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NDT Perspectives

Quality standards for predialysis education: results from a consensus conference

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ABSTRACT

This position statement was compiled following an expert meeting in March 2013, Zurich, Switzerland. Attendees were invited from a spread of European renal units with established and respected renal replacement therapy option education programmes. Discussions centred around optimal ways of creating an education team, setting realistic and meaningful objectives for patient education, and assessing the quality of education delivered.

Keywords: education, end-stage renal disease, guidelines, predialysis, renal replacement therapy

INTRODUCTION

End-stage renal disease (ESRD) is almost unique in that patients may choose (and can later change) their treatment modality, if there are no contraindications [1]. Education to assist this choice is mandatory in some countries [1]. Renal replacement therapy option education (RRTOE) provides patients with information on ESRD treatment options, helps them choose between treatments, and promotes self-care. Ultimately, the aim is to improve quality of life.

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Proven benefits of RRTOE include: reduced urgent dialysis starts, reduced time spent in hospital and improved resource utilization [2]; earlier placement of permanent vascular access or peritoneal catheter [3]; a greater likelihood of choosing a self-care modality [4]; extended time to requiring dialysis [5]; improved adherence [6]; reduced anxiety and fear [7]; and reduced mortality [8]. These benefits lead to considerable cost savings [2].

Such benefits have been reported in high-quality RRTOE programmes. In practice, however, there is only moderate patient satisfaction with RRTOE [9, 10]. The reasons include: (i) programme content not reflecting patient needs [6]; (ii) programme does not stress that patients have an active choice of modality [11]; (iii) main motivators for the patient (flexibility, independence, feelings of security [12]) are not taken into account; (iv) materials used in programme are of poor quality [13] or unproven effectiveness in chronic kidney disease (CKD) patients; (v) potential bias on side of healthcare professionals (HCP) towards a particular modality.

Current guidelines [1,14–17] have been very valuable in stressing the need for high-quality, unbiased patient education. However, these lack detailed guidance on key aspects of RRTOE.

This position statement provides clear recommendations on important aspects of RRTOE based on current evidence and in the context of pre-existing guidelines. Suggestions for both minimal and optimal quality standards for RRTOE are presented.

METHODOLOGY

A consensus meeting was organized by Baxter Healthcare Corporation, and took place on 26 March 2013 in Zurich, Switzerland. Six nephrologists, eight nurses and one clinical psychologist from 12 renal units were invited to participate. Selected units had either extensive experience with RRTOE or included at least one member of staff performing research on RRTOE. Of the invitees, four nurses, five nephrologists and one clinical psychologist from nine renal units agreed to participate.

In preparation for this meeting, participants completed a questionnaire that was designed by Baxter Healthcare Corporation. This questionnaire was built to obtain information on all aspects of RRTOE (P. Prieto-Velasco et al., unpublished data). It was broken down into the following sections: the renal unit and patients, the RRTOE team, how RRTOE is provided and what topics are covered, how quality is assessed, and how RRTOE is funded.

The agenda was sent to participants before the meeting. In the morning of the meeting, the results of the questionnaire were presented and discussed. Later, experts split into four groups to brainstorm and discuss quality standards for the RRTOE team, processes, content/topics and media/material/funding. Each group discussed one topic. The suggestions of each group were presented to the whole group, and discussed further. In the afternoon, experts split into three groups. All groups discussed quality measurements for RRTOE. As before, the conclusions of each group were presented to the whole group and discussed. The conclusions and recommendations from these discussions form the basis of this position statement.

At the meeting, there was no designated chairperson. Staff of Archimed medical communication ag were tasked with keeping the meeting on time, facilitating the discussions and taking minutes. Staff of Baxter Healthcare Corporation did not contribute to the discussions.

Following the meeting, an outline of a position statement (based on the meeting minutes) was created by Archimed

medical communication ag. This outline was circulated to all authors, who provided feedback. This feedback was implemented, and a draft version was composed. This process of feedback and redrafting was repeated several times until all authors provided final approval. All authors were expected to thoroughly review and provide suggestions for improving each draft.

For the suggested quality measurements, a comprehensive list of potential quality standards was generated from the meeting, from current guidelines and from a literature search. Two rounds of voting took place: one round each for minimal and optimal standards.

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Team for education

An overview of the recommendations is presented in Table 1.

Who should be in the team? At a minimum, the RRTOE team consists of a nephrologist and a CKD nurse. Optimally, there are additional members of the RRTOE team. These include a dietitian, a psychologist, a social worker, a physical therapist and an expert patient.

Rationale. A nephrologist and nurse are necessary to provide the patient with the knowledge and support to make a decision on renal replacement therapy (RRT). Nurses may have more patient contact and are often the main RRTOE providers.

