

“Collateral beauty” in perinatal palliative care

Experiences and needs of medical and non-medical professionals caring for parents continuing pregnancy after life-limiting prenatal fetal diagnosis: A grounded theory study

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Background

- Increased research about perinatal palliative medicine
- Most existing studies focus on affected families
- A special care situation for professionals: individual, comprehensive, sensitive, interdisciplinary
- Research on the subjective perspective of professionals is scarce
- A lack of structured perinatal palliative care programs in german speaking countries

Study aims

Identifying

- **experiences and needs** of involved medical and non-medical care providers
- **existing care structures**
- **requirements** for a structured Perinatal Palliative Care program

--> **qualitative approach**

Methodology

Grounded Theory

- Theoretical sampling
- parallel data collection and analysis

Data collection:

Semi structured Interviews

Analysis:

Coding according to Grounded Theory (Kathy Charmaz, 2014)

- Situational Analysis (Adele Clarke, 2018):
 - Situational maps, Social worlds/Arenas maps, Positional maps

theoretical sampling:

- 1) determination of initial sample
- 2) further recruitment based on data analysis

Semi – structured Interview

Main Questions

1. What were your experiences in dealing with affected families?
2. What experiences do you have with regard to care structures?
3. How do you cooperate with other disciplines and institutions?



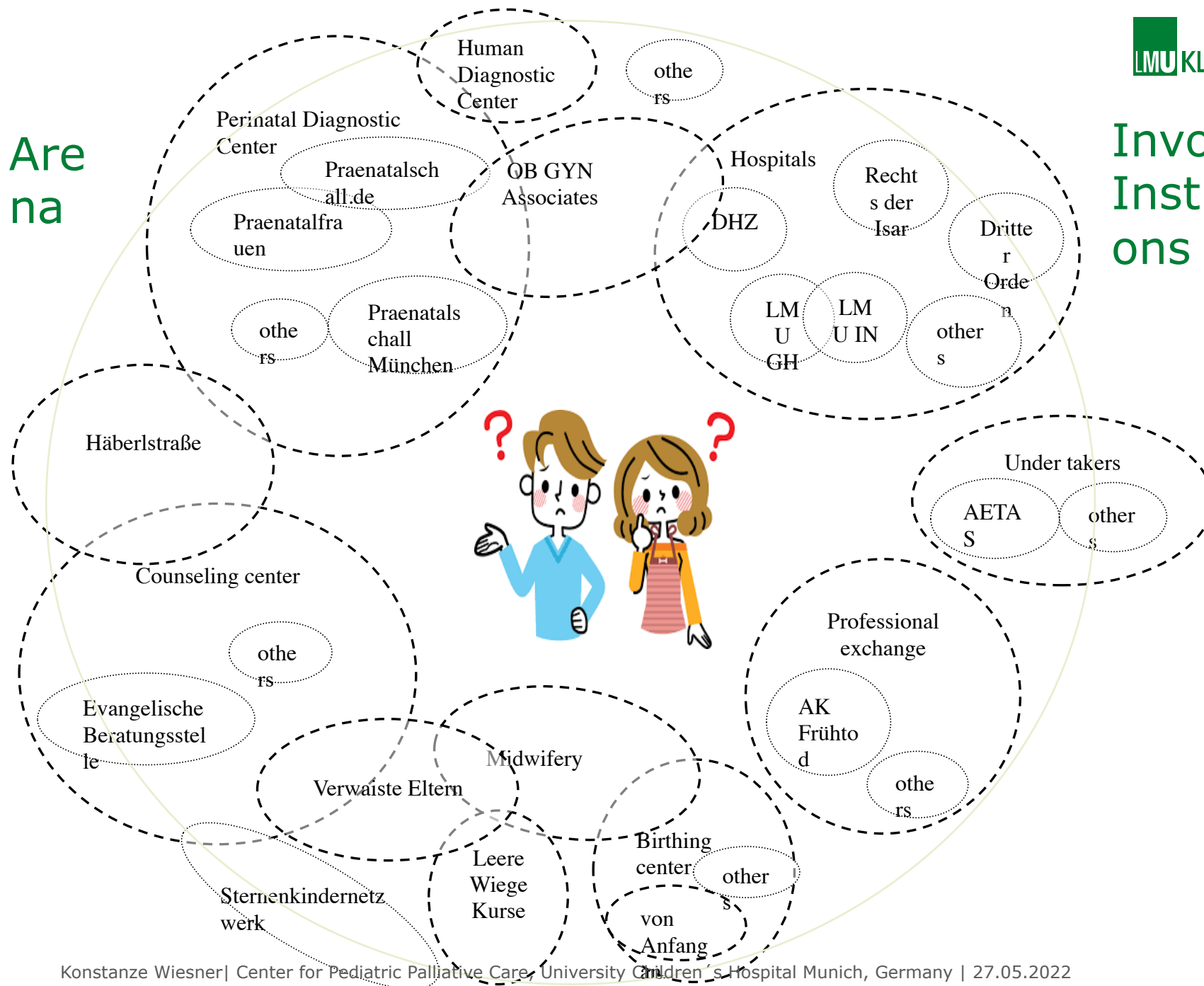
| Profession | Number of interviews |
|-------------------------------|-----------------------------|
| Prenatal diagnostician (MD) | 4 |
| Gynecologist and obstetrician | 2 |
| Palliative care physician | 1 |
| Neonatologist | 2 |
| Midwife | 3 |
| Psychologist | 1 |
| Pastoral care worker | 1 |
| Pregnancy conflict counselor | 1 |
| Undertaker | 1 |
| Nurse | 2 |

