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# Availability of advance directives in the emergency department

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## **Summary**

BACKGROUND: Emergency departments (EDs) are crowded with critically ill patients, many of whom are no longer able to communicate with the emergency staff. Substitute decision makers are often unknown or not reachable in time. The availability of advance directives (ADs) among Swiss ED patients has not yet been evaluated. The purpose of this prospective survey was to investigate the prevalence of ADs among ED patients and to identify factors associated with the existence or absence of ADs.

METHODS: In a prospective survey, we enrolled consecutive patients from 10–30 July 2017 who visited a tertiary care ED. Patients completed a written, standardised and self-administrated questionnaire during the waiting time. The primary endpoint was the prevalence of ADs in ED patients. Secondarily, we defined predictors associated with the existence or absence of ADs. Two months after the first survey, there was a written follow-up survey asking patients without ADs whether they had completed an AD in the meantime.

RESULTS: Fifty-eight of 292 enrolled ED patients (19.9%) had a completed AD. Overall, 49.3% of the survey population was female. Patients having an AD were older (69.5 years, interquartile range [IQR] 57-81 vs 39 years, IQR 27–56) and had more comorbidities (67.2% vs 38.9%) compared with patients without ADs. The four leading reasons given for not having an AD were: 33.6% never considered completing one, 26% did not know about ADs, 14% preferred family to make decisions, 11.6% felt it was too early to make such a decision. Predictors for having an AD were older age (p <0.001), being in long-term medical treatment by a specialist (p = 0.050), being Swiss (p = 0.021) and living with nursing care (p = 0.043). Of the ED patients with ADs, 46.6% discussed their AD with the family and 31% with their general practitioner. Results of the follow-up survey showed that eight participants had completed an AD in the meantime. The prevalence of ADs increased from 19.9% to 22.6%.

DISCUSSION: During the last 20 years, the percentage of patients having an AD has not changed. Even today, only every fifth ED patient has a completed AD. Nearly two thirds of ED patients never considered completing one

or did not know about ADs. Therefore, there is an urgent need to better inform and sensitise the public, so that they will define in a timely manner legally valid and specifically defined decisions about future medical treatments and wishes by completing individual directives.

**Keywords**: advance directives, prevalence, emergency department, prospective survey

#### Introduction

Emergency departments (EDs) are crowded with critically ill patients, many of whom are no longer able to communicate with the emergency staff. Emergency physicians often treat patients in the ED for the first time and are unaware of patients' values and beliefs regarding end-of-life care. In emergency situations, substitute decision makers are too often unknown or not reachable in time. Therefore, advance directives (ADs) clearly defining patients' values and beliefs regarding end-of-life decisions are indispensable, especially for patients who are incapacitated or in a life-threatening situation. Even when patients have an AD, they are often not available in emergencies [1, 2]. Life-threatening situations occur daily in the ED. Therefore, it would be helpful if clear directives were available [3, 4]. Nevertheless, there are some difficulties in interpreting ADs, because many of them are not complete or do not indicate clear treatment strategies [1, 2, 5, 6]. In 2004, Fagerlin et al. even suggested that ADs had failed in their aim because they are too general and superficial [2]. The authors called for abandoning the living will in its classic style and recommended more specific and individually designed forms of AD (e.g., questionnaires) [2]. Independent of age and health status, people need to clearly document end-of-life decisions in an AD or any other form, and discussing them beforehand with relatives and/or general physicians is of great advantage. Thus, ADs are essential documents for protecting patient autonomy and providing

Nevertheless, ADs are still infrequently completed and the proportion of people having an AD ranges from 5% to 25% [5–10]. As a result of national public work, the number of ADs has increased from 26% to 46% in Germany since 2012 [11]. In Switzerland, two out of three adults are informed about Ads, but only 22% of those surveyed had signed such a document [12]. Increased age or need of hos-

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pital admission in the past year led to increased prevalence of ADs up to 50% in these sub-populations [8, 9, 12]. Intensive care patients show a prevalence of ADs (29.7%) similar to the general population, but in only one third were the ADs stored in medical records [13]. Furthermore, every second AD was incorrectly completed or the content was difficult to interpret [13]. In summary, the literature about ADs is focused mainly on elderly, and intensive- or palliative-care patients [5, 8, 9, 12].