Unbiased education may require an education team that is independent of the care team. However, the authors feel that a close relationship to the patient is important and easier to develop if both teams are the same. Moreover, there is risk of unduly stressing the patient by having to meet a large number of HCPs.

Some guidelines recommend that RRTOE teams are multidisciplinary [16, 17, 18]. Education from multidisciplinary teams [versus care from a nephrologist(s) alone] may be advantageous

Table 1. Team for education

	Current guidelines					Suggested quality standards	
	UK [14]	UK [16]	Europe [1]	France ^a [18]	USA ^b [17]	Minimal	Optimal
Who should be in the team?							
Nephrologist and CKD nurse	-	-	-	-	-	Y	Y
Dietician, psychologist, social worker, physical therapist, expert patient	-	-	-	-	-	-	Y
Multidisciplinary team	-	Y	-	Y	Y	-	Y
At least one physician	-	-	-	Y	-	-	-
What knowledge, training and experience should the team have?							
Knowledge of CKD	Y	-	-	-	Y	Y	Y
Knowledge and experience of treatment modalities	Y	-	-	-	Y	Y	Y
Training in principles of adult education	Y	Y	-	-	Y	-	Y
Training in motivational interviewing/communication skills	-	-	-	-	-	-	Y
Training in how to avoid bias when giving information	-	-	-	-	-	-	Y
At least 40 h of theoretical and practical training	-	-	-	Y	-	-	-
Skills in patient communication	-	-	-	-	Y	-	-

Y, guidelines/advice explicitly recommend this point; -, no explicit recommendation of this point; CKD, chronic kidney disease.

^aGuidelines not specific to educating patients with CKD.

^bThe US Medicare programme offers reimbursement for CKD education if provided by a physician, nurse practitioner, physician assistant or certified nurse specialist.

in terms of clinical parameters and survival [19]. However, study limitations preclude forming firm conclusions [20].

A National Institutes of Health consensus conference proposed a team consisting of a nephrologist, nurse, dietitian, social worker and mental health professional [19]. The authors agree, and would add a physical therapist and expert patient.

A physical therapist can help prevent uraemia-related decline in muscle function and improve quality of life (QoL) [21]. Expert patients provide peer-to-peer support and may cover practical topics of daily living missed by the HCP. They may form an important part of the RRTOE team, as there is evidence that patients are more likely to choose a modality suggested by another patient rather than a doctor [22]. Another study showed that use of non-medical staff for patient education had a limited but positive effect on patient satisfaction and hospitalization [23].

If multidisciplinary RRTOE is not possible, education from a single nurse may facilitate transition to self/home-care modalities [24].

What knowledge, training and experience should the team have? Knowledge of CKD and hands-on experience of all treatment modalities are minimum requirements for RRTOE team members. Optimally, the team also has training in the principles of adult education, motivational interviewing/communication skills and how to avoid bias when giving information.

Rationale. The authors believe that a theoretical knowledge of the disease and treatment options is not sufficient to provide education, and that practical hands-on experience is required. French guidelines stipulate that each member of the team should receive at least 40 h of theoretical and practical training in providing therapeutic patient education [18].

Training in adult education will help the team to utilize pedagogical strategies. Training in motivational interviewing/communication skills will help the team draw out and convey information from/to the patient more effectively. Training in how to avoid bias will enable the team to put aside their own preferences and opinions (meeting guideline requirements for unbiased education).

The authors agree that the role of the expert patient in the programme should be clearly defined and communicated in advance. Depending upon the nature of this role, the expert patient may require training. Such training may be knowledge-based (e.g. understanding of different modalities) or skill-based (e.g. training in avoiding bias when presenting information). However, training requirements (or the lack of) will vary from centre to centre.

The authors stress that a psychologist in the team should be trained in supporting patients in decision-making *in the renal context*. However, such training is currently not widely available.

Guidelines state that modality choice should be made by a *well-informed* patient and that the education programme should provide *well-balanced* information. The authors believe that it may be important to recognize when the patient is making a modality choice that is not based on logical, systematic analysis of the pros and cons, but rather by using intuition or relying on incomplete/biased information [22]. Of course,

some patients who rely upon intuition or limited information may still reach a decision on modality that they are satisfied with in the long term.

Processes

An overview of the recommendations is presented in Table 2.

When should RRTOE begin? Beginning RRTOE at least 12 months before the predicted start of dialysis allows time to establish dialysis access, for the patient to accept their situation, and take part in the decision-making. If this is not possible, then RRTOE begins upon referral for dialysis. Optimally, commencement of RRTOE is based on the level of disease (CKD Stage 4, progressive) and the rate of disease progression.

