



## **Lay Summary**

### Medical end-of-life decisions: prevalence and trends in Switzerland

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## 1. Background

An increasing number of old and oldest-old – and generally multimorbid – persons suffers a phase of terminal illness at the end of their lives. Progress in medical therapies and treatments have strongly increased the ability to prolong patients' lives. This inevitably promotes situations, in which physicians are challenged to make decisions with an impact on the patient's survival time. Examples for such medical end-of-life decisions (MELD) were withholding potentially life-sustaining treatments or administering (potentially) life-shortening drugs. However, when it comes to the study of what doctors really do and how they decide in real end-of-life situations, reliable data is scarce and generally restricted to particular settings. For Switzerland there was only once (in 2001/02) a survey covering the general population, namely an international study assessing the prevalence of medical end-of-life decisions in six European countries: the Netherlands, Belgium (Flanders), Denmark, Sweden, Italy (Emilia-Romagna, Trento, Tuscany, Veneto) and Switzerland (German-speaking part). Our NRP 67 base project "Medical end-of-life decisions in Switzerland – prevalence and trends" aimed at providing recent data on medical end-of-life decisions in all parts of Switzerland. The coverage of all language regions is important, since it may be expected that medical end-of-life practices are based on the one hand on medical reasoning and legal context, but on the other hand also on cultural norms and attitudes of patients, relatives and attending physicians.

Over the last years, the subject of continuous deep sedation until death (CDS) has become an important focus of research and a more common practice in medical end-of-life care. CDS is the medical term used for drug-induced sleep until death. Important aspects of current debates surrounding CDS are ethical concerns about its use, intentions, risks and significance in palliative care. There is large unexplained variation in the incidence of continuous deep sedation until death across countries and care settings as well as an unexplained increase in frequency in the last 10-15 years. Preliminary results of our base study reveal this international trend by pointing out a fourfold increase of patients continuously deep sedated until death in Switzerland from 2001 to 2013. In order to fill this important knowledge gap, the Steering Committee of the National Research Program granted our application "Terminal sedation – palliative care or slow euthanasia?" within the frame of its bonus of excellence program, allowing us to enhance our base project.

In the last decade patient centered care has become more prevalent. At the same time, guiding principles in many medical settings tend to avoid redundant and/or ineffective treatments to prolong patients' life and to focus on improving quality of life in the remaining life-span instead. End-of-life care can include situations where sufficient symptom control can only be achieved using medications in dosages that may go along with a possible life-shortening effect. Here, it becomes crucial how doctors act and how the preferences of the patients and the persons involved are accounted for.



## **2. Goals of the project**

Our base project aimed at assessing valid and actual information on kind and frequency of medical end-of-life decisions in Switzerland and to compare these results between the Swiss language regions but also with those from the 2001 survey and from other European countries.

Main goal was to achieve an up-to-date clear and detailed picture of the current situation concerning end-of-life decision-making in Switzerland, to explain important variation, to unravel possible future trends and to uncover potential for optimizing decision-making processes in end-of-life care.

More specifically, the base project aimed at

- 1) giving an up-to-date assessment of the main features of end-of-life decision-making of physicians in Switzerland;
- 2) evaluating the changes in the German-speaking part of Switzerland since the hitherto only survey of this kind in 2001;
- 3) establishing for the first time comparisons between current practices in the German-, the French- and the Italian-speaking part of Switzerland and an understanding how cultural differences are reflected in the medical practice;
- 4) comparing European patterns and trends based on similar studies conducted in the Netherlands, Belgium and France;
- 5) disentangling physician / patient / cultural / regional health-care-system factors which impact on end-of-life decision-making (e.g. socio-demographic characteristics of patients and physicians).

In the prolongation project we focus on the assessment and main background characteristics of continuous deep sedation until death (CDS) to gain more insights into the specific practice and current situation of sedation in Switzerland and to explain the significant changes over time found in the base study in German-speaking Switzerland.

More specifically, for CDS practice in Switzerland we aim at

- 6) better understanding of the current practice of decision-making process in CDS;
- 7) disentangling physician / patient / cultural / regional health care system factors which affect CDS decision-making;
- 8) investigating the impact of cause of death on CDS in Switzerland;
- 9) identifying possible explanations for the change in CDS prevalence over time.



### 3. Methods

Following the structure of the 2001 international survey, the Swiss Federal Statistical Office drew between August 7, 2013 and February 5, 2014 weekly a random sample of all deaths registered among residents aged one year or older and having died not more than 180 days before registration. On this basis and under conditions of strict anonymity, the Epidemiology, Biostatistics and Prevention Institute of the University of Zurich (EBPI) mailed a four-page questionnaire to the respective death certifying physician. If the certifying physician was not the attending physician, he was asked to pass the questionnaire to the attending physician. Non-respondents received at most two reminders (last shipment on April 15, 2014).

