

Support for children and their families when a parent is seriously ill or injured- a review of research

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Presentation content



- Children as next of kin – a Swedish national project
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Children as next of kin

- Implementation of UNCRC within the Swedish Health Care Act, from 2010.
- Professionals are made responsible to address the needs of children under 18 years of age, to make sure they receive information, advice and support when a parent has a serious physical illness or injury, a mental disorder or psychiatric disability, abuses alcohol or other drugs, or dies.
- The Swedish National Board of Health and Welfare instigated a national project to implement the new law entitled "Children as next of kin"

Children as next of kin

- Linnaeus University and Swedish Family Care Competence Centre responsible for the project.
- Overall aim is to establish a knowledge base to support children as next of kin, and to educate health and social care staff, NGOs and families about support available.
- The area of the least research: When a parent has a serious physical illness or injury, or even disability.
- Studies of official registers, How many? How are they? (Hjern et al 2012)

Aim

- To conduct a systematic review of published research to identify support interventions for children and their parents when a parent suffer from physical illness or injury.
- Lack of material in an initial literature search; a scoping review with two broad aims:
- To summarize and disseminate the research finding concerning support interventions
- To identify gaps and promising innovative approaches in existing research

Consequences for children

- Consequences depend on welfare structures, social support, characteristics of the family, the parent's illness and the child's ability to adjust and cope.
- Research show an ambiguous picture about whether children are at risk for long-term negative consequences.
- Children when a parent has cancer; insomnia anxiety, headaches and symptoms of depression (Visser et al 2005)
- No increase in children's externalisation of problems or in their ability to interact socially (Krattenmacher 2012)
- No long-term consequences for adolescent (Jantzer et al. 2013)
- A study of children's school results show a small but significant negative effect (Hjern et al 2014).

Difficulties for children and their families:

- A progressive or unpredictable illness or disability (Ireland & Pakenham 2010)
- Young children have less social network of their own (Visser et al. 2005)
- Lone parent families,
- Children assuming significant care responsibilities- Young carers (Becker 2007, Banks et al 2001)
- Economic pressures (Coles et al. 2007)
- Lack of information for children; keep their worries from parents (Bogosian et al. 2010)

Method

Inclusion criteria: Interventions for children 1-18 years and/or their parents. Include outcome measures for children and not just for parents.

Outcome measures might vary, measures at base-line and after (pre-post test)

Exclusion criteria: Interventions for children and parents when a parent is in terminal care. This is covered in Bergman & Hanson 2014.

