

'It's Got to Be the Patient's Decision'

Practicing Shared Decision-making in the U.K. Renal Units

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ABSTRACT: In modern medicine, patient choice and involvement in treatment decision-making are increasingly recognised as an important issue in improving the quality of healthcare, and in recent years the concept of shared decision-making has attracted attention as a new approach in the medical encounter. This model is particularly appropriate in life-threatening situations in which no best treatment exists and there are trade-offs between benefits and risk of available treatments. In this article, I demonstrate how clinical uncertainty makes shared decision-making difficult in practice, using the case of elderly patients with end-stage renal failure based on data collected by interviewing renal healthcare professionals in the U.K. I then propose the possibility of 'patient choice' becoming a burden for some elderly patients and the institutionalisation of shared decision-making, and discuss the importance of building a good relationship between healthcare professionals and patients to facilitate shared decision-making.

KEYWORDS: choice, elderly, end-stage renal failure, medical decision-making, patient choice, uncertainty

Introduction

Imagine that you are an 85-year-old patient and have been given a diagnosis of end-stage renal failure (ESRF). Your doctor recently told you that you would have to decide soon which treatment option to take in order to be ready for the time when your kidney function will decline even further and consequently you will feel more ill. In terms of kidney disease you feel relatively fine at the moment, so it is very difficult for you to think about the future treatment. Your daughter, who is married with two children, lives near you, and your daughter and your son-in-law had a discussion with a renal nurse regarding the treatment options. You learned that dialysis will not cure your disease but may prolong your life. If you decide to have dialysis, you will have to go to a dialysis centre three times a week and stay there at least four hours each time to get dialysed. The dialysis centre is

far from your home and your daughter is too busy to take you to the dialysis centre as she has a full-time job. There is an ambulance service to give you a lift to the centre, but it would take a long time to get there and to come back home, so you would otherwise need to secure transport to get there yourself. The renal nurse informed you that the other option is called conservative care, which treats and controls symptoms of ESRF without using dialysis. With conservative care, you may not live as long as patients receiving dialysis, but you will be more likely to have a better quality of life; for example, by spending more time at home than in a hospital, which enables you to see your grandchildren more. Your daughter would like you to have dialysis, as she would like you to live longer. You would also like to live longer, but you are worried that dialysis may drain you physically and mentally. During the meeting, the nurse gave you some leaflets about the two options to read at home



and discuss with your family. Renal staff would like to discuss the options and your preferences further with you and your family when they see you next time, and also mentioned you could talk to a counsellor if necessary. Renal staff will provide you with any support you need, but you will have to make a decision. The nurse has said that you have about six months to make a decision, as once you choose dialysis, you will have to follow the surgical process well before starting dialysis.

Similar scenarios to that described above have played themselves out in the context of renal medicine since the option of conservative care was added to traditional renal replacement therapy (RRT) options. Patient choice and involvement in treatment decision-making have been increasingly recognised as an important issue in improving the quality of healthcare, and in recent years the idea of shared decision-making has attracted attention as a new approach in the medical encounter. Shared decision-making is characterised as (1) the involvement of both patient and doctor; (2) information sharing by both parties; (3) a process to build a consensus about the preferred treatment; and (4) reaching an agreement about which treatment to implement (Charles et al. 1997). This model is considered most appropriate in situations of uncertainty where more than one reasonable treatment option exists and no single option is self-evidently best (Coulter 2010; Whitney et al. 2004). When there is more than one treatment option deemed to be medically equally effective, the choice should depend on patient's values, emotions and situation. It is, therefore, important for healthcare professionals and patients to share a decision-making process, namely to communicate risks and benefits of the treatment options and to explore what is important to the patient (Lally et al. 2011).

As shown in the example scenario above, decision-making for elderly patients with ESRF takes place in an uncertain and confusing context. In a situation like this, shared decision-making is in theory the most appropriate approach; however, in practice it can often create very complex issues. In this article, I investigate how shared decision-making is practiced by exploring the experiences of renal healthcare professionals treating patients aged seventy-five and older with ESRF in the U.K., with particular focus on the decision-making process about whether to have dialysis or conservative care. I will firstly look at how shared decision-making was developed and what it aims to achieve in theory. I will then give an account of how and why the option of conservative care was developed as an alternative to dialysis in renal medicine.

