Interkantonale Hochschule
für Heilpädagogik

Lay Summary

PALCAP – Palliative Care for People with Intellectual Disability

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23.08.2015

Schweizerischer Nationalfonds
zur Förderung der wissenschaftlichen Forschung

End of Life
National Research Programme NRP 67

1. Background

Medical care has improved to such an extent in recent decades that people, including those with intellectual disability (ID), are living longer (Havemann & Stöppler, 2004). As people live longer they are more likely to die over a prolonged period from incurable, chronic illnesses that occur more frequently in old age. Therefore people with ID, as they belong to the ageing population, will also experience a greater number of chronic illnesses and an increase in associated end-of-life discussions and decisions than before.

Intellectual disability affects approximately 1-3% of the population (Masch et al., 2004). The term covers a wide range of abilities and disabilities, skills and limitations, but always includes the following three aspects: (a) a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence); (b) a significantly reduced ability to cope independently, expressed in conceptual, social, and practical adaptive skills (impaired adaptive functioning); and (c) early onset (before adulthood), with a lasting effect on development (AAIDD, 2013).

There is a growing need for high quality palliative care for people with ID. In Switzerland, more than 70% of adults with ID are living in residential homes (Adler et al, 2011). Knowledge and skills are required for dealing with the end of life of the clients. Strategies that will facilitate an improvement in self-determination in palliative care and end-of-life decisions for people with ID, living in residential homes, are needed.

In 2012 only little was known about the situation in palliative care in residential homes for people with disabilities in Switzerland. In the sphere of care the FOPH (2010) stated an unequal access to offers of palliative care for people in Switzerland and specialists in the field of health care frequently are not fully aware of the objectives and approaches of palliative care.

Based on the results of international studies (McCarron et al., 2011; Ryan et al., 2011; Todd, 2004; Tuffrey-Wijne, 1998, 2002, 2003; Tuffrey Wjine et al., 2008) it could be assumed that, also in Switzerland, staff in residential homes for people with ID is confronted with questions regarding self-determination, consent to treatment and participation in end-of-life decisions and requires support to cope with palliative care needs.

2. Goals of the project

The aim of the study was to examine availability, content and implementation, e.g. communication strategies and staff education, of written palliative and end-of-life care policies, as well as the place of dying, the provision of palliative care and the involvement of residents in end-of-life decisions, and to describe god practice in supporting self-determination of people with ID in end-of-life decisions.

Relating to the situation in Switzerland, several questions arose in this context. The aim of the study was to find answers to the following questions:

- How many residential homes for people with ID provide their residents with the possibility to stay in the residential home until they die? How do these residential homes differ from those that do not offer this end-of-life service?
- Are written policies on palliative care, end-of-life care and end-of-life decisions available in the residential homes for people with ID in Switzerland? What is their content, what are the implementation strategies and is there a collection of data on important aspects of palliative and end-of-life care for the purpose of quality assurance? What are the differences between the residential homes with complex, simple or no written policies?
- What is the percentage of people with ID, living in residential homes, who died in the last five years, either in residential homes for people with ID, in hospitals or in their family home? What is the prevalence and nature of end-of-life decisions, when people died in residential homes for peo-

ple with ID and who was involved in palliative care and end-of-life decisions? Does complexity and degree of implementation of written palliative and end-of-life care policies affect the documentation of provision of palliative care and participation in palliative care and end-of-life decisions?

- What are the challenges of promoting participation and self-determination in palliative care and end-of-life decisions in residential homes for people with ID? Which factors support institutional staff, nurses, doctors and palliative care teams to promote participation and self-determination in palliative care and end-of-life decisions and how can good practise be described?

3. Methods

An explanatory sequential mixed methods design (Creswell et al. 2008) has been used to gain comprehensive insight in the situation on palliative and end-of-life care for people with ID living in residential homes. Subsets of participants from the initial quantitative phase were used for further phases.

Phase I) A cross-sectional survey in residential homes for people with ID in Switzerland has been conducted to examine availability, content and implementation, e.g. communication strategies, staff education and quality assessment of written palliative and end-of-life care policies, as well as the place of dying, provision of palliative care and involvement of residents in end-of-life decisions. The questionnaire was based on previous studies on written policies on palliative care and implementation strategies in residential homes for people with ID in Belgium (D'Haene et al., 2010) and end-of-life decisions for people with ID (Wagemans et al., 2010).

