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
• Aim
• Method
• Results
• Implications for research
• Implication for practice
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

Records identified through the database searches
Search in March 2015: 4432

Abstract review (n=4432)

Excluded (n=4216)

Fulltext review (n=216)

Excluded n=200
Population: 145
Intervention: 49
Design: 8

Potentially eligible articles n=14

Contact with experts n=10

Excluded n=10
Population: 1
Intervention: 9

Included studies n=14
## Overview of included studies

<table>
<thead>
<tr>
<th>Study and Origin</th>
<th>Physical illness</th>
<th>Design</th>
<th>Sample (children)</th>
<th>Intervention</th>
<th>Outcome measure and results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Camp, convalescent interventions</strong></td>
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<tr>
<td>(Coles et al., 2007) Australia</td>
<td>Multiple sclerosis</td>
<td>Pre- and posttest, Follow up 1 month</td>
<td>9-14 years n=20</td>
<td>Fun in the Sun Camp, 6 days, child sessions 1-2 hour/day Manualized Provided by a team of psychologist and occupational therapist</td>
<td>Children’s reports: + Stress appraisal + Knowledge of MS + Social support + Adjustment + Caregiving impact 0 Coping strategies 0 Family functioning</td>
</tr>
<tr>
<td>(John et al. 2013) Germany</td>
<td>Breast cancer</td>
<td>Pre-post design follow up 3- and 12 month</td>
<td>3-14 years n=116</td>
<td>Getting Well Together, 3 weeks Child sessions and mothers’ sessions Manualized</td>
<td>Children’s reports: + Psychological health + Emotional symptoms</td>
</tr>
<tr>
<td>Study</td>
<td>Cancer</td>
<td>Quasi-experimental</td>
<td>School age</td>
<td>Culturally adapted family intervention</td>
<td>Children’s reports:</td>
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<tr>
<td>(Davey et al., 2012) USA</td>
<td>Cancer</td>
<td>Quasi-experimental</td>
<td>School age</td>
<td>3 child session of 90 minutes, 2 family meetings</td>
<td>0 Depression 0 Anxiety + Communication with parent</td>
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<tr>
<td>(Lewis et al., 2015) USA</td>
<td>Breast cancer</td>
<td>RCT</td>
<td>8-12 year</td>
<td>The Enhancing Connections Program, 5 educational counselling meetings with mothers, exercise book for children Study protocol</td>
<td>Children’s reports: + Behavioral-emotional adjustment + Depression 0 Anxiety</td>
</tr>
<tr>
<td>(Thastum et al., 2006) Denmark</td>
<td>Cancer</td>
<td>Quasi-Experimental</td>
<td>8-15 year</td>
<td>Family therapy counselling, 5-6 family meetings, 1 hour No manual</td>
<td>Children’s report: + Depression 0 Relationship parent-child 0 Health related quality of life</td>
</tr>
<tr>
<td>(Murphy et al., 2011) USA</td>
<td>HIV</td>
<td>RCT, Follow up at 3-6-9 month</td>
<td>6-12 years</td>
<td>Teaching, Raising and Communicating with Kids (TRACK), 3 counselling mother session Manualised unknown Provided by counsellor</td>
<td>Children’s reports: + Depression + Self-concept + Parent-child attachment + Family cohesion</td>
</tr>
<tr>
<td>Study</td>
<td>Region</td>
<td>Intervention</td>
<td>Follow-Up Schedule</td>
<td>Sample Size</td>
<td>Outcomes of Interest</td>
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<tr>
<td>(Rotheram-Borus et al., 2001) USA</td>
<td>HIV RCT</td>
<td>Follow up every third month- 24 months</td>
<td>11-18 years n=412 n=205</td>
<td>Experimental group n=207 control group</td>
<td>+ Emotional distress + Anxiety + Self-esteem + Problem behavior + Stressful family event</td>
</tr>
<tr>
<td>(Rotheram-Borus et al., 2004) USA</td>
<td>HIV RCT</td>
<td>Follow up at 6-years</td>
<td>n=423 m=20,9 age n=212 experimental group n=211 control group</td>
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<td>+ Employment + School attendance + Dependent on public welfare + Conflict solving + Personal expectations + Somatic symptoms</td>
</tr>
<tr>
<td>(Rotheram-Borus et al., 2012) USA</td>
<td>Project Teens and Adults Learning to Communicate (TALC)</td>
<td>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</td>
<td>TALC Los Angeles</td>
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<tr>
<td>Study</td>
<td>Location</td>
<td>Type</td>
<td>Follow up</td>
<td>Age</td>
<td>Intervention</td>
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<tr>
<td>(Mitrani et al., 2011)</td>
<td>USA</td>
<td>HIV</td>
<td>RCT</td>
<td>4, 8, 12 month</td>
<td>6-18 years</td>
</tr>
<tr>
<td>(Li et al., 2014)</td>
<td>China</td>
<td>HIV</td>
<td>RCT</td>
<td>3-6 months</td>
<td>6-18 years</td>
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</tbody>
</table>
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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