

A WHITE ROSE COLLABORATION
REPORT OF A WORKSHOP
7th & 8th NOVEMBER 2016

Fostering and sustaining UK,
multidisciplinary, family-
focused care across the life-
course:
A White Rose collaboration
in long-term condition
management

Professor Veronica Swallow

Professor Angela Tod

Dr Joanna Smith

April 2017

People Helping People



INTRODUCTION

Care of persons with long-term conditions (LTCs) is a key health-policy priority. LTCs account for 70% of health/social-care spending. In *Better Value in the NHS* (2015) the Kings Fund predicts that improving service quality and cost-effectiveness for people with LTCs will remain critical for the foreseeable future. International evidence indicates that LTCs in early-life can affect individuals' health and wellbeing across the life-course. Around 15 million people in England live with one or more LTCs, family members may contribute to their care and one person's LTC can impact on the whole family's health and wellbeing. Families respond differently to LTCs but family response is closely related to clinical outcomes.

In 2013 the Chief Medical Officer urged professionals to 'think family at every interaction' to ensure family-health and well-being is central to multi-professional practice, and to develop innovative tools to support/promote this. Research indicates that family relationships have the potential for health-promoting effects, yet family-focused care across the life-course is not central to the NHS. Little is known about: how UK health and social-care professionals understand family support; how family-life, family-health and social-care intersect; or what tools/interventions exist to support and promote family-focused care for those with LTCs across the life-course. Currently there is no collaboration between the White Rose universities (Universities of Leeds, Sheffield and York) in the field of family-focused care of LTCs across the life-course, yet LTC management across the life-course is an area that is strategically important for policy and research funders. This proposed collaborative project will enable us to establish a Research Development Group (RDG) in the field of family-focused care of LTCs across the life-course. The collaboration has the potential to achieve significant short and medium-term outcomes that will bring added value to the investment in this project, and will pave the way for us to achieve important long-term outcomes to benefit families living with LTCs. The project builds on and benefits from the strengths of the three Universities bringing together LTC expertise across the life-course and creating a unique multi-disciplinary collaboration between the White Rose universities.

Objectives:

1. Establish a virtual, multidisciplinary RDG: 'Family health and social-care research across the life-course' that combines expertise in LTC research in psychology, nursing, allied health and social care in the three Universities;
2. Systematically review the UK literature in this area;
3. Harness existing links with international family experts;
4. Establish a patient and public involvement (PPI) group of consumers to advise from family perspectives;
5. Define aims/objectives for future collaborative grant application/s around support strategies where family members have LTC/s.

Proposed activities:

1. Project inception event for applicants/consumers to refine timetable and determine RDG, patient and public involvement (PPI) and early career researcher (ECR) groups' aims, objectives and milestones;
2. Convene a PPI group;
3. Develop White Rose project web-page to support dissemination and demonstrate collaboration;
4. Undertake a systematic literature review;
5. Deliver a 1.5-day workshop for the applicants, consumers and key UK family-focused colleagues.

This report summarises the workshop

Master Classes were delivered by:

- a. Professors Knafl and van Riper, America (Conceptual/methodological underpinnings of international family research);
 - b. Professor Shields, Australia (International evidence for family-centred care);
 - c. Dr Østergaard (Developing family-cardiology nursing in Denmark);
6. Draft funder's report and manuscript reporting review;
 7. Define aims/objectives/design for a grant application to begin developing/evaluating; innovative tool/intervention/s to foster and sustain family-focused LTC care across the life-course.

WHITE ROSE PROJECT TEAM MEMBERS

Professor Veronica Swallow, Principal Investigator (PI), Professor of Child & Family Health, School of Healthcare, University of Leeds;

Professor Angela Tod, Co-Investigator, Professor of Older People and Care, School of Nursing & Midwifery, University of Sheffield;

Dr Joanna Smith, Co-PI, Project Coordinator, Lecturer in Children's Nursing, School of Healthcare, University of Leeds;

Dr Linda Milnes, Co-Investigator & Patient and Public Involvement (PPI) Lead, Associate Professor in Children's & Young People's Nursing, School of Healthcare, University of Leeds;

Dr David Saltiel, Co-Investigator, Lecturer in Social Work, School of Healthcare, University of Leeds;

Dr Alison Rodriguez, Co-Investigator, Lecturer Child and Family Health, School of Healthcare, University of Leeds;

Professor Yvonne Birks, Co-Investigator, Co-Director of Social Policy Research Unit, University of York;

Professor Penny Curtis, Co-Investigator, Professor of Child and Family Health and Wellbeing, School of Nursing & Midwifery, University of Sheffield;

Dr Parveen Ali, Co-Investigator, Lecturer, School of Nursing & Midwifery, University of Sheffield;

Dr Jill Thompson, Co-Investigator & Co-PPI Lead, Lecturer, School of Nursing & Midwifery, University of Sheffield;

Professor Sue Kirk, Co-Investigator, Professor of Family and Child Health, School of Nursing, Midwifery and Social Work, University of Manchester;

Professor Bryony Beresford, Co-Investigator, Co-Director of Social Policy Research Unit, University of York.

The team and expert presenters



WEB PAGE

<https://www.whiterose.ac.uk/collaborationfunds/fostering-and-sustaining-uk-multidisciplinary-family-focussed-care-across-the-life-course/>

THE VENUE

Devonshire Hall, situated in a quiet residential area just one mile from the main University of Leeds campus; the traditional 'Oxbridge' style hall created a welcoming and friendly atmosphere for the workshop participants to engage and share ideas about family focused care.



ORGANISATION

Dr Joanna Smith was the overall coordinator of the event with administrative support from Suky Sihra.

Professors Veronica Swallow and Angela Tod organised the workshop programme and co-chaired the event.

Dr Linda Milnes and Dr Jill Thompson led and supported the service user and carer involvement.

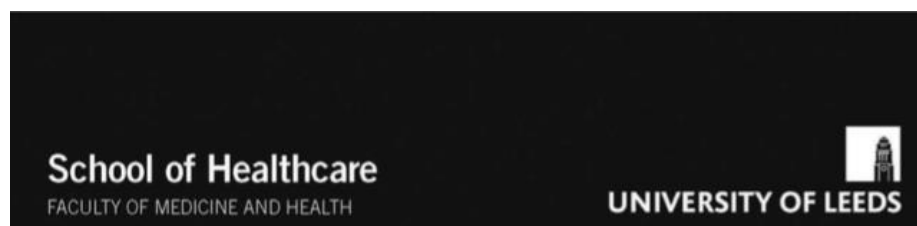
TWITTER

Key messages were shared using Twitter:

@UoLchildnursing

#CYPuOL





Fostering and sustaining UK, multidisciplinary, family-focussed care across the life-course: A White Rose collaboration in long-term condition management

A WHITE ROSE COLLABORATION PROJECT

Venue: Devonshire Hall - University of Leeds <http://www.meetinleeds.co.uk/devonshire-hal>

Co-Chairs: Professor Veronica Swallow (VS), University of Leeds Professor Angela Tod (AT) Sheffield University

Aims of the Workshop: To explore and discuss family focussed care across the life-course in the UK and Engage with the most recent evidence around family focussed care; Identify an action plan for a future research proposal