Phase II) Topic-guided problem centred group interviews with caregivers, nurses and staff of palliative care services have been conducted to get a deeper insight in good practice in order to explore challenges and support factors that enhance self-determination and participation of people with ID in palliative care and end-of-life decisions in residential homes.

The study has been accompanied by a group of experts which were invited and informed after every phase.

4. Results

All residential homes for adults with ID in Switzerland were addressed in October 2013. Thus 437 facilities for people with disabilities were asked to participate. 37% (n= 162) completed the questionnaire on written policies (128 of them answered also the questions on died people), 83 residential homes answered the very short questionnaire by phone (19%) and 9 residential homes answered a short questionnaire on paper (2.1%). The total response rate was 58% (table 1).

	Response quote		Completed also questionnaire on died persons	
	%	n	%	n
Long questionnaire	37%	162	29%	128
Questions by phone	19%	83	0	0
Short questionnaire	2%	9	0	0
Total	58%	254	29%	128

Table 1 Different stages of the questionnaire

Missing data created difficulty in data analysis. For reasons of meaningfulness, data sets of completed questionnaires were selected to present specific questions regarding written policies or staff training in residential homes for people with ID and questions on end-of-life decisions for people with ID, and multiple imputations (linear interpolation) were used for complex analysis of a data set of all residential homes, where directors answered the whole questionnaire.
Directors of 233 residential homes answered the question, if residents have the possibility to stay in the residential home until they die, even if they have high care requirements. Out of these 233 residential homes, 171 (73.4%) provide care for people with ID.
Directors or caregivers of 128 residential homes provided detailed answers on 233 deaths (table 2).

	Total answers		Care for people with ID		Care for people with other disabilities	
Questions	n	%	N	%	n	%
Possibility to stay	233	100%	171	73.4%	62	26.6%
Written policies	128	100%	88	76.6%	30	23.4%
Number of deaths	233	100%	156	77.0%	77	33.0%

Table 2 Samples of different stages of the questionnaire

Only one third of the residential homes for people with ID provide their residents with the possibility to stay in the residential home until they die, even if they have high care requirements. 233 directors or caregivers answered this question. In 38.6% of the residential homes (90 residential homes), residents cannot stay after retirement. In 29.2% of the residential homes (68 residential homes) the possibility to stay until the end of life is only given, if residents do not have high care requirements. In 32.2% of the residential homes (75 homes) residents can stay until the end of their life, even if they have high care requirements. The chi-squared test shows that more residential homes for people with ID (especially with severe or complex needs) provide the residents with the possibility to stay until the end of their live χ2 (2, *n* = 233) = 10.401, *p* = .006) (Wicki & Meier, 2015).

Written policies on palliative care *and* end-of-life decisions are only available in 17.2% of the residential homes for people with ID in Switzerland. Directors of group homes have considered a range of issues when formulating their policies on end-of-life care for clients with disabilities and two third of them have conducted or planned training on palliative care or end-of-life decisions.
46 out of 128 residential homes (36%) have written policies on palliative care or end-of-life decisions. 22 residential homes (17.2%) have both policies. In 17 residential homes (13.3%) only written policies on end-of-life decisions are available and in 7 residential homes (5.5%) only policies on palliative care are available. In residential homes for people with ID more written policies on palliative care and end-of-life decisions are available than in residential homes for people with other disabilities than ID (policies on palliative care: χ2 (1, *n* = 128) = 3.582, *p* = .044, policies on end-of-life decisions: χ2 (1, *n* = 128) = 5.431, *p* = .014).
Directors of group homes have considered a range of issues when formulating their policies on end-of-life care for clients with disabilities. Most frequently mentioned issues (in more than 90% of the policies) are "communication with relatives" (96%), physical, psychological and spiritual wellbeing of the person (93%)

and “do-not-resuscitate orders” (94%). Withdrawing or withholding of potentially life-prolonging treatment is mentioned in about 54% of the policies. Only a few policies and related training events consider the distinctive features of end-of-life care for people with ID (information about illness and treatment options, assessment of decisional capacity, communication).

Most of the residential homes for people with disabilities in the study population have conducted or planned training on palliative care or end-of-life decisions. 53.1% of the residential homes (68 out of 128) have conducted or planned training on end-of-life decisions and 68.8% (88 of 128) on palliative care. The Chi-squared test shows no differences on conducted or planned end-of-life care training between residental homes for people with ID and residential homes for people with other disabilities, $\chi2$ (1, n = 128) = .209, p = .420.