This will be followed by an analysis of renal healthcare professionals' discussion with patients who needed to decide whether to have dialysis or not in order to explore how shared decision-making takes place and how any difficulties that occur during that process are dealt with. Finally, I will discuss the possibility that shared decision-making is practised in favour of the healthcare professionals and the smooth running of the unit as an institution rather than for the benefit of the patients.

Theoretical Models of Decision-making

Before the idea of shared decision-making appeared, the dominant approach to making medical treatment decisions had been a paternalistic model (Charles et al. 1999a). An assumption underlying such a model is that the doctor will make the best treatment decision for the patients and can do so without involving them in the decision-making process. The information exchange is unidirectional, from healthcare professionals to patients, and patients are assumed to have a passive and dependent role, while doctors are seen as dominating the medical encounter and using their skills to diagnose and recommend tests and treatment for the patient (Charles et al. 1997; Lally et al. 2011). The paternalistic model, however, began to be questioned in the 1970s; patients started to harbour feelings of distrust towards doctors and medicine due to the doctors' often self-righteous attitudes towards patients and treatment decision-making (Morioka 1997). With the advancement of medicine, new medical technologies, such as in vitro fertilisation, organ transplant, and gene therapy, came into being. Such technologies created situations directly affecting and affected by the patients' personal values and beliefs about life and death. Under these circumstances, the paternalistic model, which leaves the patient outside the decision-making process, became increasingly questioned (Morioka 1997). A wider choice of treatments also became available entailing different types of trade-offs between benefits and risks. Since it was the patients rather than the doctors who would have to live with the consequences of these trade-offs, the assumption that doctors were in the best position to make a treatment decision for patients became increasingly challenged (Charles et al. 1999b). Moreover, with the prevalence of social security and health insurance, medicine had become an issue beyond a mere private relationship between doctors and patients, including more complicated issues such as the changing position of patients as con-

sumers and the economic issues arising from the cost of medical care given the increasing number of people needing it. Patients started to be considered as having their own right to receive and/or choose medical care (Morioka 1997).

In response to these changes, a more patient-centred approach has evolved. For example, the informed decision-making model, which involves a partnership between doctor and patient and increases patient-centredness, has gained popularity. In this model the doctor leads the information exchange stage, and provides the patient with information including all relevant treatment options and their risks and benefits, but decision-making steps are assumed to be the sole prerogative of the patient, who makes his/her own decisions. In this model, doctors act as sources of expert clinical information without playing an active role during the decision-making process (Charles et al. 1999a, 1999b). According to Charles et al. (1997), the paternalistic model leaves the patient outside the decision-making process, while the informed model leaves the doctor outside by limiting his role to one of information transfer.

In contrast to the informed model, the shared decision-making model involves doctor and patient on an equal footing in the exchange of ideas. The shared decision-making model is defined as 'a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences' (Right Care Shared Decision Making Programme 2012). It aims to help patients play an active, autonomous role in decision-making concerning their health and treatment, which is the ultimate goal of patient-centred care (Gravel et al. 2006).

Shared decision-making has been promoted prominently by the governments in the U.S., Canada and U.K. (Elwyn et al. 2010), and in the U.K. it has been an important feature of the white paper 'Liberating the NHS' (Department of Health 2010), which sets out the Government's long-term vision for the future of the NHS (National Health Service in U.K.) (Lally et al. 2011). The NHS has been investigating how health professionals can make shared decision-making a part of routine practice (ibid.). Some recent literature has, however, proved that its implementation is difficult and slow (Elwyn et al. 2010; Gravel et al. 2006; Legare et al. 2008; Olthuis et al. 2013). In the following sections, I will take cases of patients with chronic kidney disease (CKD) in order to explore how shared decision-making occurs in practice. To begin with, I will give a detailed account of CKD and the treatment options.