There is greater likelihood of having an AD among ED patients if they are older, have a poorer health status, are widowed, and have children and a primary care provider [14]. Nevertheless, there is still too little knowledge regarding the prevalence of ADs among ED patients. Twenty years ago a survey conducted in the USA on the prevalence of ADs in the ED showed that 77% of ED patients did not have one [3]. In a 2003 survey in Australia, only 7.9% of general ED patients had a completed AD [15]. In 2012, Gill et al. found a similar prevalence of ADs of 19.3% in an urban Canadian ED [16]. To our knowledge, no reliable data about the prevalence of ADs in Swiss EDs is available. Therefore, the aim of the prospective survey was to investigate the prevalence of ADs among Swiss ED patients, to determine the reasons for not having an AD and to identify factors associated with the existence or absence of an AD.

#### Methods

In a prospective survey, from 10 to 30 July 2017 we enrolled consecutive patients who visited a Swiss tertiary care ED. The period for patient enrolment was established a priori as follows: one week from 8:00 to 18:00, one week from 14:00 to 23:00 and the final week from 23:00 to 8:00.

Two months after the index survey in the ED, we contacted patients without an AD by email for a follow-up survey and asked them whether they had now completed an AD, and if not, we asked again about the reasons for non-completion.

All patients included were aged 18 or older and had completed a written, standardised and self-administrated questionnaire during the waiting time in the ED. Patients were excluded if they were less than 18 years old, had language barriers, refused to participate, had cognitive difficulties and diseases that might yield unreliable answers or were unable to read and/or write.

The study was presented to the local ethics committee. Ethics approval was not needed according to the Swiss legal requirements and current version of the World Medical Association Declaration of Helsinki.

#### Survey settings

The survey was performed in a tertiary care ED with an annual intake of nearly 45,000 adult patients suffering from various disorders of differing severity (e.g., from internal medical problems, surgical to urological disorders, head injuries and/or (poly-)trauma cases). The ED offers a full interdisciplinary and interprofessional emergency service around the clock. The catchment area of the ED is the greater region of Zurich and it covers highly specialised services for patients with indication for centre transfer, such as head trauma or transplant patients, in nearly the entire German-speaking area of Switzerland.

The prospective survey was conducted by a medical master's degree student in collaboration with a well-trained ED research physician. The medical master's student was present in the ED from Monday to Friday.

The student contacted all ED patients during their waiting time in the ED. All patients enrolled were given a written survey to answer, comprising a paper-based, standardised and easily self-administered questionnaire. The time to complete the questionnaire was about 15 minutes. During this time, the student was readily available for any questions, assistance and support.

The questionnaire was based on a previously developed and validated questionnaire and translated from English into German by a qualified translator [16]. The questionnaire contained demographic parameters that were personrelated such as age, gender, nationality, family status, level of education and living situation (appendix 1). After this general part, the survey focused on the following: knowledge and availability of ADs; who among relatives and/ or general physicians were informed about the presence of an AD; who had been involved in the decision-making process; whether patients took the AD along to the ED or in the event of hospital admission; when the patients had completed the AD (<6 months, 6-12 months or >12months ago), and whether it had been revised in the past. Furthermore, reasons for not having an AD were assessed: knowledge of what an AD is, but never considered completing one; no knowledge regarding the AD; a need for more information; preference that the family decides if it is needed; premature for such a decision; an AD is present at home and there are plans to sign it; concern that not every possible medical treatment would be carried out if an AD was signed; concern that the wishes spelled out in the AD would not be respected, and finally, no AD for religious reasons. Participants were also asked for possible reasons for completing an AD in the future: the right of self-determination, recommendation by relatives/family, as a means to determine one's final stage in life or to end a period of prolonged and undesirable suffering.

Additionally, we evaluated whether patients without an AD would complete one after the current survey, and if they were willing to participate in a follow-up survey two months after this index survey.

Two months after the index survey in the ED, all patients who did not initially have an AD and who had indicated their willingness to participate in the follow-up survey were contacted. All patients were contacted by email for the follow-up survey (appendix 2), and were asked whether they had completed an AD in the meantime, and if not, what the reasons were for not completing one.

#### **Endpoints**

The primary endpoint was the prevalence of ADs among ED patients. Secondarily, reasons for not having an AD were evaluated and predictors associated with the existence of ADs were identified.

The follow-up survey provided information about the effect of the primary survey on the prevalence of ADs over the passage of time by reporting the number of completed AD 2 months following the index survey in the ED. Reasons for not completing an AD in the meantime were evaluated.