Rationale. Only US guidelines [17] specify a time period before dialysis start (9–12 months) by which RRTOE should begin. This takes account of the time required for patients to accept the potential need for RRT, decide on their preferred treatment, and for placement and maturation of dialysis access, potential revisions and/or a second access. The authors would recommend the more conservative 12 months—considering the huge variation in medical resources worldwide and the potential danger to the patient from receiving access too late.

The authors also believe that 12 months would offer patients and families a greater chance to come to terms with the physical, social and financial changes they will be faced with before they are required to reach a decision on modality.

Optimally, RRTOE would begin based on the level [14, 16, 17] and rate of disease progression, and also be available upon request to all patients.

Questions have been raised over the suitability of RRT (and hence RRTOE) for elderly patients—particularly those with comorbidities [25]. The authors believe that further data are required before recommendations can be made.

Crash landers are patients who commence RRT within 3 months of initial referral. For these patients, the shock of their situation may not allow them to absorb or process the information they are provided with during RRTOE [26]. Therefore, the optimal time to educate on treatment choice may be well after the start of dialysis. While there may be reluctance to do this, as such patients are already installed on a particular modality, it is still the obligation of the RRTOE team to help all patients make a well-informed treatment choice.

Who should receive RRTOE? RRTOE is made available to:

- (i) CKD Stage IV and V patients (planned and unplanned starts);
- (ii) patients expressing an interest in changing modality;
- (iii) all patients upon request. Optimally, family, friends or caregivers of patients also attend RRTOE.

Rationale. Patients need RRTOE if they are to take a well-informed decision on their treatment [1]. In addition, relatives and friends may feel more confident about dialysis following RRTOE [12]. Relatives may also better understand the logistical, social and financial changes facing the family [12]. There is evidence that modality choice can impact the emotional status and coping of caregivers [27].

Table 2. Processes

	Current guidelines					Suggested quality standards	
	UK [14]	UK [16]	Europe [1]	France [18] ^a	USA ^b [17]	Minimal	Optimal
When should RRTOE begin?							
9–12 months prior to anticipated dialysis need	–	–	–	–	Y	–	–
At least 12 months before predicted start of dialysis	–	–	–	–	–	Y	–
Upon referral for dialysis	–	–	–	–	–	Y	–
At ‘appropriate stage’ of CKD	Y	–	–	–	Y	–	Y
Stage IV (progressive) or stage V CKD	–	Y	–	–	– ^c	–	Y
Stage III CKD and rapidly deteriorating condition	–	Y	–	–	–	–	–
Early stage [estimated glomerular filtration rate (eGFR) <30 mL/min]	–	–	–	–	Y	–	–
Who should receive RRTOE?							
CKD patients (stage IV/V)	Y	Y	Y	–	Y	Y	Y
Planned start	–	Y	Y	–	Y	Y	Y
Unplanned/emergency start	–	Y	Y	–	Y	Y	Y
Changing modality	–	–	–	–	–	Y	Y
CKD patients (any stage)	–	–	–	–	–	–	–
Upon request from the patient	–	–	–	–	–	–	Y
Other							
Families	–	Y	Y	–	Y ^c	–	Y
Caregiver	–	Y	–	–	Y ^c	–	Y
Friends	–	–	–	–	–	–	Y
Should RRTOE be individualised? If so, how?							
Assess whether patient’s knowledge is sufficient to make an informed decision on modality	–	–	–	–	–	Y	Y
Individual learning styles/pace considered	Y	Y	–	Y	Y	–	Y
Information tailored to the stage and cause of CKD, the associated complications and the risk of progression	Y	–	–	–	–	–	Y
One key contact person (trained in decision-making psychology) per patient	–	–	–	–	–	–	Y
Support in coping with psychological aspects of CKD should be offered	Y	–	–	–	–	–	Y
Regular contact with patient’s general practitioner	–	–	–	Y	–	–	Y
Regular contact between the patient and nephrologist/nurse	–	–	–	–	–	–	Y
RRTOE delivered in place of the patient’s choosing	–	–	–	–	–	–	Y
How many sessions are required?							
At least 1	–	–	–	–	–	Y	–
As many as required	–	–	–	–	–	–	Y
2–3	–	–	–	Y	–	–	–
3–6	–	–	–	–	Y	–	–
When should RRTOE finish?							
When the pre-defined objectives of the RRTOE have been met	–	–	–	–	–	Y	–
Continue into treatment phase	–	Y	–	–	–	–	Y

Y, guidelines/advice explicitly recommend this point; –, no explicit recommendation of this point; RRTOE, renal replacement therapy option education; CKD, chronic kidney disease.

^aGuidelines not specific to educating patients with CKD.

^bThe US Medicare programme offers reimbursement for CKD education if provided by a physician, nurse practitioner, physician assistant or certified nurse specialist.

