Service Improvement theme

Decision-making for renal replacement therapy treatment options: a literature review

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EXECUTIVE SUMMARY

Health policy strongly advocates patient empowerment and involvement and evidence supports the claim that shared decision-making and involvement can lead to positive patient outcomes. However, evidence shows that health professionals may underestimate the amount of involvement that patients want, and as an element of this, how much information patients want. There is also evidence that shows that doctors cannot always predict the choices that patients will make. This is as likely to be the case for renal patients as it is for others.

The processes by which people make decisions are varied, and complex and because attitudes, opinions, life experience and emotion will all play a fundamental part in how people make decisions, the use of heuristics, rather than a more deliberative, systematic approach is likely to occur. For renal patients, preserving quality of life and maintaining a sense of normality are important outcomes from decision-making, and it is likely that compensatory approaches are employed in order to achieve this.

Patient characteristics are likely to affect patient preferences for involvement but are also likely to influence how healthcare practitioners interpret these preferences. It is important therefore that organisations as well as individual practitioners pay attention to this aspect and consider how best to respond to individuals, as opposed to stereotypes. As a patient’s preference for involvement and information can change over time as a result of a number of factors, such as changes in health status affecting absorptive capacity, it also appears important for preferences to be re-established at a number of points of disease progression and at different places within the care pathway.

The relationship between the patient and the healthcare professional is critical in determining how patients are involved in their care and how decision-making is enacted. Patients are more likely to want to be involved in decision-making, if they feel their physician actively encourages them to do so.

Practitioners and providers should be aware that renal patients may be receiving different information about the relative merits of different options, depending on their clinician’s skills, knowledge and disposition and therefore standardising information to incorporate all modality options is important. Systemic barriers to involvement in decision-making must be addressed. These might include acknowledging the limitations inherent within the structure of the standard consultation and using patient interactions with different healthcare practitioners more creatively to minimise time constraints and to support patients to enter into the consultation process more effectively.

Much could be done to improve the literature provided by renal units and it might be worth establishing a more collaborative approach to this nationally. There are some simple techniques and small changes that could be introduced to improve the provision of information more generally such as; presenting the most important information first, ensuring information is concise, avoiding jargon and explaining medical terms, personalizing messages, encouraging questions and checking on understanding. Narrative-based text, illustrations and pictographs can reinforce textual messages and help patient recall by
providing more memory jogs and the teach-back method is also proven to help patients retain clinical information. Information should pay as much attention to lifestyle preservation, and self-efficacy, as it does to clinical outcomes and technical aspects of care.

Decision aids (or decision support interventions) can improve a renal patient’s knowledge of treatment options, create realistic expectations of the benefits and harms, reduce difficulty with decision-making, and increase participation in the process. However, it is important that in addition to an information component, providing factual information to patients, there is also a deliberative component – to support patients to make decisions that agree with their values. Appropriate and timely education and professional support are thought to be important in encouraging greater use of out-of-centre modalities and a combination of individual intervention and group education appears to have particular benefits for patients - resulting in improvements in knowledge, reduction in uncertainty and reduction in decision regret.

Renal patient preferences for PD focus on greater privacy, freedom and flexibility, whereas patient preferences for in-centre HD focus on a planned schedule, regular social contact and a sense of security in health professionals. Whatever initial choice of modality option patients make, it appears that once started, they seldom change. Organisations may therefore consider how patients, initiating on non-self-care options can be encouraged and supported to consider self-care options at some future stage into dialysis.

Other renal patients’ experiences of care are important, not just for peer support but also because they will form part of the evidence that people use to make decisions. Organisations may therefore want to consider how this happens in a more strategic way, in order to encourage greater uptake of self-care modalities. In addition, the opinions of friends and families can be influential, particularly in relation to the support that would be required to facilitate certain modality choices. Therefore acknowledging this influence and involving family, carers and friends in the process of decision-making at an early stage is critical.

Little is known about how people make decisions across the trajectory of CKD and not just in relation to RRT modalities. It seems logical however to suggest that where patients have had limited ability to be involved and to share decision-making up to the point of choosing a modality option, that they will find it more difficult to engage with a new approach. Patients should therefore be encouraged to be as actively involved in their care and share decision-making as they express a wish to be as early as possible in their disease progression to establish and develop a mode of interaction which is normalised and productive.
1.0 Introduction

The aim of this literature review is to explore the social science and practice-based literature around treatment decisions for renal replacement therapy. Renal replacement therapy (RRT) is required when kidney function is no longer able to support life. There are a number of potential treatment options for renal patients.