DAY 1 Monday 7th November 2016 Fenton room: workshop

Byford room: registration, breakout & lunch

09.30	Coffee/Tea/biscuits on arrival
10.00	Introduction VS / AT
10.05	Professor Andrea Nelson, Head of School of Healthcare and Deputy Dean, Faculty of Medicine: Welcome to the University of Leeds
10.10	Setting the scene: Why Family Focussed Care political, practical and policy perspectives, aims for the two days VS and AT
10.30	THEME 1- The empirical evidence for family focussed care Professor Linda Shields, Charles Sturt University, Australia The international evidence: Cochrane reviews of Family Centred Care
10.30	2 minutes for points of clarification from audience
10.50	Dr Joanna Smith, University of Leeds Developing a protocol of a Systematic Review of Family focussed care in the UK 2 minutes for points of clarification from audience
11.10	Discussion / Q&A around both presentations led by AT /VS
11.30	Coffee / Tea

Continued	
	THEME 2- Models of family focussed care: Concepts, Implementation, and Evaluation
11.45	Professor Kathy Knafl and Professor Marcia van Riper, University of North Carolina at Chapel Hill, USA
	Family Research: Conceptual and Methodological Issues 2 minutes for points of clarification from audience
12.15	Dr Ostergaard, University of Southern Denmark Developing family-cardiology nursing in Denmark 2 minutes for points of clarification from audience
12.25	Discussion / Q&A around both presentations led by AT / VS
12.45	Buffet lunch
13.45	Introduction to afternoon session AT / VS
14.00	Small group discussions around themed issues arising from morning discussions
14.45	Group feedback from table discussions
15.20	Outline plans for Day 2
15.30	Coffee/ Tea and space for talking
16.30	Close
17.30	Optional early dinner at Brasserie Blanc, Victoria Mill, Sovereign St, Leeds LS1 4BJ
	DAY 2 Tuesday 8th November 2016 Evans room: workshop, breakout & lunch
9.00	Coffee/Tea/biscuits on arrival
9.30	Summary from Day 1 and refocus AT/ VS
9.40	Kathy Knafl & Marcia van Riper Using Conceptual Frameworks to Guide Collaborative Research Endeavors
10.00	Question Time , Expert discussion panel comprising Kathy, Marcia, Linda, Birte
10.30	Coffee
11.00	Experts' surgeries (individual appointments)
11.50	Summing up and close VS, AT, JS
12.00	Buffet Lunch
	Notes and thoughts

PARTICIPANTS

There were 26 participants at the event from a range of backgrounds with personal and professional experiences of family-focused care across the life-course.

Expert speakers

Professor Linda Shields	Charles Sturt University, Australia
Professor Kathy Knafl	University North Carolina
Professor Marcia van Riper	University North Carolina
Dr Birte O stergaard	University of Southern Denmark

Patient Public Involvement (PPI) and Engagement Representatives

We were delighted that our PPI members were able to attend the workshop, sharing their experiences, offering suggestions and adding humour to the event.

Kauser Iqbal	Arthur Pitchforth
Gulaeb Ahmed	Mary Pitchforth
Val Littleton	Simon Stones
Manoj Mistry	

Delegates

Dr Parveen Ali	University of Sheffield
Dr Anne Broedsgaard	University of Copenhagen
Professor Penny Curtis	University of Sheffield
Dr Christine English	University of Northumbria
Dr Paul Galdas	University of York
Gayle Garland	University of Leeds
Kauser Iqbal	PPI representative
Mrs Val Littleton	PPI representative
Dr Sarah Kendal	University of Huddersfield
Professor Sue Kirk	University of Manchester
Dr Linda Milnes	University of Leeds
Manoj Mistry	PPI representative
Dr Sarah Neil	University of Northampton
George Peat	PhD Student, University of Leeds
Claire Pickerden	White Rose
Dr Alison Rodriguez	University of Leeds
Dr Jo Smith	University of Leeds
Simon Stones	PhD Student, University of Leeds & PPI representative
Professor Veronica Swallow	University of Leeds
Beth Taylor	PhD Student, University of Sheffield
Dr Jill Thompson	University of Sheffield
Professor Angela Tod	University of Manchester

A W A R M W E L C O M E

Professor Andrea Nelson, Head of the School of Healthcare and Deputy Dean, Faculty of Medicine, University of Leeds welcomed our expert speakers from the U S A , A u s t r a l i a and D e n m a r k to E n g l a n d , and all attendees to Leeds and the University. She emphasised the importance of family nursing and health care across the life-course to the School, Faculty, University, the wider H E sector and the N H S .

A n d r e a reinforced our goal of promoting and embedding family focused health care for people in the U K and across the life-course who are living with long-term conditions, and wished everybody a very successful and enjoyable two days.

A n d r e a n o t e d

R e s e a r c h indicates that family relationships have the potential for health-promoting effects, yet family-focused care across the life-course is not central to the N H S

U n t i l n o w , there has been no collaboration between the W h i t e R o s e Universities in the field of family-focused care of long-term condition management across the life-course and highlighted this is an area that is strategically important for policy and research funders

T h e r e is great potential for the workshop to stimulate productive research collaborations between the W h i t e R o s e Universities, our colleagues in other U K and overseas universities (in particular our expert speakers and workshop delegates) and the N H S

S E T T I N G T H E S C E N E

T h e workshop was co-chaired by Professors V e r o n i c a S w a l l o w and A n g e l a T o d .

V e r o n i c a and A n g e l a opened the event with an introductory session on: *S e t t i n g t h e s c e n e : W h y F a m i l y F o c u s e d C a r e ? P o l i t i c a l , p r a c t i c a l a n d p o l i c y p e r s p e c t i v e s*, and set out the aims for the two days. They highlighted that long-term

A i m s

- E x p l o r e and discuss family focussed care across the life-course in the U K
- E n g a g e with the most recent evidence around family focussed care
- I d e n t i f y an action plan for future research proposal/s

conditions in early-life can affect individuals' health and wellbeing across the life-course, and that around 15 million people in England live with one or more long-term condition/s so family members may contribute to their care.

T h i s means that one person's long-term conditions can impact on the whole family's health and wellbeing and of course families respond differently to long-term conditions, yet family response can be closely related to outcomes.

V e r o n i c a and A n g e l a highlighted that family relationships have the potential for health-promoting effects, yet because family-focused care across the life-course is not central to the N H S , little is known about how U K health and social-care professionals understand family-support, how family-life, family-health and social-care intersect and what tools exist to support/promote family-focused care for those with long-term conditions across the life-course. Finally they detailed the wider objectives for this W h i t e R o s e collaboration Project (page 1).

T H E M E S

T h e workshop presentations were grouped into two themes:

T h e e m p i r i c a l e v i d e n c e f o r f a m i l y f o c u s e d c a r e

M o d e l s o f f a m i l y f o c u s e d c a r e : C o n c e p t s , I m p l e m e n t a t i o n , a n d E v a l u a t i o n

P a g e s 7-8 provide a summary of the workshop presentations; the full presentations can be accessed at:

<https://www.whiterose.ac.uk/collaborationfunds/fostering-and-sustaining-uk-multidisciplinary-family-focussed-care-across-the-life-course/>

THEME 1-Professor Linda Shields, Charles Sturt University, Australia The international evidence: Cochrane reviews of Family Centred Care

Linda set the scene for our workshop by describing a Cochrane Review on family centred care (FCC) for hospitalised children aged 0-12 years that she led in 2012. Inclusion criteria were: Randomised controlled trial (RCT), children aged 0-12 years and admitted to hospital where a FCC intervention was reported to be implemented. The FCC score assessed using a recognised tool needed to be > 26 . Types of intervention could include:

- Environmental interventions as evidenced by collaboration with the family and/or child in the design or redevelopment of facilities;
- Family-centred policies, which may include open visiting hours for siblings or extended family, and parent participation in their child's care to the extent they choose. Communication interventions could include parental presence and participation at daily interdisciplinary ward rounds and family conferences to plan future care, developing collaborative care pathways where both parent and/or child and health carer document issues and progress;
- Educational interventions could include structured educational sessions for parents of technologically dependant children, programs to equip staff to provide care within a family-centred framework, and preadmission programs;
- Family support interventions such as flexible charging schemes for poor families, referrals to other hospital or community services.

