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Advance directives and real-world end-of-life clinical practice: a case–control study

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ABSTRACT

Background Advance directives (ADs) have been legally regulated to promote autonomy over health decisions among patients who later lose decision-making capacity.

Aims and objectives To analyse the differences in clinical practice at end of life among people who had completed an AD versus those who had not.

Methods Retrospective case–control study (1:2), matched by age, sex, year, cause of death and region of residence. The data sources used were the ADs registry, central registry of insured persons, hospital discharge, pharmacy and billing databases, and the mortality registry. Conditional logistic regression models (crude and adjusted by socioeconomic level) were performed. The outcome variable was the frequency of medical procedures performed during the last year of life.

Results 1723 people with ADs who died in Catalonia during 2014–2015 were matched with 3446 dead controls (without ADs). Thoracentesis was the procedure with the greatest reduction among women with an AD (adjusted OR (OR_{adj}) 0.54, 95% CI: 0.32 to 0.89) in conjunction with artificial nutrition (OR_{adj} 0.54, 95% CI: 0.31 to 0.95). Intubation was the procedure with the greatest reduction (OR_{adj} 0.56, 95% CI: 0.33 to 0.94) among men. Slight differences could be seen in the case of cancer deaths. There were no relevant differences when adjusting by socioeconomic level.

Conclusions ADs are an effective tool to adjust the realisation of some procedures at end of life. These results can help better plan for the treatment of patients with ADs, as well as increase the awareness among clinical personnel, families and the general population.

INTRODUCTION

Many countries have enacted laws that recognise advance directives (ADs) as the legal instrument that can best ensure an individual's wishes regarding

Key messages

What was already known?

- ▶ Advance directives (ADs) have been legally regulated to promote autonomy over health decisions among patients who later lose decision making capacity.
- ▶ Earlier studies on ADs have been carried out examining the clinical record or by means of surveys, not using population-based registries.

What are the new findings?

- ▶ Patients who died and had written an AD received invasive or life-sustaining procedures less frequently than persons who died without completing an AD.
- ▶ This paper has analysed individual information from more than 5,000 people (1,723 with ADs), one of the largest samples analysed so far.

What is their significance?

- ▶ These results can help better planning of the treatment of patients with ADs, as well as increasing the awareness of ADs, as is an indication that some part of society makes end-of-life decisions in advance.

life-sustaining medical treatment are respected when decision-making capacity is lost, and that can elect a surrogate decision-maker. Therefore, ADs are a guard against unwanted and often futile interventions that only prolong the dying process, and so help to relieve anxiety about loss of control and the burdens that can fall on others during end-of-life healthcare.¹

Defining the level of healthcare resources that a person needs at the end of their life does not involve only the aspects related to their clinical situation, but must depend on many other factors—such as socioeconomic (SEC) status, availability of family and social support, and personal values and wishes—which are

generally difficult to evaluate and are rarely taken into account. Moreover, since the percentage of patients who have written ADs is usually small, it makes it more difficult to take them into account. Undoubtedly, knowing the values and desires of the patient through advance planning allows for much more individualised and respectful care. Recently, advance care planning, a complex process that includes not only ADs, but also personal reflection and discussion with clinicians about the patient's wishes, the appointment of a healthcare representative and changes to the healthcare system, has increasingly been considered.² The effects of different types of advance care planning have been studied in various settings and populations, and there is evidence that it positively impacts the quality of end-of-life care.^{3,4}

At the end of the year 2000 in Catalonia, and in 2002 in the rest of Spain, laws that allow citizens to draw up an AD were approved.^{5,6} Two years later, and to grant a certain security, a non-compulsory registry for these types of documents was established. Approximately 44.4% of the population admits to knowing about the option to complete an AD, and 63.1% express their willingness to do so.⁷ However, it is a scarcely used resource and only 2% of the Catalan population has an AD in place.⁷ Internationally, completion rates are higher for older Americans (up to 70%) and Australians (30%),^{1,8–10} much lower in Germany,¹¹ the Netherlands¹² and the UK,¹³ with rates between 8% and 10%, respectively, and even lower uptake of ADs has been reported in other nations such as Spain¹⁴ and China.¹⁵

Despite the desire for ADs, earlier studies have shown that they are not as effective as thought.^{16–18} However, most of these studies have been carried out examining the clinical record or by means of surveys, not using population-based registries.

