

PALLIATIVE CARE FOR PEOPLE WITH INTELLECTUAL AND MULTIPLE DISABILITIES. A SURVEY OF RESEARCH AND PRACTICES

Background

UN-Convention on the Rights of Persons with Disabilities (UN-CRPD)

- right to full and effective participation without any limitations (Preamble)
- right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (Art. 25)
- right to enjoy legal capacity on an equal basis with others in all aspects of life and to get support in self-determined decision making (Art. 12)

Aim of the research project (2017-2020):

- exploring the situation both in palliative and disability services with a special view on the service users and relatives
- drafting recommendations for developing adequate support for people with intellectual disabilities in palliative care condition

Methods: multi-perspective design:

- Secondary data analysis and data collection;
- semi-structured interviews with experts, service users and relatives;
- focus group discussions with service users;
- testing of concepts for person-centred planning and advance care planning;
- advisory board providing knowledge from different disciplinary views (medicine, nursing, spiritual care, ethics, psycho-social services, special education) and expertise from important scientific communities (DGP), expert bodies, and user representatives.

Participatory research is guaranteed by a supervisory board of service users.

Group discussions with persons with ID show quite clear concepts of dying and wishes according to adequate support in this vulnerable situation.



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Current situation in Germany

- Persons with intellectual and multiple disabilities are generally underrepresented in palliative care services (EAPC White Paper 2015)
- Special situation in Germany: missing generation because of systematic "euthanasia"-murders during the Nazi-regime:
 - disproportional increase of elderly persons with disabilities in Germany;
 - disability services and palliative care and hospice services are not well prepared for end-of-life care for people with ID and PMID;
 - extremely separated care system causes barriers to equal enjoyment of support from different welfare authorities (welfare-mix) (Schäper 2006b);
- legal capacity is not fully recognized in decision making in the end of life (Wicki/Hättich 2016).

First results:

Lack of sufficient data on numbers of deceased persons with ID, on places of death, causes of death as well as on special needs and conditions for end-of-life care in disability services and palliative care services.

Secondary data analysis based on statistics of welfare authorities: death rates:

The number of persons with ID dying in residential homes and settings of community living is increasing. The average death rate of adults with ID using disability services in the region Westphalia-Lippe is 18,8 (per thousand), while the death rate in the general adult population in Germany is 13,4.

Death rates	2014		2015		2016	
	deceased persons	death rate	deceased persons	death rate	deceased persons	death rate
Community living	29	5,10	45	7,50	39	6,16
Residential Homes	210	16,07	246	18,77	262	20,03

Figure 1: Death Rates (own survey) based on data by regional welfare authority.

Interviews with adults with ID on their concepts of dying, analysed by the methodology of Grounded Theory:

- All participants know that we all have to die.
- They show similar emotions on others' death and according to their own death as people without intellectual disability.
- They are able to articulate their needs on dying and death very clearly ("... that helping hands be with us..." / "... belonging to others..."), but their wishes are determined by institutionalized settings ("I don't want to be discourteous, but it would be fine to have some of my favourite music when I am going to die").
- Lifelong participation seems to be the key to the possibility of effective participation in important decisions in the end of life (Duchardt et al. 2018).

Conclusion:

Crossing network lines between the support systems is crucial for adequate capacity building.

Pedagogical expertise is needed to ensure participation esp. for persons with profound and multiple disabilities, which is a core subject corresponding to the human rights in the end of life.

Further steps in the project will focus on a quality of care and possibilities to ensure full and effective participation in the end of life.

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