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Abstract

The literature reveals that current nephrology practice in obtaining informed consent to dialysis falls short of ethical and legal requirements. Failure to meet these requirements represents a significant challenge, especially where the benefits and risks of dialysis have shifted significantly with the growing number of older, comorbid patients. The importance of informed consent for dialysis is heightened by several concerns including 1) the proportion of predialysis and dialysis patients who lack capacity in decision making and 2) whether older, co-morbid and frail patients understand their poor prognosis and the full implications to their independence and functional status of being on dialysis. This article outlines the ethical and legal requirements for a valid informed consent to dialysis: 1) that the patient was competent, 2) the consent was made voluntarily and 3) that the patient was given sufficient information in an understandable manner to make their decision. It then considers the application of these requirements into practice, across different countries. In the process of informed consent, the law requires a discussion by the physician of the material risks associated with dialysis and alternative options. We argue that legally and ethically this discussion should include both the anticipated trajectory of the illness and the effect on the life of the patient with particular regard to the outcomes most important to the individual. In addition, a discussion should occur about the option of a conservative, non-dialysis pathway. These requirements ensure that the ethical principle of respect for patient autonomy is honoured in the context of dialysis. Nephrologists need to be open to, comfortable with and skilful in communicating this information. From these clear, open, ethically and legally valid consent discussions a significant dividend will hopefully flow for patients, families and nephrologists alike.

Introduction

In the modern era there has been a significant shift in the demographics of patients with end stage kidney (ESKD), with an increase in older and frailer patients who have multiple co-morbid conditions. This change has highlighted the imperative of carefully balancing the benefits and risks of dialysis treatment. This balance has medical, ethical and legal dimensions. Nephrologists, like all physicians, are well aware of the need for and importance of informed consent. There is, however, a major disconnect between that awareness and the reality of adherence to the requirements for informed consent for dialysis. (See Table 1 and Figure 1). There are many possible causes for these deficits in practice, including an inadequate understanding of the legal requirements of informed consent; inadequate training or modelling of these conversations; a perception that prognostic data is insufficiently robust to make clear recommendations or, if countenanced, a reluctance to disclose such information; a belief that nephrologists have an ethical and/or legal obligation to offer dialysis to all patients and that failure to do so exposes clinicians to possible litigation; and a level of discomfort in having these conversations. Each of these challenges needs to be addressed. None are insuperable.

In this paper, we outline the legal requirements for a valid informed consent to dialysis at common law. Common law jurisdictions are those which are derived from English judge-made law including England and Wales, Northern Ireland, Eire, Australia, New Zealand, Canada and the United States. While there are jurisdictional differences, the basic legal elements of consent are shared across these countries.

Understanding the nature and content of informed consent to dialysis is important medically, ethically and legally. This process is especially important in light of:

(i) the rapid growth in the number of older patients commencing dialysis (1),
(ii) questions surrounding the capacity of patients with ESKD (2),
(iii) literature comparing the survivorship of older, frailer more comorbid dialysis patients with those on a conservative, non-dialytic pathway (3)
(iv) concerns expressed about the levels of information currently given to patients by nephrologists in the process of consent (4,5) and, as a result,

(v) uncertainty that patients understand the likely trajectory of their illness and the full implications of dialysis on their life, independence and functional status.

Elements of consent

The basic elements of a legally valid informed consent are:

1. The patient must have the decision-making capacity to consent to the treatment.
2. The consent should be an informed one with information given in an understandable manner.
3. The consent should be made freely and voluntarily.
4. The consent must cover the treatment given.

If any one of the elements is absent, the consent is legally invalid. An exception to this process is where a competent patient waives this right and hands over the process of decision making to another person, usually their family (6). The literature reveals a significant disconnect between these legal requirements and current nephrology practice (See Table 1). Ethicists have added further elements to the process of informed consent including the importance of a physician recommendation, a decision in favour of a clinical plan and authorization of that chosen plan in the signing of a consent form (7).

Capacity

An 84 year old man has ESKD secondary to hypertensive nephrosclerosis. During discussions about dialysis, it becomes obvious that the patient has significant short term memory loss and is struggling to manage at home.

