Dialysis or conservative care for frail older patients: ethics of shared decision-making

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\textbf{ABSTRACT}

Increasing numbers of frail elderly with end-stage renal disease (ESRD) and multiple comorbidities are undertaking dialysis treatment. This has been accompanied by increasing dialysis withdrawal, thus warranting investigation into why this is occurring and whether a different approach to choosing treatment should be implemented. Despite being a potentially life-saving treatment, the physical and psychosocial burdens associated with dialysis in the frail elderly usually outweigh the benefits of correcting uraemia. Conservative management is less invasive and avoids the adverse effects associated with dialysis, but unfortunately it is often not properly considered until patients withdraw from dialysis. Shared decision-making has been proposed to allow patients active participation in healthcare decisions. Through this approach, patients will focus on their personal values to receive appropriate treatment, and perhaps opt for conservative management. This may help address the issue of dialysis withdrawal. Moreover, shared decision-making attempts to resolve the conflict between autonomy and other ethical principles, including physician paternalism. Here, we explore the ethical background behind shared decision-making, and whether it is genuinely in the patient’s best interests or whether it is a cynical solution to encourage more patients to consider conservative care, thus saving limited resources.

\textbf{INTRODUCTION}

Increasing numbers of frail older patients are developing end-stage renal disease (ESRD) as a direct result of population ageing. Many will have multiple comorbidities and limited life expectancy; providing dialysis can be burdensome for the individual and results in an increasing economic cost for society. Six months after starting dialysis, less than a third of nursing home residents are alive or have maintained their baseline values of physical function [1]. Around 30\% of over 75-year-olds have been reported to withdraw from dialysis [2,3], suggesting significant levels of dissatisfaction with the quality of life on dialysis or poor tolerance of the therapy. The growing realization that dialysis may not suit all patients, especially older patients with multiple comorbidities (who will be referred to as the frail elderly in this paper), has led to the emergence of choosing the non-dialysis pathway, otherwise known as conservative care. Shared decision-making has been proposed as a way of supporting patient-centred care and avoiding unwanted interventional treatments. In the non-dialysis literature, there is increasing evidence that when given a choice, patients are less likely to use interventional treatments [4–6]. However, it has also been suggested that the shared decision-making approach is simply a means towards minimizing the use of expensive healthcare resources. In this paper, we will review the ethical basis and empirical evidence around shared decision-making, looking specifically at dialysis decisions among frail older patients with ESRD.

\textbf{MEDICAL ETHICS}

A helpful starting point for ethical analysis in healthcare is Beauchamp and Childress’s four principles approach: autonomy, non-maleficence, beneficence and justice. Autonomy is the respect for individual decisions. Non-maleficence is avoiding causing harm. Beneficence pertains to relieving, lessening or preventing harm and providing benefits and balancing benefits against risks and costs. Justice ensures that benefits, risks and costs are fairly distributed [7].
CONCEPTS OF AUTONOMY AND PATERNALISM IN MEDICINE

As defined by Beauchamp and Childress, autonomy is the ‘independent exercise of individual choice, free from controlling interference by others and personal limitations that prevent meaningful choice [7].’ Paternalism is the traditional practice whereby the ‘doctor knows best’ and makes the decision for the patient. Many clinicians will believe that they are acting in the patient’s interest by practicing paternalism. However, many aspects of patients’ lives are not revealed during clinical encounters, as shown by cross-sectional studies which determined the physician’s preferences in decision-making [8]. Individual clinicians may also be bound by their own cultural beliefs, biases about treatment options and economic considerations.

THE MIGRATION FROM PATERNALISTIC TO AUTONOMY FOCUSED DECISION-MAKING

Qualitative studies into discussions of kidney disease trajectory with older patients by Schell et al. support that the patient’s understanding of kidney disease and their interaction with their nephrologists can strongly impact treatment decisions [5]. The data collected showed that patients are shocked by their diagnosis; uncertain how their disease will progress and lack preparation for living with dialysis. It could be argued that dialysis decisions for this population require a paternalistic approach, due to the challenges nephrologists face in explaining the complexity of ESRD and the difficulty for patients to understand these complex issues [5]. However, the freedom to make one’s own decisions is intrinsically valuable to humans even if those decisions are sometimes difficult. Furthermore, an autonomy-focused approach to decision-making would enhance patient understanding and preparation for life on dialysis, ultimately leading them to make the right personal choice and should ensure that decisions are more closely aligned with the values and beliefs of individual patients. This approach would narrow the gap between how nephrologists and the frail elderly discuss and understand ESRD.

