

Withholding treatment and intellectual disability: Second survey on end-of-life decisions in Switzerland

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Abstract

Background: 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 will experience an increase in end-of-life discussions and decisions.

Aim: The aim of this study was to explore the prevalence and nature of end-of-life decisions for people with disabilities in Swiss residential homes.

Design: A cross-sectional survey in the three biggest German-speaking regions in Switzerland (N = 209) was conducted.

Setting: All of the residential homes for adults with disabilities (N = 209) were invited to participate in a cross-sectional survey. The response quote was 76.7%. Directors provided information on 82 deaths. Chi-square and t-tests were used to study differences in prevalence and nature of end-of-life decisions between people with intellectual disability (ID) and people with other disabilities.

Results: An end-of-life decision was taken in 53.7% of the cases (n = 44). For people with ID, the decision to withhold treatment had been taken more often (28.9%, 13 cases) than for people with other disabilities (8.1%, 3 cases) (χ^2 (1, N = 82) = 5.58, p = 0.017).

Conclusion: The study provides insight in end-of-life decision-making for people with disabilities in Switzerland. The results have implications on surrogate decision-making for people with ID living in residential homes. As the study partly confirms the results of previous studies, further studies will be necessary.

Keywords

Intellectual disability, end-of-life decisions, residential homes

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Medical care has improved to such an extent in recent decades that people are living longer. For some cohorts of people with intellectual disability (ID), the increase in life expectancy far exceeds the mainstream.^{1,2} 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.^{3,4} The specific palliative care needs of people with ID have only recently become a focus of research attention. As there is no national register of the population of people with ID in Switzerland, there is hardly any empirical evidence about end-of-life decisions for people with ID in this country. Therefore, the study focuses on end-of-life decisions for people with ID living in residential homes in three regions in Switzerland.

Intellectual disability affects approximately 1%–3% of the population.⁵ 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; (b) a significantly reduced ability to cope independently, expressed in conceptual, social, and practical adaptive skills and (c) early onset (before adulthood), with a lasting effect on development.^{6,7} This

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definition has also been used and is still used in Swiss legislation.

Possible medical end-of-life decisions, in principle, include 'whether to withhold or withdraw potentially life-prolonging treatment (e.g. mechanical ventilation, feeding tubes and dialysis), whether to alleviate pain and other symptoms with, for example, opioids, benzodiazepines or barbiturates in doses large enough to hasten death as a possible or certain side effect'.⁸ Medical end-of-life decisions in Swiss health care also include physician-assisted suicide, which can be defined as the administration, prescription or supply of drugs to end life at the patient's explicit request.⁹ Palliative sedation is not chosen to end life, but to alleviate symptoms and/or pain, however, may have the side effect to shorten life.

According to Swiss law, a patient must give informed consent to a proposed medical intervention. If a person lacks decision-making capacity, an attempt must be made to obtain information on their presumed wishes by means of a declaration of values or a legal representative, as a surrogate decision maker has to make that decision. If neither option is possible, then action has to follow in accordance with the person's best interest. According to the Swiss Academy of Medical Sciences (2013) 'acting in the best interests of the patient' means 'carrying out measures that seem to be indicated, medically and in connection with the care of the patient, and to which a hypothetical reasonable person in a similar situation would presumably agree'.¹⁰ From 2013, the legal situation on representatives' decisions has changed. The new decision instituted a standard instrument 'official assistance', or legal representative – in place of standardized measures. If a person is no longer able to handle their own affairs as a result of ID, psychiatric disorder or similar debility, and the support provided by family members, private volunteers or public services is insufficient, the authorities have to tailor a support package for that person. They must determine the tasks and roles to be fulfilled by the official assistant in accordance with the needs of the person concerned. Family members also have a decision-making power with medical decisions.¹¹

International research has described a number of potential problems that complicate end-of-life decisions for people with ID. Important problems include the complexity of chronic illnesses and their implications, as well as the ethical issues involved in terms of decision-making and consent for treatment.^{12–14} People with ID have been found to experience more delays in receiving the diagnosis and treatment of illnesses than people without ID.^{15,16}

Wagemans et al.¹⁷ analysed retrospective medical files of people with ID, who had died between 2002 and 2007 in one residential home in the Netherlands housing 335 residents. They found that in 57% of cases (27 out of 47 cases), one or more end-of-life decisions had been made. This was a higher percentage of end-of-life decisions than Van der Heide et al.⁸ found for the general population in the Netherlands (44%). It could potentially be attributed to the fact that the general

population study was done earlier and people were less aware of end-of-life issues at that time. Furthermore, people with ID were hardly involved in the end-of-life decisions, while their relatives, legal representatives and paid care staff often played an important role.^{3,17,18}

