Scale Development: Theory and Applications*. London: SAGE.

[Google Scholar](#)

17. ↵

1. Fedewa MM,
2. Oberst MT

(1996) *Family caregiving in a pediatric renal transplant population*. *Pediatric Nursing* 22(5): 402–407, 417.

[Find it @ CCCUMedlineOrder article via InfotrieveGoogle Scholar](#)

18. ↵

1. Fielding D,
2. Moore B,
3. Dewey M,
4. et al

(1985) *Children with end-stage renal failure: Psychological effects on patients, siblings and parents*. *Journal of Psychosomatic Research* 29(5): 457–465.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

19. ↵

1. Furth SL

(2005) *Growth and nutrition in children with chronic kidney disease*. *Advances in Chronic Kidney Disease* 12(4): 366–371.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

20. ↵

1. Furth SL,
2. Hwang W,
3. Neu AN,
4. et al

(2003) *Effects of patient compliance, parental education and race on nephrologists' recommendations for kidney transplantation in children*. *American Journal of Transplantation* 3: 28–34.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

21. ↵

1. Gayomali C,
2. Sutherland S,
3. Finkelstein FO

(2008) *The challenge for the caregiver of the patient with chronic kidney disease*. *Nephrology, Dialysis, Transplantation* 23(12): 3749–3751.

[FREE Full Text](#)

22. ↵

1. Gerritsen JC,
2. Van der Ende PC

(1994) *The development of a care-giving burden scale. Age and Ageing* 23: 483–491.

[Abstract/FREE Full Text](#)

23. ↵

1. Gerson AC,
2. Furth SL,
3. Neu AM,
4. et al

(2004) *Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. Pediatric Transplantation* 8(6): 543–550.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

24. ↵

1. Goldstein SL,
2. Graham N,
3. Burwinkle T,
4. et al

(2006) *Health-related quality of life in pediatric patients with ESRD. Pediatric Nephrology* 21: 846–850.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

25. ↵

1. Hasegawa A,
2. Oshima S,
3. Takahashi K,
4. et al

(2005) *Improvement of quality of life in tacrolimus-based pediatric renal transplant recipients and their caregivers, including donors. Transplantation Proceedings* 37(4): 1771–1773.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveGoogle Scholar](#)

26. ↵

1. Hinkin TR

(1995) *A review of scale development practices in the study of organizations. Journal of Management* 21(5): 967–988.

[Abstract](#)

27. ↵

1. Horsburgh ME,
2. Laing GP,
3. Beanlands HJ,
4. et al

. (2008) *A new measure of 'lay' care-giver activities. Kidney International* 74(2): 230–236.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

28. ↵

1. Hulstijn-Dirkmaat GM,
2. Damhuis EHW

(1994) *Peritoneal dialysis treatment in children and parental stress. Acta Paediatrica: An International Journal of Paediatrics* 83(9): 972–976.

[Find it @ CCCUCrossRefGoogle Scholar](#)

29. ↵

1. Kepreotes E,
2. Keatinge D,
3. Stone T

(2010) *The experience of parenting children with chronic health conditions: A new reality. Journal of Nursing and Healthcare of Chronic Illness* 2(1): 51–62.

[Find it @ CCCUCrossRefGoogle Scholar](#)

30. ↵

1. Kiliś-Pstrusińska K,
2. Wasilewska A,
3. Medyńska A,
4. et al

. (2013) *Psychosocial aspects of children and families of children treated with automated peritoneal dialysis. Pediatric Nephrology* 28(11): 2157–2167.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveGoogle Scholar](#)

31. ↵

1. Mollaoğlu M,
2. Kayataş M,
3. Yürügen B

(2013) *Effects on caregiver burden of education related to home care in patients undergoing hemodialysis. Hemodialysis International* 17(3): 413–420.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

32. ↵

1. Montgomery RV,
2. Gonyea JG,
3. Hooyman NR

(1985) *Caregiving and experience of subjective and objective burden. Family Relations* 34(1): 19–26.

[Find it @ CCCUCrossRefWeb of ScienceGoogle Scholar](#)

33. ↵

1. Murphy J

(2008). *Medically stable children in PICU: better at home*. *Paediatric Nursing* 20: 3.

[Find it @ CCCUMedlineOrder article via InfotrieveGoogle Scholar](#)

34. ↵

1. Oppenheim AN

(1996) *Questionnaire Design, Interviewing and Attitude Measurement*. London: Continuum International Publishing.

[Google Scholar](#)

35. ↵

1. Poulshock SW,
2. Deimling T

(1984) *Families caring for elders in residence: Issues in the measurement of burden*. *Journal of Gerontology* 39: 230–239.

[Abstract/FREE Full Text](#)

36. ↵

1. Rattray J,
2. Jones MC

(2007) *Essential elements of questionnaire design and development*. *Journal of Clinical Nursing* 16(2): 234–243.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveGoogle Scholar](#)

37. ↵

1. Reiss J

(2005) *Managing chronic diseases: Care of children with chronic illness teaches some lessons*. *BMJ* 330: 963–964.

[FREE Full Text](#)

38. ↵

1. Reynolds JM,
2. Garralda ME,
3. Jameson RA,
4. et al

(1988) *How parents and families cope with chronic renal failure*. *Archives of Disease in Childhood* 63: 821–826.