16 studies were included (1 x Cochrane review, 1x quasi experimental study and 14 x qualitative studies). Quality was assessed using Cochrane Risk of Bias assessment tools. In conclusion Linda explained that parents wish to participate in their hospitalized child's care. However the nature and extent of this involvement has to be negotiated on an individual family basis. Although it appears that nurses and other health care professionals have a reasonably good understanding of the elements that constitute family-centred care, incorporation of these into practice is not uniform. The difficulty is that the change requires challenging professional power.

Reference:

SHIELDS, L., ZHOU, H., PRATT, J., TAYLOR, M., HUNTER, J. & PASCOE, E. 2012. Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database Systematic Review*.

THEME 1- Dr Joanna Smith: Summarise and synthesise findings of systematic reviews of family-focused care and related terms

Jo is leading the review with support from Information Specialists in Leeds Institute of Health Sciences at the University of Leeds and began by outlining the questions guiding the review:

1. How is family-focused care (FFC) defined?
2. What other constructs are related to FFC, specifically FCC, family-focussed practice (FFP) and family-centred practice FCP?
3. What models of FFC exist across the life-course in health & social care to support people with long-term conditions within the UK?
4. What interventions, if any, have been developed to support FFC across the life-course for people with long-term conditions?
5. What is the evidence that FFC interventions to support people with long-term conditions across the life-course are cost and clinically effective?

Jo explained that the working definition guiding this review is:

Family-focused care is an approach to care delivery, whereby health professionals respect and respond to the needs of the patient and their family as a complete unit, recognising the family role in supporting and being involved in care.

Inclusion criteria, studies:

- Across the life-course - adults and children with a long-term condition;
- That have evaluated: 1) Family-focused care; 2) Family-centred care; 3) Family-centred practice; 4) Family-focused practice in relation to:
 - Interventions (for example family therapy, support, counseling, education)
 - Family experiences and perspectives;
 - Health or social care professionals' experiences and perspectives;
- Across health and social care contexts.

The next stages of the review were outlined:

- Finalise review protocol, publish in PROSPERO and develop screening tool & data extraction template;
- Undertake review & disseminate findings in a high impact journal;
- Develop a database of published research on family-focused care & related terms;
- Identify position of family-focused care in the UK family;
- Set objectives for future collaborative grant application/s around support strategies for long-term conditions.

THEME 2: Professor Kathy Knafl and Professor Marcia van Riper, University of North Carolina at Chapel Hill, USA Family Ties:

A Discussion of Strategies for Building a Research Cooperative

Kathy and Marcia drew on their own family research that is widely cited in the literature to explore and discuss two potential strategies for us to consider as we build a UK research cooperative:

Strategy 1 – Identify an Organizing Framework

Drawing on examples such as the Self and Family Management Framework (Grey et al 2014), in particular viewing environment as a facilitator or barrier, and considering family outcomes, they suggested that a general organizing framework can:

- Foster positioning of each member's research in the context of the group;
- Highlight underlying shared interests;
- Accommodate a broad spectrum of family research interests;
- Encompass multiple health challenges and methodological approaches.

Strategy 2 – Shared Measures of Family Functioning:

The National Institute of Health (NIH) definition of common data elements (CDEs) is 'a data element that is common to multiple data sets across different studies' (<http://www.nlm.nih.gov/cde>; National Institutes of Health, 2014 a, b).

CDEs are generated from the same set of instruments used to consistently measure a set of concepts of interest to many researchers. Comparison of data across studies is more accurate and relevant when researchers are investigating questions using the same data elements and measures.

Reviews of Established Self-Report Measures of Family Functioning include:

- Family Assessment Device (FAD)
- Family Assessment Measure (FAM)
- Family Relations Index (FRI)
- Family Environment Scale (FES)
- Self-Report Family Inventory (SFI)
- Family Adaptability and Cohesion Evaluation Scale (FACES)
- Systemic Clinical Outcome and Routine Evaluation (SCORE)
- Family APGAR (APGAR)
- Feetham Family Functioning Scale (FFFS)
- McCubbin Framework Scales (McCubbin)

Discussion focused on the ways in which this White Rose collaboration can go forward to shape our strategy

THEME 2- Dr Ostergaard, University of Southern Denmark Developing family-cardiology nursing in Denmark

Birte outlined a recently completed study she led in Denmark that aimed to study the effect of two methods of treatment for heart failure;

- Conventional treatment with referral to heart failure clinics;
- Family Focused Nursing as supplement to conventional treatment of outpatients in heart failure clinics.

Primary outcomes

Health Related Quality of Life at 3 months, 6 months and 1 year follow-up

Secondary outcomes

Self-care behavior (self-care, family resources, self-efficacy and depression)

Time to occurrence of readmission

Time to occurrence of readmission for heart failure

Time to occurrence of death

468 consecutively enrolled patients were randomly allocated to two groups by external web-based randomization and stratified for affiliated center and NYHA-classification.

Family interventions used included: CFAM – Calgary Family Assessment Model

Birte explained that so far she has presented the study at six international conferences and an abstract was submitted to the next International Family Nursing Conference in Spain 2017 to present the results regarding the primary outcomes about health related quality of life. The first article regarding validity and reliability of the Danish version of the European Heart Failure Self-care Behaviour scale was recently published:

Reference:

ØSTERGAARD, B., MAHRER-IMHOF, R., LAURIDSEN, J. &

WAGNER, L. 2016. Validity and reliability of the Danish version of the 9-item European Heart Failure Self-care Behavior Scale. *Scandinavian journal of caring sciences*.

KEY MESSAGES FROM GROUP DISCUSSIONS

Discussion points from the PPI group led by Linda Milnes and Jill Thompson with Val Littleton, Kauser Iqbal, Manjoi Mohammed, and Gulaeb Ahmed included:

- Differences exist within and across families - and change over time so a responsive approach is needed;
- Carer's role very important and the ideal is a model where the carer is at the centre of care with the 'patient';
- Changing levels of responsibility by carers exist and it is important to recognise that there can be resentment in families against the person who is the 'main' carer;
- Isolation of carer a big factor – seeking support for themselves within the community and online, how can this isolation be reduced?
- Family dynamics need to be redefined with individual families regularly as circumstances change;
- There is a need for regular reviews of care and carers;
- The impact of the geographical positions of family members who are involved in family management;
- The impact of caring for someone is often underestimated or not recognised - creates ill health and stress;
- Who supports the carer whose employment options /income may be restricted by caring responsibilities;
- Families/carers may go outside of the family for support if a PA is being employed for example 'Carers Leeds'?
- Important to educate health professionals on how to help carers - signpost to available groups;
- Regular definition and re-definition of family; Think about looking at family as a unit with all their health needs
- To tackle the above we need to be reflexive practitioners and researchers and challenge any spoken or un-spoken assumptions about FFC that may exist.

Core principles of reflexive Family Focused Practice:

- Based on sound assessment;
- Participatory practice/research;
- Empowering and reflexive;
- Services that are scalable, affordable and sustainable;
- Whole systems approach - can't just be patchy activity, need to link with relevant services/processes.