Chronic Kidney Disease and the Development of Conservative Care

Renal death accounted for around 1–2 per cent of all deaths (5,000–10,000 deaths) in England and Wales in 2007 (Prentice 2013). CKD is a long-term, slow but progressive condition that can cause serious health complications, and preventing and treating CKD has been a high priority for the government, Department of Health and NHS for many years in the U.K. (NHS 2011). Based on an estimated glomerular filtration rate (eGFR),¹ CKD is categorised into five stages, and the most severe of these stages is known as established renal failure or end-stage renal failure (ESRF), which is an irreversible decline in kidney function categorised as stage 5 CKD (eGFR<15ml/min). At this stage, renal replacement therapy (RRT) should be considered for all patients. This could be a kidney transplant, dialysis or nondialytic treatment (conservative kidney care) (NHS 2011).

The use of RRT is increasing steadily, and the increase is highest among patients aged seventy-five years old and older. Most older people treated with RRT receive haemodialysis; however, this is a challenging treatment requiring thrice weekly hospital visits, and dialysis leads to loss of functional status (i.e. an individual's ability to perform normal daily activities required to meet basic needs) in older, frailer patients (Tamura et al. 2009). Although RRT usually prolongs life, it also increases frailty and loss of independence (Chandna et al. 2011; Jassal and Watson 2009; Jassal et al. 2009), particularly for the elderly and for patients with multiple comorbid conditions. Dialysis can, therefore, impose a considerable burden on patients and their families, and for some people it may not be beneficial in terms of quality of life. As a result, a conservative-care pathway has been increasingly recognised as an alternative treatment option for those who may not benefit from dialysis, and is now offered as an established treatment choice in most U.K. renal units. This pathway consists of the active treatment for established kidney failure without RRT, providing control of symptoms, non-dialytic correction of electrolyte and fluid imbalances, management of anaemia, and end-of-life/palliative care. The emphasis is on maintaining quality of life for the patient, their families and other people close to them (Alston 2013).

Although the conservative-care pathway involves active treatment as explained above, it does not involve the life-sustaining treatment, dialysis. Therefore, it is assumed that whether to have dialysis or conservative care can be a life-critical decision for many patients. Data on the outcomes, such as survival

and quality of life of patients on conservative care, are essential in order to inform such decision-making. There is, however, a lack of high-quality evidence and recent research shows mixed findings.² This has caused an uncertain and complex situation amongst healthcare professionals when helping patients make a decision about whether to have dialysis or not.

Study Design

The study reported in this article is part of a larger study, CKMAPPS (Conservative Kidney Management Assessment of Practice Patterns Study), U.K. As part of the study, semi-structured interviews were conducted with a total of sixty healthcare professionals from nine renal units across England in 2012. The interviews were conducted to explore the organisation and provision of conservative care to patients in the selected units, and the healthcare professionals' views and experiences of treating patients aged seventy-five and older who opt for conservative care. The primary aim of these interviews was to inform the development of a national survey questionnaire (the second stage of the larger study). This article, therefore, should be treated as a sub-study, which is written based on the analysis of data originally collected for a different purpose.

Situations of Uncertainty

In the following sections, I will give a detailed account of uncertain and complex situations that many healthcare professionals are faced with when discussing conservative care with patients, followed by how they manage such uncertainty in practice.

Many renal healthcare professionals interviewed in this study recognised that there were some patients who unexpectedly responded well to dialysis, whilst others did not respond well and experienced complications directly as a consequence of the treatment and 'died horribly'. Many healthcare professionals were also aware of difficulties in assessing the suitability of conservative care for patients. One of the renal nurses interviewed expressed that she wished to have a manual or a guideline, which would help her assess the suitability for conservative care. A consultant nephrologist also expressed the difficulty in explaining treatment options to patients due to the clinical uncertainty about the outcomes of conservative care.

