

RESEARCH PROTOCOL

The Online Parent Information and Support project, meeting parents' information and support needs for home-based management of childhood chronic kidney disease: research protocol

Veronica Swallow, Kathleen Knafl, Sheila Sanatacroce, Andrew Hall, Trish Smith, Malcolm Campbell & Nicholas J.A. Webb

Accepted for publication 5 November 2011

Correspondence to V. Swallow:
e-mail: veronica.swallow@manchester.ac.uk

Veronica Swallow MMedSci PhD RSCN
Senior Lecturer
University of Manchester, UK

Kathleen Knafl MA PhD FAAN
Associate Dean for Research
University of North Carolina at Chapel Hill,
USA

Sheila Sanatacroce PhD RN CPNP
Associate Professor
University of North Carolina at Chapel Hill,
USA

Andrew Hall BA MEd CertEd
Senior Lecturer
University of Manchester, UK

Trish Smith Msc RSCN
Clinical Nurse Specialist - Nephrology
Royal Manchester Children's Hospital, UK

Malcolm Campbell MSc PhD
Lecturer
University of Manchester, UK

Nicholas J.A. Webb DM FRCP FRCPC
Consultant Paediatric Nephrologist
Royal Manchester Children's Hospital, UK

SWALLOW V., KNAFL K., SANATACROCE S., HALL A., SMITH T., CAMPBELL M. & WEBB N.J.A. (2012) The Online Parent Information and Support project, meeting parents' information and support needs for home-based management of childhood chronic kidney disease: research protocol. *Journal of Advanced Nursing* 00(0), 000–000. doi: 10.1111/j.1365-2648.2011.05908.x

Abstract

Aim. This article is a report of a protocol for studying the development and evaluation of an online parent information and support package for home-based care of children with chronic kidney disease stages 3–5. The study is funded by a National Institute of Health Research, Research for Patient Benefit Grant awarded (December 2010). Approval to undertake the study was obtained from the Department of Health National Research Ethics Service (June 2011).

Background. Children with chronic kidney disease require skilled, home-based care by parents, supported by professionals. Parents have identified a need for continuously available online resources to supplement professional support, and structured resources tailored to parents' needs are highlighted by policy makers as key to optimizing care; yet, online resource provision is patchy with little evidence base.

Methods. Using mixed methods, we will (i) conduct parent/child/young person/professional/patient and parent volunteer focus groups to explore views on existing resources, (ii) collaboratively define gaps in provision, identify desirable components, develop/test resources and conduct a feasibility randomized controlled trial, and (iii) of usual professional support versus usual support supplemented by the package. Eighty parents of children with chronic kidney disease will be randomized. Primary outcomes will assess parents' self-efficacy and views of resources, using standardized measures at entry and 24 weeks, and semi-structured interviews at 24 weeks. We will finalize trial components for a later definitive trial.

Discussion. By working collaboratively, we will derive a detailed insight into parents' information and support needs and experiences of using the package, and should see improved parental self-efficacy.

Keywords: chronic kidney disease, home-based support, nurses and health professionals, Online, research protocol, sick children

Introduction

Parents of children and young people (children) with chronic kidney disease stages 3–5 (CKD) have identified a need for continuously available online materials to supplement (not replace) existing professional support, and assist home-based care giving of their child's medical condition. Kidney function is assessed by estimated glomerular filtration rate (eGFR) and CKD is classified on this basis: stage 3 refers to moderate kidney impairment, stage 4, severe impairment and stage 5, established renal failure (ERF). This article presents a protocol for a study to develop and evaluate with families, nurses, other multidisciplinary team members and volunteers an online parent information and support (OPIS) package for use when managing CKD at home.