The law presumes that an adult patient has the capacity to consent to medical treatment (8). That presumption, however, is open to challenge. If there are concerns it is prudent to organise a formal assessment of capacity. That prudence is especially important in view of the contemporary demographic profile of dialysis patients where, in developed nations, the age cohort of dialysis patients that has the greatest prevalence is the 65-84 year age group.

Decision-making capacity has three elements: understanding the information provided, retaining that information and reasoning to reach a final decision (9). Capacity should be assessed in relation *to the specific decision being made at that time.*

There are two common clinical situations where difficulties with capacity may occur. The first is the patient with the uremic symptoms of drowsiness or confusion. The second is the patient with dementia. It is important to note that these conditions per se do not mean that the patient lacks capacity to make an informed consent. The issue is whether the patient understands, retains and reasons with sufficient capacity at the time the consent process occurs.

Voluntariness

A 72 year old man has polycystic kidney disease. He has had two renal transplants. The second is failing. He informs his family that, after considerable thought, he has chosen not go back onto dialysis. His nephrologist says to the patient - "I don't think that is the right decision; in my view you really do not have a choice and you should go back onto dialysis." One daughter repeatedly says to her father - "You must start. Mum has gone. We can't lose you too. I couldn't bear it if you went." The patient consents to recommencing dialysis.

The law states that, for a medical consent to be valid, it should be made voluntarily and without undue influence (10). Distinguishing clinician recommendation and family opinion from undue influence can be difficult. In the English case of *Re T (Adult : Refusal of Treatment*) (11), the court emphasised that patients, by definition, are vulnerable due to their illness, and rely on the support of family and carers. The key difference between valid support and undue influence is the undermining of the independence of the patient (11). Lord Donaldson posited the test of undue influence as:

> Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself ? In other words "Is it a decision expressed in form only, not in reality ?" (11)

Variations on the scenario above are relatively familiar. Inevitably, family members will have and express an opinion on dialysis. If the patient above commences dialysis the question is not simply whether he was influenced but whether his will was overborne. In the above scenario, the nephrologist is incorrect, in both fact and law. The patient does have the choice of conservative kidney management and common law states that a competent adult has the right to refuse treatment (12).

Level of information required

A 74 year old man has ESKD secondary to hypertensive nephrosclerosis. His nephrologist says to him "we will need to prepare you for dialysis." He is told he will be referred to a vascular surgeon who will arrange vascular access and that his dialysis will occur three times per week.

The common law states that to exercise the right to determine what shall be done with his or her own body, a patient needs to be adequately informed by the clinician (13).

Broadly speaking, common law approaches this issue in two ways:

1. *The law of battery* states that if a patient has a medical or surgical intervention without that person's consent then the clinician has committed a wrong to that person. The information required to ensure consent is advice as to the nature and effects of the intervention (13).

2. *The law of negligence.* As physicians, nephrologists owe their patients a duty of care. The standard of care is what a nephrologist would reasonably be expected to do in the examination, diagnosis and treatment of their patients. The latter includes the *doctrine of informed consent.* This doctrine requires that "the voluntary agreement by an individual to a proposed procedure, given after appropriate and reliable information about the procedure, including the potential risks and benefits has been conveyed to the individual." (14) This doctrine is recognised in common law jurisdictions.

What level of information is required to be given by a nephrologist? In the context of dialysis it is 1) the nature of dialysis, 2) relative risks associated with dialysis and 3) alternatives to dialysis. In many jurisdictions, while courts may refer to the accepted practice of a body of nephrologists, the court is the ultimate judge as to whether that practice meets their standard of care (13). So it is not sufficient for a nephrologist to simply rely on common practice ("we don't usually go into too much detail") regarding consent to dialysis.

