Involving children as next of kin in adult palliative care - a crucial challenge

RESEARCH GROUP

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BACKGROUND TO THE COUNTY COUNCIL PROJECT

Children of parents in need of palliative care are vulnerable and have an increased risk of ill health

Children have rights to receive information, advice and support

DEFINITIONS

Children

Age 0-17 years old

Next of kin

Someone close to the child, person that the child lives with or knows well, e.g. a neighbor, a close friend to the family

The child and its relative have a preferential right of interpretation of who counts as next of kin

In 2010, an addition to the Swedish Healthcare Act was introduced which declares that health services must consider a child's needs and right to information, advice and support if the child's parent, or another adult whom the child lives permanently with:

- has a psychiatric disability
- has serious physical illness or injury
- has substance abuse problems
- unexpectedly dies

THE COUNTY COUNCIL IN SÖRMLAND STARTED AN INTERVENTION IN TWO PALLIATIVE UNITS

To develop and implement local action plans to be used as guidelines when encountering children as next of kin in palliative care

- 2013: Planning of the project and contacts with the research group
- 2014: The project started
- 2015: The project was completed

…THE COUNTY COUNCIL IN SÖRMLAND STARTED AN INTERVENTION IN TWO PALLIATIVE UNITS

The units:
- home-based palliative care (A)
- hospice care (B)

Each group (A n= 11; B n= 15) participated in six work sessions

A project leader participated to facilitate the process

THE RESEARCH PROJECT

AIM

To evaluate the development of the local action plans to implement child centeredness and children's rights as next of kin in adult palliative care.

Research questions:

1. How are the directives of child centeredness and their rights visible in the work processes and the action plans?
2. What are the health professionals reflections about encountering and making children as next of kin visible?
3. Are there any changes in awareness and perceptions among health professionals after the development of local action plans for children as next of kin?
4. What characterizes the learning processes and the knowledge translation?

DESIGN AND METHODS

Mix methods has been used – quantitative and qualitative

- Questionnaires were sent to health professionals at the palliative care units in the county. One questionnaire before the start of the project and the other after the project ended.
- Following the process of the health professionals work session by observation and recording the discussions.

DATA

- The county counsil´s project description
- Transcribed text from work sessions
- The local action plans developed
- Structured and a semi-structured questionnaires

HOW THE DIRECTIVES OF CHILD CENTEREDNESS AND RIGHTS WAS VISIBLE IN THE WORK SESSIONS

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The analysis was made from the directives in the project description:

1. The Child perspective "considering how a situation, decision or action will influence the child, directly or indirectly"
2. The Child's perspective as "supplementing the adult's child perspective and contributing its own view of events"
3. Selected articles in the UN Convention on the Rights of the Child (UN 1989)

DEDUCTIVE ANALYSIS OF THE TRANSCRIPTS FROM THE SESSIONS

The concepts are defined as described in Söderbäck, Coyne and Harder, 2013 and Coyne, Hallström, Söderbäck, 2016

- The child perspective is defined as finding out the specific child's own understanding, perceptions, experiences and observations of a situation. The child's perspective can be obtained by observing and paying attention to the child.
- The attention towards the child constitutes the health professional's child perspective, which is a prerequisite for meeting the child's needs and adapting to them in a situation where the child is serving as next of kin.

…DEDUCTIVE ANALYSIS

The Child's rights in the UN Convention on the Rights of the Child (UN 1989) focusing on:

- non-discrimination (Art.2),
- the best interests of the child (Art.3),
- parents' responsibilities (Art.5, 18),
- the right to life and development (Art.6),
- the right to participate in decisions affecting the child, to express oneself and be listened to (Art.12),
- the right to privacy (Art.16),
- the right to protection from abuse (Art.19).

RESULTS

The number of utterances revealing any relevant meanings related to the directives about the child perspective, the child's perspective and the children's rights perspective was low (N=136).

BUT

Overall along the sessions it was obvious that the health professionals got aware of their duty to follow the content in the UN Convention on Children's Rights (UN, 1989).

However they faced difficulties when meeting children in their clinical practice of adult palliative care.