The first study on end-of-life decisions in residential homes for people with disabilities in Switzerland showed a high prevalence of end-of-life decisions. In 164 out of 233 residents who died between 2008 and 2012 (70.4%), end-of-life decisions had been made. The results pointed out that for people with ID, the decision to withhold life-prolonging treatment was more often taken (46.2%, 72 out of 156 residents with ID) than for people with other disabilities (24.7%, 19 out of 77 residents with other disabilities) ($\chi^2(1, N = 233) = 9.992, p \leq 0.01$). It was discussed that the relatively high proportion of end-of-life decisions in Swiss residential homes for people with ID could have been caused by residential home directors' false interpretation of the category 'pain relief and symptom control'. When the statistics in the first study were run without that variable, end-of-life decisions were made in only 47.2% of all deaths.⁴

Therefore, the aim of this second study on end-of-life decisions in Switzerland was to verify the results of the first study. The prevalence and nature of end-of-life decisions for people with disabilities in Swiss residential homes of the three biggest German-speaking regions was explored. The question was whether there is a difference in end-of-life decisions and involvement between people with intellectual disability and people with other disabilities (sensory, physical and psychological).

Method

A cross-sectional survey with written questionnaires was conducted. The directors of all residential homes for adults in the three biggest German-speaking Swiss regions (canton Zurich, Berne and St. Gallen) were addressed ($N = 209$). The contact details were provided by the social departments of the three regions. A letter with information on the project and the questionnaire was sent to the directors of these residential homes in October 2014. Directors were informed that they will be called by phone 1 or 2 weeks later. Specially trained students called directors, who did not answer the questionnaires until this date, and asked the questions by phone. Answers are provided by 76.6% of the residential homes.

The characteristics of residential homes were not assessed in this second survey. Directors gave detailed information on the gender and disability of persons who died in 2013. Age at death and cause of death were assessed. Cause of death was assessed with closed questions: 'accident', 'suicide', 'heart and circulation diseases', 'respiratory diseases', 'cancer', 'nervous diseases' and 'others or unknown'. The instrument used to receive detailed information on end-of-life decisions was based on the questionnaires developed by Wagemans et al.¹⁷ and Van der Heide et al.⁸ Directors and carers were

Table 1. Characteristics of residents.

	Total (N = 82)	With ID (N = 45)	Without ID (N = 37)
	% (n)	% (n)	% (n)
Gender			
Male	68.3 (56)	64.4 (29)	73.0 (27)
Female	31.7 (26)	35.6 (16)	27.0 (10)
Reason of death			
Heart and circulation diseases	29.3 (24)	26.7 (12)	32.4 (12)
Respiratory diseases	11.0 (9)	15.6 (7)	5.4 (2)
Cancer	11.0 (9)	6.7 (3)	16.2 (6)
Nervous system diseases	14.6 (12)	17.8 (8)	10.8 (4)
Others or unknown	28.0 (23)	33.3 (15)	20.6 (8)
Age at death (Mean, SD)	57.2 (16.2)	57.2 (18)	57.2 (14.1)

ID: intellectual disabilities; SD: standard deviation.

asked, ‘which of the following end-of-life decisions with presumably life-shortening side effects, had been made?’ Directors and carers could choose several answers: ‘intensified pain relief and symptom control’, ‘abandoning life-prolonging treatment’, ‘not to use artificial nutrition or respiration’, ‘palliative sedation’ or ‘assisted suicide’.

Data analyses were performed with descriptive statistics, SPSS software (release 21.0). There was no missing data. Chi-square tests were used to assess whether differences between end-of-life decisions made for people with ID and for people with other disabilities were statistically significant. $p < 0.05$ was considered as statistically significant.

Ethical consideration was not required according to Swiss law.

Results

The survey delivered data on 82 people who had died in 2013 in 43 of the responding 156 residential homes for people with disabilities (27.6%). These 43 residential homes provide place for about 2000 residents. An intellectual disability had 45 died persons and there were 27 people without ID, but they had other disabilities (sensory, physical and psychological).

The mean age of death was 57.2 years, and the median was 59 years. The range was from 15 to 104 years. The standard deviation was 16.2 years. The underlying cause of death in 24 cases (29.3%) was heart and circulation diseases, in 9 cases respiratory diseases (11%) and in 11 cases cancer. For 12 persons, the presumed first cause of death was a disease of the nervous system (14.6%). For 23 residents (28%), directors or carers communicated another presumed first cause of death or the cause of death was not known (Table 1).