In the U.S. case of *Canterbury v Spence*, the court held that a physician should explain to a patient all the material risks of the treatment that a reasonable person in the position of the patient would be likely to attach significance (15). Since that case many courts in the US have followed the reasonable patient standard (16). In Canada, the Supreme Court in *Reibl v Hughes* agreed with this reasoning (17). In Australia, the High Court in *Rogers v Whitaker* (13) held that when physicians discuss the relative risks associated with treatment they have "a duty to warn a patient of a material risk inherent in the proposed treatment; a risk is material if, in the circumstances of the particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it." (13) The Supreme Court of the United Kingdom in *Montgomery* (18) endorsed the *Rogers v Whitaker* test of what constitutes a material risk. In Eire, the Supreme Court of Ireland has, in more recent cases, favoured a move towards the reasonable patient standard (19). In New Zealand, the requirement to gain informed consent is codified : every patient must be provided with the information that a reasonable patient, in the patient's circumstances, would expect to receive (20).

The material risks associated with dialysis

Nephrologists have a duty to warn the patient of any material risk inherent in the process of dialysis. This might include the nature of ESKD, the role and nature of dialysis, the need for a dialysis routine and regular monitoring, changes in lifestyle and schedule, changes in diet, the known symptom burden of dialysis patients and the general complications of dialysis including post -dialysis fatigue, intra-dialytic hypotension, headaches, cramping, sepsis and issues of vascular access. The law requires a discussion that includes both general information and how this information relates to the individual patient in their circumstances.

It can be argued that the entire cohort of patients with ESKD might attach significance to a discussion about further material risks when they consider their individual situation, seeking to balance the inevitable imposition of dialysis upon their former life against their expected survival and likely quality of life. This is particularly relevant for patients who have characteristics associated with a poor prognosis on dialysis, including frail patients, many older patients, patients with significant comorbidities, chronic malnutrition and for whom the nephrologist estimates a limited prognosis (21). For these patients nephrologists might conclude that dialysis is likely to cause more harm than good. If the nephrologist reaches this conclusion with regard to a particular patient, ethicists would argue that the nephrologist is obliged to inform the patient and *recommend against dialysis* (7).

In terms of the content of the information given, there are two areas of information that are particularly important: the anticipated trajectory of the disease and the impact of dialysis on the life of the patient. Both aspects should be discussed with an emphasis on the outcomes most important to the patient recognising that there are limitations in the currently available tools measuring both.

(a) Trajectory

> *Several years ago I asked…a capable and thoughtful nephrologist, "What is the most serious ethical problem in clinical nephrology?" Without hesitation she said, "our failure to inform patients with end stage renal disease of their [statistical] prognosis."*(4)

> *Prognostic information is the single most important piece of information that patients need to make informed choices.* (22)

For an individual patient, accurate prognostication of a patient's life expectancy is challenging. Invariably, it involves a complex combination of objective measures and clinical intuition (23). Therein lies a challenge for physicians in communicating both clinical prognosis and uncertainty. Doing both is entirely appropriate. Indeed, Michel and Moss saw clear advantage of this combination for patients with ESKD. They stated "[i]n fact, it is in situations of clinical uncertainty that patients most want to introduce their extramedical values to assist in the decision-making process; thus candor about uncertainty of prognosis may encourage shared decision making." (5) When dialysis is being considered, prognostic information may be presented to the patient in various ways. The first is annual mortality data, specifically in age-specific cohorts. Another is to compare the prognosis of patients with ESKD who pursue dialysis versus conservative management. Criteria found to be statistically associated with poor prognosis in dialysis patients have been listed above. In terms of conservative management, in one study, patients of average age 82 with ESKD who chose conservative management survived a median of 16 months and about one-third survived 12 months past a time when dialysis might otherwise have been indicated (eGFR below 10 mls/min) (24). While prognostic instruments may not be sufficiently sensitive or specific to inform an individual patient of their exact prognosis, they are informative at identifying high risk patients (25).

(b) The impact on the life of the patient

> A discussion about quality of life alone, as captured by current instruments, cannot capture the full implication of commencing dialysis on a patient and their family (25). Those impacts include limitations on their independence, time spent in the hospital or dialysis centre either on dialysis or with the complications of treatment, interference with usual daily activities including pastimes, changes in diet, the distance and time of travel to dialysis units, especially in rural and remote areas, problems with mobilising if frail and the ubiquity of post-dialysis fatigue and other symptoms. Patients approaching ESKD are often willing to trade months of life expectancy to reduce the burdens and restrictions on travel and independence imposed by dialysis (26). A summary of the material risks to be discussed in the process of informed consent for dialysis is provided in Table 2.