^cAlso recommended by the National Kidney Foundation [15].

Despite potential advantages of a modality change, most patients remain with a single modality throughout their entire treatment [28, 29]. Therefore, HCPs should regularly (e.g. once per year) enquire whether the patient is satisfied with their modality choice. If not, the patient should be referred for RRTOE (see also 2.5).

The authors believe that late-referred patients should have the same RRTOE as early-referred patients.

Should RRTOE be individualized? If so, how? At the earliest, RRTOE ends when the patient has sufficient knowledge to make an informed decision regarding treatment modality. If the patient does not have sufficient knowledge, then a more individualized approach to RRTOE is warranted. Optimally, the following are available: (i) A key contact person is present to help the patient work through the material in the order

and speed of the patient’s choosing and help deal with psychological aspects of the disease. (ii) There are regular updates on the patient’s condition between the education team and the patient’s general practitioner (GP). (iii) There is regular contact between the patient and the nephrologist/nurse. (iv) There is an option for RRTOE to be delivered in the place of the patient’s choosing (i.e. home or hospital), within time and budget constraints.

Rationale. Patients have different learning abilities and styles, as well as different concerns and wishes. Thus, the educator should identify those patients who have not gained sufficient knowledge following RRTOE and offer them a more individualized approach.

In France, additional recommendations are made: any educational activity should be preceded by an individual interview

to determine the patient's needs and learning style in order to tailor the programme to their requirements [30].

The patient's readiness to reach a treatment decision should be taken into account. This is best gauged by an HCP who has undergone training in the psychology of decision-making in a renal context.

The stage at which materials are presented and the pace of learning should depend on the patient's general condition, age, comorbidities, potential problems with memory and/or cognitive impairment, progression rate, disease stage and desire for active RRT.

Regular updates within the RRTOE team and with the patient's GP will help. In many countries, the GP has the best overview of the patient's history and current condition. In France, informing the GP of the patient's participation in RRTOE is recommended in the guidelines [6].

While the patient would ideally be able to choose the setting for RRTOE, this may not be practical. Regardless of patient preferences, having at least one appointment at the patient's home may help gauge their financial and social circumstances.

How many sessions are required? At least one session of RRTOE is required. Optimally, as many sessions as required to independently reach an informed and balanced decision on modality are held.

Rationale. Current guidelines stating a minimum number of sessions for RRTOE are the US guidelines (3–6 sessions) [17] and French guidelines (2–3 sessions/year) [18].

The authors working in centres with a large catchment area felt that a single 1-day RRTOE session was more suitable for fragile patients who needed to travel a long distance. Other authors felt that one session is not sufficient for the patient to reach an informed decision—particularly when considering the relatively large amount of information to be absorbed and the life changes required. Telephone sessions (or internet-based learning) may provide a partial solution.

When should RRTOE finish? RRTOE finishes when the pre-defined objectives of the RRTOE have been met. Optimally, RRTOE finishes when the patient has chosen a form of RRT, with regular follow-ups being conducted into the treatment phase.

Rationale. Upon commencement of RRTOE, clear objectives should be set in consultation with the patient (see also 'Quality Assurance'). Therefore, RRTOE should not finish before these objectives have been met. A fundamental objective should be to provide patients and relatives with sufficient and appropriate information to make a treatment modality choice.

Optimally, RRTOE would continue beyond the point where the patient has made a decision on treatment modality. Regular follow-ups are important to check whether the patient remains satisfied and does not wish to change to another modality/conservative care. Such follow-ups can be particularly important following large changes in life circumstances (e.g. death of a spouse) or early problems with the chosen modality that may require patients to re-evaluate their choice.

Content

An overview of the recommendations is presented in Table 3.

What topics should be included? The minimal topics covered in all RRTOE programmes are: (i) Topics requested by the patient. (ii) Unbiased information on CKD and the four treatment options [haemodialysis (HD), peritoneal dialysis (PD), transplantation and conservative care], and how well they match the patient's beliefs and values. (iii) An explanation that it is possible for the patient to change modality if there are no contraindications. (iv) Clarification of the patient's right to stop dialysis. (v) Ways to delay disease progression.

Optimally, the following topics are also covered: (i) Interviews to understand the patient's history, lifestyle, pain levels, comorbidities, physical activity levels, diet, culture, beliefs, wishes and expectations, what the patient knows and wants to know about the disease, patient's social network, how much the patient wants to be involved in the treatment. (ii) Implications of CKD upon finances (reduced capacity to work, insurance, treatment costs). (iii) Impact of CKD upon QoL. (iv) Dealing with emotional stress. (v) Practical topics (e.g. transportation to/from treatments, contacting a patient association, and making an advanced healthcare directive). (vi) Understanding kidney function test results and blood test results. (vii) Timing of placement of dialysis access. (viii) Medication required.