#### Statistical analysis

The distributions of variables were expressed as means and standard deviations (SDs) for normally distributed data and medians and interquartile ranges (IQRs) for non-normally distributed data. Data were tested for normality with the Kolmogorow-Smirnow test and quantile-quantile plots of dependent variables were created.

The primary endpoint (number of ADs), categorical characteristics and question answers were presented as proportions.

For the predictor analysis, we defined a priori a cut-off for age of  $\geq$ 65 years, according to the most commonly used definitions of seniors, namely the arbitrary use of the age of retirement at 65 years [5].

To identify predictors for having ADs, a stepwise backward regression analysis was used. Subsequently, univariate and multivariable logistic regression analyses, adjusted for potential confounders such as age, gender and comorbidities, was performed. The potential confounders were a priori defined according to the literature and clinical expertise.

For all results, we reported point estimates, 95% confidence intervals (CIs) and p-values (<0.05 considered significant). We conducted the statistical analyses using the statistical program STATA SE (version 15, Stata Corp., College Station, Texas).

#### Results

For the survey, 417 patients were potentially evaluated. Seventy-nine patients (18.9%) were excluded for several reasons: language barrier, lack of time during the waiting period in the ED, or recommendations not to perform the survey by the treatment team because of severe or even

life-threatening health conditions. Additionally, 46 patients (11.0%) refused participation in the survey and were therefore excluded. Finally, we enrolled 292 ED patients fulfilling the inclusion criteria during the 3 weeks of the study period.

Fifty-eight of 292 enrolled ED patients (19.9%) had a completed AD. The remaining 234 ED patients did not have an AD. Nearly half of the survey population (49.3%) was female. Patients having an AD were in general older (median 69.5 years, IQR 57–81 vs 39 years, IQR 27–56), had more comorbidities (67.2 vs 38.9%), especially more often an underlying malignant disease, and had a median number of hospital stays during the previous 12 months one greater than the patients without ADs (table 1).

Patients having an AD were more often Swiss (72.4 vs 56.4%), had more children (median 2, IQR 0–2 vs 0, IQR 0–2) and were less often single (22.4 vs 48.3%) compared with patients without ADs (table 1). There were similar distributions of the education level and living situation between both groups. Patients with an AD had a general practitioner less often (57.9 vs 80.8%) but more often a medical specialist such as an oncologist or cardiologist (67.2 vs 37.2%) (table 1).

Table 2 presents survey results of the patients with ADs. Three-quarters of the patients had signed the AD more than 12 months ago. They had discussed it mostly with family members (46.6%) or their general practitioner (31.0%). Patients commonly completed ADs in the presence of friends (51.7%) or relatives (32.8%). Seventeen patients (29.3%) with an AD had revised it in the past.

Only one patient had taken the AD to the ED, whereas 19% stated they would take it when planning a hospital admission (table 2).

Table 1: Participants' characteristics.

			All participants n = 292	No advance directive n = 234 (80.1%)	Having advance directives n = 58 (19.9%)
Age (years)			46 (29–63)	39 (27–56)	69.5 (57–81)
Sex (female) (%)			144 (49.3%)	112 (47.9%)	32 (55.1%)
Comorbidities (%)		130 (44.5%)	91 (38.9%)	39 (67.2%)	
Malignant disorder (%)			17 (5.8%)	11 (4.7%)	6 (10.3%)
Number of hospital admission	s during the last 12 months		0.5 (0-1)	0 (0–1)	1 (0–2)
Sociodemographics	Nationality (%)	Swiss	174 (59.6%)	132 (56.4%)	42 (72.4%)
		Other	99 (33.9%)	90 (38.5%)	9 (15.5%)
		Double nationalities (incl. Swiss)	19 (6.5%)	12 (5.1%)	7 (12.1%)
	Number of children	Number of children		0 (0–2)	2 (0–2)
	Civil status (%)	Single	126 (43.2%)	113 (48.3%)	13 (22.4%)
		Married	123 (42.1%)	94 (40.2%)	29 (50%)
		Divorced	27 (9.2%)	19 (8.1%)	8 (13.8%)
		Widowed	16 (5.5%)	8 (3.4%)	8 (13.8%)
	Education level (%)	Academic	136 (46.6%)	106 (45.3%)	30 (51.7%)
		Professional honour	116 (39.7%)	95 (40.6%)	21 (36.2%)
		None	40 (13.7%)	33 (14.1%)	7 (12.1%)
	Housing (%)	Living with others	171 (58.6%)	140 (59.8%)	31 (53.4%)
		Living alone	90 (30.8%)	69 (29.5%)	21 (36.2%)
		Supervised living	7 (2.4%)	1 (0.4%)	6 (10.3%)
		Other	24 (8.2%)	24 (10.3%)	0%
	General practitioner (%)		240 (82.2%)	189 (80.8%)	51 (57.9%)
	Being in a long-term medical treatment by a specialist (%)		126 (43.2%)	87 (37.2%)	39 (67.2%)
Results were reported as med	dian (25th-75th percentile)	1		•	•