Alternative treatment options

A patient with ESKD has three treatment options: dialysis, a conservative, non-dialysis pathway or renal transplantation. The legal obligation of a physician to explain to a patient other approaches to treatment was recognised in the Canadian case *Haughian et al v Paine* (27) and in Australia by Justice Kirby in *Rosenberg v Percival* (28). To Kirby, the failure to inform the patient of available alternatives means that "[a]ny choice by the patient…is meaningless." (28)

A discussion about alternative options should be specific to the individual patient. For some patients this should include providing a clear explanation of the concept and content of conservative kidney management. It is important that the patient and family understand that conservative care is not medical abandonment and that the nephrologist will continue to review the patient. Ideally, conservative management should be a combination of excellent renal and palliative medicine (29). Over time, it is hoped a synthesis of these disciplines – kidney supportive care - will be a standard part of the practice of all nephrologists.

Issues of communication

Nephrologists should be bilingual: they should speak the plain language of their patients and the technical language of their discipline. In terms of providing information and advice it is critically important that the nephrologist uses language that is clear and understandable to the patient.

The second issue is the nature of the nephrologist-patient relationship. As with all health professionals, this is not a relationship of equals. There is an intrinsic vulnerability in being a patient, both physically and in terms of knowledge. For patients, the relationship with the nephrologist is one based on trust. In terms of informed consent, this places a responsibility on the doctor to be careful in acting upon that implied trust. As Beran stated "[t]he doctor must ensure that the relationship is not used as a 'blunt instrument' to achieve a desired outcome but rather should empower patients to decide their fate." (30)

Overarching this discussion of communication is the importance of giving patients time to consider carefully their options, to talk to their family and, where necessary, have further discussions with their nephrologist. Importantly, as Miller stated in the context of information giving to patients with ESKD and dialysis : "To know what the patient would like to know, we need simply to ask, but having done so, we must then be silent and listen." (4) (See Table 3). Finally, it is important to acknowledge that the provision of information to patients in a pre-dialysis setting may come from many sources including senior renal nurses and social workers. Nevertheless, the law holds the physician overseeing dialysis as ultimately responsible to ensure that the patient has made a valid, informed consent to treatment.

In the clinical scenario described at the beginning of this section, the information provided to the patient was procedural, not contextual. It did not contain any information on the benefits and risks involved in having dialysis, any explanation of prognosis or any discussion about quality of life. There was no discussion of the possibility of a conservative kidney management pathway. Finally, the patient was not informed that they had the right to refuse treatment at any time. The process of informed consent described in that case fell short of the standard we are espousing in this paper.

Cultural and religious perspectives

Informed consent to medical treatment is founded on the principle of autonomy. Such a principle is regarded in diverse ways across cultures and religious faiths. For some, autonomy is paramount; for others it may be a foreign world view (31) whereby the cultural imperative may require that important decisions are made by the head of the family or collectively within families or close knit groups. This process may include the belief within families that difficult news will result in their loved one losing hope; the primacy of filial obligations favouring the commencement of, or rejecting the withdrawal from, dialysis; the belief that forgoing dialysis constitutes abandonment, an immoral act or euthanasia; and, finally, a cultural prohibition against mentioning to the patient the trajectory of the illness, prognosis or death and dying. Recognition of these cultural and religious dimensions by nephrologists is important in all aspects of decision making including the process of informed consent (32).

Role of guidelines and codes of ethics

In their deliberations, courts view professional guidelines and protocols seriously. While they may not be necessarily authoritative in those deliberations, courts find these sources of professional recommendations and practice extremely helpful and, indeed, may find that they inform the content of the duty of care. The main guidelines in Nephrology on informed consent are set out in Table 5.

The right to refuse dialysis

A competent adult may refuse medical treatment including dialysis, even if that treatment is needed to stay alive (12). It does not matter whether the patient's reasons for taking this decision are "rational, irrational, unknown or even non-existent." (11)

Emergency dialysis

An exception to the legal imperative of obtaining consent is a medical emergency (33). Dialysis may be initiated in the context of an acute illness and rapid or unexpected loss of kidney function. Once the emergency has resolved an informed consent process should commence for future dialysis management. The exception to this approach is where the patient, when competent, has expressly stated that he or she does not wish to commence dialysis even and including in the context of an emergency.