I think most of the nephrologists will find it very tricky when a GP [general practitioner] sends you a

ninety-year-old lady with multiple comorbidities, with eGFR of 10 – how do you approach that? Do you say, 'well you are going to die without dialysis'; 'you are probably going to die on dialysis and you're probably going to have a worse quality of life'; I really don't know. (Consultant nephrologist, unit 4, participant 22)

Uncertainty is amplified by the fact that the decision-making is about a *future* treatment option; namely, when the disease will have become more symptomatic. Discussing treatment options early on in the patient's pathway is important as it allows proper surgical preparation before the need for RRT and also allows patients, their family and carers time to think about the treatment options available before the patient becomes too sick and confused to make his/her own decision. The patient, however, inevitably has to imagine a situation he/she has never been in, in order to decide whether to have dialysis or not. Renal healthcare professionals also understood this difficulty for patients and explained that it was also challenging for renal staff to explain treatment options:

We haven't been very successful in putting [patients] in positions where explaining that we are talking about a decision for when [patients] become symptomatic, not about a decision [when they] feel fine at the moment. It's that abstract ... that sort of 'what if', theoretical situation that [patients] might come to in the future. (Consultant nephrologist, unit 5, participant 32)

Making a decision about a future treatment option means that some time will elapse between the decision and the treatment. In case of ESRF patients who choose dialysis, they usually have six to twelve months before starting dialysis, in which period they have a surgical procedure for dialysis preparation (i.e. fitting a fistula on the skin which provides easy and reliable access to the bloodstream for haemodialysis). By having the fistula created well before dialysis, patients are ready to start it whenever their eGFR level decreases to a critical level.

On the contrary, those who choose conservative care do not have such special procedures. Some renal units have dedicated conservative-care clinics which patients start to go to once they opt for conservative care, but at other units patients will still be consulted in the same clinics as before or they start to be mainly seen by their GPs in the community. When patient's health starts to deteriorate as their eGFR level decreases, palliative care service will be more involved in their care until their death. Many healthcare professionals reported that during the conservative-care pathway, some patients suddenly change their minds

to have dialysis. This was not considered desirable by healthcare professionals for medical reasons: it usually involved an emergency procedure of creating a temporary catheter, which would increase the possibility of infection and other complications. Patients change their mind mainly when they become symptomatic and deteriorate significantly, or when their family members want them to have dialysis.

I mean the five [patients I mentioned earlier] have definitely chosen not to have dialysis treatment and are slowly dying with kidney failure, and those five people are sufficiently symptomatic that if they wanted to change their mind I think they would have done so by now, but there may be a significant number of people who have said that at the moment I don't want to have dialysis treatment. But they haven't really had to test that decision by becoming ill from kidney failure [so they may change their mind when they become ill]. (Consultant nephrologist, unit 5, participant 33)

As the above consultant nephrologist indicated, up until they reach the symptomatic phase, patients who opt for conservative care can be seen as an uncertain entity whose status is changeable and undefined. Some healthcare professionals emphasise that these kinds of patients should not be officially categorised as conservative-care patients and that they should be distinguished from those who are definitely on conservative care. Such an indefinable status of patients should also be 'revisited' until these patients make a firm decision.

Such undefined status of conservative-care patients was also mentioned by Tonkin-Crine et al. (2014) who, as part of the larger study CKMAPPS, interviewed forty-two patients aged seventy-five years or older on a pre-dialysis, a dialysis, or a conservative-care pathway. They reported that some conservative-care patients described how they would have dialysis if they 'had to have it' or if they 'got really ill', which suggested that conservative care was conceptualised by some patients as a temporary management strategy that might change with deteriorating health. It also appeared that changing treatment from conservative care to dialysis happens more frequently to patients having little or no discussion with healthcare professionals about the illness trajectory or death and dying. It may be difficult for some healthcare professionals to discuss such issues simply due to the nature of the subjects, and the clinical uncertainty about the outcomes of conservative care may also amplify the difficulty. However, if healthcare professionals do not talk to patients about the illness trajectory or death and dying (vital information for patients to decide about

'future' treatment options), the number of patients likely to revise their treatment decision at a later stage assumedly increases.

In summary, uncertainty experienced by the healthcare professionals is related to: (1) lack of high-quality evidence about survival and quality-of-life outcomes of conservative care when discussing treatment choices with patients; (2) the particular nature of decision-making in a situation in which a patient needs to decide about a future treatment option; and (3) the undefined status of conservative-care patients until the point of their physical deterioration. These three factors are also inextricably entwined each other. In the next section I will explore how healthcare professionals manage such uncertainty when discussing treatment choices with CKD patients.