Background

In the UK, growing numbers of children aged 0–19 years are treated for CKD, with the South Asian population showing a prevalence 2.5 times that of the White population (Griffin & MacGregor 2005, DOH 2006, Lewis 2008). Treatments can be complex and intrusive and are managed by multidisciplinary teams (MDT), but usually delivered by parents who receive MDT support. In our previous research, parents described the skilled care they delivered at home, often involving patients in their own care. Parents identified a need for reliable, continuously available, online materials to supplement (not replace) existing forms of support and to empower them when professionals are less accessible (Scott *et al.* 1997, Swallow & Jacoby 2001a, 2001b, Swallow *et al.* 2008, 2009, 2011a, 2011b). Structured resources tailored to parents' cultural, learning and ethnic needs are recommended; yet, little research exists to inform professionals when creating resources (DOH 2006).

Previous research does help us to begin understanding how families share treatment regimens with MDTs (Thorne & Paterson 2001, Coulthard & Crosier 2002, Santacroce 2003, Sinha & Webb 2006, Swallow 2008, Swallow *et al.* 2008, Tong *et al.* 2008, Kieckhefer *et al.* 2009, Knafl *et al.* 2009) and how family management styles vary (Knafl *et al.* 2009, Morton *et al.* 2010), although until recently, little evidence existed that reported actual interactions between carers and professionals when skills are transferred. In our prior research, parents participated in MDT-led learning and assessment that was both planned and spontaneous; nurses were a key element of professional care-giving in this context; moreover, they often acted as family learning brokers (Wenger 1998, Swallow 2008, Swallow *et al.* 2008). Fathers'

involvement in care-giving is increasingly recognized, although fathers' contributions are often less 'visible' to MDTs, so some receive information second-hand (Wysocki & Gavin 2004, Hovey 2005, Sullivan-Bolyai *et al.* 2006, Swallow *et al.* 2011a, 2011b).

When parents of children with CKD experienced difficulty processing health information [a concept defined as Health Literacy (HL) (Speros 2005)], this sometimes led to them not recognizing clinical changes, and some were reluctant to acknowledge comprehension difficulties in case their parenting was criticized (Swallow 2008), thus increasing their likelihood of web-searching for continuously available support to enhance self-efficacy (Bandura 1997). Some parents purchased computers to access the internet for clinical information. Studies also highlight the challenge for professionals of supporting parents' variable care-giving needs at a distance (Tuffrey & Finlay 2002, Swallow 2008), while professionals may not always be equipped to fulfil information signposting roles (Ellins & McIver 2008).

Existing online CKD material focuses on news or clinical research rather than on care-giving, yet increasing internet use by society (Tuffrey & Finlay 2002, Ferguson & Frydman 2004, Ellins & McIver 2008, National-Statistics-Online 2008, OFCOM 2008, Whyte & Hunter 2008, ITU-D 2010) has transformed NHS clients' relationships with information, making it more likely that parents will search online for supplementary information, although unreliable sites exist (Darzi 2008). Changing trends in internet use, a dearth of research on what parents think about existing formats of online information and support and a 'digital divide' between those who do/do not have internet access (OFCEM 2008) means that we need a detailed examination of what online support parents use and would like. Studies are now advocated in which the first generation of e-patients are taught to manage care with the best support IT can provide and where professionals and patients develop and evaluate new models of e-patient innovation (Ferguson & Frydman 2004, Ellins & McIver 2008). Opportunities now exist to co-create online support helping parents to be 'expert' carers (Coulter & Ellins 2007, Fox 2009). Most health information is produced at a higher than average reading age, making it difficult for many consumers to understand (Ellins & McIver 2008). It is recommended that consumers be involved in information development at every stage (Wagner *et al.* 2007, Ellins & McIver 2008) and the OPIS project will begin addressing these issues. The study was awarded a National Institute of Health Research, Research for Patient Benefit Grant (PB-PG-0110-21305) 14th December 2010.

