

# Usefulness of questionnaires on advance directives in haemodialysis units

Angel Rodríguez Jornet<sup>1</sup>, Loreley Ana Betancourt Castellanos<sup>1</sup>, Maria Isabel Bolós Contador<sup>1</sup>,  
Juan Carlos Oliva Morera<sup>2</sup> and José Antonio Ibeas López<sup>1</sup>

<sup>1</sup>Nephrology and Computer Services, Parc Taulí University Hospital, Parc Taulí, Sabadell (Barcelona), Spain and Sanitary Corporation and <sup>2</sup>Parc Taulí University Hospital, Parc Taulí, Sabadell (Barcelona), Spain

Correspondence and offprint requests to: Angel Rodríguez Jornet; E-mail: arodriguez@tauli.cat, arodrijornet@hotmail.com

## ABSTRACT

**Background.** As renal replacement therapy has become universal practice in medicine, there is a need to consider whether this treatment is suitable for elderly people. These patients have high comorbidity and may require dialysis withdrawal in certain clinical circumstances. Advance directives (ADs) drawn up by patients facilitate treatment-related decisions if they lose cognitive capacity. Questionnaires dealing with possible extreme clinical circumstances can thus help clinicians and relatives reach pertinent decisions in such cases.

**Methods.** We studied the usefulness of questionnaires on ADs in patients who started periodic haemodialysis over a period of 10 years. Telephone interviews were conducted to assess satisfaction level among relatives/representatives of deceased patients who had been advised to limit therapeutic efforts in certain clinical situations. The questionnaire was assessed using a six-factor degree of satisfaction.

**Results.** Four hundred and forty-three questionnaires were distributed over a period of 10 years. A total of 41.3% of patients stated that they wished to limit therapeutic efforts in the serious clinical situations presented; 37.9% refused to complete the questionnaire; 14.7% expressed their wishes without any written confirmation; and 6.1% expressed their wish to continue on dialysis in all situations. Two hundred and twenty-four patients had died by the study end date. The cause of death in 20.2% was scheduled dialysis withdrawal. Representatives reported an extremely high degree of satisfaction with the questionnaire (94.7%). Younger people, however, were more reluctant to consider and answer questionnaires on ADs.

**Conclusions.** Questionnaires on ADs are a useful tool in daily nephrology practice and should be distributed to those patients willing to consider the limitation of therapeutic efforts in extreme clinical circumstances. In general terms, these questionnaires should be given to all elderly patients.

**Keywords:** questionnaires on advance directives, usefulness

## INTRODUCTION

Prolonged life expectancy of patients undergoing renal replacement therapy has gone hand in hand with an increase in the number of dilemmas regarding artificial life support and quality of life. The definition of quality of life may vary according to the person who is judging it (patient, professional, family). It is not an absolute value and can change depending on the underlying disease (diabetes mellitus, primary glomerulopathy), psychosocial aspects (family integration), adaptation to the environment (social integration), technological advances (erythropoietin, mode of dialysis) and, in short, the personality of each and every patient. They may worry not only about the quality of their own survival, but also about the burden that they may pose to their relatives [1]. Patients should decide on the treatment that is presented to them and the consequences that this treatment can have on their quality of life. As long as patients retain their ability to decide, they can express their advance directives (ADs) in a document so that their wishes can be taken into account in the event of gradual loss of cognitive capacity due to progressive dementia or cardiorespiratory failure. These ADs have been associated in practice with ‘good deaths’ for relatives of those

patients who died following the decision to withdraw from dialysis [2]. This ‘good memory’ is the result of the decision-making process, which takes into account the deceased patient’s values.

Intervention of nephrologists in withdrawal of dialysis (WD) is extremely disparate and varies considerably according to geographical location and even to the doctors’ personal position. This may differ considerably from each patient’s personal values. A recent article [3] highlights these differences in European Dialysis and Transplant Association (EDTA) countries.

This study describes our experience from a public hospital in Catalonia where questionnaires on ADs (QADs) are given by the nephrology service to patients on renal replacement therapy in the form of periodic haemodialysis within a few weeks of therapy initiation. We evaluated the degree of satisfaction and usefulness of the QAD, as assessed by relatives/representatives of patients who had died from WD.

## MATERIALS AND METHODS

The Parc Taulí Hospital in Sabadell, Catalonia, Spain, is a public hospital covering a catchment area of 450 000 inhabitants working predominantly in the industrial and service sector, with its own Ethics Committee since 1991. In 1992–93, guidelines for dialysis initiation/withdrawal for patients on renal replacement therapy (Table 1) were drawn up by the Ethics Committee, in conjunction with the nephrology service, other health professionals, non-health professionals and patient representatives.