Rationale. There is no medical evidence to prefer HD over PD [1]; the large majority of patients are eligible for both modalities. Thus, which modality to use should be the choice of the well-informed patient [1]. In most European countries, it is a legal requirement to inform patients of all treatment modalities [6]. Patients with contraindications to a particular modality should receive a clear explanation of why that modality is not being recommended for them.

For some patients, a much greater decision than what type of RRT to have is whether to have RRT at all [11]. Therefore, the HCP should be aware that they may have to deal with this topic before presenting the different treatment options in great detail.

Patient needs and expectations will play a large role in determining the content of RRTOE sessions.

Materials and Resources

An overview of the recommendations is presented in Table 3.

What materials/resources should be used in RRTOE? The following materials/resources are used in RRTOE: (i) One-to-one meetings with staff (including a contact nurse) at the unit. (ii) Written booklets appropriate to disease stage, level of education and cultural/religious background. (iii) Multimedia showing the dialysis modalities in action.

Optimally, the following materials/resources are also used: (i) Patient decision aids; (ii) Tours of dialysis facilities. (iii) Online material (with carefully chosen websites). (iv) Non-mandatory meetings with expert patients. (v) Videos including interviews with dialysis patients. (vi) Group education sessions may be considered.

Table 3. Content and materials and resources

	Current guidelines					Suggested quality standards	
	UK [14]	UK [16]	Europe [1]	France [18] ^a	USA ^b [17]	Minimal	Optimal
Content							
What topics should be included?							
Topics requested by the patient	-	-	-	-	-	Y	-
CKD and how it affects people	Y	Y	-	-	Y ^c	Y	-
CKD treatment options with pros and cons	Y	Y	Y	-	Y ^c	Y	-
RRT and the preparation required	Y	-	-	-	Y	Y	-
Conservative management	Y	-	-	-	Y	Y	-
Possibility of another modality (if no contraindications)	-	-	Y	-	-	Y	-
Right to stop dialysis	-	-	-	-	-	Y	-
Ways to delay the progression of disease	-	-	-	-	Y	Y	-
Ways to better manage CKD (inc. diet)	Y	Y	-	-	Y ^c	Y	-
Individualized content for patient based on interviews to understand their history, lifestyle, etc.	-	-	-	Y	-	-	Y
Impact of CKD upon QoL, work and money	Y	-	-	-	Y	-	Y
Coping with and adjusting to CKD	Y	-	-	-	Y	-	Y
Practical information (e.g. transport to/from treatment, patient association details)	-	-	-	-	-	-	Y
Advanced healthcare directives	-	-	-	-	Y	-	Y
Interpreting kidney function tests	-	-	-	-	Y	-	Y
Electrolyte and acid/base disturbances (if present)	-	-	-	-	-	-	Y
Blood pressure control	-	-	-	-	-	-	Y
Blood sugar control	-	-	-	-	-	-	Y
Timing of placement of dialysis access	-	-	-	-	Y	-	Y
Medication required	-	-	-	-	-	-	Y
Useful questions to ask the HCP	Y	-	-	-	-	-	Y
Preserving upper extremity veins for future dialysis access	-	-	-	-	Y ^c	-	-
Materials and resources							
What materials/resources should be used in RRTOE?							
Individual conversations	-	Y	-	Y	Y	Y	Y
Written materials	-	Y	-	-	Y	Y	Y
DVDs/CDs	-	Y	-	-	-	Y	Y
Tours of dialysis facilities	-	-	-	-	Y	-	Y
Online material	-	-	-	-	-	-	Y
Expert patients (present and virtual)	-	Y	-	-	Y	-	Y
Group work	-	Y	-	-	Y	-	Y
Patient decision aids	-	-	-	-	-	-	Y
How should the RRTOE take account of language and cultural differences?							
Medical interpreters are available ^d	-	-	-	-	-	Y	Y
Written materials are translated ^d	-	-	-	-	-	Y	Y
Picture sets are available	-	-	-	-	-	-	Y
Cultural/religious views on transplantation considered	-	-	-	-	-	-	Y

Y, guidelines/advice explicitly recommend this point; -, no explicit recommendation of this point; RRTOE, renal replacement therapy option education.

^aGuidelines not specific to educating patients with CKD.

^bThe US Medicare programme offers reimbursement for CKD education if provided by a physician, nurse practitioner, physician assistant or certified nurse specialist.

^cAlso recommended by the National Kidney Foundation [15].

^dFor key culturally and linguistically diverse populations.

Rationale. Well-trained staff are an extremely valuable resource in RRTOE, and can help guide and support the patient.