The study

Purpose and aims

The study will build on previous research by developing, and evaluating the feasibility and user acceptability of, an online support package for parents of children with CKD. In collaboration with parents, patients, nurses, other members of the multidisciplinary team and voluntary groups, we aim to develop and evaluate the OPIS and the technological infrastructure to match parents' needs to the amount and type of information they require, acknowledging the considerable differences between parenting children and young people. Material developed in collaboration with English speaking parents will be subjected to assessment by the SMOG readability formula then translated into the other most commonly spoken languages participants identify. This study is part of a phased approach to developing and evaluating an intervention that meets the learning needs of. Our aims are

- To explore views of parent care-givers, patients and professionals on existing and new online forms of parent information and support, the forms of information and support parents (and patients) would like more of and how these would best be delivered to parents.
- To build on findings from the point above and with parents/children/young people/professionals/voluntary sector representatives collaboratively develop an educational online parent information and support package (OPIS) to facilitate home-based care-giving, pilot it with parents to obtain detailed feedback and refine the OPIS.
- To conduct a pilot randomized controlled study of OPIS to assess its feasibility and user acceptability, finalize trial components and define a protocol for a later, national definitive RCT.

If the intervention is effective, we would seek funding to support a later national RCT evaluating feasibility and effectiveness of OPIS on parent care-giving.

Design

To achieve breadth and depth of analysis, the study uses a combination of quantitative and qualitative methods and participatory techniques (Waterman *et al.* 2001). The design aims to support research participation by children, fathers, mothers, professionals and volunteers (Swallow & Macfadyen 2004, Swallow *et al.* 2007, Macfadyen *et al.* 2011). The study's conceptual framework, based on Wenger's (Wenger 1998) social theory of learning, emphasizes learning as situated in communities of practice (CoPs) encompassing learning as experiencing, doing, belonging

and becoming. The study will recruit from one specialist centre where children are currently treated for CKD 3–5. Inclusion criteria require participating families to have existing home computers and internet access.

In CKD management: parents may perform the vast majority of care-giving, including tasks that are complex and demanding (DOH 2006:14), so parent (and patient) views are important targets for professional interventions designed to empower parents. To maximize recruitment, Community Professionals who share care with children's kidney units will be notified of the study. The outcome will be a well-developed, rigorously evaluated online package, tailored to care-giving needs of parents of children of all ages.

Phase 1

Participants

A purposive sample of 40 children (0–19 years) with CKD (10 South Asian and 30 English to reflect ethnic proportions of the CKD population) identified through unit records, their parents ('new' and 'experienced' care-givers) and professionals will be invited to participate in one of approximately ten homogeneous focus group (Ritchie & Lewis 2003) (children under 4 years will not participate in focus groups) comprising:

- Parent: mother, father or couple (acknowledging the fact gender-specific preferences may exist (Katz 2002, Swallow 2008, Macfadyen *et al.* 2011, Swallow *et al.* 2011a); South Asian (with interpreter if needed) or English language.
- Patient: (i) aged 4–12 years, using suitable techniques such as 'draw and tell' (ii) aged 13–19 years, using suitable techniques to engage young people.
- Professional/volunteer: MDT, community professionals and volunteers.

Data collection

Groups, involving 8–10 participants and lasting approximately 30–60 minutes each will be conducted by experienced researchers at a time and place convenient to participants, digitally recorded and later transcribed. Views on advantages and disadvantages of existing CKD-specific and generic online forms of information and support, and use and accessibility of supplementary online resources will be explored, to collaboratively define the components desirable in an online package. Discussion prompts designed to stimulate debate, gain insights and generate ideas to pursue in greater depth will include demonstrations of existing online resources verified by professionals. Topic guides will be regularly refined to reflect emerging issues (Ritchie & Lewis 2003).

Data analysis

Data will be analysed using Framework Analysis' (Ritchie & Lewis 2003, Swallow *et al.* 2007), a systematic, method for handling large amounts of qualitative data. Independent reviews of data samples will be discussed by researchers until consensus is achieved.

Phase 2

Participants

We will establish a 'virtual' development group comprising four children and four young people with CKD (English and South Asian), their parents and interpreter if needed; the researcher and technologist appointed, health professionals and voluntary sector representatives.