Since publication of the guidelines, we have gathered data on all patients who died from WD in accordance with the guidelines protocol and compared these with patients who died from other causes [4]. Since 2005, the haemodialysis unit has distributed QADs to all patients on renal replacement therapy within a few weeks of therapy initiation. This document describes extreme clinical situations that may lead health professionals to consider the need to withdraw dialysis. QADs were handed to patients during haemodialysis sessions by one of our nephrologists trained in bioethics, who also explained the contents of the document to ensure patients understood the

**Table 1. Clinical situations where non-initiation/withdrawal of dialysis is advised in the protocol**

- |  |
|--|
| <p>a. If substantial loss of cognitive capacity:</p> <ul style="list-style-type: none"> <li>● irreversible advanced dementia</li> <li>● severe mental retardation</li> <li>● persistent vegetative state</li> </ul> <p>b. In case of serious psychiatric disorder with impaired/minimal patient cooperation in treatment:</p> <ul style="list-style-type: none"> <li>● irreducible chronic psychosis</li> </ul> <p>c. If presence of other diseases carrying a poor prognosis (survival &lt;6 months):</p> <ul style="list-style-type: none"> <li>● untreatable solid malignancy, metastatic</li> <li>● refractory haematologic malignant disease, not treatable</li> <li>● irreversible terminal liver, heart or lung disease (in these cases, bed-ridden patients needing significant help for daily activities)</li> <li>● multisystem failure with highly unlikely survival prognosis</li> </ul> |
|--|

questionnaire. Patients were asked to reply to questions about their surrogate decision-maker, treatment by dialysis, artificial feeding, mechanical respiration and resuscitation following cardiorespiratory failure in extreme clinical circumstances, in the event of cognitive loss. Patients were requested to keep the QAD for discussion with the family and representative and to return the questionnaire within 3 months. Patients were informed that they were under no obligation to answer the questionnaire, and if they or their family required further information, this would be provided by the nephrologist who gave them the questionnaire, their own nephrologist or a member of the nursing staff, depending on their wishes. The QAD was either in Catalan or in Spanish; when patients did not know either of these languages, the questionnaire was discussed through a translator, generally a member of the patient’s family (three black sub-Saharan, five Arabs, one Czech). For a summarized copy of the QAD, see [Supplementary data](#), Appendix 1.

QADs were given to patients a few weeks after initiation of periodic haemodialysis, when we considered that the patients had assimilated their new clinical situation. In cases of patients having an acute clinical event, the QAD was given once this acute event had been managed. A period of 3 months was allocated before return of the QADs, whether completed or not.

QADs were assessed yearly and information updated on deceased patients, transplants and losses through change of address. Fifty percent of patients responded that they were willing to record their ADs in the event that they lost their decision-making capacity [5], and this figure did not vary throughout the course of the study. Only one patient asked to change his ADs after a period of time. Age was the only statistically significant difference between patients who were willing to record limitation of therapeutic efforts (LTE) in irreversible clinical circumstances (71.2 years) and those who were not willing to answer the questionnaire (62.2 years) [5].

We reviewed the questionnaires on LTE distributed between 1 June 2005 and 31 August 2015 and selected the questionnaires answered by patients who had died in those 123 months. We also separated answered and unanswered questionnaires from patients who had died following WD. We conducted a telephone survey among relatives/representatives or surrogate decision-makers of the deceased patients in the weeks after death. In the telephone conversation, we asked to speak to a relative of the deceased patient and asked whether they knew the deceased well. Once the identity of both parties had been established, we asked to speak to the patient’s representative in cases where the interlocutor was not the representative, and we phoned again if this person was absent in that time.

Two important questions were included in the telephone survey:

- i. The family member/representative’s perceived usefulness of, and satisfaction with, the QAD at the time of LTE decision, on a scale of 1–6, following the criteria applied on the Likert scale [6] and modified to include six possible response options: (1) advice not to distribute the questionnaire as unhelpful or harmful; (2) questionnaire

not useful; (3) doubts about its usefulness; (4) quite useful; (5) very useful; and (6) essential.

- ii. In the representative's opinion, the degree of perceived patient satisfaction/anxiety when the QAD was answered, following the same criteria as the modified Likert scale, with the six response options.