There is a huge spread in quality of written materials available. Information should be accessible, readable, understandable, accurate, balanced and comprehensive in description, recently updated, evidence based, written by credible authors and identify sources for further information [13]. High-quality multimedia can provide an opportunity for the patient to see the dialysis techniques in a relaxed environment.

Patient decision aids (PDAs) refer to materials that have been designed to support patients in making decisions about

screening, treatment or other interventions. These can take any form, such as booklets, diagrams or digital materials. PDAs have been linked to greater patient participation and more suitable treatment choices [31]. A suitable PDA is one that the educator feels comfortable and confident using and that also meets the quality criteria given by the International Patient Decision Aid Standards (IPDAS) Collaboration (<http://ipdas.ohri.ca>).

Visits to the unit may reduce anxiety in patients who later opt for in-centre care when RRT actually begins—particularly as they will already know how to reach the facilities and the time required. However, in the short-term, patients may feel more anxious following this visit.

In the authors' experience, younger patients are more likely to use the Internet to research their treatment options. Suitable websites should be suggested to guarantee accuracy and quality of information.

An expert patient may be able to provide support, understanding and insight to the RRTOE patient in ways that an HCP cannot. However, the views of the expert patient are naturally biased towards their own experiences, and may carry a disproportional influence upon modality choice.

Videos that include interviews with patients receiving dialysis have been successfully used in RRTOE [32]. This approach allows the HCP to have greater control over the information presented to the patient. It is important that such media are quality checked to ensure that a wide range of patients and views are presented, in order to ensure that the material informs rather than biases the patient.

The suitability of group education sessions may be considered on a centre-by-centre basis. The potential advantages include: (i) patients may feel less alone in their situation; (ii) some patients will ask questions useful for others in the group that the others have not thought of; (iii) a group session focussed on self-care may increase the chance of patients choosing a self-care modality. The potential disadvantages include: (i) logistical challenges (e.g. finding a suitable time/place); (ii) possible lack of a common language/culture in highly diverse areas; (iii) potential biasing effects of other patients.

How should the RRTOE take account of language and cultural differences? It is necessary to have medical interpreters and (if helpful) translations of the written material available for

key culturally and linguistically diverse (CALD) populations. Optimally, picture sets are available for sessions with CALD patients speaking a language rarely encountered by the centre or country in question. It is important to consider religious and cultural perspectives (of both the patient and the HCP) with regard to all treatment options. Cultural differences impact the perceived roles of doctor/patient and understanding of health/disease.

Rationale. Better healthcare outcomes can be achieved by ensuring that further investment in culturally specific programmes and workforce development is in line with the number of CALD communities and their needs.

Quality assurance

An overview of the recommendations is presented in Table 4.

How should the quality of RRTOE be evaluated? A quality evaluation uses one or more of the following indicators: (i) The percentage of patients starting treatment with the modality they chose at the end of RRTOE. (ii) Proportion of planned initiations with established access/pre-emptive transplantation. (iii) Patient satisfaction with modality choice (e.g. 3 months after treatment start). (iv) Proportion of patients who have undergone a formal education programme prior to initiation of RRT. (v) Patient satisfaction with the level of information they have received. (vi) Register of patients with End of Life Care needs. (vii) Proportion of those patients identified as having End of Life Care needs who have a workable Advance Care Plan.

Table 4. Quality assurance

	Current guidelines	Suggested quality standards	
		Minimal	Optimal
Bioclinical evaluations¹			
The percentage of patients starting on modality of choice		Y	
The distribution of patients between dialysis modalities			Y
Proportion of planned initiations with established access/pre-emptive transplantation	Y ^a	Y	
Psychosocial evaluations			
Patient satisfaction with modality choice (evaluated at regular intervals)		Y	
Quality-of-life measurements (e.g. EQ-5D)			Y
Measurement of patient involvement			Y
Pedagogical evaluations²			
Proportion of patients who have undergone a formal education programme prior to initiation of RRT	Y ^a	Y	
Clearly defined target population; objectives; curriculum; pedagogical tools; criteria for evaluating effectiveness (including clinical, QoL); and sources of finance	Y ^b		Y
Patient satisfaction with the level of information they have received		Y	
Other			
Register of patients with End of Life Care needs	Y ^a	Y	
Proportion of those patients identified as having End of Life Care needs who have a workable Advance Care Plan	Y ^a	Y	

Y, guidelines/advice explicitly recommend this point (^aRenal Association, UK [16]; ^bFrance [18]). QoL, quality of life.

¹Other bioclinical evaluations mentioned in pre-existing guidelines: Inpatient/outpatient status of planned initiations [16]; mean eGFR at time of pre-emptive transplantation [16]; proportion of incident RRT patients transplanted pre-emptively [16]; proportion of incident patients on transplant waiting list at RRT initiation [16]; number of patients withdrawing from dialysis as a proportion of all deaths on dialysis [16].

