”I think it’s a bit early for now”: impact of psychological factors on drafting advance directives among cancer patients Running title: Advance directives for cancer patients

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Abstract: Various studies have shown that the drafting of Advance Directives (AD) is relatively uncommon. This study was performed to explore cancer patients' attitudes toward advance directives, and their reasons for completing or not completing advance directive forms. The research included interdependent steps designed to gradually collect patients' agreement and comments concerning their participation in an AD study. A thematic content analysis was performed on patients' comments. A total of 147 patients spontaneously agreed to participate before the presentation of the specific theme (AD) of the study. A large majority of the sample reported having no knowledge about ADs. Of the patients who initially agreed to participate, two-thirds declined after the presentation of the theme of the study. The reasons of patients who declined to participate related to avoidance of the issue of death, a focus on present time perspective, or an ambivalence between the AD proposal and recovery plans. This study provides further evidence of the difficulties for patients to express their willingness to engage in AD discussions or research. The extent of the psychological issues experienced by patients and the level of avoidance they expressed raise many questions about the ethical issues and the spread of advance directives used in oncology settings.

Keywords: living wills, advance directives, attitudes toward death, managed care, clinical ethics

INTRODUCTION

The implementation of ADs in the French Constitution is recent (April 2005).[1] In this national context, advance directives (ADs) are defined as the written expression of one person's wishes to limit or stop one or more treatments that may be proposed, whenever this person would no longer be able to express his/her wish or consent to medical treatment.[1-2] For several years, in France, end-of-life conditions have been the subject of numerous ideological debates, political demands, and ethical and professional reflections. In this context, the promulgation of the *Law on patients' rights and end-of-life conditions* (called the Leonetti Law) on April 22nd, 2005 strengthened the legislative framework on end-of-life, encouraging multidisciplinary team discussions regarding medical and ethical principles that could guide decision-making. Introduced by the Leonetti law, ADs are a new framework for French patients and healthcare professionals. Moreover, law N° 2016-87 of February 2nd, 2016 created new rights for patients.[2] Since this law was passed, medical doctors have been obliged to comply with patients' ADs in all conditions except in the case of vital emergencies or when ADs are "manifestly inappropriate".

Various international studies conducted with healthy people or people with acute, chronic, or incurable diseases have shown that the drafting of ADs is relatively uncommon (5 to 25%). [3-7] These rates did not increase during the last decade despite a largely positive attitude towards this legal provision. In France, according to the National Institute of Demographic Studies' (INED) survey conducted in 2010, only 2.5% of patients near end of life had drafted ADs.[8] Another study was conducted in the admissions office of the University Hospital of Nancy using a self-administered questionnaire. It showed that a majority of patients (57.5%) did not know about the possibility of drafting ADs. However, a large proportion (93%) of these patients were in agreement with the writing of instructions such as

ADs.[9] Moreover, a qualitative study conducted amongst 186 care center users over the age of 75 found that 90% of them had never "heard" about ADs before the inquiry.[10] After having been informed about the objectives of ADs, more than 80% of people stated that they were "not interested" in the drafting of ADs because they were not personally concerned.

The low use of ADs in France could be explained by their recent introduction into the health care system. However, a low use of ADs is also observed in countries such as the United States and Australia, where ADs were developed in the early 1990s. AD studies highlighted a paradox between the massive popularity of ADs amongst the population, even seriously ill patients, and the very low use of this legal document. The reason people choose to complete AD forms or not requires a better understanding of the knowledge, attitudes, and beliefs regarding ADs and of how they interact with and affect behaviour.[11] Despite the importance of this topic, there are very few empirical data in France about critically ill patients' perceptions towards the advance directives.

Cancer is the most prevalent disease in France, with more than 385,000 new cancer cases diagnosed annually (211,000 men and 174,000 women).[12] The most common cancers among men are prostate, lung, and colorectal. For women, it is breast, colorectal and lung. The number of cancer-related deaths in France is estimated at almost 150,000 per year, which represents almost 30% of annual deaths in France. France is one of the European countries with a high rate of cancer, both among men and women. It also has a high cancer mortality rate, particularly amongst men. The rate of use of palliative care for cancer management in hospitals is 52% (lung cancer 62%, prostate cancer 41%)[13].

This study was performed to assess the prevalence and attitudes towards ADs among cancer patients who are particularly concerned by decisions about life-sustaining treatment. As pointed out in a recent systematic review[14], there is evidence that patients with advanced

cancer vary in their willingness and desire to engage in advance care planning discussions and research.