AUTONOMY-FOCUSED DECISION-MAKING

To explain the autonomous ideal towards decision-making, we shall use a simple analogy of purchasing a Hoover at a department store. ‘What’s the best Hoover?’ you ask the sales assistant. If she just replied with ‘Buy Hoover A, that’s what everyone buys,’ you would most likely buy Hoover A, but with no knowledge or understanding of why it was the best Hoover. Similarly, for the frail elderly, the current method of decision-making means that they are recommended dialysis by the physician, but with little understanding of how it will impact their lifestyle [5].

In a fully autonomous version of this scenario, you would be directed to the store’s website, replete with facts and figures about their different vacuum cleaners. This model is successful for adults who are confident to (and wish to) assimilate complex information to decide the best Hoover for them. However, to choose from all the different types of Hoover powers, sizes, bagged or bagless, could be potentially overwhelming for the frail elderly and even verging on distressing.

A third approach would be to follow a shared decision-making model. Here, the sales assistant would reply to your original question with, ‘Well, that depends. Do you want a Hoover that’s heavy or light? Will you need to carry it up the stairs? Do you find changing Hoover bags a hassle? How often will you be using it? What’s your budget?’ This would make you consider your personal values in choosing the best Hoover for you, i.e. one that is compatible with your lifestyle. Similarly, if the frail elderly were given the opportunity to consider which lifestyle factors mattered to them, then this would help physicians facilitate the decision-making process. The best treatment can then be chosen based on these lifestyle factors, perhaps resulting in better outcomes as patients have increased understanding of the treatment they are undergoing.

However, do the frail elderly want to participate in autonomy-focused decision-making? Flynn et al. looked into preferences for participation in healthcare decision-making in older people and found that only 57% desired personal control over their medical decisions. The subjects chosen all had graduated from Wisconsin high schools in 1957 [9]. Despite having adequate mental capacity, older people may be less inclined or confident to advocate for themselves. Thus an autonomy-focused model would be problematic among those less able to assert their opinions and negotiate with health professionals.

The fully autonomous model not only risks overwhelming individuals with information but it also completely undermines the role of the sales assistant/doctor. Societal awareness of human rights, emergence of the internet and other information sources encourage patients and their families to think that they can manage their medical affairs. Too much knowledge can be detrimental for patients and doctors, especially as patients may find such information confusing and distort their perceptions of various treatments. As Schell et al. have shown, elderly patients are often left confused and unaware of the impacts of dialysis treatment when the decision is made for them [5]. The role of the clinician using an autonomy-focused or shared decision-making approach is to guide the decision-making process, ascertaining the patient’s preferences and personal values, using these to guide what information is discussed with the patient, thereby helping them choose the best treatment.

CONCEPTS OF BENEFICENCE AND SHARED DECISION-MAKING

Providing necessary information to enable patient decision-making is a paramount duty of a doctor and respects beneficence [10]. As we have established, a fully autonomous
approach can be problematic among the frail elderly. Yet providing inadequate information about diagnosis has been shown to leave patients feeling powerless and their autonomy violated; patients may view the unknown as ‘frightening,’ preferring more knowledge to none [5]. This situation is not compliant with beneficence. Avoiding patients having unrealistic expectations through dynamic information exchange promotes trust and further strengthens the physician-patient relationship [11]. However, Schell et al. found that nephrologists often avoid discussing patient’s prognosis and disease progression due to difficulties in predicting these events, leaving elderly patients with a sense of uncertainty and therefore unable to be involved in sharing decisions with their physician [5]. To make a decision about treatment selection (or non-selection), patients need all the appropriate facts about their prognosis, the natural history of their disease without treatment and the resulting complications if they choose treatment. Thus, a suitable medium is needed whereby patients can have a level of involvement in the decision-making that they are able to adhere to. The beauty of shared decision-making is that it enables a balance between autonomy and paternalism, while promoting beneficence.

Shared decision-making has been proposed as the ‘pinnacle of patient-centered care,’ with healthcare professionals involving patients in the decision-making protocol [4]. The UK government supports this model with the latest White Paper entitled ‘Equity and Excellence: Liberating the NHS’, emphasizing that ‘shared decision-making will become the norm: no decision about me without me’ [12]. This paradigm involves the physician sharing information with the patient regarding their medical condition and promotes accommodation of the patient’s values and preferences [4,14]. Evidence suggests that patients who are engaged in decision-making are more motivated and that their clinical outcomes are greatly improved [15–19]. Thus, choices from a shared decision-making approach are more likely to be in a patient’s overall best interests. This approach is emerging as the key to the appropriate management of long-term conditions. It is a personalized model which can be adapted according to each patient’s situation [13]. Clinicians are therefore able to aid patients in making the right medical decision for them, thus leading to improved clinical practice and outcomes.

