

**What do I want to be done at end-of-life?
Disease awareness, knowledge of clinical
procedures and of advanced directives in
patients with chronic progressive diseases**

**¿Qué quiero que se haga al final
de la vida? Concientización sobre
enfermedades, conocimiento de
procedimientos clínicos y directivas
avanzadas en pacientes con
enfermedades crónica progresivas**

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Abstract

Many steps forward within the legal field to facilitate end-of-life communication have been taken, but Mediterranean countries can be considered as a step back. Aim of our observational cross-sectional study is to observe disease awareness, knowledge of clinical procedures and of advanced directives in patients with chronic progressive diseases in Italy. Methods. 115 subjects (23 with Amyotrophic Lateral Sclerosis – ALS, 30 with Chronic Heart Failure – CHF, 32 with Chronic Kidney Failure – CKF, and 30 with Advanced Cancer – AC) were assessed on health literacy, their right to be informed and meaning of Advance Directives (AD) and of Advance Declaration of Treatment (ADT). Results. 86% of patients claimed the right to know diagnosis and prognosis and to be informed of disease progression. Patients did not know the meaning of invasive therapy (52%) and of aggressive treatment (81%). 72% did not know the meaning of AD and of ADT; 94% believed that AD or ADT could partially or totally guarantee patient's will to make decisions on end-of-life, with frequency difference on AD or ADT efficiency between CHF and ALS patients ($p=.01$). Once informed on the definitions of AD (legally binding) and ADT (not legally binding), ALS patients preferred legally binding directives, compared to patients with AC and with CHF (ALS vs CHF $p=.005$; ALS vs AC $p=.001$). Patients with CKF would prefer legally binding proposal compared to CHF patients ($p=.02$).

To inform and to guide patients from diagnosis to end-of-life should be an integral part of medical practice.

Keywords: chronic progressive diseases, end-of-life, advanced directives.

1. Introduction

The relentless evolution of medical knowledge and the incessant progression of technology has led to the necessity to keep on modifying and updating the communication about (and planning for)

end-of-life. Preparing patients and their families for the changes that will accompany the illness progression and for the need for shared decision-making, may facilitate the avoidance of aggressive treatment, invasive procedures, and unnecessary interventions [1].

The quality of health information, its effective communication between patients and their health care providers are fundamental in patient-centered care [1]. Moreover, the advance care planning adoption has evidence in impacting positively on quality of end-of-life care [2]. As to chronic progressive diseases, even if they are incurable and inexorably leading to death, they may have different path ways at end-of-life, requiring different active participation of patients in the decision making process of care.

In this study, we have taken into account four chronic diseases whose diagnosis envisages its' end-of-life prognosis. Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disorder invariably leading to death; about 70% of ALS patients die within 2-5 years from symptoms onset due to respiratory failure [3; 4]. As to Chronic Kidney Failure (CKF) prognosis, end-of-life care and clinical decision-making stems from a complex algorithm taking into consideration co-morbidities, age, quality of life issues, frailty and functional status assessment, and dialysis modality [5]; on the other hand, ambiguity in prognosis estimation remains a significant issue [6]. Even if at diagnosis of Chronic Heart Failure (CHF) the disease trajectory in patients' mind is not clearly understood and disease prognosis could be not easily defined by clinicians [7], its terminal stages require a thorny patient-centered «planning for the worst» communication [8]. Among the diseases taken into account, Advanced Cancer (AC) is the most studied as to prognosis and end-of-life issues. End-of-life management is well established by palliative care procedures.

Patients' knowledge and expectations of end-of-life management constitute an important clinical and research issue, in the presence of a contemporary extreme heterogeneity of legislation and advance care planning regulation in Western countries. US [9];

10] and many EU Northern countries have made great strides forward within the legal field in order to facilitate end-of-life communication and decisions, but the Mediterranean area countries can be considered as backward, with the exception of Spain [11].

As to our knowledge communication between patients, caregivers, and health care providers about end-of-life issues is often a challenge in Italy, both due to legal lack and to the physicians perceived difficulties in end-of-life communication. In fact, in Italy only recently, has the Senate definitively approved the law on informed consent and Advance Directives [12; 13].

Although until now legislation allowed patients, who are still able to express their opinion, to refuse medical treatments, there was a complex legal situation regarding patient autonomy whenever she/he is not able to communicate and/or to take a decision by herself/himself [14].

