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Wish to die and hasten death in palliative care: a cross-sectional study factor analysis

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► Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2021-003080).

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Received 29 March 2021
Accepted 5 August 2021

Check for updates

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To cite: Belar A, Martinez M, Centeno C, *et al*. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/bmjspcare-2021-003080

ABSTRACT

Objectives The wish to die (WTD) is a complex experience sometimes accompanied by intention to hasten death. The aim of this study is to identify the predictive factors for WTD and hastening death intention (HDI) in Spanish patients with advanced illness.

Methods This is a subanalysis of a larger cross-sectional study conducted on patients experiencing advanced illness (N=201). Sociodemographic data and data related to symptom burden (Edmonton Symptom Assessment System-Revised), depressive and anxious symptoms (Hospital Anxiety and Depression Scale), demoralisation (Spanish version of the Demoralisation Scale), perceived loss of dignity (Patient Dignity Inventory) and WTD (Assessing Frequency and Extent of Desire to Die) were collected. The analysis used univariate and multivariate logistic regression.

Results The prevalence of WTD in the sample was 18%, with 8 out of 36 patients reporting HDI. The independent factors predictive of WTD were (1) knowledge of approximate prognosis (OR=4.78; 95% CI 1.20 to 10.8; p=0.001); (2) symptom burden (OR=1.05; 95% CI 1.00 to 1.09; p=0.038); and (3) the Demoralisation Scale subsection 'lack of meaning and purpose in life' (OR=1.61; 95% CI 1.30 to 1.99; p=0.000). An independent predictive factor for HDI was the Demoralisation Scale subsection 'patients' distress and coping abilities' (OR=1.47; 95% CI 1.04 to 2.08; p=0.028), while having religious beliefs was a protective factor (OR=0.13; 95% CI0.17 to 0.97; p=0.047).

Conclusions Demoralisation was found to be the only common triggering factor for WTD and HDI, although experiences share certain features. Identification of the predictive factors for WTD and HDI may contribute to their prevention and management.

Key messages

What was already known?
- ► The wish to die (WTD) is a complex and dynamic experience influenced by anxiety, depression and perceived loss of dignity.
- ► Existential distress may influence the experience of WTD and the intention to hasten death.
- ► Not all patients with WTD have hastening death intention (HDI) and triggering factors may differ.

What are the new findings?
- ► This study identifies the salience of demoralisation, distress and ineffective coping strategies and the lack of purpose and meaninglessness in patients presenting with WTD and HDI.
- ► This study identifies the predictive factors for patients expressing HDI.

What is their significance?
- ► These findings can help guide the development of goals of care for patients with WTD and prevent its occurrence.
- ► Awareness of the factors that can trigger HDI will assist identification of affected patients and guide their goals of care.

BACKGROUND

The wish to die (WTD) is common in patients with advanced illness.[1–3] Between 11% and 55% of patients have sporadic WTD,[1–3] while 3%–20% have more persistent thoughts.[1–3]

The scientific literature has described different experiences of WTD,[4] referring to them with varying terminologies such as 'desire to die' or 'wish to hasten death', with no differentiation or consideration of the term's nuances.[1 4] A terminological consensus process concluded that the phenomenon should be called 'wish to hasten death'.[5] However, it is common knowledge that all WTD experiences do

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not include hastening death intention (HDI), although these are embedded in WTD.[2] Thus, this study follows a recent terminological analysis of the issue, referring to the global phenomenon that includes both sporadic or persistent experiences of WTD and explicitly noting when patients expressed HDI, both as real plans and as passing thoughts.[1]

Research has associated the experience of WTD with different factors,[4] namely physical (ie, pain, dyspnoea, tiredness),[2 3] psychoemotional (ie, depression, anxiety),[2 6–9] existential spiritual (ie, existential suffering, perceived loss of dignity)[2 8] and social (ie, feeling that one is a burden).[9]

Health professionals often shy away from exploring and discussing WTD with patients.[10] A superficial understanding of the phenomenon risks medicalising the situation rather than developing appropriate goals of care or taking preventive measures.[10]

Although WTD should be understood within the sociocultural context of the individual experiencing it,[11] there has been little research on the topic in Spain.[6 8 12] Moreover, as WTD does not always include HDI, it could be hypothesised that HDI is associated with specific factors. There has been no research on why some patients with WTD present with HDI, while others do not.