2.8% of the residents, living in residential homes, died in 2013. Between 2007 and 2012 more than 50% of all residents died in the residential home. The mean age of death was 56 years.

2.8% of the residents, living in residential homes, died in 2013. In 78 out of 128 residential homes one or more residents died between 2007 and 2012. The residential homes provided detailed information on 233 people who died. There were 156 people with ID and 77 people without ID but with other disabilities (sensory, physical, psychological); 22 of them with multiple disabilities.

54.9% (128 persons) died within the residential home, 36.9% (86 persons) in the hospital and few residents died at the parents’ home or in a hospice. The mean age of death was also the median (56 years); the range was from 17 to 98 years. The standard deviation was 14.4 years. The mean age of residents with severe ID and/or other severe disabilities is even lower (55.3 years, SD 14.8 years).

The residents experienced a high prevalence of end-of-life decisions (70.4%). The decision to abandon life-prolonging treatment has been made more often for people with ID than for people with other disabilities and people with ID were less involved in end-of-life decisions than people with other disabilities

An end-of-life decision been made for 164 residents (70.4%). In total, 139 residents (59.7%) received pain relief or symptom control, while the homes decided to abandon potentially life-prolonging treatment or not to use artificial nutrition or respiration for 91 residents (39.1%). 33 residents (14.2%) received palliative sedation. Finally, there were three cases of assisted suicide.

The decision to “abandon life-prolonging treatment” was made for 73 out of 156 deceased people with ID (46.8%). For people with disabilities other than ID this decision was made only for 18 out of 77 cases (23.4%). The difference is significant ($\chi2(1, \underline{n} = 233) = 11.878, \underline{p} = .000$).

Where an end-of-life decision had been made family members were involved in the decision-making process in 120 of 164 cases (73.2%). Legal representatives were involved in 142 cases (86.6% of all cases, where an end-of-life decision had been taken). Nurses were involved in 136 cases (82.9%). People with ID were less involved in end-of-life decisions than people with other disabilities. The Mann-Whitney test shows that this difference is significant, U = -5.123, $p < .001$.

The chi-square test shows, if written policies on end-of-life care are available, more residents had a do-not-resuscitate order or advanced care planning document when they died (χ^2 (2, $\underline{n}$ = 233) = 25.774, $\underline{p}$ = .000) and (χ^2 (2, $\underline{n}$ = 233) = 27.733, $\underline{p}$ = .000).

The following factors support institutional staff, nurses, doctors and palliative care teams to promote participation and self-determination in palliative care and end-of-life decisions:

- **Analysing the age structure of residential homes, developing guidelines on palliative care and end-of-life decisions and implementing those through continuing education**
- **Carers and nurses need guidelines and expertise, which help them talking about the important issues with the person, to document the discussion and to share the result with an interdisciplinary team. With advanced care planning wishes, values and beliefs of people with ID concerning death and dying can be documented, advanced directives can be included.**
- **Care staff in residential homes for people with ID needs expertise and resources available for palliative care.**

Subsequent to the survey, seven cases of people with intellectual disability (different gender, age and language regions) were selected from the detailed documented cases of death, where either treatment was stopped or artificial nutrition or respiration was not used (table 3).

	Gender	Age of death	Disability	Care require-ments	Number of residents	Staff per resident	Mean Age of residents	Written policies	Cooperation with PC-Team	Decision	ACP	Degree of involve-ment	Influence on decision	Participants
Ahorn	f	62	physical, pschological, ID	1	150	?	38.3	PC + EoL	y	Abandonment of treatment, not to use artificial nutrition	y	5	y	Group-leader, main carer, priest, Hospiz-leader
Buchser	m	70	ID and psychological	3	45	1.2 VZE	56	no	n	To treat or not to treat	n	4	y	Director, main carer, nurse, 2 other carers
Cornus	f	56	physical, pschological, ID	3	45	1.2 VZE	56	no	n	Abandonment of treatment	y	5	y	Director, main carer, nurse, 2 other carers
Douglasie	m	69	ID	1	74	0.6	49	PC + EoL	y	No decision	y	2	n	Director, 2 nurses
Erle	f	64	ID, Alsheimer	2	116	0.5 VZE	46	no	n	Not tu use artificial nutrition or respiration	y	2	n	Director, main carer, nurse, other person
Föhre	m	57	ID	1	304	1.6 VZE	45	PC + EoL	n	Abandonment of treatment	n	3	y	Director, main carer, pedagogical leader
Grevillea	m	60	ID	2	35	1.8 VZE	58.6	EoL	y	Abandonment of treatment, not to use artificial nutrition	y	1	n	Group-leader, 2 nurses

Table 3 Characteristics of cases and participants in problem-centred interviews

The analysis of the problem-centred group interviews, according to Witzel (1985, in Lamnek 1995), with caregivers, nurses and staff of palliative care services, shows the most important challenges for the caregivers providing palliative care for residents in care facilities for adults with disabilities in Switzerland are 1) the low age of death, 2) communication problems, 3) the assessment of the decisional capacity of people with ID in medical decisions, 4) the involvement of people with ID in end-of-life decisions and the 5) organisational structure.

