

Netzwerk für die Versorgung schwerkranker Kinder und Jugendlicher e.V.

Evaluation of Specialized Paediatric Palliative Home Care in Germany – A qualitative study of parents' perspectives

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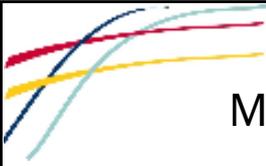
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Research questions

1. Which desires, ideas and needs exist in paediatric palliative home care in Lower Saxony, Germany?
2. Are there changes in care provision after the implementation of Specialized Paediatric Palliative Home Care (SPPHC), as subjectively perceived by parents?
3. Which areas in SPPHC are capable for improvement?

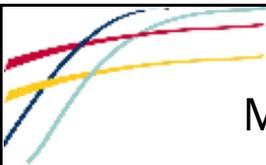


Methods: Data collection

- 20 semi-structured interviews
- Period: 06/2012 – 02/2013
- Inclusion criteria
 - Children suffering from life-limiting or life-threatening conditions
 - Complex symptoms and need of a particularly demanding care
 - Care of the child in the family home, either by the SPPHC team or by other care providers
 - Parent's readiness to participate in the study

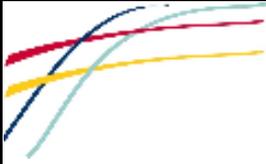
If the child had already died:

- Approach to the parents not earlier than 6 month after the child's death



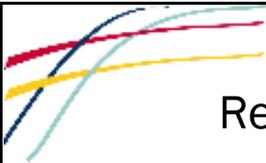
Methods: Data analysis

- Content analysis (Mayring)
 1. Structuring
 - Identification and definition of main categories of pediatric palliative home care that are important for parents
 2. Evaluating
 - Target: Parent's satisfaction with care
 - Basis: main categories
 - Development of an ordinal evaluation chart from the entire data base → specification: very good- good - bad - very bad
 - Application for all cases



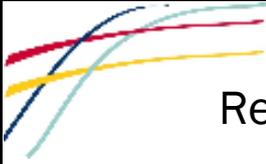
Sample

- 20 Families
 - From all over Lower Saxony
 - 13 parents with prior experience in SPPHC, 4 of them obtaining home care during the time of the interview
7 families without experience in SPPHC
 - 8 families living in urban and 12 based in rural areas
- 20 Children
 - 3 - 18 years old
 - 7 children had already died before of the interview
 - Diverse diseases



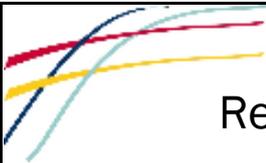
Results I: Main categories

1. Benefit of care
2. Continuity of care
3. Care providers as a team
4. Dealing with the issues death and dying / hospice and palliative care
5. Provider's communication / cooperation with parents
6. Parent's information



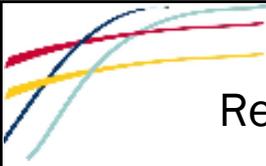
Results I: Main categories

1. Benefit of care
 - a. Orientation towards processes and needs
 - b. Improved quality of life
 - c. Empowerment
 - d. Administrative und organisational relief
 - e. Physical and psychological relief
 - f. Shared responsibility
 - g. Exclusive time for spouses / partners / siblings



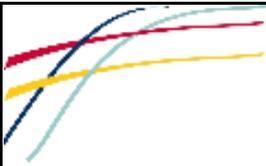
Results I: Main categories

2. Continuity of care
 - a. Telephone accessibility in case of crisis
 - b. Freedom to choose the place of residence
 - a. continuous expert support
 - b. End of life care
 - c. Follow up / grief and bereavement support



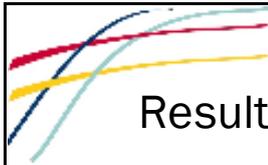
Results I: Main categories

3. Care providers as a team
 - a. Coordination among service providers
 - b. Needs-oriented involvement of different professions
 - c. Mediation between other service providers and parents



Results II: Evaluation

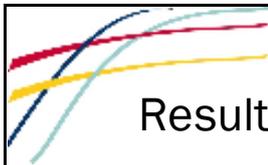
	Families with SPPHC (n = 13)		Families without SPPHC (n = 7)	
	(Very) Good Evaluation	(Very) Bad Evaluation	(Very) Good Evaluation	(Very) Bad Evaluation
Benefit of care	11 (84,6%)	2 (15,4%)	4 (57,1%)	3 (42,9%)
Continuity of Care	10 (76,9%)	3 (23,1%)	4 (57,1%)	3 (42,9%)
perception of care providers as a team	9 (69,2%)	4 (30,8%)	4 (57,1%)	3 (42,9%)



Results III: Room for improvement

1. Physician's presence and communication
(5 out of 13 parents); example:

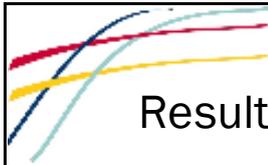
I would like to see him [SPPHC doctor] [...] to come over from time to time. And that we can arrange things with him [...]
(Father (42) of a child receiving SPPHC)



Results III: Room for improvement

2. Psycho-social support
(4 out of 13 parents); example:

And to see a psycho..., well, I would not go there to have such conversations. [...] I have already had quite a few of these talks.[...] When I talk to an acquaintance [...], she gives me advice, [...] something is coming back from her. While from the psychologist, there is nothing coming back. (Mother (43) of a child receiving SPPHC)

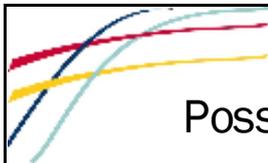


Results III: Room for improvement

3. Follow-up care

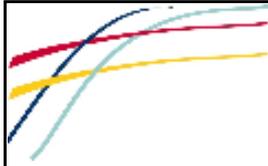
(2 out of 4 parents of a deceased child); example:

To determine the point of time [i.e. the end of the support by the SPPHC team] from the outside, [...] that was of course a little painful for me. Instead of phasing it out slowly [...] (Mother (40) of a child having received SPPHC, that died at home as wished by the family)



Possible issues for discussion

- Symptoms / Improved quality of life no main categories?
- Homogeneous category system vs. heterogeneous environment?
- Evaluation scheme: Intercoder reliability vs. validation by parents?



Conclusion

- The implementation of SPPHC was rated positively by the concerned families
- Options for improvement could be identified

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