Data collection

Building on phase 1 analysis, we will collaboratively determine desirable components of the OPIS package, identifying appropriate existing resources to use, and produce pilot resources to address identified gaps in existing provision. A working group will be convened (comprising the PI, technologist and researcher appointed) to write resources that MDT members will review for accuracy. Resource design will take advantage of technological capabilities (Fox 2009) (providing these can be readily accessed by parents) that are sufficiently developed to support implementation of online resources.

Data analysis

Material will be assigned to one of two categories (need-to-know, useful-to-know) and will, as far as possible, use familiar 1 or 2 syllable words, short sentences of up to 15 words and short paragraphs. To reflect normal speech, the second person pronoun 'you' will be used rather than the 'first or third' person. Medical terminology will be defined in non-technical language. Common terms used by professionals but not used colloquially by parents will be linked to a glossary defining these terms. Written and visual material will be designed to encourage specific actions rather than simply stating facts and will use a friendly rather than reproachful tone. Material will be broken into small sections with sub-headings to help organize information flow. Parent and patient interaction will be invited by, for instance, offering short 'self-test' quizzes, presenting frequently asked questions/answers and scenarios for consideration using illustrations and photographs, and providing links to reliable, in-depth resources. Materials will be designed to match gender, culture and ethnicity so depicting the population's diversity (Memghini 2005) and assessed using the SMOG readability formula before being translated for South Asian parents and

piloted in four focus groups: parent (i) English, (ii) South Asian and patient: (iii) child and (iv) young person to obtain in-depth feedback for further refinement and development.

Phase 3

The OPIS will be sited in a University, password-protected, online learning environment available only to the phase 3 intervention group and the research team. We will pilot the OPIS to inform the national RCT by testing its impact on a range of variables, determining initial data for the primary outcome measures, informing sample size calculation and monitoring recruitment rates.

Participants

At least 30 participants per group is recommended for pilots (Lancaster *et al.* 2004) so we aim to recruit 80 'new' and 'experienced' parental (biological, step or adoptive) care-givers of 20 South Asian and 60 White children who commenced management for CKD in the preceding 3 years and require home-based care (40 per group to allow for a 25% attrition rate). Parents will be randomly assigned to intervention or control groups (Streiner & Norman 2008) stratified for care-giving status (new or experienced); level of home-based clinical care-giving (low or high) to help ensure equal distribution of these important factors between groups; and be assessed at pre-test on all variables. Other potentially important variables will be compared between groups descriptively at baseline to check for any potential imbalance. The random allocation sequence will be generated using nQuery Advisor 6.0, concealed from researchers and parents/patients prior to allocation, although parents will not be blind to the intervention.

Data collection

Background measures. We will gather demographic data (child's: age, gender, post-code, diagnosis; age of CKD onset; parents': age, gender, ethnicity, language, educational, socio-economic status) and ask mothers and fathers to report the clinical tasks they currently undertake, to help us identify patterns of care-giving. Seventy seven percent of dependent UK children live with their biological mother and father regardless of parents' marital status (ONS 2009). Ethnicity will be coded according to the 2001 Census groups. Parents' age at leaving full-time education will be recorded.

Primary outcome measures

The five outcome measures being used are:

- The Rapid Estimate for Adult Literacy in Medicine (REALM) involves subjects reading aloud a list of medical

words arranged in increasing order of difficulty. This has face, criterion and construct validity for use as a screening tool in the UK (Memghini 2005).

- The 12-item, Service System Subscale of the Family Empowerment Scale (FES) explores parents' relationships with health professionals and the level of comfort in asking questions/voicing their opinions (Koren *et al.* 1992).
- The Family Management Measure (FaMM) was developed to measure how families manage caring for a chronic condition and the extent to which they incorporate management into family life (Knafl *et al.* 2009).
- The Dads Active Disease Support Scale (DADS) assesses the amount of support offered by fathers, and mothers' perceptions of the quality of that support (Wysocki & Gavin 2004).
- The Suitability Assessment of Materials (SAM) Instrument evaluates 22 criteria and calculates a suitability score (Wagner *et al.* 2007).