The aim of our observational cross-sectional research is to study disease awareness, knowledge of clinical procedures, and of advance directives, in patients with different chronic progressive diseases, in Italy, and to describe possible differences among groups.

2. Method

2.1 *Patients and procedure*

From March to July 2013, all inpatients were consecutively recruited. Inclusion criteria were: diagnosis of Amyotrophic Lateral Sclerosis (ALS) or Chronic Kidney Failure (CKF) or Chronic Heart Failure (CHF) or Advanced Cancer (AC); MMSE \geq 24; effective understanding of spoken Italian language; willingness to participate in the study expressed through informed consent. The exclusion criteria were: severe cachexia, coma, sedation, cognitive deficits interfering with language and reasoning, psychiatric or severe psy-

chological disorders prior to the onset of the disease; refusal or difficulties to take part in the project.

Upon written informed consent 115 subjects (23 with Amyotrophic Lateral Sclerosis – ALS, 30 with Chronic Heart Failure – CHF, 32 with Chronic Kidney Failure – CKF, and 30 with Advanced Cancer – AC) were considered eligible. Patients were interviewed by a senior specialist psychologist in a quiet place (often at the bedside), respecting their privacy. Patients were assisted in compiling the Italian version of the *McGill Quality of Life Questionnaire* (MQOL-It) [15; 16]; a structured interview was then carried out and at the same time answers were transcribed. At the beginning and at the end of the psychological assessment, patient's self-reported anxiety level (on a five point Likert scale, ranging from *not at all anxious to extremely anxious*) was evaluated. The evaluation was performed after an average of one week from hospitalization in order to allow patient to settle.

The study design and protocol were approved by the local Scientific Committees and Institutional Review Board (775 CEC) and were in accordance with the code of Ethics of the World Medical Association (Declaration of Helsinki, 1967).

2.2 Instruments

The *McGill Quality of Life Questionnaire – Italian version* (MQOL-It) is a self-report instrument that assesses Quality of Life (QOL) in patients suffering from terminal diseases [15; 16]. It consists of 16 items which lead to: four subscales (Physical symptoms, Psychological well-being, Existential well-being, and Support); a Total score and a Single Item Score (SIS) originates from rating overall QOL from very bad (0) to excellent (10). A systematic review on feasibility of measurement instruments suitable for use in palliative care described the MQOL as having the best ratings for its measurement properties [17].

A 12-items structured interview was designed to evaluate patients' disease knowledge, right to be informed and to give consent to treatments; the answers were based on a fixed and close-ended choice of answers. Questions were presented in the same order, thus ensuring reliability and data comparisons (see Appendix).

2.3 Data Analysis

Descriptive statistical analysis were performed on patients' characteristics, with the sample divided on the basis of the predominant diagnosis (ALS, CKF, CHF, AC) reporting mean and standard deviations for the MQOL-It and frequency distribution of the answers of the 12-item structured interview. Categorical data were compared using the chi-square test or Fisher's exact test; analysis of variance tested differences between groups on MQOL-It (given a normally distributed data). A p-value <0.05 was considered statistically significant and a Bonferroni correction was performed to divide the critical p value ($\hat{\alpha}$) by the number of comparisons being made. The STATA release 14 package was used for the analysis.

3. Results

Patients' characteristics are represented in Table 1.

As to self-reported anxiety, 93% of patients declared a level of anxiety between nothing or little (no statistically significant differences between the two assessments emerged) in both assessments.

MQOL-It scores are reported in Table 2.

As to QOL, significant differences between groups were found in relation to the subscale Physical symptoms: Bonferroni post-hoc comparisons showed a significant difference among ALS patients and the groups with CKF and CHF ($p = .002$ and $p = .006$ respectively).