End-of-life decisions

An end-of-life decision was made for 44 residents (53.7%). In total, 36 residents (43.9%) received intensified pain relief

or symptom control, while the homes decided to withhold live-prolonging treatment (abandon treatment or not use artificial nutrition or respiration) for 33 residents (40.2%). 16 residents (19.5%) received palliative sedation. Finally, there were four cases of physician-assisted suicide.

The decision not to use artificial nutrition or respiration had been made in 36.3% of the cases (30 residents). For residents with ID, the decision not to use artificial nutrition or respiration had been made for 42.2% of the residents (19 residents), while this decision had been made only for 29.6% of the residents with other disabilities than ID (11 residents). But the chi-square test shows no significance in this difference ($\chi^2(1, N = 82) = 1.36, p = 0.17$).

The decision to withhold treatment had been made for 19.5% of all residents (16 residents). This decision had also been made more often for people with ID (28.9%, 13 residents) than for people with other disabilities (8.1%, 3 residents). The chi-square test shows that this difference is significant ($\chi^2(1, N = 82) = 5.58, p \leq 0.05$).

The decisions to not use artificial nutrition or respiration and to abandon treatment can be summarized as ‘withholding life-prolonging treatment’. This decision was made for 22 out of 45 deceased people with ID (48.9%). For people with disabilities other than ID, this decision was made for only 11 out of 37 cases (29.7%). This difference again is not significant ($\chi^2(1, N = 82) = 3.099, p = 0.062$) (Table 2).

Discussion

The first study on end-of-life decisions in Switzerland showed a high prevalence of end-of-life decisions for residents who died in residential homes for people with disabilities between 2008 and 2012 (70.4%, 164 of 233 died residents). The results of the first study also pointed out that in Switzerland’s residential homes for people with disabilities, physicians, carers and representatives made more often decisions concerning withholding life-prolonging treatment for people with ID than for people with other disabilities, and

Table 2. Prevalence and nature of end-of-life decisions in residential homes for people with disabilities in Switzerland 2013 (N = 82).

	Total (N = 82)	With ID (N = 45)	Without ID (N = 37)	F	p
End-of-life decisions: yes	53.7 (44)	62.2 (28)	43.2 (16)	2.941	.068
Intensified pain and symptom relief	43.9 (36)	48.9 (22)	37.8 (14)	1.077	.218
Not to use artificial nutrition or respiration (1)	36.6 (30)	42.2 (19)	29.6 (11)	1.366	.174
Withhold treatment (2)	19.5 (16)	28.9 (13)	8.1 (3)	5.583	.017
Palliative sedation	19.5 (16)	22.2 (10)	16.2 (6)	.466	.346
Physician assisted suicide	4.9 (4)	3.5 (1)	8.1 (3)	n.a.	n.a.
Withholding life-prolonging treatment (1) + (2)	40.2 (33)	48.9 (22)	29.7 (11)	3.099	.062

ID: intellectual disability.

Table 3. Prevalence of end-of-life decisions in residential homes for people with disabilities in Switzerland 2008–2012 and 2013 (N = 315).

	Second survey (N = 82)	First survey (N = 233)
	% (n)	% (n)
End-of-life decision: yes	53.7 (44)	70.4 (164)
Pain relief and symptom control	43.9 (36)	59.7 (139)
Not to use artificial nutrition or respiration (1)	36.6 (30)	27.5 (64)
Abandonment of treatment (2)	19.5 (16)	18.9 (44)
Palliative Sedation	19.5 (16)	14.2 (33)
Physician-assisted suicide	4.9 (4)	1.3 (3)
Withholding life-prolonging treatment (1) + (2)	40.2 (33)	39.1 (91)

people with ID are less involved in these decisions. As the relatively high proportion of end-of-life decisions in Swiss residential homes for people with ID could have been caused by a false interpretation of the category ‘pain relief and symptom control’,⁴ the aim of the second study was to verify the results of the first study. The prevalence and nature of end-of-life decisions for people with disabilities who died in Swiss residential homes of the three biggest German-speaking regions in 2013 were explored in a second survey.

In the second study, the prevalence of end-of-life decisions found was lower (53.7%). The difference in the proportion of end-of-life decisions in Swiss residential homes for people with disabilities from the first study in 2012 to the second study in 2013 could have been caused by the interpretation of the category ‘pain relief and symptom control’. As in the first study, the question was ‘which of the following end-of-life decisions had been taken?’ and a possible answer was ‘pain relief or symptom control’, directors could have noted this category in all cases where pain relief or symptom control was used, rather than only in those cases where it was intensified or led to possible life-shortening effects. In the second survey, the question was asked in a different manner, pointing out possible life-shortening side effects and declared ‘intensified’ pain and symptom control. This category leads to different results. While in the first study, the category ‘pain relief or symptom control’ was chosen for 59.7 % of all deaths (139 of 233), it was chosen in the second survey only for 43.9% of all deaths (36 of 82). On the

other side, a higher prevalence to not to use artificial nutrition or respiration, abandonment of treatment, palliative sedation and physician-assisted suicide was found in the second survey (Table 3).