The attending physicians were requested to complete the questionnaire and to return it to the Swiss Academy of Medical Sciences (SAMS). SAMS only passed the filled-in questionnaires to EBPI after EBPI confirmed clearing of names and addresses of the respective physicians, ensuring that completed questionnaires could never be linked to a particular physician or patient. Returning the questionnaire was regarded as implicit consent of the physician to participate in the study. The study was granted an official waiver for formal ethics committee review by the Zurich Cantonal Ethics Board (KEK-StV-Nr. 23/13).

Structure of the questionnaire: After some general questions (place of death, GP or specialist, broad cause of death group, cause of death known since when, first contact with patient, "own" patient yes or no) the questionnaire asked whether the respective death had been sudden and unexpected. If answered negatively, the case was regarded as eligible for an end-of-life decision and the physician was asked the three key questions described above and whether the patient had given an advance care directive or expressed a wish to hasten death or to provide all possible life-prolonging measures. If any of the three key questions was answered positive, further information referring to the most relevant life-shortening decision was requested. In addition to an estimation of how much life was shortened and which procedures were withheld or withdrawn, the context of the decision-making process was explored, including questions whether the physician discussed the respective end-of-life practice and, in the case of a positive answer, who initiated and who was involved in the discussion; or in case of a negative answer, which were the reasons to abstain from discussion. With two additional questions the capacity of the patient to evaluate his situation and to make an adequate decision was assessed. Eventually, the physician was asked which life-prolonging treatments were applied until the end of life and whether the patient had been deeply and continuously sedated until death. At the end of the 2013 questionnaire physician-related attributes (function and setting, sex, place and period of graduation, advanced education in palliative care and life stance) were assessed.

All data from 2001 and 2013 were weighted to adjust for age- and sex-specific differences in response rates. In addition, data from 2001 were age-standardized to the age distribution of the 2013 study sample. Weighted percentages, 95% confidence intervals and P values for the comparison of 2001 and 2013 data as well as between the three language regions were computed to show frequencies and patterns of end-of-life decisions or characteristics of patients according to end-of-life decisions. Selected end-of-life decisions and place of death were analyzed by multivariable modelling (enabling to separate the genuine effects of each determinant). Analyzed determinants were characteristics of the patient (age, sex, nationality, marital status, religious affiliation, decision capacity and broad cause of death), of the physician certifying death (function and setting, sex, place and period of graduation, advanced education in palliative care and life stance) and of the patients' place of residence (linguistic area, urban-rural).



The prolongation phase encompassed a quantitative and a qualitative study part. While the former used essentially the same methods as the base project, the latter aimed at gaining additional specific information not covered by the questionnaire of the base study, using semi-structured expert interviews and qualitative focus groups to disentangle the decision processes of CDS. More specifically, we addressed:

- a) general aspects: definition and terminology;
- b) medical aspects: indications and administration;
- c) decision-making: process and influences.



#### 4. Results

Sampling fractions for our survey were derived from deaths registered in the same season of the preceding year, with the goal to reach a sample of 5,000 questionnaires for the German-, 3,000 for the French- and 1,000 for the Italian-speaking part of the country. Thus, a 21.3% sample of deaths among residents of the German-, a 41.1% sample of the French- and a 62.9% sample of the Italian-speaking part of Switzerland was drawn and 4,998, 2,965 and 1,000, respectively, referring questionnaires were mailed. On June 11, 2014, the last completed questionnaire arrived at EBPI. In sum, 3,173 (63.5%), 1,538 (51.9%) and 617 (61.7%), respectively, questionnaires were returned.

Our first paper "*Medical end-of-life practices in Switzerland: A comparison of 2001 and 2013*" documented the high and even increasing prevalence of medical end-of-life decisions in the German-speaking part of Switzerland [Bosshard et al. 2016a]. In 2013, a total of 71.4% of all deaths in our study population were non-sudden and non-unexpected and therefore eligible for end-of-life decisions. In more than 4 of 5 non-sudden deaths (58.7% of all sampled deaths), at least one end-of-life decision was made. The greatest increase was in the use of continuous deep sedation until death, which rose from 4.7% of all deaths in 2001 to 17.5% in 2013.

In order to give more details than in the first paper and to address questions raised at the presentation during the NRP 67 Sursee workshop of October 2015, we drafted a second paper "*Medical end-of-life decisions in Switzerland 2001 and 2013: Who is involved and how does the decision-making capacity of the patient impact?*" [Schmid et al. 2016].