Low age of death

The mean age of death of people with ID was 56.0 years (SD 14.4 years). Due to the low average age of death of the persons with disabilities, not only these residential homes which provide care after the retirement of the residents are facing death and dying, but all residential homes for adults with disabilities face the question on how to organize the long-term, high care needs for critically ill, dying persons with ID. Care staff members frequently have a strong desire to care for the person with ID until the end of life, sometimes because of the closely developed relationship. Residential homes analysing their age structure, developing guidelines on palliative care and end-of-life decisions and implementing those through continuing education, take the first step in that direction. Facing the low age of death, communication on these issues and planning has to start early. Enough time to discuss should be planned.

Planning

People with ID vary in their comprehension and understanding of their illness. Communication with people with ID on illness, death and dying is often needs time. Delivering bad news is a process rather than a single event and information has to be broken up in small pieces (Tuffrey-Wijne, 2013). Planning ahead enables a resident's views and preferences to be respected and followed. The resident's family and friends should be included in these discussions, as appropriate.

Residential homes developed specific guidelines and documentation to start early with this communication, to talk regularly on these issues and to document the wishes of the person with disability as well as the wishes of their relatives and legal representatives. With advanced care planning wishes, values and beliefs can be documented, what people find important, what places the persons with ID like to visit, where they find peace, what they like to be surrounded with. Advanced directives can be included.

Assessment of the decisional capacity

For informed consent to treatments, people with a life-threatening illness and their carers and families need information about options for their future care. They should be actively involved in those decisions in the way that they wish.

The assessment of the decisional capacity of the person is an important question. The capacities should be assessed in four areas: does the person understand information relevant to her condition and the recommended treatment, can she reasoning about the potential risks and benefits of her choices, can she appreciate the nature of her situation and the consequences of the choices, and can the person express the choice (Grisso, Applebaum & Hill-Fotouhi, 1997).

Carers and nurses need guidelines and expertise, which help them talking about the important issues with the person, to document the discussion and to share the result with an interdisciplinary team.

Involvement in end-of-life decisions

In Switzerland's residential homes for people with disabilities decisions on abandoning life-prolonging treatment are taken more often for people with ID than for people with other disabilities, and people with ID are less involved in these decisions. The likelihood of experiencing the decision to abandon life-prolonging treatment is 2.5 times higher for residents with intellectual disabilities than for residents with other disabilities. The factors determining the prevalence and nature of end-of-life decisions for people with ID are still unknown. But for relatives, representatives and carers it will be important, to document the patient's wishes and values concerning end-of-life decisions, to assess the decisional capacity of people with ID, to regularly involve the person with disability in end-of-life decisions and to document the decision-making-process (see also Wicki, 2014).

Organizational structures

In residential homes for people with disabilities in Switzerland only few staff is trained on specific health care procedures to support particular residents. But they have a big knowledge of the resident with a disability. It is important to document the knowledge and to support palliative care staff with this knowledge. The end-of-life stage can be demanding for other residents and staff and access to support will be crucial. Care staff in residential homes for people with ID needs expertise and resources available for palliative care. Short trainings on palliative care approach, grief and bereavement, end-of-life care as well as assessment of pain, symptom-control and psychological support are helpful. Staff with an awareness of what they would be facing is capable of determining, whether they have the right expertise, equipment and knowledge to find support e.g. for palliative care, decision-making and their own psychological and emotional wellbeing. The required structures, like for example conciliar visits or joint trainings, have to be set up in the organizations early enough (see also Wicki, Meier & Franken, 2015).

5. Significance of the results for science and practice

The survey of the residential homes, the interviews, the discussions with the directors and caregivers of the residential homes, show that in only one third of all residential homes the residents have the possibility to stay until the end of life, even if they have high care requirements. However, there is no such thing as one specific model on how to organize the care and support of people with a lifetime disability, living in residential homes for the disabled in Switzerland on cantonal and regional level, but decentralised solutions and the option for a stay in the residential homes as long as possible, are preferred.