Deciding for the incompetent patient

The law states that if a patient is incompetent then the physician should examine any advance care plan made by the patient when competent and discuss with a designated surrogate decision maker. If the patient has not expressed their wishes or nominated a surrogate decision maker, the physician should approach whoever is the medical surrogate decision maker under the provisions of the law in the relevant jurisdiction. This decision-making process should be based on what the person would have chosen if competent *in combination with* the medical recommendations. In the context of dementia, that recommendation should be based on the anticipated clinical trajectory of dementia, the troubling sequelae to the initiation of dialysis in nursing home residents including patients with dementia (34) and the Renal Physicians Association guidelines which recommended that "It is appropriate to forgo dialysis for patients with…irreversible, profound neurological impairment…" (21)

Resolution of conflict

In the process of decision making, there may be conflict between the family and the nephrologist. Legally and ethically, physicians are under no obligation to provide treatment, including dialysis, where the physician conscientiously feels that this treatment is inappropriate or excessively burdensome to the patient. Strategies here include recommending a cooling off period for the family to consider the matter further, seeking the second opinion of another nephrologist and, most definitively, bringing the case to a court to resolve the issue.

Conclusions

There are two common themes to the challenges to nephrologists in informed consent to dialysis: awareness and preparedness. Awareness necessitates knowledge and understanding of the law of consent, summarized in Table 2. Preparedness is the willingness of nephrologists to expand consent conversations beyond the mechanical aspects of dialysis to include topics such as prognosis, quality of life, the aspects of life that matter most to the patient and the option of conservative kidney management. An important dividend that flows from such an open and transparent approach is that any other discussion about future planning or crisis management becomes easier to initiate and conduct. A consent discussion is foundational. All later discussions will be far more comfortable in its shadow.

Table 1

A disconnect between the legal requirements and current practice

1. The vast majority of nephrology patients want to be given as much information as possible, good or bad, including prognosis (35).

2. Patients expect that this information should be given without needing to prompt the nephrologist (35).

3. In a study of maintenance dialysis patients, nearly 70 % reported that the risks and burdens of dialysis had never been mentioned prior to commencing dialysis and only 1 % of patients recalled the option of a conservative pathway being discussed (36).

4. In a study of dialysis patients in Boston, none of the patients reported having a discussion about prognosis with their nephrologists. In that study, nephrologists reported that, for 60 % of patients, they would not provide any estimate of prognosis even if the patient insisted on knowing (37).

5. In a study of dialysis patients, they reported that, in their pre-dialysis discussions, there was no mention of prognosis or how dialysis may affect their lives. The nephrologists, in turn, conceded that they did not discuss prognosis unless prompted. Many patients felt a sense of resignation to dialysis, especially when the nephrologists framed the decision as choosing between life and death (38).