Assumptions about Family Focused Practice include:

- Family is an appropriate 'unit of care';
- Everybody has a family;
- Family will be able to help;
- Family intervention/care/focused care will be positive;
- The family environment is good/nurturing
- Family is safe and benevolent;
- Home is the best place for someone with long-term conditions.

Questions to be addressed:

- What do we mean by family?
- How do we reduce isolation and/or stigmatization of carers and promote their choice, dignity and privacy?
- What are family members' perspectives of family focused practice and knowledge of existing local support?
- How is community care integrated into family focused care?
- How to respond to changes to family units, e.g. increase in the geographical dispersion of family members?
- What might be the unintended consequences of family focused care?
- How to manage assumption that siblings will automatically take on the caring role at age 18 and/or resentment from children over parents' caring role?
- How do we promote being a reflexive family focused practitioner whilst resources are being reduced?
- How can assumptions about family focused care be addressed; for example *where there are issues of mental capacity*.

Criticisms of Family Focused Care include:

- It is about shifting responsibility from professionals to family who are already fatigued by care responsibilities;
- Family focused care involves making people's narratives public;
- At extremes of the life-course for example for old/young people, those with/without capacity, it is easier to be clear about who makes decisions and how family focused care can make a contribution. It is less clear for those at other stages;
- If we assume family focused care is 'a good thing' and orientate care in a family focused care way, there is a risk of inequality; those without family or with challenging family may struggle to access care;
- Where safeguarding issues emerge family focused care may be complex;
- Family focused care should be empowering but need to make sure that services are there to respond to action taken by families.

Challenges of Family Focused Care include:

- How to deal with conflicting needs/goals/views within the family and how that is accounted for in family focused care;
- Incorporating social and political influences on health and wider determinants;
- Family focused care may mean challenging some coping behaviors that emerge from underlying attitudes and values e.g. privacy, protecting independence, preserving dignity. Interfering with these may have adverse consequences;
- Family focused care may uncover conflicts e.g. protecting rights of the individual versus family, changing power dynamics, communication and information sharing between patient/family. Where issues of mental capacity apply this is more complicated;
- Balancing risks / benefits of family focused care and moral judgments by society/professions/services for example obesity.

WORKSHOP SUMMARY

The workshop has paved the way for the project team to begin defining aims, objectives and research designs for future grant applications in order to consider how best to develop/evaluate innovative tool/intervention/s to foster and sustain family-focused LTC care across the life-course.

Feedback from the workshop highlights the value of a collaborative venture such as this, e.g. one participant said:

Thank you for inviting me to attend the workshop: it was excellent and very inspiring to be part of the discussions. Very keen to be involved in any way that is appropriate - lots of food for thought. So good to see everyone and make those connections too. Well done to you and your team for the friendly feel and efficient organisation of the event.

Future actions include to:

Identify: a unifying framework, core measures, a data sharing strategy, creative dissemination methods, and ways to maintain contact with international experts and lay representatives and a mechanism to share research ideas and identify priorities.

Building on the workshop we have created:

A 'virtual' international group of family-focused researchers and educators to begin addressing key research questions that we identified during the workshop

A group of interested and experienced service users and carers who will guide and advise us and collaborate on future project

SELECTED FAMILY REFERENCES FROM KATHY KNAFL

Nature & Purpose of Family Research

Bengtson, V.L., Accock, A.C., Allen, K.A., Dilworth-Anderson, P., & Klein, D.M. (2005). Theory and theorizing in family research. In V.L. Bengtson, A.C. Accock, K.A. Allen, P. Dilworth-Anderson, & D.M. Klein (Eds.), *Sourcebook of family theory and research* (pp. 3-33). Thousand Oaks, CA: Sage.

Beutler, I. F., Wesley, R., & Bahr, K. S. (1989). The family realm: Theoretical contributions for understanding its uniqueness. *Journal of Marriage and the Family*, 51, 805-816.

Carr, D., & Springer, K. (2010). Advances in families and health research in the 21st century. *Journal of Marriage and Family*, 72, 743-761.

Crane, D.R., & Marshall, E.S. (Eds.). (2006). *Handbook of families and health: Interdisciplinary perspectives*. Thousand Oaks, CA: Sage.

Dolgin, J. (2014). Neither father nor doctor “know best”: From tradition to choice in the family and on the wards. *Journal of Family Theory & Review*, 6, 62-75.

Fisher, L., Terry, H. E., & Ransom, D. C. (1990). Advancing a family perspective in health research: Models and methods. *Family Process*, 29, 177-189.

Ganong, L. (2011). Return of the “intimate outsider”: Current trends and issues in family nursing research revisited. *Journal of Family Nursing*, 17, 416-440.

Ganong, L. H. (1995). Current trends and issues in family nursing research. *Journal of Family Nursing*, 1, 171-206.

Grzywacz, J. (2009). Issues in families and health research. *Family Relations*, 58, 373-378.

Litman, T.J. (1974). The family as a basic unit in

health and medical care: A social-behavioral overview. *Social Science & Medicine*, 8, 495-519. (A classic paper) Peterson, G., & Bush, K. (Eds.) (2012). *Handbook of marriage and the family* (3rd Ed.). New York City: Springer.

Ronka, A., & Korvela, P. (2009). Everyday family life: Dimensions, approaches, & current challenges. *Journal of Family Theory & Review*, 1, 87-102.

Conceptual Underpinnings of Family Research

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family*, 66, 51-566.

Daly, K. (2003). Family theory versus the theories families live by. *Journal of Marriage and the Family*, 65, 771-784.

Deatrick, J., Knafl, K., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *Journal of Nursing Scholarship*, 31, 209-214.

Gillette, M., & Gudmunson, C. (2104). Utilizing evolutionary life history theories in family studies. *Journal of Family Theory & Review*, 6, 5-17.

Gilliss, C. L. (1983). The family as a unit of analysis: Strategies for the nurse researcher. *Advances in Nursing Science*, 5(3), 50-59.

Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. (2015). A revised Self- and Family Management Framework. *Nursing Outlook*, 63, 162-170.

Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self and family management of chronic conditions. *Nursing Outlook*, 54, 278-286.

Griffin, D., & Gonzalez, R. (2003). Models of dyadic social interaction. *Philosophical Transactions of the Royal Society of London, Series B Biological Sciences*, 358(1431), 573-581.

Harman, J. J., & Amico, K. R. (2009). The relationship-oriented information-motivation-behavioral skills model: A multilevel structural equation model among dyads. *AIDS and Behavior*, 13(2), 173-184.

Knafl, K., Deatrick, J., & Gallo, A. (2008). The interplay of concepts, data, and methods in the development of the Family Management Style Framework. *Journal of Family Nursing*, 14, 412-428.

Knafl, K., Deatrick, J., & Havill, N. (2012). Continued development of the Family Management Style Framework. *Journal of Family Nursing*, 18(1), 11-34.

Knafl, K., Darney, B., Gallo, A., Angst, D. (2010). Parental perceptions of the outcome and meaning of normalization. *Research in Nursing & Health*, 33, 87-98.

Knafl, K., & Deatrick, J. (2003). Further refinement of the family management style framework. *Journal of Family Nursing*, 9, 232-256.

Larsen, A., & Olson, D. H. (1990). Capturing the complexity of family systems: Integrating family theory, family scores, and family analysis. In T.W. Drape & A. Marcos (Eds.), *Family variables: Conceptualization measurement, and use* (pp. 19-47). Newbury Park, CA.: Sage.

Lingler, J. H., Sherwood, P. R., Crighton, M. H., Song, M. K., & Happ, M. B. (2008). Conceptual challenges in the study of caregiver-care recipient relationships. *Nursing Research*, 57(5), 367-372.