The aim of this study is to identify the predictive factors for WTD and HDI in a Spanish population.

METHODS

We analysed a cross-sectional study of 201 patients with advanced illness from all over Spain admitted for palliative care in two different hospitals in Navarra between January 2018 and November 2018. More than 64% of the patients were from different regions.[1] Patients who met the following criteria were included: (1) with advanced illness (progressive and irreversible disease); (2) expecting death in a maximum period of 1 year according to the referring physician (negative answer to a 'surprise question'); (3) awareness of the life-limiting nature of the disease; (4) ability to conduct a fluent conversation in Spanish; and (5) with cognitive capacity.

Collection of sociodemographic and clinical data (online supplemental file A) preceded two face-to-face clinical encounters with participants to gather information about their experiences of WTD and HDI (within 48–96 hours). The semistructured interviews followed the 'Assessing Frequency and Extent of Desire to Die' (AFEDD)[13] guideline (online supplemental file B), which explores WTD through five possible answers to direct questions about the existence or frequency of WTD ('No', 'Almost never', 'Sometimes', 'Not daily, but almost every day' and 'Daily'). Another question explores the presence of HDI among those presenting with WTD: 'Just thought about it (about the WTD but not about HDI)', 'Have talked with someone about it (about the WTD but not about HDI)', 'I have thought about ending life, but never would do it (the patient though about HDI)', and 'Yes, there is a plan (the patient has a HDI)'.

Data related to symptom burden (Edmonton Symptom Assessment System-Revised, ESAS-r),[14] depressive and anxious symptoms (Hospital Anxiety and Depression Scale, HADS),[15] perceived loss of dignity (Patient Dignity Inventory, PDI)[16] and demoralisation (Spanish version of the Demoralisation Scale, DS-II (es), with two subscales: (1) meaning and purpose in life and (2) distress and coping strategies) were collected.[17] The latter refers to the patient's ability to cope with the illness trajectory. These variables have been considered triggering factors for WTD in previous studies.[2 6 8]

Data analysis

Logistic regression was used to analyse the relationship between WTD and HDI with the following research variables: sociodemographics, and physical, emotional and existential concerns. Logistic regression took place when responses (in this cases categories) were known in advance and the classification model was fed by them. Results from the multivariate regression model will be highlighted.

The AFEDD guideline measures two distinct but interrelated experiences: WTD and HDI. In order to study the distinguishing factors for each, data regarding WTD and HDI were analysed independently.

The logistic regression analysis of WTD included the entire study population (N=201) and assigned response labels according to the significant presence or absence of WTD. Patients experiencing WTD 'sometimes', 'not daily, but almost every day' or 'daily' were included in the sample of patients with WTD.

To distinguish the factors associated with HDI, we considered only the population with WTD (n=36). This included patients who had never thought about hastening death (n=28) and also those who answered 'I have thought about ending life, but never would do it' (n=5) or 'Yes, there is a plan' (n=3). The last two groups of patients were included in the HDI group. They were compared against those who have never thought about hastening death.

STATA V.15 was used for descriptive and statistical analyses. Results with a p value <0.05 were considered significant.

RESULTS

The prevalence of WTD in the overall sample was 18% (36 of 201), with HDI identified in 8 (22%) patients of the subsample. Of the whole sample (N=201), 46% were female, with a mean age of 67. Most participants claimed to have religious beliefs (86%), a national norm, and almost all knew their diagnosis (97%). The Karnofsky score for 76% of the patients was between 50 and 70. Of the patients, 21% had moderate to severe anxiety, while 26% presented with severe depression.