²Other pedagogical evaluations mentioned in pre-existing guidelines: yearly evaluation of the programme by the organizers [18]; procedure for defining objectives for individual patients and a personalized therapeutic education programme [18]; maintaining a file that tracks progress towards patient's objectives [18]; proportion of patients who report that they have been offered a choice of RRT modality [16]; evidence of formal continuing education programme for patients on dialysis [16]; percentage of incident RRT patients followed up for >3 months in dedicated pre-dialysis or low clearance clinic.

Optimally, one or more of the following indicators is used: (i) QoL measurements (e.g. EQ-5D). (ii) Measurement of patient involvement. (iii) Clearly defined: target population; objectives; curriculum; pedagogical tools; criteria for evaluating effectiveness (including clinical, QoL); and sources of finance.

Rationale. The main aims of high-quality RRTOE are to help the patients: (i) choose the treatment modality that would produce the greatest satisfaction, adherence, and maintenance or increase in QoL; (ii) plan for their immediate and long-term future. Quality assurance should examine whether the course is meeting these aims. It should also evaluate the more standard pedagogical criteria for any course of education.

Some of the authors use the proportion of patients choosing a self-care modality as a quality assessment tool. These authors are affiliated to renal units that have set promotion of self-care as an objective of RRTOE. The large majority of patients appear to be suitable candidates for a self-care modality. An American study assessing the medical and psychosocial eligibility of 1303 CKD patients for RRT reported that 98% were eligible for HD, 87% were eligible for PD, and 54% were eligible for transplantation [33].

CONCLUSION

This position statement endorses current guidelines, and offers further guidance to ensure patients receive high-quality education aimed at helping them make an informed choice of modality.

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CONFLICT OF INTEREST STATEMENT

All authors have served as consultants to Baxter Healthcare Corporation. M.P.-V. has advised, consulted or received speaker honoraria from Baxter, Fresenius, Gambro, Abbvie, Shire and Sanofi Renal. A.M. is on the speaker list for Sanofi, BMS, MSD, Shire, Amgen and Pfizer. T.G. has served as a consultant to Gambro AB and Amgen. The results presented in this paper have not been published previously in whole or part, except in abstract format.