The five leading reasons for not having an AD were as follows: 33.6% knew what an AD is, but have never considered completing one, 26% did not know about ADs, 14% needed more information, 14% preferred that the family makes the decision and 11.6% indicated it was too early to make such a decision (table 3). Other reasons for not having an AD are presented in table 3. Overall, there was a similar distribution of reasons between gender, comorbidity and nationality groups. Nevertheless, some interesting differences could be detected. Of 76 participants who "did not know about ADs" (table 3), 59.2% were male and 40.8% were female. Another difference was evident in the reason "prefer family to make the decision": 26 of 41 patients (63.4%) were Swiss compared with 36.6% non-Swiss. Nineteen patients reported that they had an AD at home and had planned to sign it (table 3). Interestingly, 13 of these 19 patients (68.4%) were younger than 65 years. Eleven of these 13 patients were between the ages of 55 and 65.

Patients were asked for potential reasons for completing an AD in the future. The majority of participants indicated they would sign ADs to protect their right of self-determination (39.4%), to determine the final stage in life (23.6%) or to stop prolonged and undesirable suffering (18.8%). Twenty-one participants would sign an AD only if relatives were to recommend it (7.2%) or if they had experienced a "bad" hospital stay (0.7%).

Factors associated with an increased likelihood for ADs are presented in table 4. Predictors for having an AD were older age (p <0.001), being Swiss (p = 0.021), being in long-term medical treatment by a specialist (p = 0.050), and in the situation of supervised living with nursing care (p = 0.043) (table 4).

Overall, 125 of the 234 patients initially without an AD were willing to participate in the follow-up survey 2 months after the index survey in the ED. Two months later, of these 125 patients contacted, 54 patients (43.2%) completed the follow-up survey. Eight participants had com-

Table 2: Survey results for patients having advance directives.

		Having advance directives n = 58 (19.9%)
Fime since advance directive signed	<6 months	6 (10.3%)
	6–12 months	8 (13.8%)
	>12 months	44 (75.9%)
Advance directive discussed with:	Family	27 (46.6%)
	General practitioner and family members	18 (31.0%)
	Pro Senectute*	6 (10.3%)
	Alone	4 (6.9%)
	Friends	3 (5.2%)
Advance directive <b>completed</b> with:	Friends	30 (51.7%)
	Family members	19 (32.8%)
	General practitioner	4 (6.9%)
	Alone	4 (6.9%)
	General practitioner and family	1 (1.7%)
Advance directive taken along to the emergency department visit		1 (1.7%)
In general, advance directive taken along when admitting to hospital		11 (19.0%)
Advance directive taken along every time		1 (1.7%)
Places where advance directive can be found	At home	28 (48.3%)
	In the hospital	5 (8.6%)
	In the organisation for accompanied suicide	1 (1.7%)
	No answers	24 (41.4%)
Revision of advance directive in the past		17 (29.3%)
ast revision	<6 months	6 (10.3%)
	6–12 months	4 (6.9%)
	>12 months	7 (12.1%)

<sup>\*</sup> Pro Senectute is a social service of the canton Zurich (Switzerland) informing, supporting and advising the senior population and their relatives.

 Table 3: Reasons for not having a signed advance directive.