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Table 1 Predictive factors for wishing to die and hastening death intention

The wish to die and clinical factors (N=201)

Variable	Response options	Multivariate logistic regression OR	95% CI	SE	P value*
The wish to die and clinical factors (N=201)					
Information about the disease†	Diagnostic but not prognostic	1.00	1.20 to 10.8	2.26	0.001*
	Diagnostic and prognostic	4.78			
Depression history	No	1.00	1.42 to 9.13	1.69	0.232
	Yes	2.35			
Anxiety history	No	1.00	1.15 to 10.4	2.41	0.258
	Yes	2.72			
Receiving specialised palliative care‡	No	1.00	1.09 to 7.07	0.85	0.308
	Yes	1.68			
Karnofsky performance status	0–100	0.98	0.93 to 0.99	0.02	0.155

The wish to die and patients' systematic evaluations (N=201)

Variable	Evaluation tool (score)	Multivariate logistic regression OR	95% CI	SE	P value*
Symptom burden	ESAS-r (0–100)	1.05	1.00 to 1.09	0.02	0.038*
Coping abilities§	DS-II subscale (0–16)	0.84	0.66 to 1.06	0.10	0.141
Meaning in life§	DS-II subscale (0–16)	1.61	1.30 to 1.99	0.17	0.000*
Depressive and anxious symptoms	HADS (0–42)	1.01	0.94 to 1.09	0.04	0.773
Self-perceived dignity	PDI (25–125)	0.99	0.95 to 1.04	0.02	0.673

Hastening death intention and patients' systematic evaluations (n=36)

Variable	Evaluation tool (score)	Multivariate logistic regression OR	95% CI	SE	P value*
Symptom burden	ESAS-r (0–100)	1.09	0.99 to 1.20	0.05	0.067
Coping abilities	DS-II (0–16)	1.47	1.04 to 2.08	0.26	0.028*

*Statistical significance at p<0.05.

†Information about the disease: information that patients were given referring to the diagnosis and prognosis of the disease.

‡Patients receiving specialised palliative care due to their complex needs.

§DS-II (es) has two subscales: (1) meaning and purpose in life and (2) distress and coping abilities.

DS-II (es), Spanish version of the Demoralisation Scale; ESAS-r, Edmonton Symptom Assessment System-Revised; HADS, Hospital Anxiety and Depression Scale; PDI, Patient Dignity Inventory.

About 25% of the patients were demoralised (online supplemental file A).

Predictive factors for WTD

The multivariate study found that awareness of both diagnosis and prognosis was significantly predictive of WTD (OR 4.78; 95% CI 1.20 to 10.8) (table 1), while sociodemographic characteristics were not (online supplemental file C).

Systematic evaluations of patients using multivariate analysis identified high symptom burden (ESAS-r) (OR 1.05; 95% CI 1.00 to 1.09) and high scores on the 'meaning and purpose' demoralisation subscale (DS-II) (OR 1.61; 95% CI 1.30 to 1.99) as independent predictive factors. The multivariate analysis considered additional factors such as depressive and anxious symptoms (HADS) and perceived loss of dignity (PDI) and distress and coping strategies (DS-II) (table 1). Although these factors have been suggested as a significant result of the univariate analysis, they had no independent predictive power.

Predictive factors for HDI

Religious beliefs were the only sociodemographic and clinical factor associated with HDI (OR 0.13; 95% CI 0.17 to 0.97), with these being protective factors (online supplemental file D).

The initial univariate analysis of the factors derived from the systematic evaluation of the patients identified (1) symptom burden (ESAS-r), (2) 'distress and coping strategies' demoralisation subscale, (3) 'meaning and purpose' demoralisation subscale, and (4) depressive and anxious symptoms (HADS) as potential predictive factors. These four were included in the first model subjected to multivariate analysis, where symptomatic burden and 'distress and coping strategies' demoralisation subscale showed near significance (p=0.128 and p=0.096, respectively). The second multivariate

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analysis with a model of only these two factors found independent predictive value for the 'distress and coping strategies' subscale (OR 1.47; 95% CI 1.04 to 2.08) (table 1).