The control group will receive care-giving information from the MDT in the standard way; the intervention group will receive standard information plus instruction on use of and (password protected) access to OPIS via home computer(s). During the pilot, OPIS use will be tracked online. After 24 weeks, primary outcome measures will be repeated with both groups to compare pre/post-intervention outcomes. We will collate feedback from all target parents. Case-note reviews will identify and record documented clinical discussions relating to forms of information provision (e.g. in discharge letters/summaries). We would expect parents in the intervention group to report improved scores in all measures [for FaMM, improved (higher) scores on scales indicative of greater ease in family management and lower scores on scales indicative of more difficulty]. Data will be entered into SPSS to produce descriptive statistics.

Data analysis

The main analyses will be intention-to-treat (dropouts will not be contacted for ethical reasons, although their data will be used where possible), with protocol violations being assessed carefully as part of a feasibility analysis. Analysis will concentrate on the estimation of confidence intervals for differences in outcome measures between groups and associated effect sizes to inform a full RCT, rather than formal hypothesis testing (Streiner & Norman 2008). Parameter estimates will be used to calculate the potential sample size required for a full RCT.

After the 24-week assessment, both parent groups will participate in individual or couple semi-structured interviews.

Discussion will focus on parents' experiences of information/support provision (standard or standard plus OPIS). Tracking data will be used during interviews with the intervention group to elicit understanding of how, when and why participants' used online resources. Interview transcripts will be analysed using Framework. Secondary analyses will record any reported problems using computers, OPIS clarification requests to professionals and indicators of treatment adherence. If the OPIS is effective, we would aim to seek further funding to conduct a UK-wide, definitive RCT, evaluating the impact of OPIS on parental self-efficacy.

The project management group (PMG) comprising applicants and staff appointed will meet monthly with additional meetings if difficulties arise and will report progress or difficulties to the project steering committee (PSC). The PSC (comprising applicants, staff appointed, parent and voluntary sector representatives) will meet at 0, 12 and 24 months to monitor progress against the project plan and act as a data monitoring committee.

Ethical considerations

The study was approved by the UK National Research Ethics Service (13th June 2011 11/NW/0268), a university ethics Committee and an NHS Trust R&D Department. Study documentation use ages appropriate formats for children and will if necessary be translated into a different language for parents or children. After receiving written and verbal explanations participants will provide signed consent and be assured that the study is not 'testing' knowledge or 'judging' care-giving skills. Participants will be offered support, via a clinical psychologist if participation causes distress. No person-identifiable information will be shared between participants or used in reporting. Refusal to participate or later withdrawal will not jeopardize relationships in the Trust.

Validity and reliability rigour

The complex nature of childhood CKD information provision and the specialist nature of home-based CKD management mean that families may seek care-giving advice from Community Professionals and hence their views will also be sought. During phase 3, there is potential for an increase in clinical consultation time if participating parents wish to discuss the project with professionals and the OPIS may stimulate further clinical questions by parents to professionals. To address this potential, technical questions about OPIS will be redirected to the researcher and clinical advice-giving relating to the OPIS will be noted by the clinician and gathered during case-note reviews. To optimize rigour, we

What is already known about this topic

- Parents of the growing numbers of children with chronic kidney disease stage 3–5 perform the majority of clinical care-giving at home, including tasks that are complex and demanding.
- Parents and policy makers have identified a need for accessible, evidence-based, online resources to supplement existing nursing and multidisciplinary team support, and empower parents' home-based clinical care-giving.
- Further research is needed to develop and evaluate online parent information and support resources in collaboration with families, professionals and the voluntary sector involved with chronic kidney disease.

What this paper adds

- An evidence-based, online parent information and support package will be developed in a children's kidney unit in collaboration with families, professionals and volunteers.
- A pilot, feasibility randomized controlled trial of usual support versus usual support supplemented by the package will be conducted with parents of 80 children with chronic kidney disease to assess the effectiveness of the package.
- We will use standardized measures and semi-structured interviews at 0 and 24 weeks to determine parents' views of the online parent information and support package, and define a protocol for a later definitive national trial.