Appendix. Topics of the Structured Interview

Item 1	Patients have a right to the truth regarding their disease.
Item 2	It's proper for the doctor to inform patients about their disease evolution even in the event of poor prognosis thinking about your present situation.
Item 3	You are aware of your disease evolution (not at all; enough, more information needed; I don't need more information).
Item 4	You have received enough information concerning your rights in the social and working environments (e.g. legal disability).
Item 5	You think that the time devoted to communicating you your diagnosis was appropriate.
Item 6	You think that the information received on diagnosis and disease progression will come in handy concerning future choices.
Item 7	According to you, «invasive therapy» means: a) A procedure which entails implementation of any invasive acts (i.e. the insertion of a medical instrument device (e.g. probe, catheter etc. into the body), in a natural or an artificial way (e.g. injection, incision, etc.) for diagnostic/therapeutic purpose (correct answer). b) Use of aggressive means which could be harmful to the patient's health. c) An operation that entails the removal of body-parts.
Item 8	According to you «aggressive medical treatment» means: a) Therapy inflicted on patients despite their consent or their relatives' consent. b) High-risk therapy carried out by unskilled staff. c) Implementation of treatments which proved ineffective in relation to the objective pursued (correct answer).
Item 9	Do you know the meaning of these expressions: Advance Directive and Advance Declaration of Treatments? Definition of AD and ADT is provided by the interviewer.
Item 10	Now that you know the meaning of AD and ADT, do you think that they could be tools that guarantee the patient's will to make decision regarding the end of her/his life?
Item 11	If this is the case, which of these two would you deem ethically and juridically adequate?
Item 12	At the present moment you feel you would like to talk about them with your doctor or other health professionals?

Fig. 1. Topics of Structured Interview

Table 1. Study sample characteristics					
	ALS (n = 23)	CKF (n = 32)	CHF (n = 30)	AC (n = 30)	Total (n = 115)
Age (years)	60.2 (±8.8)	62.6 (±15.4)	71.4 (±9.1)	70.7 (±9.9)	66.2 (10.8)
Gender					
Male	7 (30%)	19 (59%)	26 (87%)	18 (60%)	70 (61%)
Female	16 (70%)	13 (41%)	4 (13%)	12 (40%)	45 (39%)
Marital status					
Married/cohabitant	16 (69%)	19 (59%)	14 (47%)	14 (47%)	63 (55%)
Single	2 (9%)	5 (16%)	7 (23%)	5 (17%)	19 (16%)
Widow/Widower	3 (13%)	6 (19%)	7 (23%)	8 (27%)	24 (21%)
Divorced	2 (9%)	2 (6%)	2 (7%)	3 (10%)	9 (8%)
Education					
< High school	13 (56%)	16 (47%)	20 (66%)	26 (87%)	75 (65%)
High school	9 (40%)	14 (44%)	9 (30%)	4 (13%)	36 (31%)
Degree	1 (4%)	2 (6%)	1 (4%)	0	4 (3%)
Work status					
Employed	4 (17%)	15 (47%)	1 (3%)	0	20 (17%)
Not employed	19 (83%)	17 (53%)	29 (27%)	30 (100%)	95 (83%)
Religion					
Catholic	18 (78%)	29 (91%)	29 (97%)	28 (93%)	104 (90%)
Agnostic/atheistic	3 (13%)	3 (9%)	1 (3%)	1 (3.5%)	8 (7%)
Other	2 (9%)	0	0	1 (3.5%)	3 (3%)

Categorical variables are presented as number and percentage in parentheses.

More than half of the sample agreed on the necessity of being informed by medical team about their disease evolution even if their prognosis was poor (item 2). As to information upon social and working rights (item 4) patients with CHF felt being less informed about social and employment rights than the other groups (CHF vs ALS $p = .01$; CHF vs CKF $p = .04$; CHF vs AC $p = .03$). Moreover, relevant differences on how much time should be dedicated to communicate the diagnosis and provide patients with information regarding their illness, were found (item 5). Patients with ALS were the most satisfied (74%) while those with CHF the least satisfied (43%) (ALS vs AC $p = .05$; CHF vs AC $p = .01$). Concerning the usefulness for future choices of the information received (item 6) ALS (74%) and CHF (80%) patients stated that the information received on diagnosis and disease pro-

gression had been useful to take decisions on subsequent choices, compared with patients with AC (47%) and CKF (50%) (ALS vs AC $p = .001$; CHF vs CKF $p = .03$; CHF vs AC $p = .01$).