DISCUSSION

Clinical predictive factors

Demoralisation was a key trigger of WTD experience among the patients studied. Demoralisation measured with the DS-II (es) consists of two components: 'meaning and purpose' and 'distress and coping strategies'. The first has been extensively studied. Morita *et al*[18] presented lack of existential meaning as one of the factors underlying WTD, an association confirmed by recent quantitative international studies.[7] Freeman *et al*[19] in a multivariate analysis observed a higher probability of WTD (OR 2.68) when patients experience existential distress. Qualitative studies on WTD also report an association between existential distress and general demoralisation.[20]

We identified HDI triggers that explain why some patients with WTD present with HDI while others do not by studying HDI independent of the more general experience of WTD. No studies we know of have addressed the distinction. Despite the limitations of having low prevalence in a sample of 201 patients, we observed that patients with higher levels of distress and lower perception of effective coping strategies were more likely to present with HDI. Our literature review revealed that this is the first time distress and perceived lack of coping strategies have been considered as HDI triggers.

Symptom burden is also a key trigger of WTD and is close to statistical significance in HDI. In WTD, this relationship has been described in terms of pain or symptom burden as a whole, as well as concrete symptoms such as dry mouth,[21] tiredness,[3 19] drowsiness[3 19] and incontinence.[19]

Sociocultural factors

Although we have not found a significant association between religious beliefs and WTD, it is observed that weaker beliefs made HDI more likely. Religious beliefs, possibly due to their association with a transcendent perspective, were identified as a protective factor for HDI.

Health professionals in Mediterranean cultures often avoid communicating with patients about disease progression and prognosis.[6] Our results were confirmed by other studies that have reported uncertainty and hopelessness in patients with cancer who knew their condition was terminal. These studies suggest a WTD trigger[9 20] or even a higher number of euthanasia requests.[21] Providing patients with adequate care[22] during the disease process and offering appropriate coping strategies when giving 'bad news' may be protective factors.[23]

These findings can guide interventions for patients presenting with WTD and assist in its identification and prevention. The quality of patient communications regarding prognosis should be considered along with symptom burden and demoralisation.[23] Clarifying triggering factors for HDI could assist in the identification of at-risk patients, as well as in the development of appropriate interventions and goals of care. Early follow-up by palliative care teams may assist in the development of patient coping strategies.[24]

Exclusion of patients in their very last days of life and those with uncontrolled depressive and anxious symptoms may be a limitation. We recommend future research that explores WTD and HDI triggers separately due to this study's limited number of analysed WTD experiences out of the 201 patients.

CONCLUSIONS

Distress and ineffective coping strategies are two HDI triggers in patients with WTD. Lack of meaning and purpose in life and patient symptom burden underlie WTD. Professionals should consider these factors when identifying patients with WTD or HDI and developing prevention strategies and goals of care.

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Acknowledgements Thanks to the multidisciplinary teams in our two partner hospitals who collaborated with the research team.

Collaborators Katherine Pettus.

Contributors AB, MA and CC designed the study. AB was responsible for the data collection, supported by MM, YS and ML. AB and JL-F were involved in the data analysis and interpretation, with support from MA and CC. The final manuscript was written by AB, MA and CC with contributions from the other authors. All the authors read and approved the submitted version.

Funding This study received funding from Project PI18/01703, integrated into the Plan Estatal de I+D+I 2013-2016 and cofinanced by the ISCIII-Subdirección General de Evaluación y Fomento de la Investigación and the Fondo Europeo de Desarrollo Regional (FEDER).

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The Clinical Ethical Research Committee of the Clínica Universitaria de Navarra approved the study (no 2017.092).

Provenance and peer review Not commissioned; externally peer reviewed.

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Supplementary A.