Generating stable, authentic treatment preferences may be a difficult problem in the context of cancer decision making marked by uncertainties.[15] The principal questions addressed were: Do cancer patients agree to participate in a study on ADs? What are the reasons for participating or not participating in such a study? In addition, we wanted to provide some ethical reflections regarding the implementation of ADs in the oncology setting.

METHODS

Participants

The study was a non-randomized prospective monocentric study conducted via a questionnaire and open oral questions. Participants were patients with cancer consecutively hospitalized in the oncology inpatient service at a University Hospital in south-east France. Data were collected during a 5-month period (between February and July 2016). To be included in the study, patients had to speak French, be 18 years of age or older, and be free of neurological or psychiatric disorders.

Study design

The research included 3 interdependent steps designed to gradually collect patients' agreement to research participation, and to evaluate the potential impact of the research theme.

Step 1 – Initial enrolment. A study investigator (psychologist) informed the patients that a psycho-oncology study was currently being conducted within the oncology department regarding the experience of cancerous disease and the patients' rights to participate in medical

decisions. He asked patients if they were *a priori* interested in participating in this study. The investigator collected the provisional agreement of patients concerning their participation in the research. For patients who declined to participate, the researcher collected, via an oral open question, the reasons given by the patients to explain their refusal. For patients who agreed to participate, the following socio-demographic and medical data were collected: gender, age, marital status, type of disease, duration of disease, metastatic status, and ECOG Performance Status score that describes the patient's level of functioning in terms of their ability to care for themselves, daily activity, and physical ability (score ranging from 0 *Asymptomatic* to 5 *Death*)[16].

Step 2 – Inclusion. During a second step, immediately after obtaining the patient's opinion, the investigator asked patients who agreed to participate whether they were familiar with ADs, and what definition they could give for ADs. After that, the investigator gave the definition of ADs. The study was presented as: "A survey designed to understand the relationship that patients have with ADs. The aim is to examine the relevance of ADs for patients. Furthermore, this study provides the opportunity for every patient to write their own AD". The investigator again asked the patients if they wished to participate in this study and received the agreement of the patients. For patients who declined to participate, the researcher collected the reasons given by the patients to explain their refusal, via open oral questions.

Step 3 – Participation. For the patients who agreed to participate, the investigator provided a booklet published by the *Marseille Public University Hospital* System (AP-HM) on ADs. This booklet provides a description of the legal framework of ADs and a pre-written model of ADs developed by the AP-HM that can assist patients with the drafting process. The AD could be completed during hospitalization or at the patient's home. Patients could return the AD during their next hospitalization and complete the AD alone or with relatives. At this

stage, patients could sign the pre-written model of the AD, write their personal AD, or refuse to draft their AD.

Data collection

The socio-demographic and medical data collected during the first step were included in a database for statistical analysis. Patients' comments concerning their refusal to participate (step 1 and 2) were transcribed immediately after the meeting with the patients, by the investigator. In step 3, the investigator collected the reasons, using open oral questions, given by the patients to explain their decision (i.e. drafting the pre-written model, drafting their personal AD or their refusal).

Data analysis

Statistical analysis. The data (socio-demographic and medical information, knowledge of ADs) were expressed as frequencies and percentages for categorical variables and mean and standard deviation for continuous variables. Comparisons between groups were performed using the chi-square or Fisher's exact tests for frequencies, and the Student T-Test. Statistical significance was defined as $p<0.05$. Statistical analyses were performed using the SPSS version 19.0 software package (SPSS Inc., Chicago, IL, USA).

Patient comments analysis. The comments produced by patients (at step 1 and 2) were subject to a thematic analysis.[17] Thematic analysis consists in building a thematic structure based on an analysis of the unit of sense of the interviews. A unit of sense is the part of the data, ranging from words to paragraphs, which gives meaning to the speech. These units of sense are grouped by theme.

Ethical issues

Ethical approval for this research was obtained from the South Mediterranean I Committee for the Protection of Persons (CPP, reference number: 2015-A00692-47), and the National Agency for the Safety of Drugs (ANSM, reference number: 150534B-12). Because of the sensitivity of the study, a monitoring system by the psychologists of the oncology department was set up. Patients could contact the psychologist throughout the study period and, thereafter to prevent any potential psychological impact of the study.