The clinical situations presented in the QAD included possible cases of permanent coma, persistent vegetative state, dementia experienced with anxiety, agitation, aggressiveness and chronic non-treatable disease, incompatible with a minimum quality of life [cancer, stroke, congestive heart failure, respiratory or hepatic failure, in addition to chronic renal failure (CRF)]. In these situations, patients were asked if they wanted to continue on dialysis, be fed artificially through a nasogastric tube, be intubated and ventilated artificially, or be resuscitated following cardiorespiratory failure.

Three possible causes of patient death were given: (i) death following WD and LTE in the hospital (nephrology services or palliative care), implemented in accordance with the protocol criteria; (ii) death in the hospital following implementation of the final LTE due to an acute complication or a complication arising from a chronic process. These patients died due to the acute complication where limitation of last therapeutic efforts was applied (final LTE). Inclusion criteria were LTE confirmation in the patient's clinical records, discussion with the patients' representative and death of the patient at least 3 days after the last dialysis. The decision to implement LTE was dictated by the occurrence of an acute clinical event requiring patient hospitalization that ultimately led to the patient's death. And (iii) other causes of death.

Statistical analyses were based on the number of patients in each group and calculation of the corresponding percentages. Statistical inferences were carried out by comparing the percentages by the chi-square test. The limit of statistical significance was set at  $P < 0.05$ . Analyses were performed using version 22 of the statistical package IBM SPSS statistics for Windows.

The ethical standards in clinical research, in particular data protection of information gathered from patients and family/representatives, were adhered to. The study was approved by the hospital's Ethical Committee on Clinical Research. The authors had no conflict of interests in the methodology or reported results, as telephone calls were made by a sole interlocutor, i.e. the main researcher trained in bioethics.

## RESULTS

Four hundred and forty-three questionnaires were distributed over 123 months to 272 men (61.4%) and 171 women (38.6%) who started periodic haemodialysis for stage 5 CRF. Figure 1 shows patient responses to the QADs. The mean age of patients who answered the questionnaire was 67 years. Only 10 patients differentiated between refusing to be artificially fed or mechanical respiration, WD and being resuscitated following cardiorespiratory failure (100% rejection of artificial feeding). By the study end date (31 August 2015), 224 patients had died (mean age 76.8 years); 140 patients remained on haemodialysis (mean

age 68.7 years); and 90 had been lost, of whom 75 had had a transplant (mean age 53.2 years when answering the QAD, whereas the mean age of non-transplanted patients was 70.2, giving a statistically significant difference of  $P < 0.001$ ) and 15 had changed dialysis centre.

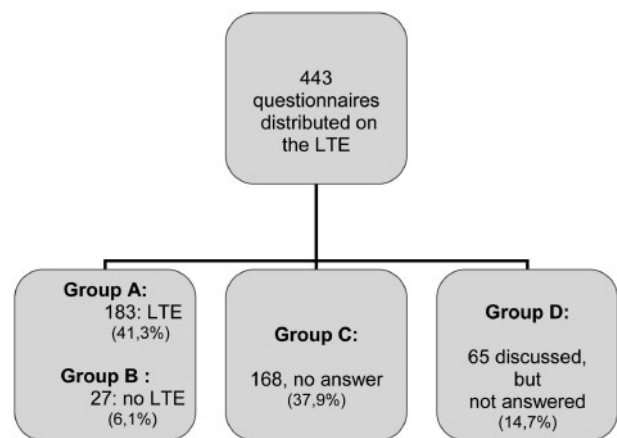
At the time of the telephone survey, 11 cases had incomplete data, unclear decisions on final WD or doubts expressed about the cause of death, etc., so the study sample was adjusted to 213 patients who had complete data.

Figure 2 shows the cause of death for these 213 patients: (i) 43 cases following LTE after scheduled WD (20.2%); (ii) 42 cases due to either an acute complication arising from a chronic process or an acute complication (19.7%); and (iii) 128 cases due to any other cause (60.1%). There were no significant differences in age between these three groups of cause of death (78, 78 and 77.3 years, respectively).

Table 2 shows patient responses to the QADs according to the clinical situation at the time of the study end date. The probability of death as a consequence of LTE or final LTE following ADs to cease dialysis, if decision-making capacity was lost or extreme complications led to clinicians considering WD (46/183), was significantly greater than if the questionnaire had not been answered (23/168) ( $P = 0.010$ ). Death following LTE/final LTE was not uncommon, even if patients had expressed in the QAD their wish to be treated with dialysis under all circumstances (45.5% of group deaths).

The telephone survey was carried out on relatives or representatives of the deceased following LTE and programmed WD, as well as final LTE, at 4- to 52-week intervals after the death of the patient.