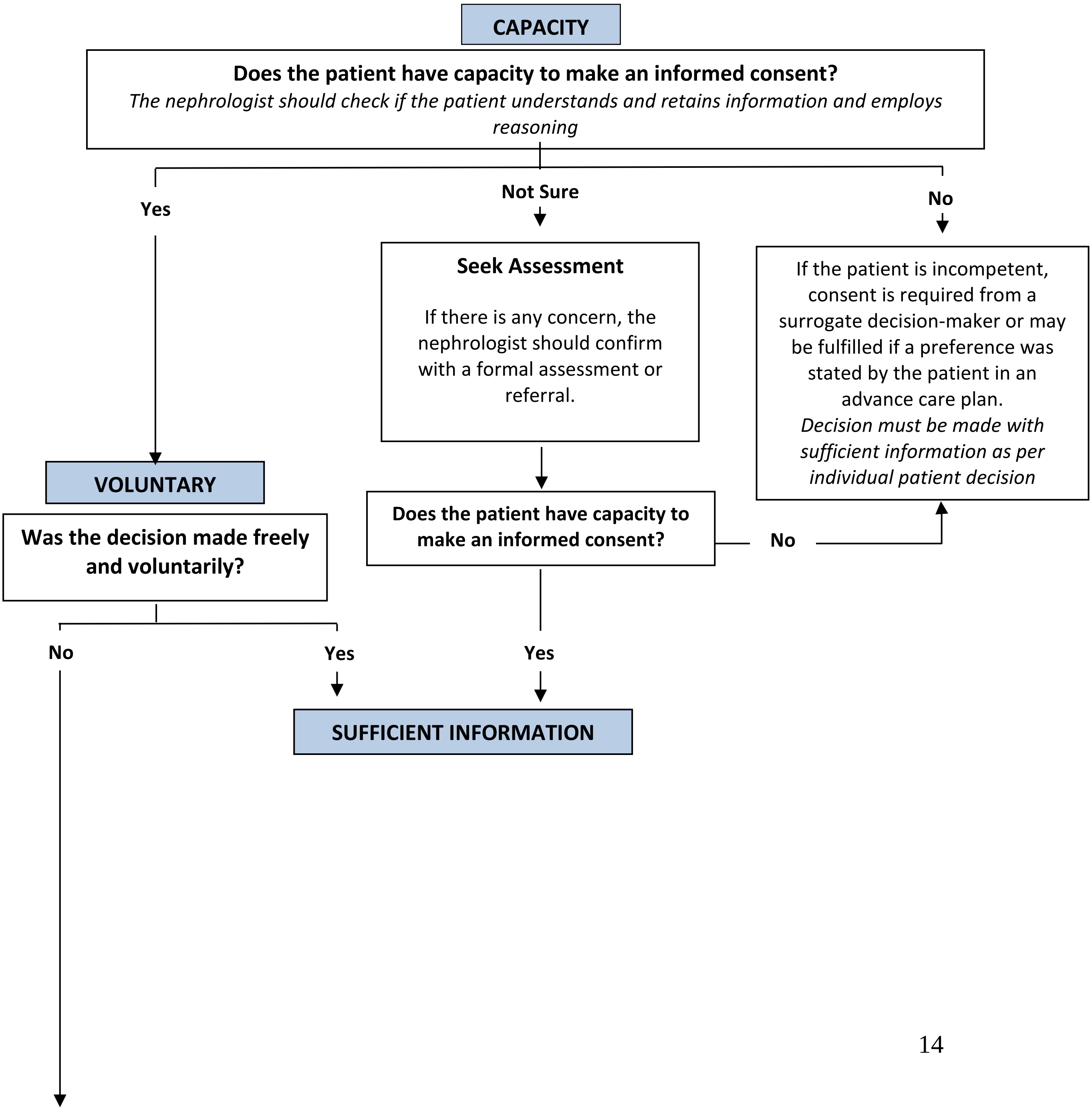
6. In a series of open-ended interviews and participant observation studies of 43 dialysis patients, only two patients perceived that the initiation of dialysis was their decision. The investigators found that “[m]ost insisted ‘there was no decision – it just happens.’ ” The investigators observed that nephrologists framed the need for dialysis in terms of “*when* you will need to start dialysis not *if*.” (39)

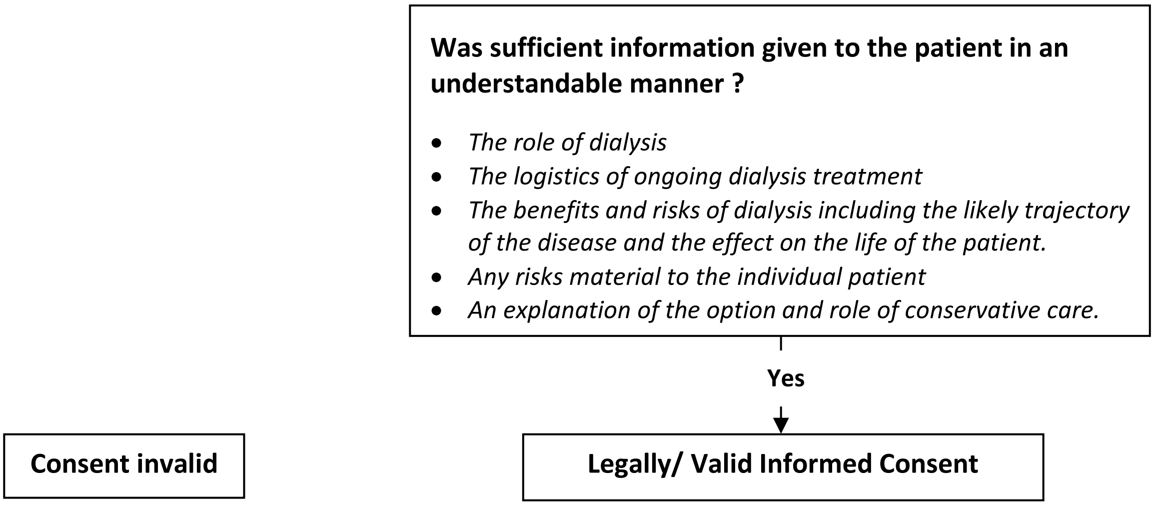
7. Among older hemodialysis patients interviewed to determine whether informed consent had been obtained, most of the patients lacked sufficient understanding of their clinical circumstances. (40)