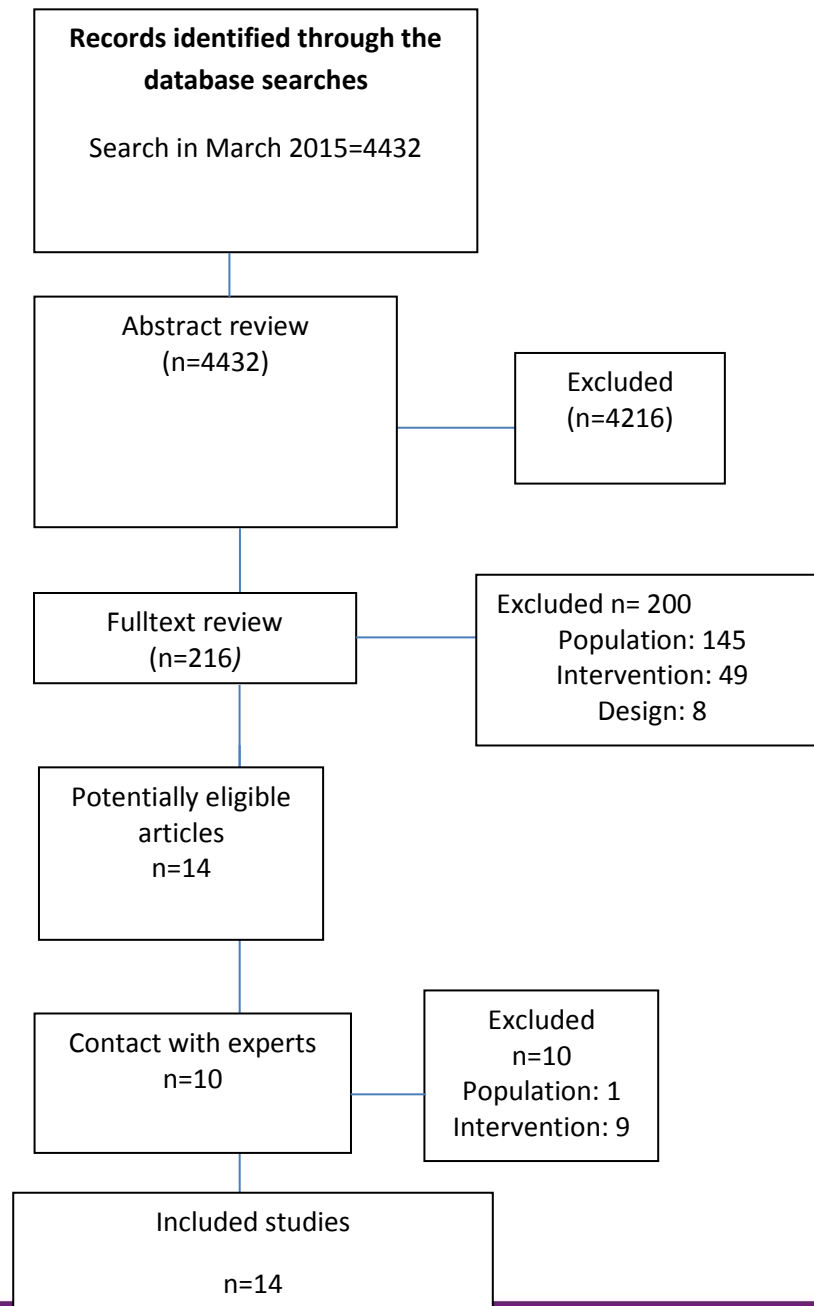


Figure 1. Overview of searches and selection of studies

Overview of included studies

	Study and Origin	Physical illness	Design	Sample (children)	Intervention	Outcome measure and results
Camp, convalescent interventions						
	(Coles et al., 2007) Australia	Multiple sclerosis	Pre- and posttest, Follow up 1 month	9-14 years n=20	Fun in the Sun Camp , 6 days, child sessions 1-2 hour/day Manualized Provided by a team of psychologist and occupational therapist	Children's reports: + Stress appraisal + Knowledge of MS + Social support + Adjustment + Caregiving impact 0 Coping strategies 0 Family functioning
	(John et al. 2013) Germany	Breast cancer	Pre-post design follow up 3- and 12 month	3-14 years n=116	Getting Well Together , 3 weeks Child sessions and mothers' sessions Manualized	Children's reports: + Psychological health + Emotional symptoms

	<p>(Davey et al., 2012) USA</p>	<p>Cancer</p>	<p>Quasi - experimental</p>	<p>School age n= 12 n= 7 experimental group n= 5 control group</p>	<p>Culturally adapted family intervention 3 child session of 90 minutes, 2 family meetings Manualized</p>	<p>Children's reports: 0 Depression 0 Anxiety + Communication with parent</p>
	<p>(Lewis et al., 2015) USA</p>	<p>Breast cancer</p>	<p>RCT</p>	<p>8-12 year N=213 Experimental group N=109 Control group N=104</p>	<p>The Enhancing Connections Program, 5 educational counselling meetings with mothers, exercise book for children Study protocol</p>	<p>Children's reports: + Behavioral-emotional adjustment + Depression 0 Anxiety</p>
	<p>(Thastum et al., 2006) Denmark</p>	<p>Cancer</p>	<p>Quasi- Experimental</p>	<p>8-15 year n=34 n=21 experimental group n= 13 control</p>	<p>Family therapy counselling, 5-6 family meetings, 1 hour No manual</p>	<p>Childrens's report: + Depression 0 Relationship parent-child 0 Health related quality of life</p>
	<p>(Murphy et al., 2011) USA</p>	<p>HIV</p>	<p>RCT, Follow up at 3-6-9 month</p>	<p>6-12 years n=80 n= 39 experimental group n=41 control group</p>	<p>Teaching, Raising and Communicating with Kids (TRACK), 3 counselling mother session Manualised unknown Provided by counsellor</p>	<p>Children's reports: + Depression + Self-concept + Parent-child attachment + Family cohesion</p>