The objective of this study is to assess the impact of ADs on clinical care at the end of life, analysing the differences in the use of medical procedures during end-of-life care among patients who had completed ADs compared with those who had not.

METHODS

A retrospective matched case–control study was designed, assigning two controls per case (1:2). The cases were those people who had completed an AD and died in Catalonia during 2014 and 2015; controls were selected in two steps from people who died during the same period, but without any ADs: first, by matching criteria for the variables age, sex, region of residency and cause of death; second, by randomly selecting two controls in each combined matching variables. The variables included in the analysis were sociodemographic (age, sex, region of residency and SEC level), cause of death (see online supplementary appendix 1) and medical procedures performed

during the last year of life (see online supplementary appendix 2).

The sources of information were the central registry of insured persons, the hospital discharge, pharmacy and billing databases, and the mortality registry. SEC level, the adjustment variable, was defined according to the information obtained from the levels of pharmaceutical co-payment, which is calculated according to personal income (or, if appropriate, according to the Social Security benefits received): exempt from co-payment, <€18 000, €18 000–100 000 or >€100 000. These four categories were renamed to very low SEC, low SEC, medium SEC and high SEC. Data from the different sources were merged in an anonymised way using the unique healthcare ID.

A descriptive analysis was performed with frequencies and percentages for both cases and controls, stratifying by sex. X^2 tests were calculated to determine associations between cases and controls for sociodemographic variables. Next, conditional logistic regression models were carried out where the dependent variable was the medical procedures performed during the last year of life. ORs, as a measure of association with a 95% CI, are presented as crude and adjusted values by socioeconomic level (OR_{adj}). A previously agreed subgroup analysis was performed for the patients whose cause of death was cancer.

All analyses were carried out with the statistical program STATA V.14.2 SE. The results with a p value of <0.05 were considered statistically significant.

RESULTS

In Catalonia between 2014 and 2015, 125 185 people died. Of those, 1723 (1.4%) had an AD, representing all the cases analysed in this study. From the same pool of deceased individuals, 3446 matched controls were chosen. Regarding the cause of death, cancer represents the highest percentage of ADs (42.7% among women and 48.1% among men), followed by circulatory system cause of death (30.0% and 27.7% among women and men, respectively) (table 1). Regarding the SEC level, there were statistically significant differences between people who had completed an AD and those who had not, with the former having a higher SEC level (table 1).

For both sexes, the frequencies of the selected procedures performed during the last year of life were lower among people who died having an AD in place versus those who did not have one (online supplementary table S1). After adjusting by SEC level, the estimates did not change, and the explained reduction remained statistically significant (table 2).

Considering that there were differences regarding the SEC level between cases and controls, adjusted models were applied to know the effect of ADs in the analysed procedures. Regarding women, the procedures with statistically significant reductions were surgery, artificial nutrition, endoscopy, blood transfusions,

Table 1 Sociodemographic characteristics of ADs patients and control patients by sex

Variable	Women		Men		P value	Cases (786)		Controls (1.575)		P value
	Cases (n=937)	Controls (n=1.871)	Cases (786)	Controls (1.575)		N	%	N	%	
Age (years)										
<65	122	13.02	248	13.25	0.99	100	12.72	199	12.63	0.99
65–74	133	14.19	267	14.27		154	19.59	309	19.62	
75–84	216	23.05	425	22.72		220	27.99	437	27.75	
85 and over	466	49.73	931	49.76		312	39.69	630	40.00	
Socioeconomic (SEC) level										
Very low SEC	77	8.22	155	8.28	<0.001	43	5.47	75	4.76	<0.001
Low SEC	610	65.10	1425	76.16		419	53.31	1102	69.97	
Medium SEC	243	25.93	279	14.91		297	37.79	384	24.38	
High SEC	7	0.75	12	0.64		27	3.44	14	0.89	
Cause of death										
Cancer	400	42.69	799	42.70	0.99	378	48.09	761	48.32	0.99
Mental diseases	43	4.59	86	4.60		27	3.44	56	3.56	
Nervous system	93	9.93	185	9.89		62	7.89	123	7.81	
Circulatory system	281	29.99	564	30.14		218	27.74	434	27.56	
Respiratory system	89	9.50	176	9.41		83	10.56	165	10.48	
Kidney diseases	31	3.31	61	3.26		18	2.29	36	2.29	