Coping with Uncertainty

West and West (2002) argued that no matter how much information or clinical 'evidence' is gathered, there will always be uncertainty at the point of making clinical decisions with individual patients. One of the easy solutions to respond to this is to pass the responsibility on to protocols and guidelines, or on to the patients (ibid.).

Patient Choice: Shifting Responsibilities of Decision-making to Patients?

The model of shared decision-making attaches a high value to patients' input. Indeed, all healthcare professionals in this study talked about the importance of involving the patient and his or her family in the decision-making process and stressed that if patients wanted to choose conservative care they should be fully informed and understand what it involved. All staff also acknowledged the importance of patient choice in deciding whether to opt for conservative care:

I think sometimes, especially for the more elderly patients, they'll have whatever the doctor wants them to have. And something we always say to them is it's got to be their decision whether they want dialysis or they don't want dialysis. (Nurse, unit 3, participant 15)

The importance of patients' active, autonomous role in engaging in shared decision-making can also be seen in healthcare professionals' attitudes when discussing treatment options with patients. Many described that they would try to take a neutral stance so that patients could make their own choice, although there were also some who took a more flexible approach by providing patients with a more guided ex-

planation to help them make a decision. This usually happened when it was obvious that patients would not benefit medically from dialysis:

You don't really want to lead people into making decisions that's not their decisions. It's all about telling them the options. [...] Sort of knowing in the back of your mind what's the best thing but not sort of influencing them in any way. (Nurse, unit 1, participant 6)

It can be very difficult for patients to opt confidently for conservative care. Asking patients to decide without giving any advice or guidance from the healthcare professionals' point of view may impose quite a burden on patients, especially elderly ones. A remark made by a social worker we interviewed makes this point evident:

Sometimes I think there are people in [a] situation that we shouldn't approach with [choice]. Ninety years of their life knowing that they go to the doctor if they are unwell, and all of a sudden they've got to make a decision that says do you want to live or do you want to die sooner. I think that's really hard. [...] It could be torture having to make that decision about the rest of their life and do I want this really difficult treatment called dialysis or not, and I think sometimes for them not to have even been approached with that choice would be a better option. [...] But the ethos in the NHS is patient choice, but sometimes that's a hard choice, and I think mentally and psychologically, it's a very difficult choice. (Social worker, unit 2, participant 11)

The 'burden of choice' has been also discussed in other research. Olthuis et al. (2013) studied the experiences of doctors, nurses and medical ethicists who became ill and needed professional healthcare. He pointed out that even for them decision-making was far from straightforward, and suggested that sharing responsibilities may impose a burden on patients. Similarly, Epstein (2013) pointed out that patients' autonomy might not be enhanced by giving them a choice; instead the choice became a burden especially for those who were ill and confused. The ethos of 'patient choice' was developed in order to promote patient autonomy in healthcare; however, in some situations 'choice' becomes a sort of additional stress and eventually disempowers patients.

Decision-making: Making the Indefinable Definable?

As shown earlier, many patients do not discount dialysis as a future available treatment option even after they opt for conservative care. For healthcare professionals, therefore, patients on conservative care who are not yet symptomatic of CKD can be considered as being in a marginal or transitional state. They are neither in one state nor in the next; they are indefinable

entities; something which is historically considered unpleasant and dangerous in many societies, and over which control is attempted (Douglas 1966). In the case of CKD patients, their indefinable, unpleasant status can be avoided if patients make a firm decision about their treatment option promptly. In the following, I theorise that decision-making plays an important part largely for the benefit of healthcare professionals and of renal units as institutional organisations, rather than purely for the benefit of patients themselves.

As mentioned previously, the situation where conservative-care patients change their mind and start dialysis as an emergency procedure is not desirable for medical reasons. Moreover, as shown below, the patients' change of mind also possibly exhausts the healthcare professionals physically and emotionally, and drains hospital resources:

Main problem [of the patient who changed his mind] was that he developed fluid overload. I suppose that's one of the ones that can be the most frightening for the patient; if they change their mind you've got to manage it quite quickly, haven't you? (Consultant nephrologist, unit 7, participant 40)

I think therein lies the problem as well because you can't give them six months to decide, because if you give patients time they will take as long as they want. And if they decide to change their mind at the last minute and you start with a permcath,³ then that is a notch against you. Why didn't they start with fistula even though we have been seeing them for six months? (Consultant nephrologist, unit 1, participant 1)

On the other hand, a patient who made a firm decision to opt for conservative care in a prompt manner at an early stage and remained as a conservative-care patient until the end was considered as a 'good' patient.