Moore, G., & Neiderhiser, J. 2014. Behavioral genetic approaches and family theory. *Journal of Family Theory & Review*, 6, 18-30.

Park, M., & Chesla, C. (2007). Revisiting Confucianism as a conceptual framework for Asian family study. *Journal of Family Nursing*, 13, 293-311.

Radina, M. (2013). Toward a theory of health-related family quality of life. *Journal of Family Theory & Review*, 5, 35-50.

Rolland, J. (1999). Parental illness and disability: A family systems framework. *Jnl of Family Therapy*, 21, 242-266.

Rosa, E., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: It's evolution from ecology to bio-ecology. *Journal of Family Theory & Review*, 5, 243-258.

Rungreangkulkij, S., & Gilliss, C. (2000). Conceptual approaches to studying family caregiving for persons with severe mental illness. *Journal of Family Nursing*, 6, 341-366.

Ryan, P., & Sawin, K. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57, 217-225.

Saxena, M., & Adamsons, K. (2013). Siblings of individuals with disabilities: Reframing the literature through a bioecological lens. *Journal of Family Theory & Review*, 5, 300-316.

Song, M., Sandelowski, M., & Happ, M. (2010). Current practices and emerging trends in conducting mixed methods intervention studies in the health sciences. In A.Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social & behavioral research* (pp. 725-747). Thousand Oaks, CA: Sage.

Van Riper, M. (2010). Genomics and the family: Integrative frameworks. In K.P. Tercyak (Ed.), *Handbook of genomics and the family* (pp. 109-139). New York, NY: Springer.

White, J. M., & Klein, D. M. (2015). *Family theories* (4th Ed.). Thousand Oaks, CA: Sage.

General Design Issues in Family Research

Botkin, J. (2001). Protecting the privacy of family members in survey and pedigree research. *Journal of the American Medical Association*, 285, 207-211.

Chesla, C., & Rungreangkulkij, S. (2001). Nursing research on family processes in chronic illness in ethnically diverse families: A decade review. *Journal of Family Nursing*, 7, 230-243.

Feetham, S. (1991). Conceptual and methodological issues in research of families. In A. Whall & J. Fawcett, *Family theory development in nursing: State of the science and art*, (pp. 55-68). Philadelphia, PA: F.A. Davis.

Deatrick, J. A., Hobbie, W., Ogle, S., Fisher, M. J., Barakat, L., Hardie, T., Reilly, M., Li, Y., & Ginsberg, J. P. (2014). Competence in caregivers of adolescent and young adult childhood brain tumor survivors. *Health Psychology*, 33(10), 1103-1112.

Greenstein, 2001, *Methods of Family Research*. Thousand Oaks, CA: Sage.

Hadley, E.K., Smith, C.A.M., Gallo, A.M., Angst, D.B., & Knafl, K.A. (2008). Parents' perspectives on having their children interviewed for research. *Research in Nursing & Health*, 31, 4-11.

Horowitz, J.A., Ladden, M.D., & Moriarty, H.J. (2002). Methodological challenges in research with vulnerable families. *Journal of Family Nursing* 8 (4), 315-333.

Hull, S., Glanz, K., Steffen, A., & Wilford, B. (2004). *Ethics and Human Research*, 26, 12-18.

Lynn, M.R. (1995). Family research: Consideration of who to study. *Journal of Pediatric Nursing*, 10, 383-384.

Mandara, J. (2003). The typological approach in child and family psychology: A review of theory, method, and research. *Clinical Child and Family Psychology Review*, 6(2), 129-146.

McCann, J.J., Hebert, L.E., Beckett, L.A., Morris, M.C., Scherr, P.A., & Evans, D.A. (2000). Comparison of informal caregiving by black and white older adults in a community population. *Journal of the American Geriatrics Society*, 48, 1612-1617.

Nelson, M. (2013). Fictive kin, families we choose and voluntary kin: What does the discourse tell us? *Journal of Family Theory & Review*, 5, 259-281.

Niska, K., Synder, M., & Lia-Hoagberg, B. (1999). The meaning of family health among Mexican-American first-time mothers and fathers. *Journal of Family Nursing* 5(2), 218-233.

Racher, F.E., Kaufert, J.M., & Havens, B. (2000). Conjoint research interviews with frail, elderly couples: Methodological implications. *Journal of Family Nursing* 6(4), 367-379.

Uphold, C., & Strickland, O. (1989). Issues related to the unit of analysis in family research, *Western Journal of Nursing*, 11, 405-417.

Qualitative & Mixed Methods Family Research

Abma, T., & Stake, R. (2014). Science of the particular: An advocacy of naturalistic case study in health research. *Qualitative Health Research*, 24, 1150-1161.

Ayres, L., Kavanaugh, K., & Knafl, K. (2003). Within and across-case approaches to qualitative data analysis. *Journal of Qualitative Health Research*, 13, 871-883.

Bell, L., Paul, D., St-Cyr Tribble, D., & Goulet, C. (2000). Strategies to elicit and analyze relational family data. *Journal of Family Nursing* 6(4), 380-399.

Conger, R.D., Brainerd, D.W., Birch, L.L., Friedberg, P.J., & Navarro, L.A. (1986). Assessing the quality of family observations: A comparative analysis. *Journal of Marriage and the Family* 48, 361-373.

Coyer, S., & Gallo, A. (2005). Secondary analysis of data. *Journal of Pediatric Health Care, 19*, 60-63.

Creswell, et al., (2011). Best Practices for Mixed Methods Research in the Health Sciences. Commissioned and published by the Office of Behavioral and Social Science Research, Washington, D.C.

Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research, 20*, 1642-1655.

Fiese, B.H., & Spagnola, M. (2005). Narratives in and about families: An examination of coding schemes and a guide for family researchers. *Journal of Family Psychology, 1*, 51-61.

Fiese, B.H., & Wamboldt, F.S. (2003). Coherent accounts of coping with a chronic illness: Convergence and divergence in family measurement using narrative analysis. *Family Process, 42*, 3-15.

Gilgun, J. (2005). Qualitative research and family psychology. *Journal of Family Psychology, 19*, 40-50.

Gilgun, J. (2004). Deductive qualitative analysis and family theory-building. In V. Bengtson, P. Dillworth-Anderson, K. Allen, A. Acock, & D. Klein (Eds.). *Sourcebook of family theory and research* (pp. 83-85). Thousand Oaks, CA: Sage.

Gilgun, J. (1999). Methodological pluralism and qualitative family research. In S.K. Steinmetz, M.B. Sussman, & G.W. Peterson (Eds.). *Handbook of marriage and the family* (2nd ed., pp. 219-261). New York, NY: Plenum Press.

Harden, J., Backett-Milburn, K., Hill, M., & MacLean, A. (2010). Oh, what a tangled web we weave: Experiences of doing 'multiple perspectives' research in families. *International Journal of Social Research Methodology, 13*, 441-452.

Harden, J.K., Northouse, L.L., & Mood, D.W. (2006). Qualitative analysis of couples' experience

with prostate cancer by age cohort. *Cancer Nursing, 29*(5), 367-377.

Humble, A. (2012). Qualitative data analysis software: A call for understanding, detail, intentionality, and thoughtfulness. *Journal of Family Theory & Review, 4*, 122-137.

Knafl, K., & Ayres, L. (1996). Managing large qualitative data sets in family research. *Journal of Family Nursing, 2*, 350-364.

Knafl, K., & Deatrick, J. (2006). Family management style and the challenge of moving from conceptualization to measurement. *Journal of the Association of Pediatric Oncology Nurses, 23*, 12-18.