ADs, advance directives.

thoracentesis, transfers to other centres and visits to the emergency department. Thoracentesis was the procedure with the greatest reduction among women, with an AD (OR_{adj} 0.54, 95% CI: 0.32 to 0.89), in conjunction with artificial nutrition (OR_{adj} 0.54, 95% CI: 0.31 to 0.95). Regarding men, the procedures with statistically significant reductions among those who had an AD were fewer than in women, and included mechanical ventilation, visits to emergency department and intubations, with the latter having the greatest reduction (OR_{adj} 0.56, 95% CI: 0.33 to 0.94).

For the people who died of cancer, statistically significant reductions were observed for women in procedures such as surgery, ostomy, endoscopy, thoracentesis and visits to emergency departments, with a greater reduction than those observed in all causes of death analyses (table 3 and online supplementary table S2). The highest reduction was for ostomy, with 84% less use (OR_{adj} 0.16, 95% CI: 0.03 to 0.79), followed by thoracentesis, with 58% less use (OR_{adj} 0.42, 95% CI: 0.22 to 0.80). For men, the reduction in the use of procedures was statistically significant in those with an AD for mechanical ventilation and visits to emergency departments. The highest reduction in men was for visits to emergency departments, with 46% less use (OR_{adj} 0.54, 95% CI: 0.38 to 0.78), followed by mechanical ventilation, with 38% less use (OR_{adj} 0.62, 95% CI: 0.40 to 0.94).

DISCUSSION

Main results of the study

This study showed that patients who died and had written an AD received invasive or life-sustaining

procedures less frequently than persons who died without completing an AD. In this sense, it seems that ADs are an effective tool when adjusting the performance of certain procedures at the final stage of life, including surgery, artificial nutrition, endoscopy, transfusions, thoracentesis and transfers to other centres among women; and mechanical ventilation, intubation and emergency consultations among men. Very few changes were observed when analysing the subgroup of patients who died of cancer, although some procedures were used even less frequently, including surgery, ostomy, endoscopy, thoracentesis and emergency consultations among women, and mechanical ventilation and emergency consultations among men.

Strengths and weaknesses/limitations of the study

Previous studies carried out in our context, being based on small population samples, have shown that ADs improve patient and physician decision-making (patients who have had a DVA are more involved in decision-making, and these decisions are more accepted by the care team),¹⁹ and the representatives' perception of a more comfortable death.²⁰ This paper has analysed individual information from more than 5000 people (1723 with ADs), one of the largest samples analysed so far. Moreover, real-word data have been used, taken from the ADs and mortality registries, as well as all clinical-administrative databases used for quality assurance and payment purposes in the Catalan public healthcare system, which include all contacts of citizens with the health services. All of this has allowed for a wider assessment of procedures and healthcare

Table 2 Frequency of the procedures performed during the last year of life among people who died in Catalonia 2014–2015 and had completed ADs versus those who had not, stratified by sex; adjusted ORs (95% CI) by socioeconomic level