Implications for practice and/or policy

- Globally, there is growing professional and policy interest in providing evidence-based online resources to support parents of children with long-term conditions.
- If found to be effective in empowering parents and promoting their self-efficacy, the package could be made available in other kidney units and be a model for other conditions.
- The package should have a significant impact on parent satisfaction, children/young peoples' experiences and clinical outcomes.

will use the Validation Framework (VF), a pragmatic approach designed for evaluating mixed methods research (Leech *et al.* 2010), and which allows for flexibility (Dellinger & Leech 2007). Data will be stored in password-protected computers available only to the researchers.

Limitations

The main limitations are: first, we are conducting the research in only one centre, which will limit generalizability of the findings; secondly, it is outside of the scope of this study to develop and evaluate child-specific resources.

Discussion

Internationally, the number of children needing home-based care for CKD Stages 3–5 is increasing. Treatment is costly (e.g. approximately £40,000 pa for dialysis per child), may be life-long and can transform children's lives, but some will need different types of therapies throughout their life. The consequences may include changing diet, avoiding certain foods and limiting fluid intake (Griffin & MacGregor 2005, Goldstein *et al.* 2008). This project will provide evidence-based resources tailored to parents' needs to strengthen home-based care-giving and optimize adherence to regimens.

Considerable differences exist between care needs of children and young people and therefore by seeking views of parents of patients of all ages and different ethnicities, and seeking patients' views, the study should help us better understand how online material can support parents. The OPIS could be a global exemplar for other conditions and may help optimize professionals' contact time with parents, so having much wider relevance in health care.

This project will provide a new, evidence-based, online information and support package that matches parents cultural, educational, ethnic and gender-specific support needs; technological skills; and the NHS technological infrastructure to the amount and type of information and forms of communication parents want. The large proportion of South Asian children with CKD means having resources available in English and the most commonly used South Asian languages will make them more accessible to all care-giving parents.

Conclusion

By working collaboratively to develop and evaluate resources that meet parents' identified needs, we will derive a detailed insight into parents' experiences of using OPIS, and should see improved parental self-efficacy.

Acknowledgements

We acknowledge peer reviewers from the University of Manchester; Dr Sara Mallinson and Dr Amanda Bingley, Lancaster University; and the anonymous National Institute of Health Research reviewers for their constructive comments

on our funding application. The study is adopted by the National Institute of Health Research Paediatric Speciality Group, and we gratefully acknowledge the support of Laura Crowther, Senior Research Administrator, Greater Manchester, Lancashire and South Cumbria Medicines for Children Research Newtork. This paper presents independent research funded by the National Institute of Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0110-21305). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Funding

Funding for this study was awarded via peer review through a National Institute of Health Research, Research for Patient Benefit Grant PB-PG-0110-21305.

Conflict of interest

No conflicts of interest have been declared by the authors.

Author contributions

VS initiated the study, VS, KK, SS, AH, TS, NJW & MC were responsible for study conception and design, for drafting of the manuscript, made critical revisions for important intellectual content, and are providing administrative, technical or material support to the study. VS, AH, TS will supervise/undertake data collection. VS, KK, SS, NJW & MC will supervise/undertake data analysis. MC is providing statistical expertise.