He was absolutely your perfect conservatively managed chap. Because when I went to him and I had a chat with him and I explained his options, and he was like, 'I'm eighty-four, I've got twelve grandchildren, I am at the end of my life. I don't need all of these shenanigans. I don't want any of that'. I believe he understood what I was saying and I believe he made a good informed decision. He died about three months later in a hospice, which was his choice. And that was the perfect example of how it can work and when a patient is in that mental and emotional place where they're accepting that, but that doesn't happen very often. (Nurse, unit 8, participant 50)

In this case, there was no fuss, and the patient's status as a conservative-care patient was definite from the beginning and retained until the end, which helped him follow conservative care properly (i.e. he died in a hospice as he wished). His 'good' decision-making

not only helped him, but it may also have helped healthcare professionals in many ways. It may have saved their time as they did not have to spend much time and energy on discussing treatment choices. The patient's calm mental state may have helped the healthcare professionals emotionally. Hospital resources may have been also saved, as he did not require the last-minute emergency admission to hospital to have dialysis. As the last statement in the above excerpt mentions, however, it seems to be quite challenging for patients to make a 'good' decision.

A similar tendency was observed in the palliative/hospice-care settings, where the hospice philosophy, originally developed for the dying individuals to die their own way, has become more routinised and institution-centred since it was absorbed into the mainstream of the healthcare system (Okamoto 2006). If patients do not follow the dying process proposed by the hospice philosophy, their 'bad' death often physically and emotionally exhausts the healthcare professionals and drains resources, as greater time is spent in care and discussion. The notion of 'good death' is, therefore, not only a matter for the dying patients and their family, but also for the healthcare professionals and the palliative care unit as an organisation. 'Good death' benefits palliative-care administrative structures by supporting their philosophies and goals and by facilitating the smooth running of the organisations (McNamara 2001).

Shared Decision-making: What Is 'Shared'?

When we give out the options, I would like to think we give out a balanced [information] of both [conservative care and RRT] options and then say go away and make your choice, take your time, you know, and you can change your mind. (Consultant nephrologist, unit 5, participant 33)

During the process of shared decision-making, patients are given autonomy and fully informed choice, which in theory gives patients freedom of choice, and maximises their chance to take the best possible choice. In this article, however, we have seen that this is not always the case in practice, at least in the instance of elderly patients who decide whether to have dialysis or conservative care.

I have demonstrated the difficulty in dealing with the clinical uncertainty, which may partly explain why the implementation of shared decision-making is difficult. As West and West (2002) argued, uncertainty cannot be 'killed'; it can be only lived with. During the process of decision-making, however, under

the ethos of 'patient choice' the decision-making responsibility can be passed on to patients, even when patients are also uncertain about their treatment choice, and they are likely to appreciate healthcare professionals' advice or even choice on their behalf. For institutional needs and the benefit of healthcare professionals, the future treatment pathway is clarified at an earlier stage, which implies that patients make a 'final' treatment decision earlier, while many of them would value the flexibility of not making this choice until a later stage.

This implies that treatment decision-making is an ongoing 'process' rather than a one-off event, and it is a product of an iterative process of information assessment (Rapley 2008). During this process, any uncertainty or difficult issues should not be avoided, but shared and talked about. For example, some healthcare professionals mentioned the difficulty in discussing end-of-life issues with patients, which is an inevitable topic to talk about when discussing conservative care. In order to be able to discuss such issues, a counsellor we interviewed emphasised the importance of having a good relationship with patients:

[Talking about conservative care with patients who do not want to talk about it] is hard, because I think you have to just be so aware and you have to be really clear about what is going on here for this person. [...] Because I think that one of the things that is really important is about the relationship you have with someone. And if you've been able to build a relationship then I think it enables some difficult things to be discussed. (Clinical counsellor, unit 2, participant 9)