Leech, N., & Onwuegbuzie, A. (2009). A typology of mixed methods research designs. *Quality and Quantity, 43*, 265-275. Morse, J., Chapter 7 "Principles of Mixed Methods and Multimethod Research Design" Creswell, et. al, Chapter 8 "Advanced Mixed Methods Research Designs"

O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *British Medical Journal, September 17*.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*, 77-84. Sandelowski, M. (1995). What it is and how to begin. *Research in Nursing & Health, 18*, 371-375.

Quantitative Family Research

Bartle-Haring, S., Kenney, D., & Gavazzi, S. (1999). Multiple perspectives on family differentiation: Analyses by multitrait-multimethod matrix and triadic social relations model. *Journal of Marriage and the Family 61*, 491-503.

Campbell, L., & Kashy, D. (2002). Estimating actor, partner, and interaction effects for dyadic data using

PROC MIXED and HLM: A user-friendly guide. *Personal Relationships, 9*(3), 327.

Chang, A., & Kelly, P. (2011). Application of a hierarchical model incorporating intrafamilial correlation and cluster effects. *Nursing Research, 60*, 208-212.

Clarke, S.P. (1995). Methodological commentary: Characteristics of families--implications for statistical analysis in family nursing research. *Canadian Journal of Nursing Research 27*(1), 47-55.

Cook, W.L., & Kenny, D.A. (2006). Examining the validity of self-report assessments of family functioning: A question of the level of analysis. *Journal of Family Psychology, 20*(2), 209-216.

Cook, W., & Kenny, D. (2005). The Actor-partner interdependence model: A model of bidirectional effects in developmental studies. *International Journal of Behavioral Development, 29*(2), 101.

Cook, W.L. (1994). A structural equation model of dyadic relationships within the family system. *Journal of Consulting and Clinical Psychology, 62*(3), 500-509.

Davis, L.L. (1993). Family scores revisited--a comparison of three approaches to data aggregation. *Western Journal of Nursing Research 15*(5), 649-657.

Deal, J.E. (1995). Utilizing data from multiple family members: A within-family approach. *Journal of Marriage and the Family 57*, 1109-1121.

Deal, J.E., & Anderson, E.R. (1995). Reporting and interpreting results in family research. *Journal of Marriage and the Family, 57*, 1040-1048.

Dick, D.M., Johnson, J.K., Viken, R.J., & Rose, R.J. (2000). Testing between-family associations in within-family comparisons. *Psychological Sciences 11*(5), 409-413.

Feetham, S.L., Perkins, M., & Carroll, R. (1993). Exploratory analysis: A technique for the analysis of dyadic data in research of families. In S. Feetham, S. Meister, J. Bell, & C. Gilliss (Eds.). *The nursing of families* (pp. 99-110). Newbury Park, CA: Sage.

Ferketich, S., & Mercer, R.T. (2002). Focus on psychometrics in aggregating family data. *Research in Nursing & Health* 15, 313-317.

Fisher, L., Kokes, R., Ransom, D.C., Phillips, S.L., & Rudd, P. (1985). Alternative strategies for creating "relational" family data. *Family Process* 24(2), 213-224.

Hofferth, S. & Caspar, L. (Eds). (2007). *Handbook of measurement issues in family research*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Jacobsen, B.S., Tulman, L., & Lowery, B.J. (1991). Three sides of the same coin: The analysis of paired data from dyads. *Nursing Research*, 40(6), 359-363.

Johnson, D.R. (1995). Alternative methods for the quantitative analysis of panel data in family research: Pooled time-series models. *Journal of Marriage and the Family*, 57, 1065-1077.

Kashy, D.A., & Snyder, D.K. (1995). Measurement and data analytic issues in couples's research. *Psychological Assessment*, 7(3), 338-348.

Kenny, D., Kashy, D., & Cook, W. (2006). *Dyadic data analysis*: New York, NY: Guilford Press.

Knafl, G., Dixon, J., O'Malley, J., Grey, M., Deatrick, J., Gallo, A., Knafl, K. (2009). Analysis of cross-sectional univariate measurements for family dyads using linear mixed modeling. *Journal of Family Nursing*, 15, 130-151.

Knafl, G., Knafl, K., & McCorkle, R. (2005). Mixed models incorporating intra-familial correlation through spatial autoregression. *Research in Nursing & Health*, 28, 348-356.

Lynn, M.R. (1995). Family research: Consideration of who to study. *Journal of Pediatric Nursing*, 10, 383-384.

Lyons, K.S., & Sayer, A.G. (2005). Longitudinal dyad models in family research. *Journal of Marriage and the Family*, 67(4), 1048-1060.

Maguire, M.C. (1999). Treating the dyad as the unit of analysis: A primer on three analytic approaches. *Journal of Marriage and the Family* 61(1), 213-223.

Maguire, M. (1999). Treating the dyad as the unit of analysis: A primer on three analytic approaches. *Journal of Marriage and the Family*, 61, 213-233.

Olsen, J.A., & Kenny, D.A. (2006). Structural equation modeling with interchangeable dyads. *Psychological Methods*, 1(2), 127-141.

Rayens, M.K., & Svavarsdottir, E.K. (2003). A new methodological approach in nursing research: An actor, partner, and interaction effect model for family outcomes. *Research in Nursing and Health*, 26(5), 409-419.

Szinovacz, M.E., & Egley, L.C. (1995). Comparing one-partner and couple data on sensitive marital behaviors: The case of marital violence. *Journal of Marriage and the Family*, 57, 995-1010.

Teachman, J.D., Carver, K., & Day, R. (1995). A model for the analysis of paired data. *Journal of Marriage and the Family*, 57, 1011-1024.

Thompson, L., & Walker, A.J. (1982). The dyad as the unit of analysis: Conceptual and methodological issues. *Journal of Marriage and the Family*, 44(4), 889-900. (a classic paper)

Thomson, E., & Williams, R. (1982). Beyond wives' family sociology: A method for analyzing couple data. *Journal of Marriage and the Family*, 44(4), 999-1008.

Uphold, C.R., & Strickland, O.L. (1989). Issues related to the unit of analysis in family nursing

research. *Western Journal of Nursing Research*, 11(4), 405-417.

West, T.V., Popp, D., & Kenny, D.A. (2008). A guide for the estimation of gender and sexual orientation effects in dyadic data: An actor-partner interdependence model approach. *Personality and Social Psychology Bulletin*, 34(3), 321-336.

Wickrama, K.A.S., Lorenz, F.O., Conger, R.D., & Elder, G.H. (1997). Marital quality and physical illness: A latent growth curve analysis. *Journal of Marriage and the Family* 59, 143-155.

Measurement of Family Variables

Alderfer, M.A., Fiese, B.H., Gold, J.I., Cutuli, J.J., Holmbeck, G.N., Goldbeck, L., Chambers, C.T., Abad, M., Spetter, D., & Patterson, J. (2008). Evidence-based assessment in pediatric psychology: Family measures. *Journal of Pediatric Psychology*, 33, 1046-1061.

DeVellis, R. (2012). *Scale development: Theory and applications* (3rd ed.). Sage: Thousand Oaks.

Ganong, L. (2003). Selecting family measurements. *Journal of Family Nursing*, 9, 184-206.

Knafl, K., Deatrick, J., Gallo, A., Dixon, J., Grey, M., Knafl, G., O'Malley, J. (2011). Assessment of the psychometric properties of the Family Management Measure. *Journal of Pediatric Psychology*, 36, 494-505.