Sociodemographic and clinical characteristics of the 201 participants

Characteristic (evaluation tool) (1)	mean (range)	n	%
Total		201	100
Age years	67 (23-94)		
Gender, female		92	46
Educational			
Without studies		3	1
Primary school /High School		109	55
Vocational training /University		98	44
Marital status			
Single, widower, separated, divorced		71	35
Married, partner		120	60
Other		10	5
Religious beliefs			
Not believer		29	14
Believer		172	86
Advanced disease (2)			
Oncologic		198	98
Others		3	2
Information about disease (3)			
Diagnostic but not prognostic		102	51
Diagnostic and prognostic		99	49
Treatment received (last 3 months)			
None		48	24
Curative treatment (4)		153	76
Previous depression history		23	11
Previous anxiety history		15	7
Receiving specialized palliative care (5)		142	71
Symptom burden (ESAS-r)	27 (0-68)		
Self-perceived dignity (PDI)	40 (25-94)		
Karnofsky Performance Status			
30-40		23	11
50-70		151	76
>70		27	13
Depressive and anxious symptoms (HADS)			
Moderate		31	15
Severe		32	16
Anxiety (HADS-A)			
Moderate		19	9
Severe		25	12
Depression (HADS-D)			
Moderate		24	12
Severe		52	26
Demoralization (DS-II, n=165)			
Moderate		32	19
Severe		5	3
Wish to die			
Sometimes		22	11
Every day or almost every day		14	7
Hasten death (in the sub-sample of 36 patients with wish to die)			
Have thought about it but never would do it		5	14
There is a plan		3	8

(1) ESAS-r: Edmonton Symptom Assessment System, revised version; DS-II (es): Demoralisation Scale Spanish version; HADS: Hospital Anxiety and Depression Scale; PDI: Patient Dignity Inventory, Spanish version
(2) Advanced disease is referred to a progressive and irreversible disease. In addition to cancer patients, patients with Amyotrophic Lateral Sclerosis (n=2) and a patient (n=1) with advanced heart failure were interviewed.
(3) Level of information that patients were given referring the diagnosis and the prognostic of the disease
(4) Curative treatment refers to those active treatments administered in order to stop or slow the progress of the disease.
(5) Patients receiving specialized palliative care due to their complex needs

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Supplementary B.

"Assessing Frequency and Extent of Desire to Die" (AFEDD) guideline

This is not a clinical instrument; it is a guide for a clinical interview; the questions should be adapted to each patient, their context/culture/vocabulary.

PRESENCE

Interviewer: "Some people in your situation may involuntarily start to think that living like this is not worth it anymore.

Lately (in the last week or two) have you thought that living like this is not worth it?

[*Asking this way normalises the situation, prevents blaming the patient and makes it easier for them to open up*]

Patient:

- No (thank you and nothing more)
- Yes (continue with the following questions)

FREQUENCY

Interviewer: "Is this a thought/feeling, you have had…?":

[*Thought/feeling; use the words the patients used*]

Explore:

- Every day
- Not every day but almost every day
- Occasionally/sometimes
- Seldom/almost never

EXTEND

Interviewer: "With regards to this thought/feeling?":

Explore:

- Have they only thought about it?
- Have they talked about/mentioned it to someone [*doesn't matter who; find out who*]
- Have they ever thought about how you would put an end to your life? :
  - Yes, but they wouldn't ever do it [*various reasons (explore) –usually spontaneous*]
  - Yes *[There is a plan – they may or may not be able to explain it]*

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Supplementary table C.

Univariant logistic regression between WTD and sociodemographic, clinical factors and systematic evaluation in 201 patients with advanced illness

Variable	Response/Evaluation tool [Score] (1)	Multivariate logistic regression			p-value (2)
		OR	95% CI	Standard error	
Age		1.03	0.99-1.06	0.01	0.058
Gender	Female	1.00	0.30-1.28	0.22	0.196
	Male	0.62			
Having religious beliefs	Not believer	1.00	0.37-2.98	0.55	0.919
	Believer	1.05			
Treatment received (last 3 months)	None	1.00	0.14-0.66	0.12	0.03*
	Yes	0.31			
Depression history	No	1.00	1.42-9.13	1.71	0.007**
	Yes	3.59			
Anxiety history	No	1.00	1.15-10.4	1.95	0.027*
	Yes	3.46			
Needing specialized palliative care	No	1.00	1.09-7.07	1.32	0.031*
	Yes	2.78			
Karnofsky Performance Status	KRN [0-100]	0.96	0.93-0.99	0.01	0.036*
Advanced disease	Oncologic	1.00	0.85-109.4	11.95	0.067
	Others (3)	9.64			
Information about disease	Diagnostic but not prognostic	1.00	1.20-10.8	1.20	0.000**
	Diagnostic and prognostic	4.63			
Symptom burden	ESAS-r [0-100]	1.17	1.01-1.36	0.09	0.035*
Depressive and anxious symptoms	HADS [0-42]	1.11	1.06-1.16	0.02	0.000**
Meaning in life	DS-II [0-16]	1.51	1.30-1.76	0.11	0.000**
Coping abilities	DS-II [0-16]	1.22	1.07-1.40	0.08	0.003*
Demoralization	DS-II [0-32]	1.22	1.13-1.33	0.05	0.000**
Self-perceived dignity	PDI [25-125]	1.04	1.01-1.07	0.01	0.001*