…RESULTS

The Child perspective (Number of utterances N =65)

- Identifying the children and making them visible (50)
- Keeping children informed (15)

The Child's perspective (N=7)

- Incorporating the child's opinion (7)

…RESULTS

The *Child rights perspective* (N=64)

- Equity / Non-discrimination (Art. 2) *n=10*
  by Establishing routines to include children as next of kin (5)
  and Documenting in the daily reports (5)
- The best interests of the child (Art. 3) *n=5*
  by Letting the child get knowledge, understanding and support
- Parents responsibilities (Art. 5 & 18) *n=23*
  by Permitting personnel to involve the child (10)
  by Reciprocal understanding /a family focus (1)
  and by Supporting the parenting (12)

…RESULTS

- Promotion, Privacy and Health (Art. 6 & 24) *n=15*
  by Supporting the child's health (5)
  by Supporting environmental needs (5)
  by Getting a good future (3)
  by Protecting the privacy of the home (2)
- Protecting against abuse (Art. 19) *n=2*
  by Suspicions of abuse
- Participation and speaking up (Art.12) *n=9*
  by Being a co-actor (7)
  by The child's initiative to speak up (2)

CONCLUSIONS ABOUT HOW THE DIRECTIVES OF CHILD CENTERENESS AND RIGHTS WAS VISIBLE IN THE SESSIONS

- In the sessions the health professionals reflected on the child perspective, the child's perspective and the need to incorporate the child's rights, but in a low degree comparing with family issues.
- However during the extended work sessions they became more attentive to issues of making the children more visible in practice.
- The proposal from the health professionals, and formulated in the local action plan, to identify any child as next of kin to the adult patient perspective and have a documentation about that the child has been informed and given attention might improve the child to be more visible.
- The professionals working in adult palliative care needed more knowledge to be able to integrate the directives on a child perspective, the child's perspective and the children's rights perspective into their personal experience.

HEALTH PROFESSIONALS´ REFLECTIONS ABOUT ENCOUNTERING AND MAKING CHILDREN AS NEXT OF KIN VISIBLE

DATA ANALYSIS

Data was analyzed by means of the resarch question:
What are the health professionals' reflections about encountering and making children as next of kin visible in adult palliative care

An inductive content analysis was applied to the transcripts of the work sessions

RESULTS

Making the child as next of kin visible for promoting health presume:

- Organizational prerequisites
- Relations with family members
- Knowledge and skills to involve the child
- The environment of caring

… RESULTS

- Organizational prerequisites
  - Guided supervision

  It´s great when we get professional supervision, but just talking with colleagues about the things that are a great burden is also important.

  - Strategies, routines and resources

…RESULTS

- Relations with family members
  - Relation with the child as next of kin

  It may take some time when it comes to meeting the children. They are in pre- school or school, and the parents may not want us there in the evenings if there isn't something special.
  - Relation with the patient as a parent

  And there, I think we have to keep in mind, the importance of supporting parents who want to involve their children because that's exactly what the parents are asking for.
  - The relation between parent and child

…RESULTS

- Knowledge and skills to involve the child
  - Health professionals' competence regarding children

  Yes, but it does not always feel that I know as much about children as I need, how they are and how they should be involved, or what they understand and perceive.
  - Commitment in the work with children as next of kin

…RESULTS

- The environment of caring
  - Entering the home environment

  It´s important to remember that it´s we who enter their home and that we will take with us the idea that there are children here.
  - The hospice care

We need toys for younger children, books and informational materials, as well as a place to feel safe at while staying in the ward.

CONCLUSION ABOUT HEALTH PROFESSIONAL´S REFLECTIONS ABOUT ENCOUNTERING AND MAKING CHILDREN AS NEXT OF KIN VISIBLE

- The implementation of a policy requires organizational prerequisites, and is complex when the health professionals lack theoretical knowledge about children´s needs and how to encourage them to be involved.
- An evolving awareness of the need to integrate the child's perspective into the action plans was obvious among the health professionals.
- The value of a more family-focused care in highlighting children as next of kin.

WHAT IMPACT HAVE THE WORK PROCESSES ON THE HEALTH PROFESSIONALS´ PERCEPTIONS REGARDING CHILDREN AS NEXT OF KIN?

SOME RESULTS FROM SURVEY ONE AND TWO (QUANTITATIVE AND QUALITATIVE ANALYSES)

RESPONSE RATE FOR SURVEY ONE AND TWO

Questionnaire 1 (baseline): 55 out of 102 employees (54 %)

Questionnaire 2 (project completed): 53 out of 108 employees (49 %)

DESCRIPTIVE, INTERVENTION GROUP, BASELINE

	(n=55)
Women	98%
Nurses	71%
Age, mean	40 years
Years working in healthcare, mean	13 years

RESULTS
- structured questions in the questionnaires

	P-value
Always or in most cases informs oneself of there being children who are next of kin to the patients	n.s.
Always or in most cases notes in the medical record if there are children who are next of kin to the patient	n.s.
Children are always or in most cases informed about the health status of the patient	n.s.
Knows if the county council has quedelines about children who are next of kin to patients	0.000
Knows if your unit has an action plan about children who are next of kin to patients	0.000

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SOME RESULTS / TENDENCIES FROM THE OPEN QUESTIONS IN THE QUESTIONNAIRES

- In the first survey, the health professionals writes about practical difficulties, such as lack of time, an explicit reason for them not informed and met the children.