Knafl, K., Deatrick, J., Gallo, A., Holcombe, G., Bakitas, M., Dixon, J., & Grey, M. (2007). The analysis and interpretation of cognitive interview for instrument development. *Research in Nursing & Health*, 30, 224-234.

Knafl, K., & Deatrick, J. (2006). Family management style and the challenge of moving from conceptualization to measurement. *Journal of Pediatric Oncology Nursing*, 23, 12-18.

Lou, H., Birthe, D., Pedersen, D., & Hedegaard, M. (2009). Questions never asked. Positive family outcomes of extremely premature childbirth. *Quality of Life Research*, 18, 567-573.

Neabel, B., Fothergill-Bourbonnais, F., & Dunning J. (2000). Issues in family care. Family assessment tools: A review of the literature. *Heart and Lung: Journal of Acute & Critical Care*, 29, 196-209.

Song, M., & Deatrick, J. 35, A review of diabetes-specific family assessment instruments. *Western Journal of Nursing Research*, 35, 405-433.

Intervention Research with Families

Berry, D., Sheehan, R., Heschel, R., Knafl, K., Melkus, G., & Grey, M. (2004). Family-based interventions for childhood obesity: A review. *Journal of Family Nursing*, 10, 429-449.

Burke, S. (2001). Effects of stress-point intervention with families of repeatedly hospitalized children. *Journal of Family Nursing*, 7, 128-158.

Carr, A., (2009). The effectiveness of family therapy and systemic interventions for child-focused problems. *Journal of Family Therapy*, 31, 3-45.

Chesla, C.A. (2010). Do family interventions improve health? *Journal of Family Nursing*, 16(4), 355-377.

Eccleston, C., Palermo, T., Fisher, E., Law E. (2012). Psychological interventions for parents of children with chronic illness (review). *Cochrane Review*, 8, 1-139.

Eustace, R. (2013). A discussion of HIV? AIDS family interventions: Implications for family-focused nursing practice. *Journal of Advanced Nursing*, 69, 1660-1672.

Eustace, R., Gray, B., & Curry, D. (2015). Family nursing intervention: What do acute care nurses think? *Research and Theory for Nursing Practice: An International Journal*, 29, 125-142.

Fisher, L. & Weihs, K. (2000). Can addressing family relationships improve outcomes in chronic disease? *The Journal of Family Practice*, 49, 561-566.

Kazak, A., (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology*, 39, 29-39.

Knafl, K., Havill, N., Leeman, J., Fleming, L., Crandell, J., & Sandelowski, M. (in press). The Nature of Family Engagement in Interventions for Children with Chronic Conditions. *Western Journal of Nursing Research*.

Lauver, D.R., Ward, S.E., Heidrich, S.M., Keller, M.L., Bowers, B.J., Brennan, P.F., Kirchhoff, K.T., & Wells, T.J. (2002). Patient-centered interventions. *Research in Nursing & Health*, 25(4), 246-255.

Martire, L., Lustig, A., Schulz, R., Miller, G., & Helgeson, V. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology*, 23, 599-611.

Martire, L., Schulz, R., Helgeson, V., Small, B., Saghafi, E. (2010). Review and meta-analysis of couple-oriented interventions for chronic illness. *Annals of Behavioral Medicine*, 40, 325-342.

McBroom, L.A., & Enriquez, M. (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator*, 35, 428-38.

Robinson, C.A., & Wright, L.M. (1995). Family nursing interventions: What families say makes a difference. *Journal of Family Nursing*, 1, 327-345.

Savage, E., Farrell, D., McManus, V., & Grey, M. (2010). The science of intervention development for type 1 diabetes in childhood. *Journal of Advanced Nursing*, 66, 2604-2619.

Swallow, V., Knafl, K., Santacroce, S., Hall, A., Smith T., Campbell, M., & Webb, N. (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*, 68, 2095-2102.

Research Reports of Family and Dyadic Studies

Alderfer, M., Canaan, A., Annunziato, R., Kazak, A. (2005). Patterns of posttraumatic stress symptoms in parents of childhood cancer survivors. *Journal of Family Psychology*, 19, 430-440.

Ariedu, G., Eustace, R., Eton, D., Breitkopf, C. (2014). Coping with colorectal cancer: A qualitative exploration with patients and their family members. *Family Practice*, 31, 598-606.

Barakat, L.P., Li, Y., Hobbie, W., Ogle, S., Hardie, T., Volpe, E.M., Szabo, M.M., Reilly, M., &

Deatrick, J. (2015). Health-related quality of life of adolescents and young adult survivors of childhood brain tumors. *Psycho-Oncology*, 24, 804-811.

Barakat, L.P., Patterson, C.A., Weinberger, B.S., Simon, K., Gonzalez, E.R., & Dampier, C. (2007). A prospective study of the role of coping and family functioning in health outcomes for adolescents with sickle cell disease. *Journal of Pediatric Hematology / Oncology*, 29, 752-760.

Beardslee, W.R., Gladstone, T.R.G., Wright, E.J., & Cooper, A.B. (2003). A family-based approach to the prevention of depressive symptoms in children at risk: Evidence of parental and child change. *Pediatrics*, 112, 119-131.

Butler, F., & Zakari, N. (2005). Grandparents parenting grandchildren: Assessing health parental stress, and social supports. *Journal of Gerontological Nursing*, 31, 43-54.

Conger, R.D., Brainerd, D.W., Birch, L.L., Friedberg, P.J., & Navarro, L.A. (1986). Assessing the quality of family observations: A comparative analysis. *Journal of Marriage and the Family* 48, 361-373.

Deatrick, J. A., Hobbie, W., Ogle, S., Fisher, M. J., Barakat, L., Hardie, T., Reilly, M., Li, Y., & Ginsberg, J. P. (2014). Competence in caregivers of adolescent and young adult childhood brain tumor survivors. *Health Psychology, 33*, 1103-1112.

Ford-Gilboe, M. (1997). Family strengths, motivation and resources as predictors of health promotion behavior in single-parent and two-parent families. *Research in Nursing and Health, 20*, 205-217.

Gallo, A., Knafl, K., & Angst, D. (2009). Information management in families who have a child with a genetic condition. *Journal of Pediatric Nursing, 24*, 194-204.

Gibson_Yping, L., Turner_Henson, A., Gerald, L., Vance, D., & Lozano, D. (2014). The relationship among family management behaviors and asthma morbidity in maternal caregivers of children with asthma. *Journal of Family Nursing, 20*, 442-461.

Glackin, M., & Higgins, A. (2008). The grief experience of same-sex couple within an Irish context: Tacit acknowledgement. *International Journal of Palliative Nursing, 14*, 297-302.

Harden, J., Northouse, L., & Mood, D. (2006). Qualitative analysis of couples' experience with prostate cancer by age cohort. *Cancer Nursing, 29*, 367-377.

Hilliard, M., Holmes, C., Chen, R., Maher, K., Robinson, E., & Streisand, R. (2013). Disentangling the roles of parental monitoring and family conflicts in adolescents' management of type 1 diabetes. *Health Psychology, 32*, 388-396.

Horner, S. (2015). An exploration of parent-child dyadic asthma management influences on quality of life. *Issues in Comprehensive Pediatric Nursing, 38*, 85-104.

Kavanaugh, K., Savage, T., Kilpatrick, S., Kimura, R., & Hershberger, P. (2005). Life support decisions

for extremely premature infants: Report of a pilot study. *Journal of Pediatric Nursing, 20*, 347-359

Knafl, K., Knafl, G., Gallo, A., & Angst, D. (2007). Parents' perceptions of functioning in families having a child with a genetic condition. *Journal of Genetic Counseling, 16*, 481-492.