Furthermore, my earlier work with cancer palliative care doctors indicated the importance of sharing uncertainty and suffering with patients (Okamoto 2006):

If there was a manual for cancer treatment, the medical staff could take an easy course. But I think it is very important to have a hard time with the patients in the decision-making process [while asking ourselves] 'What can we do? This treatment is good, but it causes side effects', and so on. To be extreme, I think it is alright even if the patient dies while he and the staff are having a hard time in deciding the best treatment for him. [...] I believe that sharing a hard time together is another way of healing. (Palliative care doctor: personal communication, 6 September 2000)

Needless to say, it is not easy for healthcare professionals to share such a hard time with patients without a well-established relationship with them. It is probably also not easy for hard-pressed healthcare professionals to share difficult time with patients physically (i.e. time and manpower) and emotionally. However, if uncertainty is avoided and removed from

the process of shared decision-making, institutionalisation of shared decision-making is a likely result, and this goes against its original aim.

Study Limitations

As mentioned earlier, this is a sub-study based on data collected for a different purpose, namely to explore the key issues surrounding conservative-care practice patterns. For data collection, therefore, only renal healthcare professionals who were involved in the care of conservative-care patients were interviewed. Additionally, conservative care is practiced differently in different U.K. units (Okamoto et al. 2014), and it is reasonable to assume that healthcare professionals' views and experiences with conservative-care patients may vary significantly between units. The current data, therefore, do not represent views and experiences held by all renal staff in the U.K. A further limitation is that data were collected only by interviews; therefore, the information obtained was inevitably self-reported, and how shared decision-making is actually practiced in the clinical setting is not elucidated from the data. It should also be noted that data presented here is only from the perspectives of the healthcare professionals, and my data analysis may have been biased by primarily identifying 'patient choice' as a burden and challenging using the healthcare professionals' perspectives only. Patients' perspectives would enhance our understanding of problems around shared decision-making. Long-term participant observation of clinical encounters between healthcare professionals and patients and their family is needed to understand further the longitudinal, interactive and organisational process of decision-making.

Conclusions

In this article, I have highlighted how clinical uncertainty makes shared decision-making difficult in practice and how the NHS ethos of 'patient choice' can become a burden for some elderly patients. If healthcare professionals attempt to avoid uncertainty during the patient's treatment decision-making process, institutionalisation of decision-making may result, which goes against the original aim of shared decision-making. Although this article focuses on the perspectives of renal healthcare professionals who were involved in the care of conservative-care patients in the U.K., it is likely that the issues could be generalised to other conditions of uncertainty, such as uncertainty in diagnosis,

and difficult decision-making in other healthcare settings. Furthermore the burden of choice identified in this study was from a healthcare professional's perspective, rather than the patients'. It is, however, very likely that some elderly patients find it stressful to make their own decision. It is reasonable to assume that many would at least appreciate having the choice of not having to decide themselves (i.e. being able to request healthcare professionals to make the decision for them).

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Notes

1. Glomerular filtration rate is a measurement of how many millilitres (ml) of waste fluid the kidneys can filter from the blood in a minute (measured in ml/min). A healthy pair of kidneys can filter more than 90ml/min. Measuring the GFR directly is difficult, and it is usually estimated using a formula. The result is called the estimated GFR (eGFR) (NHS 2012).
2. A recent systematic review of evidence on conservative care of ESRF regarding prognosis and symptom burden/quality of life showed mixed findings as to

whether dialysis prolongs survival in the elderly versus conservative care, although any survival benefit from dialysis decreases with comorbidities (O'Connor and Kumar 2012). A high symptom burden was reported by patients on conservative care (O'Connor and Kumar 2012), although the new evidence suggests that conservative-care patients had more stable quality of life compared to the dialysis counterparts (Da Silva-Gane et al. 2012). Other studies demonstrated that conservatively managed patients were more likely to die at home or at hospice than RRT patients; mean numbers of hospital admissions after diagnosis of ESRF is smaller in conservative-care patients than in RRT (Carson et al. 2009; Hussain et al. 2013; Teo et al. 2010).

3. Catheter used for dialysis. Surgically created fistulas are preferred over catheters as the risk of infections.

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