Wagemans et al.¹⁷ found that 25% of end-of-life decisions were intensified alleviations of pain or symptoms (12 of 47). In the first study, 59.7% (139 of 239) of end-of-life decisions were pain relief and symptom control. In the second survey, directors of residential homes for people with disabilities reported in 43.9% (36 of 82) of the cases intensified pain relief or symptom control with possible life-shortening side effect. A non-treatment decision was made for seven residents (14.9%) in the study of Wagemans et al.,¹⁷ some with possibly shortening life expectancy. The decision to withhold life-prolonging treatment had been made in Swiss residential homes for people with disabilities between 2008 and 2012 in 28.9% of dying residents (44 of 233), and in the second survey in 19.5% of dying residents (16 of 82). In both surveys in Switzerland, we found a higher rate than Wagemans et al.¹⁷ (Table 4).

In Switzerland’s residential homes for people with disabilities, the decision to withhold treatment has been made (mostly by parents, physicians and carers) more often for people with ID than for people with other disabilities. The first study showed that the likelihood of experiencing the decision to withhold life-prolonging treatment is more than 2.6 times higher for residents with intellectual disability than for residents with other disabilities, and patient’s degree of

Table 4. Prevalence of end-of-life decisions for people with ID in three studies.

	Second survey (deaths in 2013), (N = 82)	Palcap (deaths between 2008 and 2012), (N = 233)	Wagemans et al. ¹⁷ (deaths between 2002 and 2007), (N = 47)
	% (n)	% (n)	% (n)
End-of-life decisions	53.7 (44)	70.4 (164)	57.4 (27)
Intensified pain and symptom relief	43.9 (36)	59.7 (139)	25 (12)
Not to use artificial nutrition or respiration	36.6 (30)	27.5 (64)	17 (8)
Withhold treatment	19.5 (16)	18.9 (44)	14.9 (7)
Palliative sedation	19.5 (16)	14.2 (33)	n.a.
Physician-assisted suicide	4.9 (4)	1.3 (3)	0 (0)

disability is an important factor influencing the decision to withhold life-prolonging treatment. While in the first study, the decision not to use artificial nutrition or respiration as well as the decision to withhold treatment had been made more often for people with ID than for people with other disabilities we found in the second survey other results. In 2013, only the decision to withhold treatment had been made significantly more often for people with ID than for people with other disabilities. A possible explanation could be the change of the Swiss adult protection law in 2013. In 2013, the legal situation on representatives' decisions has changed. Before 2013, legal representatives and physicians had the right to decide for a person with intellectual disability in their 'best interest'. The new law instituted a standard instrument – 'official assistance', or legal representative – in place of standardized measures. If a person is no longer able to handle their own affairs as a result of ID, psychiatric disorder or similar debility, and the support provided by family members, private volunteers or public services is insufficient, the authorities have to tailor a support package for that person. They must determine the tasks and roles to be fulfilled by the official assistant in accordance with the needs of the person concerned, and in case of medical decisions, the person with disability should be involved with their wishes as far as possible. May carers, nurses and relatives had involved more often people with disabilities in the decision-making processes. Although the results show still a difference in the prevalence of the decisions to withhold life-prolonging treatment between people with ID and people with other disabilities, further assessments should be done.

An important limitation of the study is that end-of-life decisions were reported by directors of residential homes not by physicians. A second limitation is that we had in the first study different questions on end-of-life decisions than in the second survey. A third limitation is the retrospective design which favours recall bias. As cross-sectional study, it does not allow us to draw definite conclusions about trends in prevalence or involvement in end-of-life decisions. With a third survey, using the same questions as in the second survey, it will be possible to see longitudinal trends.

Only people with disabilities who lived in residential homes were included in both surveys. These people may have a higher degree of disability than people living in the community. As the question on end-of-life decisions and involvement of the person is also of interest for persons with disability, living within the community, a third survey should try to get data on end-of-life decisions for these groups of persons too.

Further investigation on factors determining the prevalence to withhold life-prolonging treatment for people with disabilities will have to be carried out. Health status should be assessed and longitudinal and trend studies will be necessary. In further studies, it will be important to analyse the decision-making processes.