	All participants n = 292
Knowing what an advance directive is, but have never considered completing one (%)	98 (33.6%)
Not knowing about advance directive (%)	76 (26.0%)
Need for more information (%)	41 (14.0%)
Family shall decide in case if it is needed (%)	41 (14.0%)
Too early for such a decision (%)	34 (11.6%)
Advance directive is at home, plan to sign it (%)	19 (6.5%)
Fear that not every possible medical treatment will be done if advance directive is signed (%)	9 (3.1%)
Fear that the wish will not be respected (%)	7 (2.4%)
No advance directive due to religious reasons (%)	1 (0.3%)

More than one answer was possible

pleted an AD in the meantime. Finally, the first survey in the ED had the effect of increasing the prevalence of AD from 19.9% to 22.6% (66 of 292 patients). The remaining 46 patients in the follow-up survey reported different reasons for not having completed the AD. The majority responded as follows: 11 patients had an AD at home but had not had time to complete it; 9 patients considered it too early to make such a decision; 9 other patients planned to complete one but had forgotten about it in the meantime and the course of everyday life. Additional causes, such as preference for the family making the decision, need for more information, still not having thought about it, were rarely mentioned.

## Discussion

The prevalence of ADs among ED patients was not high (19.9%). The effect of the first survey resulted in an increase of the prevalence of ADs by 2.7% within 2 months. Almost 60% of the participants did not have ADs because they had never considered completing one or did not know about it. Increased age, Swiss nationality, being in long-term medical treatment by a specialist or living with nursing care increased the chance of possessing an AD defining the patient's values and beliefs.

The last study in the US focusing on the prevalence of ADs in the general ED population was 20 years ago [3]. In Australia in 2004, the prevalence of ADs in the general ED population was even lower (7.9%) than in our study [15]. In 2012, Gill et al. published similar rates of ADs (19.3%) in the elderly urban Canadian ED population [16]. Further information on ADs in the ED was published in 2012 and focused only on senior or palliative care ED patients [17, 18]. Our findings show that after many years without any substantive research on ADs in the general ED population, only every fifth ED patient has completed an AD. Even though ADs are still infrequent among ED patients, we were able to show that after sensitisation and education by means of a simple survey, it is possible to increase the prevalence of ADs.

In older patients, the prevalence of ADs is higher than in the general ED population, ranging from 40% to 50% [3, 17, 19, 20]. In our survey, the prevalence of ADs among older patients (60.3%) was also higher and similar to other published data [17, 19, 20]. Older age (≥65 years) was identified in a review by Oulten et al. as a factor associated with an increased likelihood of ADs among ED patients [14]. In our survey, increased age ≥65 years was also identified as a predictor for having an AD. These findings are consistent with the literature focusing on the sub-popula-

tion of elderly ED patients [3, 18–20]. Furthermore, we were able to identify more factors associated with an increased likelihood of ADs in the general ED population than have been described in the literature [3]. These factors were nationality, being in long-term medical treatment by a specialist, or living in supervised accomodation with nursing care. The latter two factors especially, "being in a long-term medical treatment by a specialist" and "supervised living with nursing care", may imply that patients in our population having an AD are also at high risk, in the sense of having more comorbidities, being more ill and older. These findings corroborate the literature [3, 14].

ED patients at high-risk, such as those receiving palliative care or suffering from severe chronic diseases, have also shown an increased rate of completed ADs (23-44%) [3, 18-20]. Predictors of having an AD among senior ED patients were identified by Oulten et al.: having children, being widowed, of the Caucasian (white) race, having a general practitioner or suffering from a poor health status [14]. In our senior ED population of 68 seniors, the stepwise backward regression model was not able to identify any factor associated with an increased likelihood of ADs because the sample of senior ED patients was too small. However, our general ED population showed in a descriptive analysis that patients with an AD more often had children, and were more often widowed or suffering from malignant diseases. None of these factors could be identified by the statistical model as a factor that is associated with the possession of an AD as they are identified among senior ED patients [14].

In 1999, Llovera et al. reported for the first time that 39% of ED patients without an AD had "never thought about it before" [3]. Twenty years later, the most common reason for not having an AD in our study was that patients knew what an AD is but did not consider completing one. Twenty years of education and public work have not improved the rate of signed ADs nor the knowledge about ADs. In the past, several studies found that putting off AD completion was a severe problem [3, 6, 19, 21, 22]. Rates for procrastination ranged from 30% to 45% [3, 6, 19, 21, 22]. Procrastination seems to have decreased significantly over the last 20 years. In our study, only 6.5% of our participants reported "to have an AD at home and plan to sign one". Reasons for such a difference in procrastination between the literature and our survey may be that our study population was in median much younger, had fewer chronic diseases, were more often at low risk and represented a general population. By contrast, previous studies have focused on seniors, patients at high risk (e.g., in a palliative situation with a malignant disease or acquired immune de-

Table 4: Factors associated with an increased likelihood for having an advance directive.