RESULTS

Characteristics of the respondents

A total of 161 patients were contacted to participate in the study (Figure 1). Out of these patients, 14 declined to participate, and 147 spontaneously agreed to participate before the presentation of the specific theme (AD) of the study. The fourteen who declined did not substantially differ with respect to demographic and disease characteristics from those who initially consented to participate.

The mean age of the 147 patients who spontaneously agreed to participate was 62 years (range, 29 to 89 years), 54.4% were male. The most frequent cancer diagnoses were lung (84.4%), and nearly eight out of ten patients (76.9%) had metastatic cancer. Most patients (86.4%) had a score of 0 or 1 performance status, and 42.2% were diagnosed less than 3 months ago. A large majority of our sample reported having no knowledge of ADs (n = 134, 91.2%)

Out of the patients who initially agreed to participate, 97 (65.9%) declined after the presentation of the specific theme (i.e., Advance directives). The patients who declined to

participate in the research differed from the patients who agreed to participate by their gender and their initial knowledge of the AD. They were more frequently men and declared less knowledge of ADs (Table 1).

Comments of the respondents who declined after information on the theme

The reasons of patients who declined to participate after presentation of the research theme can be categorized into 7 themes. Table 2 provides respondents' verbatim comments as illustrations of the themes. The first theme (*Avoidance of the issue of death*) refers to the difficulties expressed by patients regarding thinking about their own death. The proposal to conduct research on ADs confronts patients with this possible risk, with an "unthinkable" situation. ADs seem to involve a relationship to death more than to the conditions of dying. Twenty-eight patients (out of the 97 who declined after the presentation of the specific theme) cited this reason to explain their decision to finally not participate in the study.

The second theme (*Focus on the present time perspective*, 22/97) refers to the mention of time (time perspective) as a reason for not participating in the study. Patients mentioned two aspects, the fact that this proposal (AD) was too early or premature in relation to their current situation; the fact that they were focused on the present and didn't wish to look forward into the future. These reasons may be comparable to a coping strategy. Focus on the present time makes it possible to eliminate the relevance of ADs which would correspond to another temporality (future).

The third theme (*Ambivalence between the AD proposal and recovery plans*, 15/97) is close, in certain ways, to the second one. In their comments, patients highlighted a "contradiction" between the main objective of the therapeutic project (recovery) and the AD. The proposal to patients to think about their own AD seem to produce a dissonant cognition

with the expected adjustment to facing cancer (maintaining a positive attitude and/or a fighting/spirit).

The fourth theme (*Current state of health as a constraint*, 11/97) related to the impact of the disease's conditions on the perceived capability of participating in the study. Patients declared that they wished to "save" their personal resources to cope with this situation, which was already difficult. The situation was referred to in vague terms (e.g., "my problems") or specific terms (e.g. tiredness).

The fifth theme (*The anxiogenic component of the AD*, 9/97) refers to the perceived psychological impact of the AD. Patients speak about the troubles or anxiety that could be produced if they think about or write their AD. The anxiety referred to the deterioration of state of health or facing up to their own death. The AD was thus associated in a certain way with the terminal stage of the illness.

The sixth theme (*Refusal without specific reason*) related to the difficulty for some patients to produce reasons to explain why they declined to participate in the study. The patients did not produce reasons that we could directly associate with the AD. Patients referred to a lack of interest (without really explaining the underlying reasons for this lack of interest) or the fact of not knowing, of not being able to produce a reason.

Finally, the seventh theme (*Feasibility and legitimacy of AD*, 5/97) referred to the beliefs expressed by the patients concerning the possibility of applying the AD (that can change over time) or the moral legitimacy of this legal measure. Patients experienced doubts about the actual feasibility of this system, writing down their wishes about their end-of-life conditions being tantamount, for example, to setting in stone an aspiration which was bound to change.

Patients who drafted their AD

From the patients who initially agreed to participate, only 50 (34.01%) agreed to participate after the presentation of the research theme (see figure 1). Of these 50 patients, 31 (21.08%) drafted their ADs, 14 dropped out for various reasons, and 5 did not draft their AD.

We can distinguish two categories of patients in those who drafted their ADs. Firstly, patients who signed the pre-written model of the AD proposed by the AP-HM stated that this model was in accordance with their own wishes and with the model of a "good death". Secondly, patients who wrote personal ADs (2.48% of the patients initially contacted in the oncology inpatient service). These patients explained the writing of their own AD by a desire to transcribe individual wishes from a personal reflection. Reading these ADs shows that they followed the AP-HM booklet (e.g., relieving suffering, not artificially prolonging life). The written ADs have a medical vocabulary with few personal explanatory elements or elements from the patient's history. In other words, the directives written by the patients did not refer to subjective elements or elements linked to their personal experience (e.g., feelings, emotions, aspirations). They were rather a "neutral" summary of rather prototypical medical options fairly similar to those presented in the AD model proposed by the AP-HM.