The survey was conducted on only 76 representatives of the 85 patients who died following LTE/final LTE. Of the remaining nine deceased patients, it was not possible to locate their representatives in four cases (elderly, unrelated, institutionalized in geriatric centres, untraceable representatives, generally hired

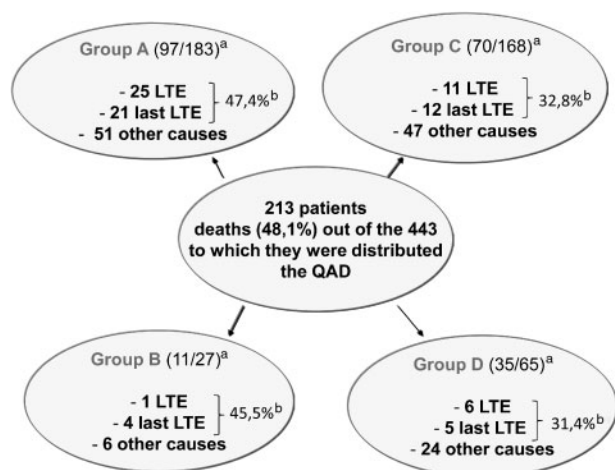


**FIGURE 1:** Patients' answers to the QADs on LTE, distributed to patients on periodic haemodialysis over 10 years in the nephrology service at the Hospital of Sabadell. Group A: wish for LTE in extreme circumstances. Group B: no wish for LTE under any circumstances. Group C: did not answer the QAD. Group D: patients who discussed the QAD but only expressed their wishes to their representative.

carers), and in five cases a precise answer could not be obtained from the theoretical representative despite two attempts.

Table 3 summarizes the representatives' responses to the question on their perceived usefulness of the questionnaire and, in their opinion, on the usefulness perceived by their sick relative at the time of LTE. Table 4 presents the representatives' responses according to groups defined by the patients' ADs. Twenty-seven representatives selected the option 'very useful', 36 included the adjectives 'exceptional' and 'essential', and in nine cases, the response given was 'quite useful'. In two cases, representatives had considerable doubts about the usefulness of the questionnaire, and in a further two cases, representatives qualified the questionnaire as harmful.

Table 5 summarizes the responses to the same above questions, but this time concerning the representatives' opinion of the patient's responses to the QAD. The responses given were



**FIGURE 2:** Deceased patients grouped according to their response to the QAD. Group A: patients who answered by expressing their wish for LTE to be applied in case of specified clinical situations. Group B: patients who expressed their wish for continuous treatment in any situation. Group C: patients who did not answer the questionnaire. Group D: patients who had spoken with their representative about LTE in case of specified clinical situations but did not want to express their wishes in writing. Patients in group A were more likely to die than those who did not respond to the QAD, and they did so more frequently by LTE or final LTE ( $P = 0.010$ ). <sup>a</sup>Number of deceased patients grouped according to their QAD response. <sup>b</sup>Percentage of deaths per LTE or final LTE in each QAD response group.

as follows: 24 cases reported the QAD was an essential questionnaire, 18 cases that it was very useful and 19 cases that it was useful. Seven responses expressed serious doubt about its usefulness, five considered the QAD to be of little use and that it may have caused anxiety in the patient, and in three cases, it was thought to be harmful to the patient.

Moreover, results showed that surrogate decision-makers gave a better evaluation of responses when the deceased patient had previously expressed a clear desire for LTE (41/41), compared with cases where the deceased patient had not previously expressed such wish (27/35), with a statistically significant difference ( $P = 0.004$ ). This trend was also evident in the relative's opinion regarding their sick relative's experience of the QAD (38/41 versus 23/35, respectively,  $P = 0.007$ ).

## DISCUSSION

Our findings here show that patient age is a very important factor when considering the subject of AD. Young people, usually with less comorbidity, do not want to consider poor prognoses that may lead to death but rather want to think of ways to improve their quality of life by means of, for example, a kidney transplant. Hence, despite being given 3 months to answer the QAD, almost 38% of patients failed to do so for this very reason. Patients who returned the QAD with the greatest time lapse often did so without answering any questions. However, this time factor was not gathered in the data. The aim of allowing a 3-month period before return of the questionnaires was to facilitate discussion with the family and relatives, and above all with possible representatives, and to give them the chance to discuss doubts they may have as a family with health professionals. Unfortunately, despite the 3-month reflection period, we still failed to obtain an answer from a large number of patients. Age is thus an important factor that differentiated between those who responded (the elderly) and those who did not. In addition, the majority of those who failed to respond were younger patients who had received a transplant.