However, the results obtained have implications on surrogate decision-making for people with ID living in residential homes in Switzerland. For relatives, legal representatives and formal carers, it is important to document the patient's wishes and values concerning end-of-life decisions to assess the decisional capacity of people with ID and to document the decision-making process. The need for family members, legal representatives and staff in residential homes to assess the decision-making capacity of the residents has been described in other studies.^{19–21} Researchers, practitioners, legal representatives and relatives have to take regular notes of the life values of residents with limited or no decision-making capacity before illness, to document life values and decision-processes including people with disabilities in end-of-life decisions even more than before.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

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Informed consent

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References

1. Haveman M and Stöppler R. *Altern mit geistiger Behinderung: Grundlagen und Perspektiven für Begleitung, Bildung und Rehabilitation* [Aging with intellectual disability: basics and perspectives for care, education and rehabilitation]. 2nd ed. Stuttgart: Kohlhammer, 2010.
2. Patja K, Iivanainen M, Vesala H, et al. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res* 2000; 44: 591–599.
3. Wagemans AMA, Van Schrojenstein Lantman-de Valk HMJ, Proot IM, et al. End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliat Med* 2013; 27(8): 765–771.
4. Wicki MT and Hättich A. End-of-life decisions for people with intellectual disability – a Swiss survey. *Int J Dev Disabil*. Epub ahead of print 10 February 2016. DOI:10.1080/20473869.2015.1107363
5. Mash E and Wolfe D. *Abnormal child psychology*. Belmont, CA: Thomson Wadsworth, 2004.
6. AAIDD AdHoc Committee on Terminology and Classification. *Intellectual disability: definition, classification, and systems of supports*. 11th ed. Washington, DC: AAIDD, 2011.
7. Salvador-Carulla L, Reed GM, Vaez-Azizi LM, et al. Intellectual developmental disorders: towards a new name, definition and framework for 'mental retardation/intellectual disability' in ICD-11. *World Psychiatry* 2011; 10(3): 175–180, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3188762/pdf/wpa030175.pdf>
8. Van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003; 362(9381): 345–350.
9. Schweizerische Akademie der Medizinischen Wissenschaften. *Medizinisch-ethische Richtlinien: Medizinische Behandlung und Betreuung von Menschen mit Behinderung* [Medical treatment and care for people with disabilities], http://www.samw.ch/dms/de/Ethik/RL/AG/d_RL_Behinderte_juni13_Web.pdf (2008, accessed 23 July 2013).
10. Schweizerische Akademie der Medizinischen Wissenschaften (SAMW). *Betreuung von Patientinnen und Patienten am Lebensende* [Care for patients at the end of life], 2013, <http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html>
11. Naef J, Hölzle-Baumann R and Ritzenthaler-Spielmann D. *Patientenverfügungen in der Schweiz: Basiswissen Recht, Ethik und Medizin für Fachpersonen aus dem Gesundheitswesen* [Advance care planning in Switzerland: basic knowledge law, ethics and medicine for professionals]. Zurich: Schulthess, 2012.
12. Bakkema N, De Veer AJE, Hertogh CPM, et al. Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study. *J Intellect Disabil Res* 2014; 58(4): 368–380.
13. Stein GL. Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges. *J Palliat Med* 2008; 11(9): 1241–1248.
14. Tuffrey-Wijne I. The palliative care needs of people with intellectual disabilities: a literature review. *Palliat Med* 2003; 17(1): 55–62.
15. Heslop P, Blair PS, Fleming P, et al. The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014; 383(9920): 889–895.
16. Emerson E and Hatton C. *Health inequalities and people with intellectual disabilities*. Cambridge: University Press, 2014.
17. Wagemans AMA, Van Schrojenstein Lantman-de-Valk HMJ, Tuffrey-Wijne I, et al. End-of-life decisions: an important theme in the care for people with intellectual disabilities. *J Intellect Disabil Res* 2010; 54(6): 516–524.
18. Bakkema N, De Veer Anke JE, Wagemans Annemieke MA, et al. Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: a national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Educ Couns* 2014; 96(2): 204–209.
19. Stein GL and Kerwin J. Disability perspectives on health care planning and decision-making. *J Palliat Med* 2010; 13(9): 1059–1064, <http://online.liebertpub.com/doi/pdfplus/10.1089/jpm.2010.0159>
20. Tuffrey-Wijne I, Whelton R, Curfs L, et al. Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliat Med* 2008; 22(3): 281–290.
21. Wicki MT. Vorsorgeauftrag und Patientenverfügung auch für Menschen mit geistiger Behinderung? [Advance care planning for people with intellectual disability?]. *Schweiz Z Heilpädagogik* 2014; 20(2): 32–38.