Procedures	Women						Men							
	Cases			Controls			Cases			Controls			Adjusted model	
	N	%	P value	N	%	OR (95% CI)	N	%	P value	N	%	OR (95% CI)	P value	
Surgery	68	7.26	<0.01	206	11.00	0.63 (0.47 to 0.84)	12.09	200	12.67	0.97 (0.73 to 1.28)	0.81			
Pain treatment	1	0.11	*	8	0.43	*	2	0.25	3	0.19	*			
Transplant	2	0.21	*	4	0.21	*	4	0.51	3	0.19	*			
Palliative care	47	5.02	0.86	92	4.91	1.04 (0.70 to 1.52)	5.85	78	4.94	1.37 (0.89 to 2.10)	0.16			
Mechanical ventilation	120	12.81	0.44	261	13.93	0.91 (0.71 to 1.16)	13.87	293	18.57	0.71 (0.55 to 0.92)	0.01			
Ostomy†	11	1.17	0.47	26	1.39	0.75 (0.34 to 1.63)	1.65	19	1.20	1.29 (0.60 to 2.78)	0.51			
Artificial nutrition	17	1.81	0.03	62	3.31	0.54 (0.31 to 0.95)	2.29	46	2.92	0.84 (0.47 to 1.51)	0.56			
Cardiopulmonary resuscitation	3	0.32	*	5	0.27	*	2	0.25	7	0.44	*			
Nasogastric probe	13	1.39	0.86	26	1.39	0.94 (0.46 to 1.93)	1.15	25	1.58	0.68 (0.29 to 1.59)	0.37			
Endoscopy	55	5.87	0.02	162	8.65	0.67 (0.48 to 0.93)	9.03	185	11.72	0.76 (0.56 to 1.02)	0.07			
Transfusions	71	7.58	0.01	201	10.73	0.69 (0.52 to 0.93)	11.07	196	12.42	0.92 (0.69 to 1.24)	0.59			
Thoracentesis	20	2.13	0.02	74	3.95	0.54 (0.32 to 0.89)	3.82	61	3.87	1.00 (0.63 to 1.59)	1.00			
IV fluids/drugs	225	24.01	0.45	481	25.68	0.93 (0.76 to 1.13)	27.74	472	29.91	0.98 (0.79 to 1.22)	0.85			
Antibiotics	109	11.63	0.31	248	13.24	0.88 (0.68 to 1.13)	14.50	252	15.97	0.97 (0.75 to 1.26)	0.83			
Tracheostomy	1	0.11	*	13	0.69	*	5	0.64	34	2.15	*			
Dialysis	12	1.28	0.07	12	0.64	2.27 (0.93 to 5.55)	1.53	25	1.58	0.95 (0.44 to 2.05)	0.89			
Amputation	2	0.21	*	9	0.48	*	6	0.76	13	0.82	*			
Intubation	21	2.24	0.73	47	2.51	0.91 (0.53 to 1.56)	2.93	73	4.63	0.56 (0.33 to 0.94)	0.03			
Transfers	152	16.22	0.05	369	19.70	0.81 (0.65 to 1.00)	16.16	314	19.90	0.86 (0.68 to 1.09)	0.21			
Emergencies	714	76.20	0.11	1496	79.87	0.85 (0.69 to 1.04)	77.55	1329	84.22	0.68 (0.54 to 0.86)	<0.01			

*Not enough cases for modelling.

†Gastrostomy, ileostomy, colostomy and resections.
ADs, advance directives; IV, intravenous.

Table 3 Frequency of the procedures performed during the last year of life among people who died of cancer in Catalonia 2014–2015 and had completed ADs versus those who had not, stratified by sex; adjusted ORs (95% CI) by socioeconomic level