REFERENCES

1. Covic A, Bammens B, Lobbedez T *et al.* Educating end-stage renal disease patients on dialysis modality selection: clinical advice from the European Renal Best Practice (ERBP) Advisory Board. *NDT Plus* 2010; 3: 225–233
2. Levin A, Lewis M, Mortiboy P *et al.* Multidisciplinary predialysis programs: quantification and limitations of their impact on patient outcomes in two Canadian settings. *Am J Kidney Dis* 1997; 29: 533–540
3. Lindberg JS, Husserl FE, Ross JL *et al.* Impact of multidisciplinary, early renal education on vascular access placement. *Nephrol News Issues* 2005; 19: 35–36, 41–3
4. Manns BJ, Taub K, Vanderstraeten C *et al.* The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int* 2005; 68: 1777–1783
5. Devins GM, Mendelsohn DC, Barre PE *et al.* Predialysis psychoeducational intervention and coping styles influence time to dialysis in chronic kidney disease. *Am J Kidney Dis* 2003; 42: 693–703
6. Tourette-Turgis C, Isnard-Bagnis C. Patient education. *Nephrol Ther* 2013; 9: 235–240
7. Gutierrez Vilaplana JM, Zampieron A, Craver L *et al.* Evaluation of psychological outcomes following the intervention 'teaching group': study on pre-dialysis patients. *J Ren Care* 2009; 35: 159–164
8. Wu IW, Wang SY, Hsu KH *et al.* Multidisciplinary predialysis education decreases the incidence of dialysis and reduces mortality—a controlled cohort study based on the NKF/DOQI guidelines. *Nephrol Dial Transplant* 2009; 24: 3426–3433
9. Pastor JL, Julián JC. Claves del proceso de información y elección de modalidad de diálisis en pacientes con insuficiencia renal crónica. *Nefrología* 2010; 1(Suppl Ext1): 15–20
10. Fadem SZ, Walker DR, Abbott G *et al.* Satisfaction with renal replacement therapy and education: the American Association of Kidney Patients survey. *Clin J Am Soc Nephrol* 2011; 6: 605–612
11. Winterbottom A, Bekker HL, Conner M *et al.* Choosing dialysis modality: decision making in a chronic illness context. *Health Expect* 2014; 17: 710–723
12. Lee A, Gudex C, Povlsen JV *et al.* Patients' views regarding choice of dialysis modality. *Nephrol Dial Transplant* 2008; 23: 3953–3959
13. Winterbottom A, Conner M, Mooney A *et al.* Evaluating the quality of patient leaflets about renal replacement therapy across UK renal units. *Nephrol Dial Transplant* 2007; 22: 2291–2296
14. National Collaborating Centre for Chronic Conditions. Chronic kidney disease: national clinical guideline for early identification and management in adults in primary and secondary care. Royal College of Physicians, 2008
15. National Kidney Foundation. KDOQI clinical practice guidelines and clinical practice recommendations for 2006 updates: hemodialysis adequacy, peritoneal dialysis adequacy and vascular access. *Am J Kidney Dis* 2006; 48(Suppl. 1): S1–S322
16. Renal Association. RA Guidelines—planning, initiating and withdrawal of renal replacement therapy. Petersfield: The Renal Association, 2009
17. Saggi SJ, Alton M, Bernardini J *et al.* Considerations in the optimal preparation of patients for dialysis. *Nat Rev Nephrol* 2012; 8: 381–389
18. Haute Autorité de Santé. *Structuration d'un programme d'éducation thérapeutique du patient dans le champ des maladies chroniques.* http://www.has-sante.fr/portail/upload/docs/application/pdf/etp_-_guide_version_finale_2_pdf.pdf
19. Bastos MG, Kirsztajn GM. Chronic kidney disease: importance of early diagnosis, immediate referral and structured interdisciplinary approach to improve outcomes in patients not yet on dialysis. *J Bras Nefrol* 2011; 33: 93–108
20. van Biesen W, Verbeke F, Vanholder R. We don't need no education (Pink Floyd, The Wall) Multidisciplinary predialysis education programmes: pass or fail? *Nephrol Dial Transplant* 2009; 24: 3277–3279
21. Clyne N. The importance of exercise training in predialysis patients with chronic kidney disease. *Clin Nephrol* 2004; 61(Suppl 1): S10–S13
22. Winterbottom AE, Bekker HL, Conner M *et al.* Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study. *Nephrol Dial Transplant* 2012; 27: 325–331
23. Plantinga LC, Pham HH, Fink NE *et al.* Use of dialysis educators beyond nurses and physicians and outcomes in patients with kidney failure. *Adv Chronic Kidney Dis* 2005; 12: 424–432
24. Hanko J, Jastrzebski J, Nieva C *et al.* Dedication of a nurse to educating sub-optimal haemodialysis starts improved transition to independent modalities of renal replacement therapy. *Nephrol Dial Transplant* 2011; 26: 2302–2308

25. Demoulin N, Beguin C, Labriola L *et al.* Preparing renal replacement therapy in stage 4 CKD patients referred to nephrologists: a difficult balance between futility and insufficiency. A cohort study of 386 patients followed in Brussels. *Nephrol Dial Transplant* 2011; 26: 220–226
26. Grimault M, Bagnis CI, Turgis CT. The first haemodialysis session as experienced by patients and caregivers. *Soins* 2010; 749: 28–31
27. Avsar U, Avsar UZ, Cansever Z *et al.* Psychological and emotional status, and caregiver burden in caregivers of patients with peritoneal dialysis compared with caregivers of patients with renal transplantation. *Transplant Proc* 2013; 45: 883–886
28. Morton RL, Tong A, Howard K *et al.* The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; 340: c112
29. Bass EB, Wills S, Fink NE *et al.* How strong are patients' preferences in choices between dialysis modalities and doses? *Am J Kidney Dis* 2004; 44: 695–705
30. Ayav C, Empereur F, Kessler M. Taking into consideration patient concerns for the elaboration of educational programs for chronic renal failure patients. *Nephrol Ther* 2013; 9: 26–31
31. Stacey D, Bennett CL, Barry MJ *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011; 10: Cd001431
32. Goovaerts T, Jadoul M, Goffin E. Influence of a pre-dialysis education programme (PDEP) on the mode of renal replacement therapy. *Nephrol Dial Transplant* 2005; 20: 1842–1847
33. Mendelsohn DC, Mujais SK, Soroka SD *et al.* A prospective evaluation of renal replacement therapy modality eligibility. *Nephrol Dial Transplant* 2009; 24: 555–561

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A survey on the methodological processes and policies of renal guideline groups as a first step to harmonize renal guidelines

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ABSTRACT

Background. Worldwide, several bodies produce renal guidelines, potentially leading to duplication of effort while other topics may remain uncovered. A collaborative work plan could improve efficiency and impact, but requires a common

approved methodology. The aim of this study was to identify organizational and methodological similarities and differences among seven major renal guideline bodies to identify methodological barriers to a collaborative effort.

Methods. An electronic 62-item survey with questions based on the Institute of Medicine standards for guidelines was completed by representatives of seven major organizations