A telephone survey was conducted to gather opinion on the perceived usefulness of the questionnaire distributed to *compos mentis* patients. Surrogate decision-makers were asked how useful they found the QAD was for their sick relative and also, in their opinion, how satisfied this relative was when answering the questionnaire. The Likert scale [6], which has been widely used for satisfaction assessments for many years, could be

**Table 2. Questionnaires on LTE distributed to patients on periodic haemodialysis, with the percentages of response reflected in the total number of patients studied, including transplants and those deceased during the 10-year study, highlighting the deaths by scheduled dialysis withdrawal or due to final decision following a complication or acute evolution**

Questionnaires on LTE distributed	Patients with questionnaire distributed, n (%) (443)	Transplanted patients, n (%) (75)	Deceased patients, n (%) (224)	Deceased patients by final LTE, n (%) (85)
Patients who expressed wish for LTE in certain clinical situations	183 (41.3)	19 (25.3)	99 (46.4)	45 (52.9)
Patients who did not want LTE under any circumstances	27 (6.1)	4 (5.3)	10 (4.7)	5 (5.9)
Patients who have spoken, but not confirmed in writing	65 (14.7)	9 (12)	33 (15.5)	11 (12.9)
Patients who did not respond	168 (37.9)	43 (57.3)	71 (33.3)	24 (28.2)

Table shows complete data on 213 of a total of 224 patients who died.

difficult to understand when questionnaires are answered over the telephone; however, it is easy to conceptualize when explained to most addressees, in this case, by the same interviewer. We believe that results obtained from the 76 valid interviews of the possible 85 do not alter the conclusions of the study.

Results obtained on the question about the usefulness of QADs clearly demonstrated the perceived usefulness of the questionnaire (Tables 3–5), especially for those surrogate decision-makers whose sick relatives responded by expressing their wish for LTE in specified clinical circumstances ( $P = 0.04$ ). To a great extent, the positive evaluation given by surrogate decision-makers of patient-answered QADs correlated with the patient's wish for LTE; there were few cases of negative evaluation, which were associated with those sick relatives who had not replied to the QAD. The reason given for the negative evaluation, or even for qualifying the questionnaire as harmful, was that the sick relative had been asked to contemplate troubling circumstances which they did not want to consider. There are many situations of patients undergoing dialysis that can lead nephrologists to consider

having patients set their ADs [2, 7], as factors such as race, ethnicity, religious beliefs and gender can all influence both patients' as well as health professionals' approach to end of life [8]. The same influencing factors also play a role in nephrologists' attitudes when faced with the subject of LTE [3, 9–11]. Although socioeconomic factors and quality of life have changed in the last two decades, it seems that there has been no evolution on the subject of AD and end-of-life care planning [11]. Certain therapeutic decisions, such as cardiopulmonary resuscitation, would not be in line with good clinical practice in clinical contexts where age and comorbidity, for example, are key factors to consider [12, 13]. Tamura *et al.* [12] reported that only 13% of institutionalized elderly patients maintained their functional status 1 year after the initiation of dialysis, and Saeed *et al.* [13] described that the majority of dialysis patients who underwent and survived cardiopulmonary resuscitation were discharged to geriatric centres due to their overall functional decline. In light of the above, although we did not achieve a 100% QAD response rate from patients, those who responded would help us in our future clinical decision-making process, with a view to achieving a greater degree of satisfaction for patients and surrogate decision-makers.

In elderly patients and those with comorbidity, conservative treatment of stage 5 CRF is a licit therapeutic option chosen by many patients when given the correct information on their clinical situation [14–16]. However, too much information on the illness may cause unwanted anxiety and despair. Appropriate information tailored to the personal values of each patient is beneficial as long as expectations of hope are emphasized and managed [14]. The decision to allow patients 3 months to respond to the QAD was based on these concepts, in an attempt to adapt the information to each patient's circumstances, so that any doubts and questions that the patient might have had when answering the questionnaire could be dealt with by health professionals.