Table 2. MQOL-It scores for each group of patients (mean±SD)						
MQOL-It	ALS	CKF	CHF	AC	F-value	p-value
Physical symptoms	5.3±2.0§#	7.1±1.9	6.9±1.9	6.0±2.3	4.45	0.005
Psychological well-being	6.5±1.5	6.9±2.0	6.6±2.2	5.6±2.1	2.20	Ns
Existential well-being	7.4±1.3	7.5±1.9	7.3±1.6	6.6±1.8	1.79	Ns
Support	8.4±1.3	7.5±2.0	7.8±1.7	8.2±1.9	1.27	Ns
Total score	6.9±1.0	7.3±1.5	7.2±1.5	6.6±1.5	1.26	Ns
Single Item Score	6.1±2.4	6.7±2.4	6.3±2.4	6.3±2.7	1.31	Ns

Bonferroni post-hoc comparisons: § ALS vs CKF $p = .002$; # ALS vs CHF $p = .006$

Answer frequencies at the 12-item structured interview are reported in Table 3 and Table 4. Values above 40% are represented in bold. As to disease evolution awareness (item 3), statistically significant differences emerged between patients with CHF and AC ($p = .05$) and between patients with CHF and ALS ($p = .01$). Patients with CHF reported more frequently the necessity to receive more information on their disease compared to patients with AC and ALS, which more frequently declared not needing more information upon their disease.

Almost all patients claimed the right of everybody to know diagnosis and prognosis and to be informed on its progression without any significant difference among groups (item 1).

Continuous variables are presented as mean \pm SD.

As to patients' understanding and knowledge of health literacy, the following emerged. Concerning the knowledge on clinical procedures, more than 60% of patients, regardless of their diagnosis,

Table 3. Answers' frequencies and percentages (in bracelet) at the structured interview (items 1-2-4-5-6-9-10-12)												
	Not at all				Enough, more information needed				I don't need more information			
	ALS	CKF	CHF	AC	ALS	CKF	CHF	AC	ALS	CKF	CHF	AC
3. Disease evolution awareness	0	1 (3)	4 (13)	1 (3)	5 (22)	14 (44)	14 (47)	8 (27)	18 (78)	17 (53)	12 (40)	21 (70)
	Don't agree at all / Not at all				Partially agree / Partially				Totally agree /Totally			
	ALS	CKF	CHF	AC	ALS	CKF	CHF	AC	ALS	CKF	CHF	AC
1. Right to the truth regarding their disease	0	0	0	0	5 (22)	7 (22)	4 (13)	4 (13)	18 (78)	25 (78)	26 (87)	26 (87)
2. Proper if the doctor informs of disease evolution even if poor prognosis	1 (4)	4 (12)	4 (13)	5 (17)	9 (39)	6 (19)	5 (17)	6 (20)	13 (56)	22 (69)	21 (70)	19 (63)
4. Have received enough information upon social and working rights	2 (9)	4 (13)	12 (40)	4 (14)	5 (22)	11 (34)	8 (26)	7 (23)	16 (69)	17 (53)	10 (34)	19 (63)
5. Appropriate time devoted to diagnosis communication	1 (4)	1 (3)	3 (10)	2 (7)	5 (22)	14 (47)	14 (47)	6 (20)	17 (74)	17 (53)	13 (43)	22 (73)
6. Usefulness of the information about diagnosis and disease evolution for future choices	0	1 (3)	1 (3)	8 (26)	6 (26)	15 (47)	5 (17)	8 (27)	17 (74)	16 (50)	24 (80)	14 (47)
9. Knowledge of Advance Directives (AD) and of Advance Declaration of Treatments (ADT)	16 (70)	19 (60)	23 (77)	25 (83)	6 (26)	11 (34)	6 (20)	5 (17)	1 (4)	2 (6)	1 (3)	0
10. Could AD or ADT guarantee patient's will to make decisions regarding their end-of-life	1 (4)	1 (3)	2 (6)	3 (10)	16 (70)	16 (50)	9 (30)	13 (43)	6 (26)	15 (47)	19 (64)	14 (47)
12. Perceived need to talk about AD and about ADT with your doctor or other health professionals	10 (43)	14 (44)	20 (67)	22 (73)	9 (39)	8 (25)	2 (6)	6 (20)	4 (17)	10 (31)	8 (27)	2 (3)

Percentages above 40% are reported in bold.

did not know the meaning of invasive therapy as well as of aggressive treatment. As to invasive therapy knowledge (item 7), patients with CKF and with CHF were more accustomed with these definitions in 69% and 57% of cases respectively. ALS patients provided more frequently incorrect answers compared to the other groups (ALS *vs* CKF $p = .0005$; ALS *vs* CHF $p = .01$; ALS *vs* AC $p = .005$). No significant differences among groups emerged concerning the knowledge of aggressive treatments (item 8), with more than 70% of patients providing wrong answers. Besides, overall more than 70% did not know the meaning of Advance Directives and of Advance Declaration of Treatment (item 9) with no significant