Risk prevention, comprehensive long-term intervention

<p>(Rotheram-Borus et al., 2001) USA</p>	<p>HIV</p>	<p>RCT Follow up every third month- 24 months</p>	<p>11-18 years n=412 n=205 Experimental group n=207 control group</p>	<p>Project Teens and Adults Learning to Communicate (TALC) 16 group sessions for children, 5-8 sessions for mothers, mother and child group sessions, up to 2 hours Manualised Provided by social worker or psychologist</p>	<p>Children's reports: + Emotional distress + Anxiety + Self-esteem + Problem behavior + Stressful family event</p>
<p>(Rotheram-Borus et al., 2004) USA</p>		<p>RCT Follow up at 6-years</p>	<p>n=423 m=20,9 age n=212 experimental group n=211 control group</p>		<p>Children's reports: + Employment + School attendance + Dependent on public welfare + Conflict solving + Personal expectations + Somatic symptoms</p>
<p>(Rotheram-Borus et al., 2012) USA</p>		<p>RCT Every third month up to 24 month</p>	<p>m= 15 age n=259 n=139 experimental group n=120 control group</p>	<p>TALC Los Angeles</p>	<p>Children's reports: 0 School attendance, 0 Grade level, 0 Conflicts 0 Family functioning 0 Depression</p>

Risk prevention, comprehensive long-term intervention

<p>(Mitrani et al., 2011) USA</p>	<p>HIV</p>	<p>RCT Follow up at 4,8,12 month</p>	<p>6-18 years N=42</p>	<p>Structural Ecosystem Therapy (SET) Meetings with mother and support person once a week for 4-8 months, duration varies Not manualized Provided by trained therapist</p>	<p>Children's reports: + Children's internalising behaviors + Children's externalizing behaviors + Parenting</p>
<p>(Li et al., 2014) China</p>	<p>HIV</p>	<p>RCT Follow up 3-6 months</p>	<p>6-18 years n= 79 n= 38 experimental group (6-12 years n=20, 13-18 years n=18), n=41 control group</p>	<p>Together for Empowerment Activities (TEA) 3 levels of activities: -6 TEA Gathering group sessions for parents -Tea Time 6 home-based activities including children -TEA Garden, 3 community events including children Manualised Provided by health educator</p>	<p>Children's reports: 6-12 year +Self-esteem 13-18 year 0 Self-esteem 6-12 year + Parental care 13-18 year + Parental care 6-12 year 0 Problem behavior 13-18 year 0 Problem behaviour</p>

Implications for research

Gap in research:

- Support in everyday life with serious illness or disability
- Outcome measures for children mainly measure internal outcomes; anxiety, depression
- Measure of school results or caregiving tasks, social support lacking
- Measures of internal outcomes use five different scales; Research would benefit from repeated use of the same scales.
- Younger children, adolescents or school-children, pre-school children are under-represented
- Studies from Scandinavia are few- evaluation of programmes

Implications for practice

- The interventions present differing scope and intensiveness
- All children need information- some need more comprehensive support
- Professionals may find inspiration to develop a variety of support interventions

- Lessons learned:
- Support that involve the extended network
- Support for parents to communicate with their children
- Children´s own speaking forum
- Ask children themselves- less optimistic than parents



Järkestig Berggren, Ulrika. & Elizabeth Hanson (Forthcoming)
Children as next of kin- a scoping review of support interventions for
children who have a parent with a serious physical illness, *Child Care in
Practice*



Thank you!

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