  ... we are often stressed out within our profession, and children who are relatives will thus be side-lined (survey 1)

  It may be difficult to create an environment which becomes relaxed for children where they dare to ask (survey 1)

- In follow-up survey, it was a tendency that practical difficulties and lack of time partly could be overcome. The children seemed to come more into focus, and the health professionals become more aware of the children, and to talk and inform the children.

  It's important that they feel seen and that we listen to them (survey 2)

  See [pay attention to] *the children* (survey 2)

...SOME RESULTS / TENDENCY FROM THE OPEN QUESTIONS IN THE QUESTIONNAIRES

- In the follow-up survey, there was an increasing in the use of the word "we".

  [and] *we keep the question alive by talking about it during different meetings* (survey 2)

- In the follow-up survey, there was some concern about that the work that has started of children's rights as next of kin not would be continued.

  It's very important that the work with children as relatives continues to develop and does not stagnant (survey 2)

CONCLUSIONS

There are difficulties and weaknesses when it comes to implementing a change in awareness among health professionals regarding children's rights to receive information when they are next of kin in palliative care for adults.

Difficulties to implement a new part of the Health Care Act.

KNOWLEDGE TRANSLATION AND THE LEARNING PROCESS

KNOWLEDGE TRANSLATION

Definition:

Knowledge translation (KT)

emphasizes the synthesis, dissemination, exchange and application of knowledge from research findings, and from other sources to influence changes in practice and improve health outcomes

(Canadian Institute of Health Research, 2016)

ASSUMPTIONS ABOUT KNOWLEDGE

- No dichotomy between theoretical and practical knowledge
- Different types of theoretical knowledge as distances from practice:
  - Reflected and conceptualized knowledge from personal experiences
  - Collegial reflected knowledge based on proven experiences
  - Scientific knowledge

(Bengtsson, 1993)

COMPARE WITH THE DEFINITION OF EVIDENCE

Three sources are weighted together:

- Scientific knowledge
- The professionals proven experiences
- The patient's/client's personal knowledge

(Nilsen, 2014)

PERSPECTIVE ON LEARNING

Evolving local action plans are assumed to be

- An organizational learning process
- Second order of learning
- Both a conceptual and instrumental learning process

Conceptual _____Instrumental

(Ellström, 2010; Nielsen & Roback, 2010)

DATA ANALYSIS

The discussions in the work sessions were analyzed by means of these research questions:

- What type of knowledge did the health professionals mostly relate to when they developed the local action plans? (deductive content analysis, Krippendorff, 2005)
- What are the characteristics of the learning process in current implementation of the policy document? (interpretation inspired by Gadamer, 1975)

RESULTS
- Types of knowledge

Work sessions	Experience based knowledge		Research based knowledge		Rules and regulations	
	Group A	Grupp B	Group A	Grupp B	Group A	Grupp B
Session 1	34 (1)*	53	13 (11)	5	8 (2)	5
Session 2	6	11	8 (2)	3	6	1
Session 3	13	2	2	0	2	3
Session 4	14	**	5 (1)	**	6 (1)	**
Session 5	13	10	2 (1)	2 (2)	4 (3)	1
Session 6	8	2	1	2	1	0

* The numbers in brackets represent how many times the project leader related to the specific types of knowledge, also included in the total amounts of frequencies.

** Session 4 in group B was not recorded.

RESULTS
- The learning process – four themes

1. Divergent visions between developing personal action preparedness and designing an action plan

We had a patient who was single and had a little son, and we cared for her for a very long time… but then she died. But the boy was together with his grandma and gandpa and aunt …all the time. And of course all of them came to visit, but…
- Shall we move on? Take next..

…RESULTS – the learning process

2. Reflections on personal experiences in relation to theoretical knowledge implies new understanding

But…I think that you can recognize in the whole working team that they have more focus on the family and the children…we were more patient centered before. Now we have a broader view…we are more family-centered. … and it is challenging ..it is demanding to think in a new way..

…RESULTS – the learning process

3. From words to actions

To make documentations is one aspect, but to act is another. The words must come out in actions… the words direct what you do

…RESULTS – the learning process

4. Inner motivation to attain further knowledge and to begin new projects

But I think that you get energy form it (the project)…What will we do next? When this is ready?

CONCLUSIONS

- The knowledge translation process must begin in the health professionals own experiences and their reflections in order for them to integrate new knowledge into action.
- The project illustrate a learning process of second order and organizational learning.
- In order to develop action plans based on scientific knowledge further incentives are needed to learn how to translate this type of knowledge into practice.

Thanks for your attention

REFLECTIONS FOR THE SEMINARY

- How aware are health professionals in adult care about the content in the Child convention?
- How aware are health professionals about the difference between of a child perspective and the child's perspective?