**Justice and Shared Decision Making**

Justice requires that equals are treated equally. If we accept that healthcare resources should be allocated according to the needs, then justice requires that need is fairly assessed. Life expectancy for the frail elderly with ESRD is unlikely to be increased with renal dialysis [1]. Given that almost one-third of patients over 75 subsequently withdraw from dialysis suggests that there is room for substantial improvement in the assessment of needs. Evidence suggests that with a shared decision-making approach, fewer patients choose interventional treatments, such as dialysis, when they are supported in actively participating in the decision-making process [6,11]. As an example, provision of decision aids to patients requiring hip and knee replacements effectively reduced surgery rates by 38%. This resulted in cost savings of between 12 and 21% over 6 months [20]. Shared decision-making has the potential to reduce inappropriate use of dialysis (e.g. in patients who find themselves unable to cope with the burdens of dialysis), resulting in better allocation of scarce resources.

**IMPLEMENTATION OF SHARED DECISION-MAKING**

Success in implementing this approach depends on many components, including good communication, trust and a solid physician–patient relationship (Figure 1). Evidence-based decision aids are tools which are designed to inform patients of the benefits, risks, relative efficacy and costs of treatments [13]. A 2011 Cochrane Collaborative review of 86 studies showed that patients with decision aids had a greater likelihood of receiving care that aligned with their personal values compared with patients who received usual care [13]. Additionally, self-management programmes and increased patient knowledge lead to improved patient satisfaction [13,21,22].

**Telling the truth—how much information?**

Truth-telling is a key to effective shared decision-making [23]. While depressing news is undesirable, humans are capable of dealing with the implications of grave diagnoses [23]. Evidence from elderly patients with renal disease has shown that patients consider the unknown as ‘frightening,’ and hence wish to be informed of their diagnosis, even if the prognosis is uncertain or poor [5]. However, the frail elderly are relatively underrepresented in these studies and so the

![Figure 1: Model of shared decision making.](https://academic.oup.com/ndt/article-abstract/28/11/2717/1822410/2717)
conclusion may not be directly transferrable. A doctor’s emotional and practical support, plus a caring family, makes the reality bearable [23]. A physician–patient relationship built upon trust and honesty helps relieve patient anxiety and promotes mental well-being [19,23]. The openness and two-way information exchange required for shared decision-making helps to strengthen this trust between the physician and the patient.

As discussed earlier, complete disclosure could overwhelm patients, thus restricting rather than enhancing autonomy [7], and it is unethical to unnecessarily worry patients. Some patients may make an autonomous decision that they do not want full disclosure and want their doctor to be the decision maker [11,23]. In these situations, withholding information recognizes that truthfulness is not a blunt revelation of fact, but is sensitive to individual needs to realize ‘when to speak and when to remain silent’ [16]. Effective communication acknowledges the importance of patient emotion as it enables them to assimilate information at an appropriate time and rate for them. Understanding patients’ emotions increases trust in their physician and diminishes their anxiety [5]. Experience and judgement are needed to determine the patients for whom full disclosure could be harmful rather than paternalistically deciding that truthful prognosis should be withheld from or given to all patients.

Physician–patient relationship

Historically, norms in medical practice over the years have led doctors (and in some cases patients) to believe that doctors know best for patients. This can be appropriate for acute and life-saving situations, but over the last few decades, medical practice has shifted to predominantly management of long-term chronic conditions. Decision-making has been viewed as part of the doctor’s duty to the patient, and it has become the norm for patients to generally agree with their physician [24]. As a result, when faced with a medical problem, patients expect to be told by their physician what treatment to choose [6,25,26]. However, societal and cultural changes, together with the increasing predominance of long-term chronic disease, have led to medical practice migrating from an approach where physician paternalism dominated, to one which addresses patient values, thus appreciating that doctors alone do not always know what is best for patients. This is especially true when the treatment choice can impact significantly on the patient’s quality of life as is the case with choosing a dialysis modality or conservative care [24]. Therefore for shared decision-making to be successful, the first step is for patients to understand that doctors cannot know the right treatment for them solely based on medical knowledge and equally for physicians to recognize the same limitations. The best choice is defined by what matters most to patients, especially when the medical outcomes are comparable [25].