18 medical and non-medical professionals from Munich

19 semi-structured expert interviews

Involved Institutions

Arena



Perception of family

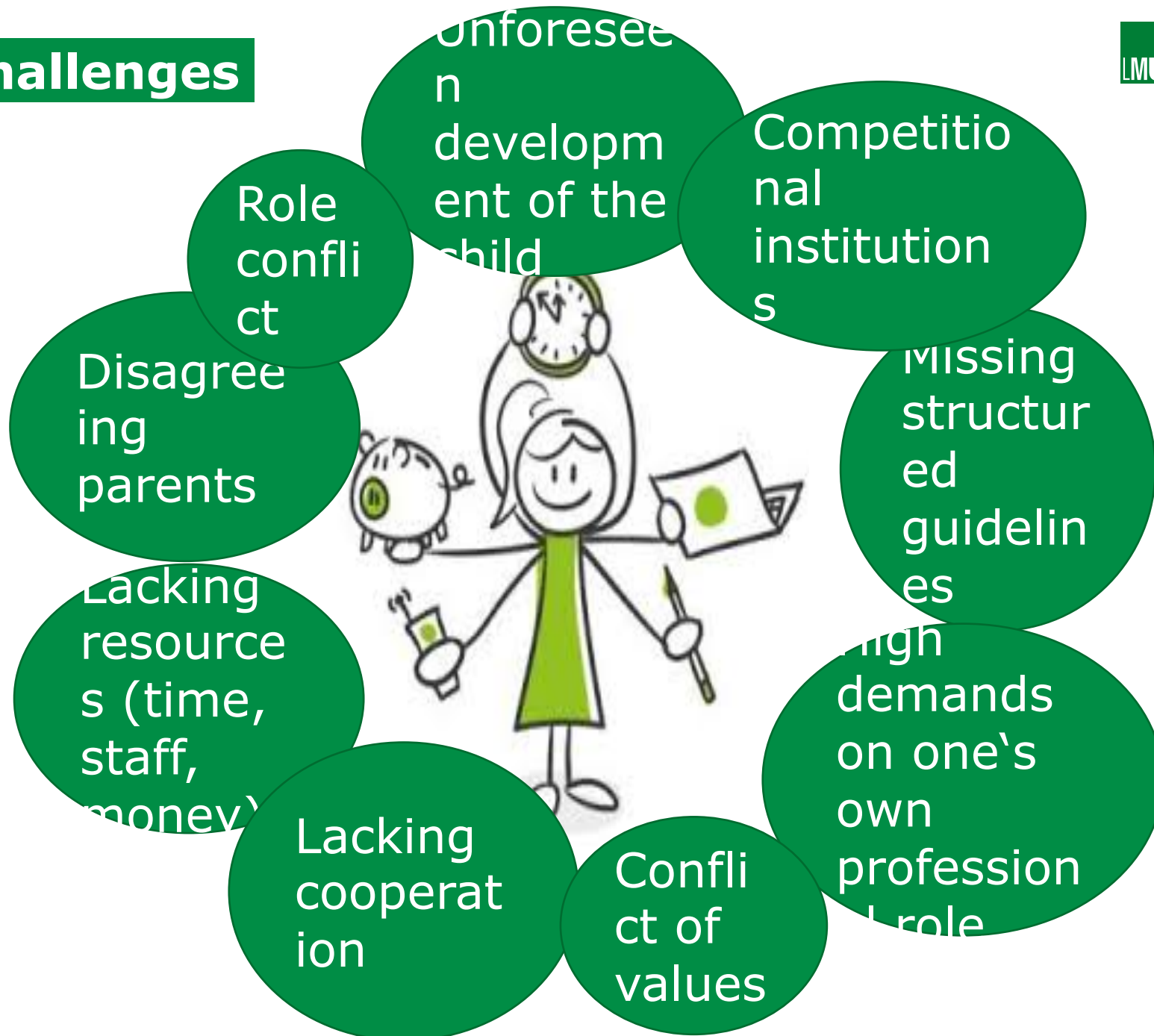
- Family as helms
- Strong families
- Spiritual familie