DISCUSSION

In France, the patients' rights to autonomy and participation in medical decisions in end-of-life have been encouraged for around ten years. The option given to patients to write their advance directives represents important progress in this regard.[1-2] The advance directives seem a priori a "good" solution to the dilemma of making medical decisions for individuals incapacitated by injury or illness, and for maintaining the patient's voice in treatment decisions by enhancing the ability of surrogate decision makers. This study, in line with previous studies in this field, highlights the paradox widely observed between the social acceptance of AD and the low rate of AD drafting[3-7], and it points out some psychological

underpinnings of advance medical decision making.

The social cognitive theory posits that expectations concerning the achievement of goals, including treatment goals and healing, stimulate feelings of self-efficacy in individuals, which in turn spark action and effort in the furtherance of these goals.[18] For cancer patients, the motivation to succeed and to achieve the most common goal (i.e., surviving cancer) constitute a framework which conflicts with the advance directives proposal. Optimism and positive thinking have become core values in the culture of cancer support, and this context can explain the resistance to thinking about death and to anticipating undesirable future end-of-life conditions.[15,19]

As the analysis of comments highlights, the proposal to draft an AD produces a state of cognitive dissonance[20] for patients. Having cognitions that are inconsistent (i.e., maintaining hope and fighting spirit vs. anticipating their own personal end-of-life or death) tends to create this unpleasant state and psychological component (anxiety, fear, distress). Cognitive dissonance can cause the patient to mobilize their energies, coping resources and adaptive strategies in order to accomplish the healing goal. One important form of dissonance reduction consists of selective exposure that refers to the avoidance of cognitive dissonance (or information). So, confronted with the "virtual" consequence of ADs, patients were confronted with a possible lack of self-worth. As suggested by the theory of cognitive adaptation[21], in this situation patients try to maintain an optimistic outlook and control over the event by avoiding "making possible" the issue suggested by the writing of their AD. In numerous studies, cancer patients preferred to delay the introduction of advance care planning to later in the illness trajectory.[13] For example, previous studies have shown that cancer and lung disease were factors associated with late completion of ADs (in the last three months of life).[22]

The ethical argument for advance directives flows from a belief in the priority of self-determination as the guiding principle in medical decision making. This ethical argument is not called into question by the results of this study. Patients exercise their right to self-determination by refusing to expose themselves to existential questioning or the writing of their AD. They express a preference which aims to "avoid" or "negotiate" the questioning induced by the AD, and in some ways, they produce affective forecasting.[23] To a "neutral" observer, cancer patients seem to be in a "proximal temporal distance"[23] concerning end-of-life and the expression of wishes concerning end-of-life medical decision making. However, by distancing ADs, patients demonstrate their "will" (or psychological necessity) to distance the symbolic meanings of ADs, and they focus on the issue of desirability.

One paradox can be pointed out, the AD aims to empower patients, but it is often perceived by them as a form of coercion, in the sense that the proposal of an AD creates pressure, interference or intrusiveness. Coerciveness is a critical dimension in determining the stressfulness of the medical condition.[24] In the determination of their future course of action, the patient may not need to be informed (of their rights) to maintain their coping strategies. As pointed out by Engelhardt[25] autonomous choice is a right, not a duty of patients. Additionally, the right to be informed is not an obligation to be informed even if the possibility of being informed must be guaranteed. Most patients appear to relinquish disclosure of AD information, preferring that the disclosure standard be that of the profession.

Furthermore, results indicate that when patients are inclined to play an active role in their end-of-life conditions, they most often choose to sign a preformatted document rather than draft their own ADs, and when they draft their own ADs, these are close to the pre-written model. This raises the question of the role that a pre-established standard document can play and its capacity to allow the expression of "valid" wishes. Validity refers here to the

poor understanding of medical care or advance care planning by patients observed in many studies, and the probability that patients do not produce "authentic" treatment preferences.[26-27]

Study limitations

There are some limitations to this study. The results from this study must be interpreted with caution because the patients were not selected randomly from the population of cancer patients, and the sample was relatively small. Furthermore, a large number of patients had a diagnosis of lung cancer (due to the skill-set of the oncology unit), and the study was performed in a University hospital, which may limit generalizability.