[Abstract/FREE Full Text](#)

39. ↵

1. Robinson B

(1983) *Validation of a Caregiver Strain Index*. *Journal of Gerontology* 38(3): 344–348.

[Abstract/FREE Full Text](#)

40. ↵

1. Ruiz Robledillo N,
2. Gonzalez Bono E,
3. Moya Albiol L

(2013) *Lack of institutional support entails disruption in cortisol awakening response in caregivers of people with high-functioning autism. Journal of Health Psychology. Epub ahead of print 9 August. DOI: 1359105313496444.*

[Google Scholar](#)

41. ↵

1. Schene AH,
2. Tessler RC,
3. Gamache GM

(1994) *Instruments measuring family or caregiver burden in severe mental illness. Social Psychiatry and Psychiatric Epidemiology 29: 228–240.*

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

42. ↵

1. Schneider RA

(2010) *The Renal Caregiver Burden Scale: Phase one. Journal of Nephrology Social Work 33: 17–21.*

[Find it @ CCCUGoogle Scholar](#)

43. ↵

1. Schriesheim CA,
2. Powers KJ,
3. Scandura TA,
4. et al

(1993) *Improving construct measurement in management research: Comments and a quantitative approach for assessing the theoretical content adequacy of paper-and-pencil survey-type instruments. Journal of Management 19: 385–417.*

[Abstract/FREE Full Text](#)

44. ↵

1. Sepúlveda AR,
2. Whitney J,
3. Hankins M,
4. et al

(2008) *Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. Health and Quality Life Outcomes 6: 28.*

[Find it @ CCCUCrossRefGoogle Scholar](#)

45. ↵

1. Stommel M,
2. Given CW,
3. Given B

(1990) *Depression as an overriding variable explaining caregiver burdens* *Journal of Aging and Health* 2(1): 81–102.

[Abstract/FREE Full Text](#)

46. ↵

1. Streisand R,
2. Braniecki S,
3. Tercyak KP,
4. et al

. (2001) *Childhood illness-related parenting stress: The pediatric inventory for parents*. *Journal of Pediatric Psychology* 26(3): 155–162.

[Abstract/FREE Full Text](#)

47. ↵

1. Teixidó J,
2. Tarrats L,
3. Arias N,
4. et al

. (2006) *Overload questionnaire for caregivers of patients on peritoneal dialysis*. *Nefrologia* 26(1): 74–83.

[Find it @ CCCUMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

48. ↵

1. Tong A,
2. Lowe A,
3. Sainsbury P,
4. et al

. (2008) *Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies*. *Pediatrics* 121(2): 349–360.

[Abstract/FREE Full Text](#)

49. ↵

1. Tong A,
2. Lowe A,
3. Sainsbury P,
4. et al

. (2010) *Parental perspectives on caring for a child with chronic kidney disease: An in-depth interview study*. *Child: Care, Health and Development* 36(4): 549–557.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

50. ↵

1. Tsai TC,
2. Liu SI,
3. Tsai JD,
4. et al

. (2006) *Psychosocial effects on caregivers for children on chronic peritoneal dialysis*. *Kidney International* 70: 1983–1987.

[Find it @ CCCUMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

51. [↵](#)

UK Renal Registry (2009) 12th annual report of the Renal Association, 2010. Nephron Clinical Practice 115(Suppl. 1): c279–288.

[Find it @ CCCU](#)

52. [↵](#)

1. Visser-Meily JM,
2. Post MW,
3. Riphagen II,
4. Lindeman E

(2004) Measures used to assess burden among caregivers of stroke patients: a review. Clinical Rehabilitation 18(6): 601–623.

[Abstract/FREE Full Text](#)

53. [↵](#)

1. Watson AR

(1997) Stress and burden of care in families with children commencing renal replacement therapy. Advances in Peritoneal Dialysis 73: 300–304.

[Find it @ CCCUGoogle Scholar](#)

54. [↵](#)

1. Weidebusch S,
2. Konrad M,
3. Foppe H,
4. et al

(2010) Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. Pediatric Nephrology 25: 1477–1485.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveGoogle Scholar](#)

55. [↵](#)

1. Weitzner MA,
2. Jacobsen PB,
3. Wagner H Jr.,
4. et al

(1999) The Caregiver Quality of Life Index-Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. Quality of Life Research 8(1–2): 55–63.

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

56. [↵](#)

1. Wolters WHG,
2. Daniels-Wegdam T,
3. Donckerwolcke RAMG

(1980) *Family reactions to the hemodialysis of a child. Acta Paedopsychiatrica 45(6): 345–352.*

[Find it @ CCCUMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)

57. ↵

1. Zelikovsky N,
2. Schast AP,
3. Jean-Francois D

(2007) *Parent stress and coping: Waiting for a child to receive a kidney transplant. Journal of Clinical Psychology in Medical Settings 14: 320–329.*

[Find it @ CCCUCrossRefGoogle Scholar](#)

58. ↵

1. Zigmond AS,
2. Snaith RP

(1983) *The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica 67(6): 361–370.*

[Find it @ CCCUCrossRefMedlineOrder article via InfotrieveWeb of ScienceGoogle Scholar](#)