This review has been undertaken in the light of findings from the West Midlands Central Health Innovation Education Cluster’s recent evaluation of four hospital renal dialysis services, to examine how services were approaching the regional policy directive of increasing the uptake of home renal replacement therapies from 5% to 35% over a period of five years. The original evaluation had three main aims:

- To describe and track what renal teams do in order to increase the uptake of CKD home therapies
- To assess the likely impact of this work on the uptake of home therapies and how this might be achieved, and to identify possible lessons for the future
- To identify broader implications for the rapid implementation of acute service changes from NHS hospital to home settings and from professional-led care to supported self-care.

The evaluation, as described, has highlighted decision-making and patient choice of treatment as complex areas and both healthcare staff and patients have indicated that these aspects of care need more attention if more patients are to be encouraged to take up home therapies. Therefore, in order to set the findings of the evaluation in a wider context, the research team commissioned a review of the literature in these areas. Although the focus is on renal patients and their choice of RRT, a previous brief literature review (Burke, 2012) had identified little previous research specifically relating to renal patients. This review has therefore been expanded to include decision-making and treatment choice in other conditions, where the complexity of decision and impact of choice is at a similar level.

The specific research questions this literature review intends to address are as follows:

- How are treatment decisions approached by patients and professionals?
- What factors impact on a patient’s treatment decisions?
- Are there specific approaches or trends within particular conditions?
- Are there any proven, novel approaches to support patient decision making?

This work was funded by the West Midlands Central Health Innovation Education Cluster (WMC- HIEC).

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1 Renal replacement therapies include transplantation, peritoneal dialysis (PD) or haemodialysis (HD). Peritoneal dialysis is a home-based treatment - modalities include continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). Haemodialysis can be carried out within a patient’s home – home haemodialysis (HHD).
2.0 Methodology

The literature searches were undertaken by the Health Service Management Centre’s specialist library and documents were identified via the following databases:

- HMIC
- Medline
- Proquest
- EBSCO
- Cinahl
- EMBASE
- Social Science Citation Index
- Social Services Abstracts
- ASSIA
- Social Care Online
- Google Scholar

Additional searches were also conducted of the reference lists from documents included in this review.

Search terms varied by database but focused on:
1. Patient decision-making, guided choice, choice model, treatment management, patient choice
2. Kidney, renal, end stage, dialysis, cancer, maternity, neurological, palliative care, chronic illness, long-term conditions

The inclusion of conditions other than renal was determined on the basis that the complexity and consequences of decisions undertaken for these conditions/diseases would be of a similar nature.

Studies were included if they focused on issues of relevance to the UK context, even when undertaken abroad. Specifically excluded were:

- Material published and/or based on data collected prior to 2000
- Articles reporting findings from studies already included in the review
- Material focusing on choice of provider rather than choice of treatment
- Material describing local case studies and potential benefits rather than presenting empirical evidence

Each abstract was reviewed against these criteria on an independent basis by two members of the research team and discussed in research team meetings before inclusion.

There is an extremely large body of literature covering many different aspects of patient involvement in general and decision-making more specifically. Though there is a large subset of this body of literature concerned with empirical research into participation in decision-making, many studies involve cancer patients and more specifically women with breast cancer. Studies specifically relating to renal replacement therapy are limited in number and generally involve small sample sizes.
This review makes reference to four systematic reviews of the literature which are not renal specific, 35 non-renal empirical studies, (of which 13 studies relate to cancer patients, including eight relating to breast cancer), and 14 renal empirical studies, details of which are given at the end of this section.

The systematic reviews included here are as follows: A review of 11 Random Controlled Trials to compare the effects of shared decision-making interventions and non-shared decision-making interventions; a systematic review of 31 papers considering the effects of demographic differences in decision-making across a range of countries (although as acknowledged by the authors, these papers draw on small sample sizes); a second review of 33 articles considering demographic differences in decision-making; and a review of 38 studies investigating health professionals’ views of the barriers and facilitators to shared decision-making.