Procedures	Women						Men										
	Cases			Controls			Cases			Controls			Adjusted model				
	N	%	OR (95% CI)	N	%	P value	N	%	OR (95% CI)	N	%	P value	N	%	OR (95% CI)	P value	
Surgery	47	11.75	18.35	147	18.35	0.01	67	17.72	0.60 (0.42 to 0.86)	140	18.32	0.99 (0.70 to 1.40)	140	18.32	0.99 (0.70 to 1.40)	0.95	
Pain treatment	1	0.25	0.50	4	0.50	*	2	0.53	*	2	0.26	*	2	0.26	*	*	
Transplant	2	0.50	0.37	3	0.37	*	3	0.79	*	3	0.39	*	3	0.39	*	*	
Palliative care	37	9.25	9.49	76	9.49	0.82	44	11.64	0.95 (0.61 to 1.48)	73	9.55	1.43 (0.91 to 2.23)	73	9.55	1.43 (0.91 to 2.23)	0.12	
Mechanical ventilation	30	7.50	10.61	85	10.61	0.11	36	9.52	0.70 (0.45 to 1.08)	116	15.18	0.62 (0.40 to 0.94)	116	15.18	0.62 (0.40 to 0.94)	0.02	
Ostomy†	2	0.50	2.12	17	2.12	0.02	4	1.06	0.16 (0.03 to 0.79)	14	1.83	0.59 (0.18 to 2.00)	14	1.83	0.59 (0.18 to 2.00)	0.40	
Artificial nutrition	9	2.25	4.24	34	4.24	0.08	9	2.38	0.50 (0.23 to 1.08)	29	3.80	0.72 (0.33 to 1.58)	29	3.80	0.72 (0.33 to 1.58)	0.41	
Cardiopulmonary resuscitation	0	0.00	0.25	2	0.25	*	0	0.00	*	0	0.00	*	0	0.00	*	*	
Nasogastric probe	10	2.50	2.12	17	2.12	0.73	8	2.12	1.17 (0.49 to 2.80)	19	2.49	1.05 (0.42 to 2.67)	19	2.49	1.05 (0.42 to 2.67)	0.91	
Endoscopy	37	9.25	16.60	133	16.60	<0.01	58	15.34	0.53 (0.36 to 0.79)	143	18.72	0.82 (0.59 to 1.15)	143	18.72	0.82 (0.59 to 1.15)	0.25	
Transfusions	51	12.75	15.36	123	15.36	0.30	51	13.49	0.83 (0.58 to 1.18)	128	16.75	0.81 (0.55 to 1.18)	128	16.75	0.81 (0.55 to 1.18)	0.27	
Thoracentesis	12	3.00	6.99	56	6.99	0.01	21	5.56	0.42 (0.22 to 0.80)	45	5.89	0.98 (0.56 to 1.70)	45	5.89	0.98 (0.56 to 1.70)	0.94	
IV fluids/drugs	114	28.50	32.58	261	32.58	0.17	129	34.13	0.82 (0.63 to 1.09)	266	34.82	1.06 (0.79 to 1.44)	266	34.82	1.06 (0.79 to 1.44)	0.69	
Antibiotics	49	12.25	14.86	119	14.86	0.29	74	19.58	0.83 (0.58 to 1.18)	130	17.02	1.30 (0.91 to 1.85)	130	17.02	1.30 (0.91 to 1.85)	0.14	
Tracheostomy	1	0.25	0.62	5	0.62	*	1	0.26	*	17	2.23	*	17	2.23	*	*	
Dialysis	3	0.75	0.37	3	0.37	0.27	3	0.79	3.40 (0.38 to 30.25)	13	1.70	0.64 (0.17 to 2.49)	13	1.70	0.64 (0.17 to 2.49)	0.52	
Amputation	1	0.25	0.12	1	0.12	*	0	0.00	*	3	0.39	*	3	0.39	*	*	
Intubation	3	0.75	1.75	14	1.75	0.12	3	0.79	0.33 (0.08 to 1.35)	23	3.01	0.28 (0.08 to 1.03)	23	3.01	0.28 (0.08 to 1.03)	0.06	
Transfers	68	17.00	21.60	173	21.60	0.08	75	19.84	0.75 (0.54 to 1.04)	180	23.56	0.90 (0.66 to 1.25)	180	23.56	0.90 (0.66 to 1.25)	0.54	
Emergencies	290	72.50	81.52	653	81.52	<0.01	296	78.31	0.94 (0.48 to 0.86)	668	87.43	0.54 (0.38 to 0.78)	668	87.43	0.54 (0.38 to 0.78)	<0.01	

* Not enough cases for modelling.

† Gastrostomy, colostomy and resections.
ADs, advance directives; IV, intravenous.

services utilisation, and representative results for the whole population.

Second, this study did not suppose an additional cost, and was carried out without reviewing clinical records and without jeopardising data anonymisation. Thus, it demonstrates the value of reusing administrative data for research purposes, something that European authorities recommend.^{21 22}

Some limitations are worth mentioning. Although we included in the analysis procedures that were performed over the course of 1 year, corresponding to all people with selected causes of death in 2014 and 2015 with ADs, some procedures are used very infrequently. Extending the study to include more years would result in a greater number of people to analyse. Having more ADs among patients without cancer would be especially interesting in the case of Alzheimer's, amyotrophic lateral sclerosis, dementia or neurodegenerative diseases to have sufficient contingents to reach higher frequencies of the analysed procedures.

Chemotherapy and radiotherapy have not been included. Related to this, the possible bias introduced because of under-reporting of procedures by healthcare professionals, common to all clinical-administrative databases, is another weakness to consider.

Finally, ADs have been analysed as a dichotomous variable (having ADs/not having ADs), while the legal document allows specifying the particular procedures a person is willing to limit or extend (although, in the latter case, the doctor is not legally obliged to perform those treatments that are not clinically indicated). So, we cannot state that the reduction in procedures in the AD cohort was consistent with the content of the ADs and whether indeed the AD was required (patient lacked capacity at the time of the decision-making). It would be interesting to carry out a more detailed analysis by means of a qualitative review of ADs and clinical records.