Clinical implications

This study is the first in France to explore perceptions of advance directives among cancer patients. This study provides further evidence of the difficulties of patients to express their willingness to engage in AD discussions or research. The extent of the psychological issues experienced by patients and the level of avoidance they expressed, question in many ways the spread of the use of advance directives in oncology settings. In the context of a recent introduction of ADs into the French health care system, further investigations are needed to corroborate these previous results, to explore in depth the psychological components that arise during a patient's decision making, the role and impact of physician-patient communication, and the ethical issues relevant in these circumstances.

DECLARATION OF INTERESTS

The authors declare that they have no competing interests.

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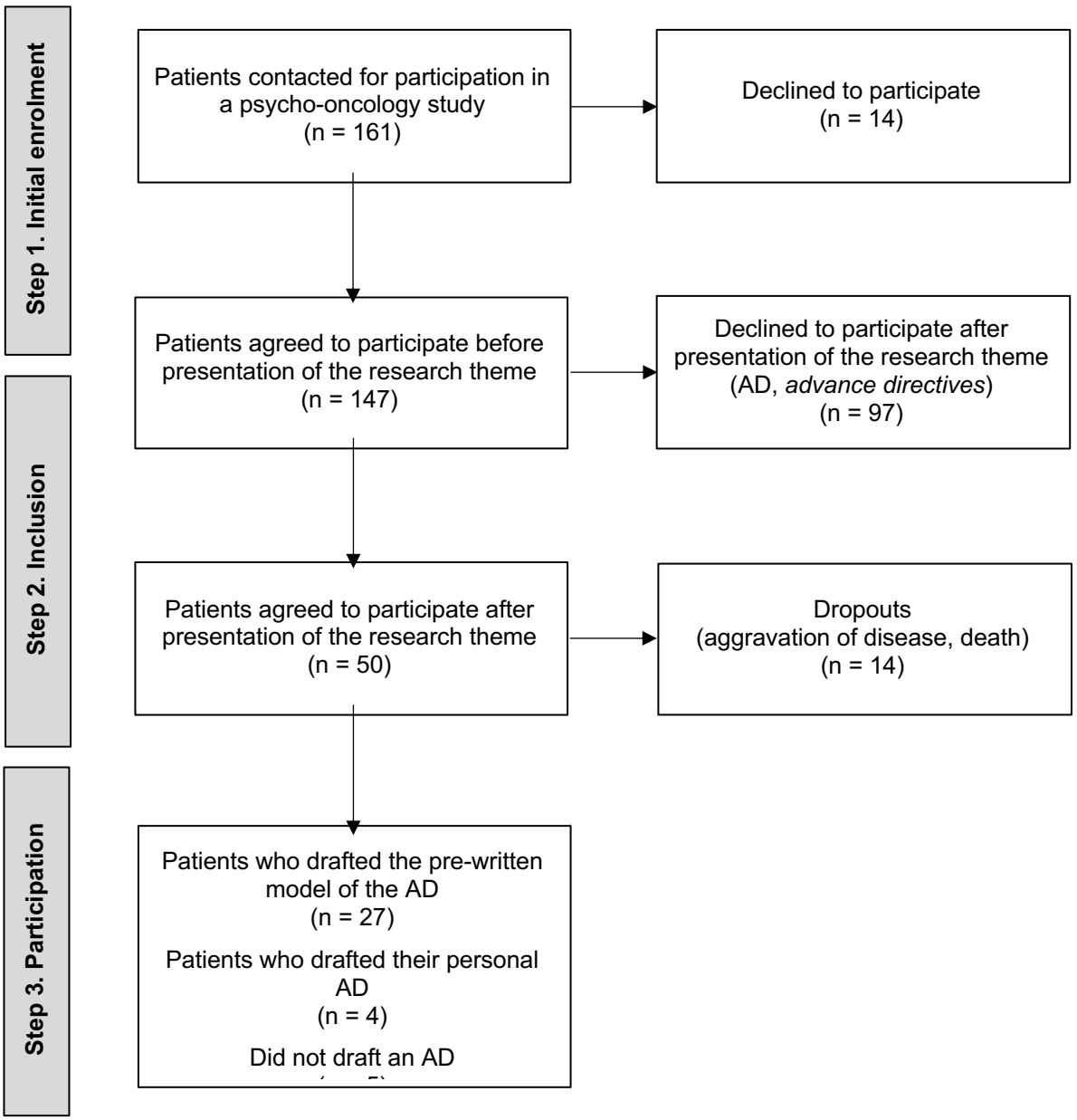