8. In national surveys of US adult nephrology fellows conducted in 2014 and 2015, nearly one in five stated they felt obligated to offer dialysis to every patient regardless of benefit (41).

9. In a Canadian study, 61 % of patients regretted commencing dialysis (42). When this cohort was asked why dialysis had been chosen over conservative management 52 % reported that it was their physician's wish and 14 % because it was their family's wish.

Figure 1: The elements of a legally valid consent for dialysis





Was sufficient information given to the patient in an understandable manner ?

- *The role of dialysis*
- *The logistics of ongoing dialysis treatment*
- *The benefits and risks of dialysis including the likely trajectory of the disease and the effect on the life of the patient.*
- *Any risks material to the individual patient*
- *An explanation of the option and role of conservative care.*

Foundational Principles of Informed Consent

- There is no legal or ethical requirement on a nephrologist to offer dialysis to all patients.
- The initiation of dialysis on a competent adult patient requires their consent.
- The patient may waive this right and give his or her decision-making power to another person (s).
- A competent patient has the right to refuse dialysis.

Table 2

Material risks of dialysis

As part of the informed consent process and underpinned by the principle of shared decision making, the following material risks should be discussed:

1. General complications of dialysis including vascular access, sepsis, intradialytic hypertension and hypotension, fluid overload and post-dialysis fatigue

2. Prognosis as assessed by available prognostic tools.

3. Anticipated effect on the life of the patient, family and carers.

Table 3

Important aspects of communication in the process of informed consent

- The importance of shared decision making as recommended by the Renal Physicians Association. (21)
- Inviting the family to be part of the discussion.

- Quiet environment
- Clear understandable language - avoid technical language.
- Nephrologist-patient relationship – recognise patient vulnerability physically and in terms of knowledge.
- Allowing patient and family an opportunity to clarify and question information
- Information may come from multiple sources – Nephrologist, Renal Nurses, Renal Social Worker.
- Give patients and families time to consider decisions.

Table 4

Recognition of and guidelines for informed consent in Nephrology

USA

Renal Physicians Association Guidelines (21).

CMS Conditions for Coverage states that patients in renal units have a basic right to informed consent that is entrusted to the medical director of the dialysis facility (43).

The American Society of Nephrology (ASN) in conjunction with the American Board of Internal Medicine Foundation's "Choosing Wisely" campaign, recommends that nephrologists "not initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physician." (44)

The American Medical Association (45)

UK

Department of Health guidelines on informed consent (46).

Canada

One of the "key and enabling" competencies of trainees in Nephrology is the ability to obtain an informed consent (47).

Australasia

In Australasia, the Caring for Australasians with Renal Impairment (CARI) guidelines for Nephrology practice emphasises the importance of an informed consent to dialysis (48).

In Australia, the National Health and Medical Research Council guidelines on the provision of information to patients (49).

The Australian and New Zealand Society of Nephrology (ANZSN) Renal Supportive Care guidelines 2013 has chapters on prognosis, the law and the ethics of dialysis (50).

New Zealand has a statutory regime governing informed consent (20).

Republic of Ireland

Irish Medical Council guidelines to physicians on informed consent (51).

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