References

- Bandura A. (1997) *Self Efficacy: The Exercise of Control*. W H Freeman, New York.
- Coulter A. & Ellins J. (2007) Effectiveness of strategies for informing, educating, and involving patients. *BMJ* 335(7609), 24–27.
- Coulthard M.G. & Crosier J. (2002) Outcome of reaching end stage renal failure in children under 2 years of age. *Archives of Disease in Childhood* 87(6), 511–517.
- Darzi (2008) *High Quality Care for All*, NHS Next Stage Review Final Report. The Stationery Office, Norwich.
- Dellinger A. & Leech N. (2007) Towards a unified validation framework in mixed methods research. *Journal of Mixed Methods Research* 1(4), 309–332.
- DOH (2006) *The National Service Framework for Renal Services: Working for Children and Young People*. Department of Health, London.
- Ellins J. & McIver S. (2008) *Systematic Provision of Information on Quality of Primary Care Services; Consumer Research Report 3: Making Health Service Information Accessible*. Health Services Management Centre, London.
- Ferguson T. & Frydman G. (2004) The first generation of e-patients. *BMJ* 328(7449), 1148–1149.
- Fox M.P. (2009) A systematic review of the literature reporting on studies that examined the impact of interactive, computer-based patient education programs. *Patient Education and Counseling* 77(1), 6–13.
- Goldstein S.L., Graham N., Warady B.A., Seikaly M., McDonald R., Burwinkle T.M., Limbers C.A. & Varni J.W. (2008) Measuring health-related quality of life in children with ESRD: performance of the generic and ESRD-Specific Instrument of the Pediatric Quality of Life inventory (PedsQL). *American Journal of Kidney Disease* 51, 285–297.
- Griffin S. & MacGregor M. (2005) Facing an epidemic of chronic kidney disease. *Clinical Medicine* 5, 521–525.
- Hovey J.K. (2005) Fathers parenting chronically ill children: concerns and coping strategies. *Issues in Comprehensive Pediatric Nursing* 28(2), 83–95.
- ITU-D (2010) Measuring the Information Society- The Information Communications Technology Development Index (IDI). ITU-D (International Telecommunication Union Development Sector), Geneva.
- Katz S. (2002) Gender differences in adapting to a child's chronic illness: a Causal Model. *Journal of Pediatric Nursing* 17(4), 257–269.
- Kieckhefer G., Churchill S., Trahms C. & Simpson J. (2009) Measuring parent-child shared management of chronic illness. *Pediatric Nursing* 35(2), 101–127.
- Knafl K., Deatrick J.A., Gallo A., Dixon J., Grey M., Knafl G. & O'Malley J. (2009) Assessment of the Psychometric Properties of the Family Management Measure. *Journal of Pediatric Psychology* 36(5), 494–505.
- Koren P., Dechillo N. & Friesen B. (1992) Measuring empowerment in families: a brief questionnaire. *Rehabilitation Psychology* 37, 305–321.
- Lancaster G.A., Dodd S. & Williamson P.R. (2004) Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice* 10(2), 307–312.
- Leech N.L., Dellinger A.B., Brannagan K.B. & Tanaka H. (2010) Evaluating mixed research studies: a mixed methods approach. *Journal of Mixed Methods Research* 4(1), 17–31.
- Lewis M. (2008) Demography of renal disease in childhood. *Seminars in Fetal & Neonatal Medicine* 13, 118–124.
- Macfadyen A., Swallow V., Santacroce S. & Lambert H. (2011) Involving fathers in research. *Journal for Specialists in Pediatric Nursing* 16(3), 216–219.
- Memghini K. (2005) Designing and evaluating parent educational materials. *Advances in Neonatal Care* 5(5), 273–283.
- Morton R., Tong A., Howard K., Snelling P. & Webstar A. (2010) The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* 340, 350.
- National-Statistics-Online (2008) *Households with Access to the Internet*.
- OFCOM (2008) *The Communication Market* (Communications, O. o. ed. London).
- ONS (2009) *Social Trends*. Vol. 39 Office of National Statistics, London.