Fig. 1. Flow diagram of patients in the study

Table 1 Demographic characteristics and health status (n = 147)

Characteristics	Patients agreed to participate in the research on AD (n = 50)	Patients refused to participate in the research on AD (n = 97)	p value [(1)]
Mean age: years (SD)	62.32 (10.88)	61.91 (9.89)	NS
Gender, n (%)			
Male	17 (34)	63 (64.9)	< 0.001
Female	33 (66)	34 (35.1)	
Disease type, n (%)			
Lung cancer	40 (80)	84 (86.6)	NS
Others [(2)]	10 (20)	13 (13.4)	
Metastatic cancer, n (%)			
Yes	35 (70)	78 (80.4)	NS
No	15 (30)	19 (19.6)	
Performance Status, n (%)			
0	20 (40)	37 (38.1)	NS
1	25 (50)	45 (46.4)	
2/3	5 (10)	15 (15.5)	
Illness duration, n (%)			
< 3 months	26 (52)	36 (37.1)	NS
≥ 3 months	24 (48)	61 (62.9)	
Knowledge of advance directives, n (%)			
Yes	9 (18)	4 (4.1)	.007*
No	41 (82)	93 (95.9)	

AD, advance directives; SD, standard deviation; NS, not significant.
[(1)] *Pearson's chi-squared* test except * *Fisher's* exact *test.*
[(2)] Others were: urology (prostate, bladder, testis, kidney), gynecological (breast, uterus, ovary, cervix).

Table 2 Summary of the thematic analysis of patient's comments

Themes	***Typical extracts***
Avoidance of the issue of death (28/97)[a]	"*I'm not there yet. The end of life, I haven't thought about it yet and I prefer to avoid it. No, I don't want to participate*." (Male with lung cancer) "*At the moment, everything is going wrong. I'm miserable. I try to hang on. I cling to the idea that I'm immortal. Maybe when it gets better*." (Female with uterus cancer)
Focus on present time perspective (22/97)	"*I'll tell you. I think it's a bit early for now. Not that I am in denial, but given the plan I've made and seeing that I'm starting the treatment, I find it a little premature*." (Male with lung cancer) "*No, sorry I don't want to participate. I live from day to day. I don't look forward*." (Female with lung cancer)
Ambivalence between the AD proposal and recovery plans (15/97)	"*I've decided that I will get better, so I think that for me it's pointless to write an AD. In fact, I would like to say, accepting the cancer is very complicated. The writing of this document is the same thing, this means that we have a very serious illness and that we can die*." (Male with lung cancer) "*No, I won't participate. In fact, by answering your questionnaire we are confronted with the fact that we won't be able to answer and that we will be at the end of our life. In writing the AD we are obliged to prepare ourselves for this. And we are asked to be positive, so it is difficult*." (Female with lung cancer)
Current state of health as a constraint (11/97)	"*No, I don't really want to. I already have my problems. If I didn't have my problems, why not, or maybe later, but now I don't feel like it*." (Male with bladder cancer) "*I'm not going to do it, I'm tired and very worried for the moment*." (Female with breast cancer)
The anxiogenic component of the AD (9/97)	"*No, I don't. It's going to upset me*." (Male with lung cancer) "*No, I can't imagine for a second that it will get worse. I'm in a state of mind where everything will be fine. So, looking forward in this situation, I find that makes me anxious*." (Male with lung cancer)
Refusal without specific reason (9/97)	"*No. I don't know, there's not too much reason to. It's not my thing*." (Male with lung cancer) "*No, I'm not interested. That's all*." (Male with lung cancer)
Feasibility and legitimacy of AD (5/97)	"*People believe that they have control over their lives, that they can derive meaning from this experience. But we don't even know if we're making progress or going backwards. And your advance directives, we'll say something one day and the next day everything will have changed. We'll realize that our opinion has changed*." (Male with lung cancer) "*No. Look, we're against it. We come from a very Christian family, very medical, very focused on experience. People should see that it is good to experience everything. We are firmly attached to hope*." (Male with lung cancer)

[a] Number of patients who mentioned this theme out of the total number of patients who declined to participate after information on the research theme (i.e. Advance directives)