	No advance directive n = 234	Having advance direc- tives n = 58	Unadjusted OR (95% CI, p-value)	Adjusted OR (95% Cl, p-value)
Senior ≥65 yrs.	33 (14.1%)	35 (60.3%)	9.3 (4.9–17.6, p <0.001)	7.9 (4.1–15.3, p <0.001)
Swiss nationality (%)	132 (56.4%)	42 (72.4%)	3.4 (1.6–7.3, p = 0.002)	2.6 (1.2–6.2, p = 0.021)
Being in long-term medical treatment by a specialist (%)	87 (37.2%)	39 (67.2%)	3.5 (1.9–6.4, p <0.001)	2.1 (1.0–4.5, p = 0.050)
Supervised living (%)	1 (0.4%)	6 (10.3%)	26.9 (3.2–228.1, p = 0.003)	11.5 (1.1–122.2, p = 0.043)

CI = confidence interval; OR = odds ratio, Results were adjusted for age, sex and presence of comorbidities

ficiency syndrome) or patients in intensive care units [5, 8, 9, 12, 13, 19]. The third most frequent reason indicated in our study for not having an AD was "prefer that the family makes the decision". These findings are similar to the literature [6, 22–24].

In the literature, a wide range of 5–65% of patients discussed the AD with their general practitioners [3, 10, 19, 25]. We found that almost every third person among our ED patients had discussed the AD with the general practitioner. Finally, patients mainly completed the AD in the presence of friends and relatives. Only four patients in our study had signed and completed the AD in the presence of a general practitioner.

The current survey reports the prevalence of having signed a valid AD and shows that only one among 58 patients with a signed AD had brought the AD to the ED. Classic ADs are indeed essential legal documents designed to protect patients' autonomy aa living will, but their interpretation is often insufficient and incomplete, especially in connection with emergency situations. Therefore, clearly stated treatment wishes and individually defined directives are needed for the ED. Already in 2004, Fagerlin et al. called for more specific and individually designed forms for ADs [2]. For patients, their relatives and ED physicians, as well as from an ethical point of view, it is more important to focus on clarifying the goals of care and describe in detail patient end-of-life medical care wishes than "just" to sign a last living will [26]. In Switzerland, the law does not define the content of ADs. Various documents are available, without specifying any further treatment concepts or giving concrete medical measures. Therefore, individually defined goals in advance care planning are essential in order to know patient's medical care wishes and how to proceed in difficult situations (e.g., in the ED, post-surgically and during an intensive care unit stay). Furthermore, repetitive evaluations and continuous adjustment of these individually reported goals are important and clearly recommended by the current research group.

## Strength and limitations

Our study has several limitations. Because of limited staff resources (master's student thesis) and the survey settings, we were not able to consecutively enrol all ED patients during the 3 weeks of observation. Additionally, critically ill patients and many patients with language barriers often had to be excluded. Nevertheless, the survey findings are similar to the scant existing literature on general ED patients and are therefore generalisable.

Another limitation is the response rate in the follow-up study. Of 234 patients without ADs, 125 respondents (53.4%) agreed to participate in the follow-up study. In the end, 54 of the 125 participants contacted completed the second survey. The response rate of 43.2% in the follow-up survey is not an excellent result, albeit still higher than the common reported response rate (about 20%) for postal questionnaires [27].

A strength is the prospective design and the enrolment during three different ED work shifts. Owing to the active onsite presence of the study team during enrolment, we had no missing data and all survey forms were fully completed. Another important strength is the follow-up survey, which led to an increase in the rate of ADs and suggested that work to raise public awareness and provision of information may change people's opinions. Further prospective investigations are needed to evaluate the effect of such public informational enhancement activity. A further strength was the multivariable regression model identifying possible factors associated with an increased likelihood of ADs.

#### Conclusion

Comparison of our data with the literature show that over the past 20 years the percentage of patients having an AD has not basically changed. Our study showed that only one in every five ED patients has a completed AD. Nearly two thirds of ED patients had never considered completing an AD or did not know about ADs. Therefore, there is an urgent need to better inform and sensitise the public to define legally valid decisions in a timely manner regarding future medical treatment and wishes by completing ADs.

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#### Potential competing interests

No conflict of interest was reported.

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Appendix 1

Original questionnaire

Appendix 2

## Follow-up questionnaire

The appendices are available as separate files at:  $\label{lem:https://smw.ch/article/doi/smw.2020.20184}.$