**Table 3. Relatives/representatives' assessment on the usefulness of the LTE questionnaire, and relatives/representatives' assessment on the usefulness and estimated response satisfaction as experienced by the sick relative**

76 surveys to relatives of the 85 deceased patients by LTE or final LTE on the usefulness of the questionnaire	Assessment by the representative on the usefulness of the questionnaire, <i>n</i> (%)	Usefulness for the patient in opinion of the relative, <i>n</i> (%)
Great usefulness of the QAD	63 (82.8)	42 (55.2)
Usefulness of the QAD	9 (11.8)	19 (25)
Doubts about usefulness of the QAD	2 (2.6)	12 (15.7)
Questionnaire not useful	2 (2.6)	3 (3.9)

**Table 4. Relatives/representatives' assessment on the usefulness of the LTE questionnaire, with answers subdivided according to the groups defined by the AD set by their sick relatives**

76 surveys to relatives of the deceased patients by LTE or final LTE	Great usefulness of QAD for the representative, % ( <i>n/n</i> )	Usefulness of QAD, % ( <i>n/n</i> )	Doubts about usefulness of QAD, % ( <i>n/n</i> )	Questionnaire not useful, % ( <i>n/n</i> )
Group A (89%; 41/46)	88 (36/41)	12 (5/41)	0	0
Group B (80%; 4/5)	50 (2/4)	25 (1/4)	0	25 (1/4)
Group C (87%; 20/23)	80 (16/20)	10 (2/20)	5 (1/20)	5 (1/20)
Group D (100%; 11/11)	82 (9/11)	9 (1/11)	9 (1/11)	0

**Table 5. Relatives/representatives' assessment on the usefulness and estimated response satisfaction experienced by the sick relative, with answers subdivided according to the groups defined by the AD set by their sick relative**

76 surveys conducted on relatives of 85 deceased patients by LTE or final LTE	Great QAD usefulness for the patient in opinion of the relative, % ( <i>n/n</i> )	QAD usefulness for the patient, % ( <i>n/n</i> )	Doubts about QAD usefulness, % ( <i>n/n</i> )	QAD harmful, % ( <i>n/n</i> )
Group A (89%; 41/46)	63 (26/41)	29 (12/41)	7 (3/41)	0
Group B (80%; 4/5)	25 (1/4)	25 (1/4)	25 (1/4)	25 (1/4)
Group C (87%; 20/23)	45 (9/20)	15 (3/20)	35 (7/20)	5 (1/20)
Group D (100%; 11/11)	55 (6/11)	27 (3/11)	9 (1/11)	9 (1/11)



Two early studies on dialysis patients [2, 17] and a more recent study on the general population [18] showed that it is becoming increasingly advisable, especially with greater life expectancy, to set ADs that define LTE in clinically appropriate situations. Family members and surrogate decision-makers of patients unable to make decisions at the time of death agree that had their sick relative drawn up an AD, it would have facilitated the decision-making process at that time. Therefore, putting in place ADs and QADs are considered good clinical practice.

When a patient loses cognitive capacity, the final LTE decision always lies with the attending doctor. However, the surrogate decision-maker does not make the decision alone, but in agreement with other health professionals and the family member or representative, thus avoiding causing unnecessary anguish, and the decision is based on professional data regarding the clinical status of the patient.

WD is a frequent cause of death in elderly dialysis patients with high comorbidity [19, 20]. This is in agreement with our findings (between 16 and 20% of deaths in our study patients) and also with previous reports [21–23]. If final LTE after an acute complication is also considered as WD, this means WD would be the cause of even more deaths. However, the term WD as a cause of death is controversial, because the theoretical incidence can vary considerably depending on the consulted register. In this respect, Murphy *et al.* concluded there is a need for scientific societies to unify the criteria for WD [21]. In our previous studies, we showed that the mortality rate following WD was 16% and could be as high as 26% if we also consider both LTE (WD generally scheduled with hospitalization in palliative care) and final LTE (death following the appearance of an acute clinical event requiring hospitalization and the final decision to withdraw dialysis) as WD [4, 5].

Physicians must be attentive to each patient's needs, although these needs may be misinterpreted if physicians impose their own preferences [7, 24]. In addition to age, socio-cultural and ethnic factors can also influence preferences in end-of-life care planning [11, 25], as these factors can influence the setting in which people die [26]. Similarly, age and likely the sociocultural context would also influence the response to the QAD, and certain sociocultural environments would value the usefulness of the QAD more highly than others. In our study, those few patients who responded to the QAD through an interpreter displayed a greater tendency towards expressing their wish for continuous treatment, whatever the circumstances, which we interpreted as possible mistrust of the questions put to them, and perhaps even of the care setting.

Interventions by nephrologists to make themselves understood by the sick are essential [27]. Despite their considerable professional experience, some clinicians are unable to make their patients respond satisfactorily when defining their preferences on the LTE in the process of setting patient ADs. However, we agree with other authors that the QAD, which is a useful tool to have for patients undergoing dialysis treatment for stage 5 CRF [10, 28], should still be distributed. When facing extreme clinical situations such as a cardiac arrest, the patient's wishes should already have been previously informed to the haemodialysis unit [29].