Knafl, K., Deatrick, J., Knafl, G., Gallo, A., Grey, M., & Dixon, J. (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing, 28*, 523-535.

Larsen, H. B., Heilmann, C., Johansen, C., & Adamsen, L. (2011). An analysis of parental roles during haematopoietic stem cell transplantation of their offspring: A qualitative and participant observational study. *Journal of Advanced Nursing, 67*, 1458-1467.

Meeker, M. A. (2004). Family surrogate decision making at the end of life: Seeing them through with care and respect. *Qualitative Health Research, 14*(2), 204-225

Lewis, S., Kagan, C., Heaton, P. (2000). Dual earner parents with disable children. *Journal of Family Issues, 21*, 10-31-1060.

Lyons, K., Zarit, S., Sayer, A., & Whitlach, C. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver.

Mandara, J. & Murray, C. (2002). Development of an empirical typology of African American family functioning. *Journal of Family Psychology, 16*, 318-337.

Mills-Koonce, W. R., Propper, C. B., Garipey, J. L., Blair, C., Garrett-Peters, P., & Cox, M. J. (2007). Bidirectional genetic and environmental influences on mother and child behavior: The family system as the unit of analyses. *Development and Psychopathology, 19*, 1073-1087.

Ozono, S., Saeki, T., Inoue, S., Mantani, T., Okamura, H., & Yamawaki, S. (2005). Family

functioning and psychological distress among Japanese breast cancer patients and families. *Supportive Care in Cancer, 13*(12), 1044-1050.

Pruchno, R., Wilson-Anderson, M., & Cartwright, F., (2009). Depressive symptoms and marital satisfaction in the context of chronic disease: A longitudinal dyadic analysis. *Journal of Family Psychology, 23*, 573-584.

Rehm, R., & Bradley, J. (2005). Normalization in families raising a child who is medically fragile/technology-dependent and developmentally delayed. *Qualitative Health Research, 15*, 807-820.

Robinson, C., Pesut, B., & Botorff, J. (2012). Supporting rural family palliative caregivers. *Journal of Family Nursing, 18*, 467-490.

Segaric, C., & Hall, W. (2015). Progressively engaging: Constructing nurse, patient, and family relationship in acute care settings. *Journal of Family Nursing, 21*, 35-56.

Stubblefield, C., & Murray, R. L. (2000). Making the transition: Pediatric lung transplantation. *Journal of Pediatric Healthcare, 14*(6), 280-287.

Timmermans, S., & Freidin, B. (2007). Caretaking as articulation work: The effects of taking up responsibility for a child with asthma on labor force participation. *Social Science & Medicine, 65*, 1351-1363.

Weine, S., Muzurovic, N., Kulauzovic, Y., Besic, S., Lezic, A., Mujagic, A., Muzurovic, J., Spahovic, D., Feetham, S., Ware, N., Knafl, K., & Pavkovic, I. (2004). Family consequences of refugee trauma. *Family Process, 43*, 147-160.

Weine, S., Knafl, K., Feetham, S., Kulauzovic, Y., Klebic, A., Selove, S., Besic, S., Mujagic, A., Muzurovic, J., Spahovic, D. (2005). A mixed-method study of refugee families engaging in multiple-family groups. *Family Relations, 54*, 558-568.

Williams, B., Mukhopadhyay, S., Dowell, J., & Coyle, J. (2007). From child to adult: An exploration

of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis. *Social Science & Medicine*, 65, 2135–2146.

Zhang, Y., Wei, M., Shen, N., Zhang, Y. (2015). Identifying factors related to family management during the coping process of family with childhood chronic conditions: A multi-site study. *Journal of Pediatric Nursing*, 30, 160–173.

Family Synthesis Research

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19–32.

Chesla, C. (2010). Do family interventions improve health? *Journal of Family Nursing*, 16, 355–377.

Cooper, H. (2010). *Research synthesis and meta-analysis: A step-by-step approach* (4th ed.). Sage, Thousand Oaks, CA.

Colquhoun, H., Levac, D., O'Brien, K., Straus, S., Tricco, A., Perrier, L., & Moher, D. (2014). Scoping reviews: Time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology*, 67, 1291–1294.

Crandell, J., Voils, C., & Sandelowski M. (2012). Bayesian approaches to the synthesis of qualitative and quantitative research findings. In *Synthesizing qualitative research: Choosing the right approach* (Hannes, K. & Lockwood, C. eds.), Wiley-Blackwell, Oxford, UK, pp. 137–159.

Davidson, K., Goldstein, M., Kaufmann, P., Knatterus, G., O'Leary, C., Spring, B., Trudeau, K., Whitlock, E. (2003). Evidence-based behavioral medicine: What is it and how do we achieve it? *Annals of Behavioral Medicine*, 26 (3), 161–171.

Egan, M., Bamba, C., Pettiere, M., & Whitehead, M. (2009) Reviewing evidence on complex social interventions: Appraising implementation in systematic reviews of the health effects of

organizational-level workplace interventions. *Journal of Epidemiology & Community Health* 63, 4–11.

Foster, M., Whitehead, L., & Maybee, P. (2016). The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centered case within a pediatric critical care setting: A synthesis of quantitative research. *Journal of Family Nursing*, 22, 6–73.

Gough, D., Thomas, J., & Oliver, S. (2012). Clarifying differences between review designs and methods. *Systematic Reviews*, 1:28. <http://systematicreviewjournal.com/content/1/1/28>

Herzer, M., Godwala, N., Hommel, K., Driscoll, K., Mitchell, M., Crosby, L., Modi, A. (2010). Family functioning in the context of pediatric chronic conditions. *Journal of Developmental and Behavioral Pediatrics*, 31, 26–34.

Higgins J. & Green, S. (2008). *Cochrane handbook for systematic reviews of interventions*. John Wiley & Sons, Hoboken, N.J. Holmbeck, G., Greenley, R., Coakley, R., Greco, J., & Hagstrom, J. (2006). Family functioning in children and adolescents with spina bifida: An evidence-based review of research and interventions. *Developmental and Behavioral Pediatrics*, 27, 249–277.

Martire, L., Lustig, A., Schulz, R., Miller, G., & Helgeson, V. (2004). Is it beneficial to involve a family member? A meta-analysis of psychoeducational interventions for chronic illness. *Health Psychology*, 23, 599–611.

Pawson, R., *Evidence-based policy: A realist perspective*. 2006, Thousand Oaks, CA: Sage.

Pope, C., Mays, N., & Popay, J. (2007). *Synthesizing qualitative and quantitative health evidence*. Open University Press, Berkshire, UK.

Sandelowski, M., Leeman, J., Knaf, K., & Crandell, J. (2013). Text-in-Context: A method for extracting findings in mixed-methods research synthesis studies. *Journal of Advanced Nursing*, 69, 1428–37.

Sandelowski, M. (2008). Reading, writing, and systematic review. *Journal of Advanced Nursing* 64, 104–110.

Sandelowski, M. & Barroso, J. (2007) *Handbook for synthesizing qualitative research*. Springer, New York, NY.

Wilkins, K. & Woodgate, R. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them voice. *Journal of Pediatric Oncology Nursing*, 22, 305–319.

F o s t e r i n g a n d s u s t a i n i n g U K , m u l t i d i s c i p l i n a r y , f a m i l y - f o c u s e d c a r e a c r o s s t h e l i f e - c o u r s e :

A W h i t e R o s e c o l l a b o r a t i o n i n l o n g - t e r m c o n d i t i o n m a n a g e m e n t

A p r i l 2 0 1 7