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Table 4. Answers' frequencies and percentages (in bracelet) at the structured interview (items 7-8-11)									
	ALS	CKF	CHF	AC	ALS	CKF	CHF	AC	
	correct				incorrect				p-value
Knowledge of									
7. Invasive therapy	5 (22)	22 (69)	17 (57)	11 (37)	18 (78)	10 (31)	13 (43)	19(63)	.002
8. Aggressive treatment	6 (26)	10 (31)	4 (13)	2 (7)	17 (74)	22 (69)	26 (87)	28 (93)	Ns
11. Preference of	AD*				ADT*				
	12 (52)	14 (44)	5 (18)	3 (10)	10 (44)	17 (53)	24 (82)	26 (87)	.0007

Percentages above 40% are reported in bold.

* AD: Advance Directives (legally binding); ° ADT: Advance Declaration of Treatment (not legally binding)

differences among groups. Most patients believed that AD or ADT could partially or totally guarantee patient's will to make decisions on end-of-life (item 10), with a slight frequency difference on AD or ADT efficiency between CHF and ALS patients ($p = .01$). As to the need to talk with health professionals about AD or ADT, differences emerged between CHF and ALS patients only ($p = .005$) with CHF patients being less motivated to deepen the AD or ADT issues.

Finally, once informed on the definitions of Advance Directives (legally binding) and Advance Declaration of Treatment (not legally binding) (item 11), ALS patients would prefer a formulation of advance directives that are legally binding, compared to patients with AC and with CHF who would prefer an indicative and non-binding formulation (ALS *vs* CHF $p = .005$; ALS *vs* AC $p = .001$). Patients with CKF would prefer also the legally binding proposal compared to CHF patients ($p = .02$).

4. Discussion

The invariance of anxiety levels, which remained low, confirms that the interview content did not have a negative impact on patients' wellbeing and the responses can be therefore considered valid. As to quality of life (MQOL-It) ALS resulted to be the most impacting disease on reported physical symptoms, whereas no other differences emerged among groups. The significant lower quality of life in ALS patients could be related to objective symptoms characteristics or to a different subjective perception of symptoms due to a more extensive awareness of disease prognosis. Further studies on this topic are needed. As to ALS and CKF, our patients report quality of life levels mainly overlapping previously reported data [18; 19] whereas patients with AC refer a higher quality of life compared to China, Hong Kong and Taiwan [20; 22].

On the other side, data comparison could be invalidated by different disease stage progression and differences in welfare organization and clinical care settings. Concerning CHF, as to the best of our knowledge, no data have been previously published. As previously shown in literature also in our study the MQOL resulted to be a sound instrument [16; 21], enabling to differentiate among different populations. Considering the worldwide substantial changes due to migration and the increasing complexity of multicultural countries characterized by many different minority ethnic backgrounds, further studies on quality of life considering both disease and cultural differences are needed.

Our patients, even if affected by diseases that impact on everyday life in many different ways, share an overall agreement upon the necessity to be properly informed, both on diagnosis and on its progression and evolution. Their right to increase disease knowledge and its' management is clear in their mind and the framework widens when inquiring on social rights also. In fact, although in percentage we can find statistically significant differences among groups, the information rights are considered relevant

in a high percentage of our sample, recognizing the role of knowledge in supporting future choices. Furthermore, it is possible to identify, from the statistically significant responses to the interview, two groups of patients, namely CHF and ALS, differing on the evolution of disease awareness and information received about their rights (items 3 and 4), with respect to the significance of invasive therapy (item 7) and on opinions regarding the anticipated Directive (item 10,11,12). This opposition between the two groups can be reflected in the difference also on physical symptoms reported by the two groups to McGill Questionnaire. Two other groups of diseases (AC and CKF) relate substantially different answers about the usefulness of the information received (item 6), the significance of invasive therapy (item 7) and choice about the advance directives (item 11 and item 12). A hypothesis that explains the different responses of the patients on end-of-life issues may rely on the different therapeutic diagnostic paths involved in the investigated diseases.