Non-initiation of dialysis or WD after initiation of treatment implies the need for continuous end-of-life care, with a view to facilitating a dignified death. This includes appropriate pain management, treatment of comorbid conditions associated with CRF and end-stage palliative management [30, 31]. It therefore requires adequate health care infrastructure and palliative care training for nephrologists [8]. It may even require discussion of the ethics underlying each case to ensure bioethical principles are applied rigorously, the concepts of quality of life are considered carefully and futility is avoided [8]. Brown and colleagues give very clear recommendations on how and when to withdraw dialysis from a patient, stressing the importance of not initiating renal replacement therapy in certain clinical contexts where patients are extremely fragile [32–35], since under certain circumstances, conservative treatment of CRF may carry the same vital prognosis for the patient [34]. The option of the conservative treatment is applied differently in each European Union country [36].

A limitation of our work is that the study made use of Spanish and Catalan versions of the QADs and was carried out on an autochthonous population, over 90% of which were Mediterranean in origin. Our experience with Arab, also Mediterranean in origin, and black sub-Saharan population groups is extremely limited. Therefore, our results should be confirmed in other populations comprising different ethnicities.

We conclude that the QAD with the possibility of LTE in extreme clinical circumstances is a tool that remains useful in daily nephrology practice. They should be distributed by trained nephrologists only to patients willing to respond, in order to avoid causing anxiety in those who refuse to consider life-threatening problems. The experience of relatives/surrogate decision-makers who have faced queries and/or decisions about LTE for their sick relatives confirms this.

## DECLARATION OF TRANSPARENCY AND ETHICS

We followed the usual ethical standards in clinical research, in particular data protection of information gathered from patients and family/representatives or surrogate decision-makers. The work was approved by the hospital's Ethical Committee on Clinical Research during a meeting concerning studies with no pharmacological treatment, to ensure data protection in processing the information. The authors have no disclosures to make regarding the methodology used or the results communicated, as the phone calls were made by a sole interlocutor, the main researcher, who is trained in bioethics. The study was not awarded any financial grant and was completed with the personal effort of the authors A.R.J., L.A.B.C., M.I.B.C., L.J.C.O.M. and J.A.I.L.

(See related article by Bos and Verberne. Use of a questionnaire to initiate advance care planning discussions in dialysis patients. *Nephrol Dial Transplant* 2017; 32: 1599–1600)

## SUPPLEMENTARY DATA

Supplementary data are available online at <http://ndt.oxfordjournals.org>.