- Ritchie J. & Lewis J. (eds) (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Sage Publications, London.
- Santacroce S.J. (2003) Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship* 35(1), 45–51.
- Scott J.E.S., Swallow V., Coulthard M.G., Lambert H.J. & Lee R.E.J. (1997) Screening of newborn babies for familial ureteric reflux. *The Lancet* 350(9075), 396–400.
- Sinha M.D. & Webb N.J.A. (2006) Shared care of children with renal disease. *Current Paediatrics* 16(4), 254–258.
- Speros C. (2005) Health Literacy: Concept analysis. *Journal of Advanced Nursing* 50(6), 633–640.
- Streiner D. & Norman G. (2008) *Health Measurement Scale*. Oxford University Press, Oxford.
- Sullivan-Bolyai S.D.C.N.S.R.N., Rosenberg R. & Bayard M. (2006) Fathers' reflections on parenting young children with type 1 diabetes. *MCN, American Journal of Maternal Child Nursing January/February* 31(1), 24–31.
- Swallow V. (2008) An exploration of mothers' and fathers' views of their identities in chronic-kidney-disease management: parents as students? *Journal of Clinical Nursing* 17(23), 3177–3186.
- Swallow V.M. & Jacoby A. (2001a) Mothers' coping in chronic childhood illness: the effect of presymptomatic diagnosis of vesicoureteric reflux. *Journal of Advanced Nursing* 33(1), 69–78.
- Swallow V.M. & Jacoby A. (2001b) Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory. *Journal of Advanced Nursing* 36(6), 755–764.
- Swallow V. & Macfadyen A. (2004) Nurses' communication skills: are they effective research tools? *Paediatric Nursing* 16(5), 20–23.
- Swallow V., Coad J. & Macfadyen A. (2007) Involving children, young people and parents in knowledge generation in health and social care research. In *User Participation Research in Health and Social Care* (Nolan M., Hanson E., Grant G. & Keady J. eds), OUPress, Buckingham, pp. 151–165.
- Swallow V., Lambert H., Clarke C., Campbell S. & Jacoby A. (2008) Childhood chronic-kidney-disease: a longitudinal-qualitative study of families learning to share management early in the trajectory. *Patient Education and Counseling* 73, 354–362.
- Swallow V., Clarke C., Campbell S. & Lambert H. (2009) Nurses as family learning brokers: shared management in childhood chronic kidney disease. *Journal of Nursing and Healthcare of Chronic Illness* 1, 49–59.
- Swallow V., Lambert H., Santacroce S.J. & Macfadyen A. (2011a) Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare?. *Child: Care, Health & Development* 37(4), 512–523.
- Swallow V., Macfadyen A., Santacroce S.J. & Lambert H. (2011b) Fathers' contributions to the management of their child's long-term medical condition: a narrative review of the literature. *Health Expectations*, doi: 10.1111/j.1369-7625.2011.00674.x.
- Thorne S.E. & Paterson B.L. (2001) Health care professional support for self-care management in chronic illness: insights from diabetes research. *Patient Education and Counseling* 42(1), 81–90.
- Tong A., Lowe A., Sainsbury P. & Craig J.C. (2008) Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics* 121(2), 349–360.
- Tuffrey C. & Finlay F. (2002) Use of the internet by parents of paediatric outpatients. *Archives of Disease in Childhood* 87(6), 534–536.
- Wagner C.V., Knight K., Steptoe A. & Wardle J. (2007) Functional health literacy and health-promoting behaviour in a national sample of British adults. *Journal of Epidemiology and Community Health* 61(12), 1086–1090.
- Waterman H., Tillen D., Dickson R. & Koning K.D. (2001) *Action Research: A Systematic Review and Assessment for Guidance*. Vol. 5, Health Technology Assessment, London.
- Wenger E. (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge University Press, Cambridge.
- Whyte K.L. & Hunter I. (2008) Internet access, utilisation and perception by parents. *Archives of Disease in Childhood* 93(5), 448–449.
- Wysocki T. & Gavin L. (2004) Psychometric properties of a new measure of fathers' involvement in the management of pediatric chronic diseases. *Journal of Pediatric Psychology* 29(3), 231–240.

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in JAN:

- **High-impact forum:** the world's most cited nursing journal and with an Impact Factor of 1.540 – ranked 9th of 85 in the 2010 Thomson Reuters Journal Citation Report (Social Science – Nursing). *JAN* has been in the top ten every year for a decade.
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 6,000 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at <http://mc.manuscriptcentral.com/jan>.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Early View:** rapid *online* publication (with doi for referencing) for accepted articles in final form, and fully citable.
- **Faster print publication than most competitor journals:** as quickly as four months after acceptance, rarely longer than seven months.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).