(1) Treatment received (last 3 months): The patient has been taking curative or life prolonging treatments in that period (i.e chemotherapy, radiotherapy); Needing specialized palliative care: Those patients due to their advanced complex disease requiring specialized palliative care; KRN: Karnofsky Performance Status Scale; Information about disease: Level of information that that the doctor in charge of the patients gave referring the diagnosis and the prognostic of the disease; ESAS-r: Edmonton Symptom Assessment System, revised version; DS-II (es): Demoralisation Scale Spanish version; HADS: Hospital Anxiety and Depression Scale; PDI: Patient Dignity Inventory, Spanish version.

(2) Model p-value= 0.0001; (*) statistical significance is $p < 0,05$

(3) Others: Amyotrophic Lateral Sclerosis (n=2) and patient with advanced heart failure (n=1)

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Supplementary table D.

Univariant logistic regression between HDI and sociodemographic and clinical factors in 36 patients with wish to die

Variable	Response/Evaluation tool [Score] (1)	Multivariate logistic regression			p-value (2)
		OR	95% CI	Standard error	
Age	n, range	0.97	0.91-1.03	0.03	0.349
Gender	Female	1.00	0.14-3.47	0.57	0.655
	Male	0.69			
Having religious beliefs	Not believer	1.00	0.17-0.97	0.13	0.047*
	Believer	0.13			
Treatment received (last 3 months)	None	1.00	0.029-7.2	1.18	0.655
	Yes	1.44			
Depression history	No	1.00	0.40-11.9	1.90	0.361
	Yes	2.2			
Anxiety history	No	1.00	0.07-6.6	0.77	0.721
	Yes	0.66			
Needing specialized palliative care	No	1.00	0.15-15.3	1.79	0.721
	Yes	1.52			
Karnofsky Performance Status	Score 0-100	1.02	0.97-1.08	0.03	0.417
Advanced disease	Oncologic	No data available			
	Others (3)				
Information about disease	Diagnostic but not prognostic	No data available			
	Diagnostic and prognostic				
Symptom burden	ESAS-r [0-100]	1.11	1.02-1.21	0.05	0.013*
Depressive and anxious symptoms	HADS [0-42]	1.12	1.01-1.24	0.06	0.031*
Meaning in life	DS-II [0-16]	1.26	1.01-1.56	0.14	0.039*
Coping abilities	DS-II [0-16]	1.47	1.05-2.05	0.25	0.023*
Demoralization	DS-II [0-32]	1.19	1.03-1.38	0.08	0.016*
Self-perceived dignity	PDI [25-125]	1.05	0.99-1.11	0.03	0.111

(1) Treatment received (last 3 months): The patient has been taking curative or life prolonging treatments in that period (i.e chemotherapy, radiotherapy); Needing specialized palliative care: Those patients due to their advanced complex disease requiring specialized palliative care; KRN: Karnofsky Performance Status Scale; Information about disease: Level of information that that the doctor in charge of the patients gave referring the diagnosis and the prognostic of the disease; ESAS-r: Edmonton Symptom Assessment System, revised version; DS-II (es): Demoralisation Scale Spanish version; HADS: Hospital Anxiety and Depression Scale; PDI: Patient Dignity Inventory, Spanish version.

(2) Model p-value= 0.0001; (*) statistical significance is $p < 0,05$

(3) Others: Amyotrophic Lateral Sclerosis (n=2) and patient with advanced heart failure (n=1)