## REFERENCES

1. Spiegel BMR, Melmed G, Robbins S *et al*. Biomarkers and health-related quality of life in end-stage renal disease: a systematic review. *Clin J Am Soc Nephrol* 2008; 3: 1759–1768
2. Swartz RD, Perry E. Advance directives are associated with “Good Deaths” in chronic dialysis patients. *J Am Soc Nephrol* 1993; 3: 1623–1630
3. Van Biesen W, Van de Luijngaarden MWM, Brown EA *et al*. Nephrologists’ perceptions regarding dialysis withdrawal and palliative care in Europe: lessons from a European renal best practice survey. *Nephrol Dial Transplant* 2015; 30: 1951–1958
4. Rodríguez Jornet A, García García M, Hernando P *et al*. Patients with terminal chronic renal failure dialysis removed under monitorization. *Nefrología* 2001; 21: 150–159
5. Rodríguez Jornet A, Ibeas J, Real J *et al*. Terminal chronic renal failure patients with dialysis removed under monitorization. *Nefrología* 2007; 27: 581–592
6. Likert RA. A technique for development of attitude scales. *Arch Psychol* 1932; 140: 44–53
7. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006; 333: 886–890
8. Joly D, Anglicheau D, Alberti C *et al*. Octogenarians reaching end-stage renal disease: cohort study decision-making and clinical outcomes. *J Am Soc Nephrol* 2003; 14: 1012–1021
9. Carson RC, Juszczak M, Davenport A *et al*. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol* 2009; 4: 1611–1619
10. Holley JL, Hines SC, Glover JJ *et al*. Failure of advance care planning to elicit patients’ preferences for withdrawal from dialysis. *Am J Kidney Dis* 1999; 33: 688–693
11. Duffy SA, Jackson FC, Schim SM *et al*. Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care. *J Am Geriatr Soc* 2006; 54: 150–157
12. Tamura MK, Covinsky KE, Chertow GM *et al*. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med* 2009; 361: 1539–1547
13. Saeed F, Adil MM, Malik AA *et al*. Outcomes of in-hospital cardiopulmonary resuscitation in maintenance dialysis patients. *J Am Soc Nephrol* 2015; 26: 3093–3101
14. Sehgal AR, Weisheit C, Miura Y *et al*. Advance directives and withdrawal of dialysis in the United States, Germany, and Japan. *JAMA* 1996; 276: 1652–1656
15. Rutecki GW, Cugino A, Jarjoura D *et al*. Nephrologists’ subjective attitudes towards end-of-life issues and the conduct of terminal care. *Clin Nephrol* 1997; 48: 173–180
16. Fissell RB, Bragg-Gresham JL, Lopes AA *et al*. Factors associated with “do not resuscitate” orders and rates of withdrawal from hemodialysis in the international DOPPS. *Kidney Int* 2005; 68: 1282–1288
17. Sekkarie MA, Moss AH. Withholding and withdrawing dialysis: the role of physician specialty and education and patient functional status. *Am J Kidney Dis* 1998; 31: 464–472
18. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010; 362: 1211–1218
19. Chan HW, Clayton PA, McDonald SP *et al*. Risk factors for dialysis withdrawal: an analysis of the Australia and New Zealand dialysis and transplant (ANZDATA) registry, 1999–2008. *Clin J Am Soc Nephrol* 2012; 7: 775–781
20. Ellwood AD, Jassal SV, Suri RS *et al*. Early dialysis initiation and rates and timing of withdrawal from dialysis in Canada. *Clin J Am Soc Nephrol* 2013; 8: 265–270
21. Murphy E, Germain MJ, Cairns H *et al*. International variation in classification of dialysis withdrawal: a systematic review. *Nephrol Dial Transplant* 2014; 29: 625–635
22. Catalano C, Goodship THJ, Graham KA *et al*. Withdrawal of renal replacement therapy in Newcastle upon Tyne: 1964–1993. *Nephrol Dial Transplant* 1996; 11: 133–139
23. Birmele B, François M, Pengloan J *et al*. Death after withdrawal from dialysis: the most common cause of death in a French dialysis population. *Nephrol Dial Transplant* 2004; 19: 686–691
24. Gallo JJ, Straton JB, Klag MJ *et al*. Life-sustaining treatments: what do physicians want and do they express their wishes to others? *J Am Geriatr Soc* 2003; 51: 961–969
25. Lockett T, Sellars M, Tieman J *et al*. Advance care planning for adults with CKD: a systematic integrative review. *Am J Kid Dis* 2014; 63: 761–770
26. Ache K, Harrold J, Harris P *et al*. Are advance directives associated with better hospice care? *J Am Geriatr Soc* 2014; 62: 1091–1096
27. Schell JO, Patel UD, Steinhäuser KE *et al*. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis* 2012; 59: 495–503
28. Holley JL. Advance care planning in CKD/ESRD: an evolving process. *Clin J Am Soc Nephrol* 2012; 7: 1033–1038
29. Moss AH, Hozayen O, King K *et al*. Attitudes of patients toward cardiopulmonary resuscitation in the dialysis unit. *Am J Kidney Dis* 2001; 38: 847–852
30. Levy JB, Chambers EJ, Brown EA. Supportive care for the renal patient. *Nephrol Dial Transplant* 2004; 19: 1357–1360
31. Brown EA, Chambers EJ, Eggeing C. Palliative care in nephrology. *Nephrol Dial Transplant* 2008; 23: 789–791
32. Feely MA, Albright RC, Thorsteinsdottir B *et al*. Ethical challenges with hemodialysis patients who lack decision-making: behavioral issues, surrogate decision-makers, and end-of-life situations. *Kidney Int* 2014; 86: 475–480
33. Brown EA. When and how should dialysis be discontinued? Non-dialysis therapy: a better policy than dialysis followed by withdrawal? *Sem in Dial* 2015; 25: 26–27
34. Murtagh FEM, Marsh JE, Donohoe P *et al*. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant* 2007; 22: 1955–1962
35. Muthalagappan S, Johansson L, Kong WM *et al*. Dialysis or conservative care for frail older patients: ethics of shared decision-making. *Nephrol Dial Transplant* 2013; 28: 2717–2722
36. Van de Luijngaarden MWM, Noordzij M, van Biesen W *et al*. Conservative care in Europa: nephrologists experience with the decision not to start renal replacement therapy. *Nephrol Dial Transplant* 2013; 28: 2604–2612

Received: 2.3.2017; Editorial decision: 7.6.2017