Given this, ostensible contradictory answers characterized our patients: on the one hand, they stressed the necessity and their right to be informed but, on the other hand, their health literacy appeared low on important topics related to end-of-life management. More than a half of our subjects, regardless of the diagnosis, were not able to describe what invasive therapies, aggressive treatments, and Advance Directives or Advance Declarations of Treatment were. Moreover, once better informed, most patients believed that AD or ADT could partially or totally guarantee patient's will to make decisions on end-of-life. Even if communication skills are improved among health professionals in the last decades and literature on this topic has grown, there is still no adequate health information about therapeutic procedures and tools that may enable the patient to be an active protagonist in disease management at end-of-life. In our opinion, these contradictions could only be apparent: abstractly thinking what would be best to know as a general point of view is different to transpose in real life

as «what I want to know in order to decide what I want to be done in end-of-life». When this happens, in our Mediterranean culture, often patients delegate relatives and share decisions inside the family and not as a single individual [11; 23]. Moreover, it is well known that patients may change their mind about treatment decision making and individual preferences on end-of-life issues in the course of the illness [24].

In end-of-life, advance care planning issues are strongly felt. Adequate health care cannot be separated neither by a good doctor-patient communication nor by accurate information. Early referral of patients suffering from chronic progressive diseases to a palliative care team may be often appropriate. Palliative care based in the community or through hospice contacts should proceed in partnership with other specialties involved. The Advance Declaration of Treatment may help to avoid excessive treatment or the therapeutic abandonment and/or patient abandonment. Moreover, the absence of adverse effects of Advance Care Planning on psychosocial outcomes is noteworthy. Patients or families who participate in ACP did not report more stress, anxiety, or depression compared to patients or families who did not participate [2]. In our context many cultural, religious, legal, ethical issues lay beyond this impasse [25; 26]. Even if Italy too has recently a new legislation on ACP, still the implementation of this new perspective founded on legal issues will be a steep trip [13]. Nevertheless, even when this aim will be reached, many difficulties will be encountered yet, due to the intrinsic characteristics of end-of-life discussions. The ADT should be the culmination of a process that involves liability and the person concerned, the doctor and the trustee, and should not be reduced to the signing of a consent. The ADT usefulness may be reached as a result of a multidisciplinary approach including accurate communication on disease, prognosis, and treatment options, and requiring the ability to reflect upon moral values, to identify needs and priorities taking into account the scope and limits of the therapeutic relationship. The

expression of will is the culmination of a process of gradual and personalized information, which is part of the therapeutic relationship between the multi-professional team and the patient. Through follow-up interviews, possibly respecting personal times, the patient and family members are helped to become aware of the problem, to evaluate alternatives, and to express their decision.

The respect of the ADT is necessary but not sufficient to ensure the best decision. Doctor and patient are both engaged in a relationship that cannot be reduced to mere rejection/approval of the proposed treatment, as in the case of informed consent. Finally, culturally different worldviews and meanings associated with health, illness, and death should not be neglected leading to a shared and active planning process on chronic disease management in its advanced stage, in respect for patient's autonomy and, if necessary, in respect for his/her individual choice to abdicate autonomy to another significant person of patient's relational environment [23].

Our study presents some limitations, first of all its small sample size. Nevertheless, its strength lies on the cross-sectional nature of its design, presenting, as only few studies do, transversal data on four different diseases.

5. Conclusions

Chronic progressive disease management requires the active participation of patients and their caregivers in the decision-making process of care; it is essential to inform and to guide patients and their families in this process from diagnosis to end-of-life. Even if the importance of identifying patients' goals and preferences is well established, the road of end-of-life communication is often paved with difficulties and no general rules can be recognized: disease characteristics, health literacy, cohort belonging and social-cultural aspects may imply differences in knowledge and expecta-

tions about end-of-life issues and about the usefulness of Advance Declaration of Treatment. The reasons for limited utilization of the available means for documenting end-of-life wishes is still a significant issue under discussion which deserves further studies.

Take home messages – Suggestions for clinical practice

Patients affected by chronic progressive diseases require to be more actively involved in the decision-making process of care, even if their health literacy is low. Once better informed on end-of-life issues, most of interviewed patients believed that AD or ADT could guarantee patient's will to make decisions on end-of-life. A palliative care approach should be incorporated into the care plan for patients and caregivers from the time of diagnosis when dealing with a progressive chronic disease.

It is important to initiate discussions on end-of-life decisions whenever the patient asks – or opens the topic.

The patient has to be informed on legal aspects regarding ADT and should be supported in naming a health care proxy.

Declaration of Interest Statement

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