Cases with at least one reported MELD significantly increased from 74.5% (2001) to 82.3% (2013) of all deaths eligible for a MELD. Forgoing of life-prolonging treatment applied to 70% of eligible deaths and intensified alleviation of pain and symptoms to 63%. There was a substantial amount of combinations of different MELDs among the same case. In fact, in more of half (51.2%) of all cases eligible for an end-of-life decision in 2013 there was forgoing of life-prolonging treatment and intensified alleviation of pain/symptoms in the very same patient, challenging the prioritization of "most important" medical end-of-life decision generally used for publications.

Only a small minority of end-of-life decisions was not discussed by the involved physician (8.4%, if missing answers on the respective questions were rated as random failure and 17.8% if they were defined as "not discussed"). Except from a slight shift from health care professionals to other physicians, the proportions of persons involved in MELDs in 2013 were almost identical to those in 2001, with either patient or relatives involved. Involvement of patients however substantially varied according to patients' decision-making capability as perceived by the attending physician and compared to 2001 even slightly decreased among those rated as fully capable. Unquestionably there remains potential for further improvement in shared decision-making.

In a third publication "*Medizinische Entscheidungen am Lebensende sind häufig*" targeting at a broad audience of physicians, the results of the two first papers were summarized and compared with international prevalence data [Bosshard et al. 2016b]. This comparison showed that in 2013 in Switzerland more deaths eligible for MELD were preceded by at least one specific end-of-life practice than in virtually all studies from other countries. MELD prevalence, however, showed substantial variation between the German-, the French- and the Italian-speaking regions of Switzerland [Hurst et al. 2017, "*Medical end-of-life practices in Swiss language regions*", submitted]. Obviously, cultural differences can lead to significant variation in MELD prevalence



within the same legal context. However, cultural differences were mediated by patient- and physician-related characteristics and settings impacting on MELD and shared decision-making [Bopp et al. 2017, to be submitted].

Practice of CDS and healthcare professionals' emotional well-being were analyzed performing a systematic review of literature published between January 1990 and October 2016, using seven databases [Ziegler et al. 2017a, *"The impact of the inpatient practice of continuous deep sedation until death on healthcare professionals' emotional well-being: A systematic review"*, submitted].

In view of the vast increase in CDS prevalence between 2001 and 2013 we looked for possible determinants of CDS in Switzerland in our survey data and summarized the results in a paper [Ziegler et al. 2017b, to be submitted]. For better understanding what professionals really intend and how they decide about CDS, the quantitative results will be further valorized with the results of qualitative expert interviews and focus groups.



## **5. Significance of the results for science and practice**

In medical end-of-life decision-making different experiences and attitudes of physicians, patients and relatives come into collision with each other. On the basis of the presented empirical data, this study contributes important, updated, and detailed knowledge about current medical end-of-life decision-making in Switzerland and its variation within the country. This enables a research-based rational and objective discussion among healthcare professionals, those involved in health policy and the general public and supports an increased awareness of ethical aspects in the field of MELD.

Our findings confirm that MELDs precede a majority of deaths occurring in Switzerland, and that the frequency of MELDs is increasing. This can be understood as a decrease of “unreasonable obstination” and thus as progress in end-of-life care. This trend may require a consolidation of healthcare professional training regarding the management of end-of-life decisions. In particular, the inclusion of patients in these decisions should be further encouraged. In view of the increase also observed in the prevalence of assisted suicide, such training may need to include content designed to help professionals respond to patients who request such assistance, in a manner respectful of both patient requests and needs and professionals’ own positions regarding voluntary death.

In addition to earlier studies that focussed on one decisive MELD, the current study provides evidence that MELDs are more often combined than single decisions. The increase in MELD prevalence holds for decisions to withhold or withdraw life-sustaining treatment as well as for decisions to provide or administer medications with the explicit intention of hastening death. It comes as no surprise that the latter is basically substantiated in a significant increase of assisted suicide. However, whereas the discussion on the legal status of assisted suicide, its limits, and the role of medicine in this field in Switzerland is already established, our study points to another ethically challenging field at the end of life that has largely been ignored by policy-making and medical guidelines out of the network of specialized palliative care so far: continuous deep sedation until death (CDS). The base study found an almost four-fold increase of this practice,. Our findings raise an important policy question as there are on-going ethical debates about the importance to clearly differentiate CDS from possibly life-shortening end-of-life decisions. Our results highlight the importance of enhancing discussions about CDS between internal, intensive-care medicine, and palliative healthcare professionals.



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