Institutional level

Many people with disabilities, their relatives and caregivers, would like self-determination for the residents of the residential homes for the disabled and, if possible, also to choose the place of death. For the directors and caregivers of the residential homes it is important to know, which strategies relating to palliative care the health administration or social office pursue in their canton. This knowledge helps directors of residential homes and caregivers defining their own task and specifying, which criteria possibly cause a change to a specialized department. This also facilitates the clear and open communication and explanation towards the persons with disabilities, their relatives and legal representatives, on the role of the caregivers and nurses and the possibilities and limits of palliative care. Good communication in the team, clear regulations, structures and arrangements are helpful to overcome these issues. Therefore it is important that palliative care guidelines are available and respective training possibilities are in place. The caregivers and nurses also have to know where they can get support for difficult situations.

Facilitating self-determination also for end-of-life decisions creates another challenge to the caregivers and nurses in the residential homes for the disabled. Raising the caregivers‘ and nurses‘ awareness regarding ethics that come up with end-of-life decisions and also questions on which role they have as caregivers and nurses are essential. How can they support the residents with intellectual disability on their behalf? Therefore it is recommended to provide the corresponding training, suitable tools to record the wishes of the persons with ID and to clarify their power of judgement and responsibilities. Also for end-of-life decisions interdisciplinary teamwork is very important.

Cantonal level

The aim of the national strategy for palliative care is to tie palliative care into the existing structures of primary health care. New structures should only be set up, if required. Therefore regular exchange regarding palliative care for people with lifetime disabilities between the cantonal social offices, health administrations and residential homes for the disabled is important. Persons with lifetime disabilities should also be considered in the cantonal palliative care strategies. Cantonal networks, like the divisions of the association palliative.ch, should also include residential homes for the disabled in their work.

The residents of the residential homes for the disabled should be able to self-determine their end of life and their place of death, if possible. A self-determined choice is only possible though, if there are options. Thus, the persons with disabilities should have the possibility to get to know other homes. This requires flexibility in the funding of test places.

Primary health care can as well be supported by setting up palliative care competences in the residential homes for the disabled. This requires strengthening of the regional palliative care programmes and their networking, as well as the networking between the palliative care departments in the hospitals or nursing homes and the residential homes for the disabled. Regional mobile palliative care services have to be developed.

National level

The residential homes for the disabled, together with long-term care facilities, are listed in the national palliative care strategy. However, the initial situation in the residential homes for people with disabilities is very specific. The residents often have been living in the homes for decades and these residential homes have a rather social-pedagogical focus and only few nursing staff. Unlike the nursing homes, the residential homes are furthermore subject to the social offices, but not to the health administrations. For this reason, the specific challenges of the residential homes for the disabled and also the specific target group "People with lifetime disabilities" should be included in the national palliative care strategy, and as well in the further strategies of the Federation (dementia strategy, long-term care strategy or project on mental health, action plan care for relatives).

The end-of-life care of people with lifetime disabilities should be taken into consideration in the training programmes for nurses and physicians. Interdisciplinary modules at the universities of applied sciences can support the exchange.

Associations and clubs, active on national level, could help raising the awareness for palliative care also in the area of care and support for people with disabilities, or see to it that in the area of palliative care people with intellectual disabilities are more considered and included as target group.

Research

There is evidence that potentially life-saving treatments are not always offered and that people with intellectual disabilities are not always sufficiently involved in end of life decision making. Actual studies support these findings and show that assumptions are sometimes made about their quality of life and ability to cope with treatment (Heslop et al. 2014; Wagemans et al., 2013; Tuffrey-Wijne et al., 2013). The consequences are potentially extremely serious. They include, at worst, a risk of premature death; but there is also a risk of compromised quality of life if, for example, people are not offered treatments to ameliorate debilitating symptoms.

Within this data set there was no possibility to analyse several factors that could determine the prevalence of the decision to abandon life prolonging treatment. Further investigation on factors determining the prevalence of abandonment of life prolonging treatment for people with ID will have to be carried out. These issues are likely to be affected by national, cultural and attitudinal influences, and could usefully be researched in a range of countries with different approaches and practices.

Also investigating the quality of palliative care for people with intellectual disabilities in a wide range of European countries will enhance understanding of how good practice can be achieved, regardless of settings, circumstances or cultures.

6. Literature

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