Even when fully informed, patients may not feel confident in their decision-making and thus would want a recommendation from their doctor. It is crucial that patients are not abandoned in the decision-making, and when they ask doctors for a recommendation they should receive one. Through a strong relationship, patients can trust doctors to give a ‘preference diagnosis,’ which is essentially a suggestion of what the patient would decide if they had the same level of information and knowledge as their doctor [25]. To make a ‘preference diagnosis,’ doctors need to engage patients in dynamic discussions, which include scientific information and patient preferences. The danger with ‘preference diagnosis’ is that gaps exist between what patients want and what doctors think they want [25]. This is reflected in studies showing that doctors believe 96% of breast cancer patients considering chemotherapy rate living as long as possible as their main priority, but the figure reported by patients is actually only 59% [27]. It is important, therefore, that the physician state whether this is based purely on their medical expertise and whether the patient’s preferences are included or not. A solid physician–patient relationship can close these gaps, as ascertaining patient preferences assists doctors in recommending the right treatment for patients [25].

CHALLENGES WITH SHARED DECISION-MAKING IN THE FRAIL OLDER PATIENT

Shared decision-making is potentially problematic to deliver in the frail older patient with ESRD for the reasons discussed above—paternalistic practice by physicians, lack of skills among clinicians to educate older people and to elicit information about patients’ personal values, difficulty for older people to assimilate complex information, and the need to individualize the correct balance in the amount of information; too much can be burdensome and too little can be frightening. In terms of the decision about dialysis or conservative care, the process is made more complex by the fact that there is no absolute starting point for dialysis—many patients have started on dialysis at relatively high levels of renal function because of their high symptom burden, which is often related to their morbidities rather than their kidney disease [28], and without considering alternative methods of extending their time without dialysis [29]. Patients and their families can also feel abandoned unless they are informed about continuing active management and support until their death if they decide not to have dialysis.

Other barriers include patients preferring no involvement in decision-making, and disagreement among health care professionals about asking patients about their preferred role in decision-making [30]. The process of shared decision-making therefore needs to be tailored to the patient’s needs and be delivered in a timely fashion. Additional barriers for the frail older patient with ESRD include impaired vision and hearing, cognitive impairment, educational and cultural expectations about healthcare decision-making and limited healthcare literacy. Furthermore, with high immigration rates to all western countries, there are significant language barriers for many patients and associated cultural differences in attitudes to healthcare [11]. Low health literacy was found to be common among chronic kidney disease patients and it is independently associated with socioeconomic factors (e.g. lower education and income) and health outcomes (e.g. higher morbidity, less knowledge of kidney disease) [26,31]. Low
health literacy not only has detrimental implications for healthcare and patient safety, but also incorrect decision-making based on misunderstanding information could cause unnecessary distress.

Despite being suggested as an ideal mechanism to assist patients in choosing the most appropriate ESRD treatment, evidence shows that shared decision-making has not been extensively incorporated into clinical practice. This is potentially due to the issues described earlier. Medical care does not always support patients’ personal preferences, as evidence suggests <10% of medical decisions meet the minimum standards for informed decision-making [13,32]. Systematic reviews identified the main barrier needed to implement this for healthcare professionals was time [33]. Routine 10-minute consultations are simply not long enough to explain to patients details about each treatment option, which has its own profile of benefits, risks and costs, alongside addressing any issues in patient’s understanding of such information. Furthermore, making important decisions can be emotionally straining on the patient and family. There is no doubt that shared decision-making can be time-consuming, burdensome and requires a degree of personal discipline for the clinician who has to be able to accept that the patient may make a decision which could be regarded as inappropriate [34]. Most renal clinicians do not have the communication skills required for these conversations, and developing or acquiring these skills are not addressed in most national or international renal education meetings or congresses.

CONCLUSION

Medicine is moving from a paternalistic approach to an autonomy-based approach. Shared decision-making is a continuum; the approach varies depending on each patient’s situation and preferences and their degree of understanding [35]. The flexibility in this model enables a compromise between patient autonomy and physician’s paternalism. Some patients may be capable of handling such information, so their shared decision-making approach is more autonomy-based, whereas others may require paternalism to play a greater role in decision-making [10].

Successful implementation of shared decision-making requires investment in appropriate staff training, particularly in communication skills, robust governance and clear guidelines about decision-making, especially in more complex situations. The time taken for these discussions also needs to be recognized as a key part of the work of the entire renal team. Continual improvement of shared decision-making will enable clinicians to target ideas for developing the model to improve the quality of patient care.

Discussing the choice of no dialysis with frail older patients is an ethical management option as enabling patients to choose conservative care respects their autonomy, while complying with paternalism and the view of the doctor that the patient outcome on dialysis would be poor. Of course, given the same facts, many frail older patients will choose to have dialysis. The same ethical principles dictate supporting the patient in that decision, even though the doctor may consider that the patient outcome is likely to be poor. Shared decision-making is an invaluable tool for ethical medical practice, and could improve patient-perceived outcomes, while indirectly reducing dialysis withdrawal rates, thus benefiting the patient, the physician and the wider healthcare community.

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