Perceived needs of parents

- individual care
- seeing unborn as a person
- being parents beyond death

Challenges



Personal commitment

**seeking
further
education
and
support**

**private
efforts**

**performi
ng
unpaid
work**

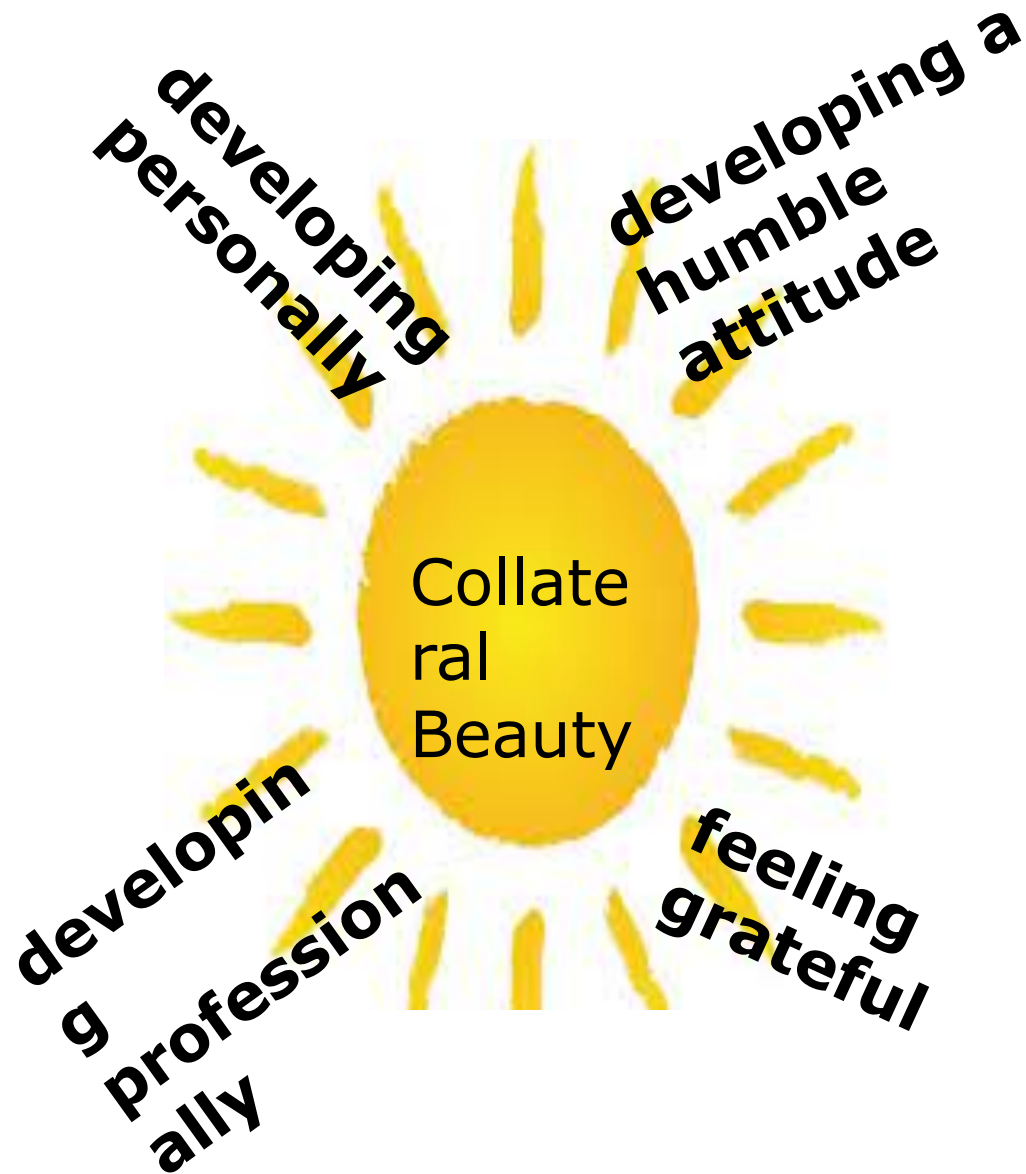


**flexible
handling
of
regulatio
ns**

Collateral Beauty

You mustn't say that it's a positive thing when a child dies – because it is not, but there is some collateral beauty. There is something positive in all this misery, if you know what I mean. (H2)

But what does she mean?



“The job gives back a lot. It can be such a ... such a kick! There is a danger of becoming addicted. (S1)”

Conclusions

Parents

... face complex care structures

... care depends on individual professionals

Professionals

... face a lot of challenges e.g. lack of resources and cooperation

... show high level of personal engagement

... experience "Collateral beauty" = professional and personal growth

... need peer support, supervision, and training





Grazie mille!

Thank you very much!

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Helpful tools