What this study adds

This study has shown that having an AD was more frequent among the patients who died of cancer than those who died because of any other cause. This could explain the strong effect of cancer deaths in this analysis. Moreover, this same pattern has been observed in other studies,²³ indicating the need to raise the awareness of ADs on non-cancer diseases.

The results showed that SEC level can influence the decision about completing an AD, but this did not influence the use of procedures at end of life when one was in place. Related to this, it is worth mentioning the change in the SEC level of the ADs population, with a higher representation of high-income classes and cancer cases in the current analysis than in previous ones.⁷ Younger age, a lower level of education and a lower income have previously been shown to be

associated with a reduced likelihood of advance care planning uptake.²⁴

The results also showed that the use of procedures at end of life is lower in women than in men, with both having completed an AD. This may indicate different preferences regarding end-of-life treatments, a higher respect for women's ADs—intensified by the fact that women tend to die once widowed, so there is no partner that could insist on a course of action—or some gender bias introduced by healthcare professionals.

It is also well known that, rather than the natural age, it is the final stage of a person's life that better determines their use of healthcare resources.^{25–27} One of the explanatory factors is the cause of death, with oncological diseases being the ones associated with higher expenses.²⁸ Access to end-of-life healthcare services is highly variable, with the worst impact on the most deprived SEC groups,²⁹ also being true in the case of access to palliative care.³⁰ Although some cost savings may be realised,^{31 32} looking at the impact of advance care planning on costs raises delicate ethical issues and unduly influences the sensitive communication process, thus jeopardising patient autonomy.

Causes of death were selected according to their frequency, with cancer, circulatory system, respiratory system and nervous system being the main causes in Catalonia, for both men and women.³³ As some cognitive impairment processes can be coded as mental diseases, this category was also included. Also, kidney diseases were included as a cause of death, and some studies have shown that ADs are useful in planning whether to continue dialysis.^{34 35}

In regard to the medical procedures, these were selected based on the possibility to adjust them during the final stage of life, some of them being specifically included in the ADs legal document, while others are invasive or life-sustaining procedures. Also, the number of visits to the emergency department and transfers to other centres, that is, long-term care centres, were included to assess the performance of palliative care at home and the possibility of dying at home. However, it seems from the study results that some techniques may have a more invasive character, despite being palliative, than others. This is the case for endoscopy and thoracentesis in comparison with, for instance, the administration of fluids/drugs or antibiotics. Intubation and mechanical ventilation, more common among men, are perhaps the most striking cases. One explanation may be that having an intravenous route for the administration of drugs is seen by patients, family members and healthcare professionals as a measure taken within usual care. Even the placement of a nasogastric tube for enteral feeding can be viewed from a similar perspective. These results reflect that ADs could be taken into greater consideration in the decision to carry out more invasive procedures, although all of them are related to end-of life care. No effects were observed regarding transfusions, which

would likely be more relevant in causes of death other than cancer.

Finally, the number of transfers and visits to the emergency department is lower in patients with ADs, although not statistically significant, which may reflect the desire of the patient for stability of care in the environment in which he or she is. Regarding palliative care, there are no statistically significant differences between patients with and without ADs. Patients usually want to talk about treatments that keep them alive, not about palliative care in specific, since they consider it part of the portfolio of their healthcare system. Regarding pain treatment, the methodology used does not allow to draw conclusions. Upcoming studies using pharmacy databases could provide evidence in this line of work.

CONCLUSIONS

ADs are a tool to improve quality of care by means of better planning of treatment and place of care in keeping with patients' wishes.^{1 8 36-38} Moreover, they may be helpful in increasing awareness among healthcare personnel, families and the population, and a tool to improve communication between healthcare professionals and families.⁸ In conclusion, this study has shown that, for some medical procedures at end of life, ADs have a performative force. This finding may be helpful in raising public awareness of ADs, as is an indication that some part of society makes end-of-life decisions in advance.

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Contributors AD-B performed all data management and led the statistical analysis and table preparation. AS-L led the data extraction, helped in the statistical analysis and table preparation, and drafted the study protocol. JMB provided the idea for the research and all the knowledge regarding ADs. IB-M provided all knowledge regarding palliative care. AG-A drafted the article, did the final write-up and coordinated the project.

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