Generally speaking, the empirical literature reviewed here relates to small sample sizes. Only three studies involved sample sizes of more than 1,000 and of these, none were UK based. One study related to 1057 Canadian cancer patients and the impact of shared decision-making on their quality of life, one related to the screening preferences of 1588 members of the US public compared to the preferences anticipated by 100 physicians, and the third, relating to gender differences in decision-making preferences, involved 2,754 patients across a full range of conditions. Only nine other studies involved sample sizes greater than 100 – of these, four were UK studies.

There are many small scale studies included here because of their direct relevance to the topics under consideration, though the ability to generalise from their findings is acknowledged. These include: a study considering professionals’ perceptions of cultural influences on decision-making – a small UK study of 13 obstetric practitioners; a three-year ethnographic study of 31 UK Pakistani Muslims investigating the importance of religion in decision-making; a study involving 57 Israeli women with breast cancer and their husbands and the influence of the latter on decision-making; and a study of 16 Australian bone marrow patients and the influence of their family on decision-making.

The renal studies included are as follows:

- **Sheu et al (2012)** empirical research in US involving six focus groups of African American and non-African American patients (n=50), stratified by ethnicity and modality, and six focus groups of their carers (n=43)
- **Chanouzas et al’s (2012)** empirical research involving 118 patients from a single renal unit in the UK
- **Sondrop et al (2011)** – empirical research involving a small focus group of six Canadian patients, three on PD and three on HHD
- **Chio and Chung (2011)** – experimental design re: the format of information - a control group of 20 patients and a second group of 20 patients (non-UK)
- **Morton et al’s (2010)** systematic review of 18 qualitative studies of decision-making and choice for dialysis, transplantation, or palliative care; reports the experiences of
375 patients and 87 carers, from the United States, Canada, Denmark, Australia, Hong Kong, and Taiwan

- Lee et al (2008) – empirical study of 24 dialysis patients in Denmark to investigate the feasibility of increasing the number of patients on out-of-centre dialysis
- Winterbottom et al (2007) - study reviewing the literature provided from 67 renal units and charities in the UK
- Key, S. (2008) review (non-systematic) of studies on education programmes
- Manns et al (2005) – empirical controlled, randomized study involving two groups of 35 patients in Canada
- Tweed and Ceaser (2005) - qualitative study, involving interviews with nine renal patients
- Mendelssohn et al (2001) - empirical research based on the responses from 240 US nephrologists to an emailed survey questionnaire

This review does not therefore claim that the findings of the literature used here can be generalised to the specific context of renal units in the UK. Nor does it claim to make any specific recommendations for practitioners or providers. However, it identifies a number of important themes and points for discussion and provides a basis for analysing the findings from the recent evaluation of hospital dialysis services, identifying broader implications for practice.
3.0 Decision-making – philosophy and principles

Key Points

- Health policy strongly advocates patient empowerment and involvement
- Shared decision-making can conflict with the ‘sick role’ adopted by some patients
- An individual’s enthusiasm for shared decision-making may be related to their level of self-efficacy
- Shared decision-making and involvement in general can lead to positive patient outcomes
- Shared decision-making is most important when ‘equipoise’ exists
- Doctors may under-estimate the amount of involvement patients want
- Doctors cannot accurately predict patient preferences
- Attitudes, opinions, emotional readiness and life experience will influence how people make decisions
- Preserving quality of life and maintaining a sense of normality are important aspects for renal patients

The National Consumer Council’s guide to health literacy (Sihota and Lennard, 2004) describes three models of decision-making: traditional, informed and shared. These are based on Charles et al’s (1999) discussion of partnerships in decision-making. In the first model, the decision is made by the health professional and interactions between patients and professionals, “are simply viewed as opportunities to reinforce instructions about treatment to obtain compliance and adherence,” (p.30). In the informed model, the health professional’s role is to provide information to enable the patient to make the decision – this model is described as preferring the patient’s sovereignty and their right to make independent autonomous choices. Shared decision-making is, “… about the patient and professional interaction being an opportunity for exchanging information and combining knowledge and expertise so that mutually agreed direction and goals can be established,” (p.30).

Recent UK health policy agenda has strongly advocated patient involvement and empowerment - see The NHS Plan (DH, 2000), The Expert Patient (DH, 2001), Our health, our care, our say (DH, 2006), High Quality Care for All (DH, 2008) and Equity and Excellence: Liberating the NHS (DH, 2010). However, there is potentially a deep-rooted tension between the patient as an empowered individual with the capacity, capability and desire to be involved and the traditional ‘sick role’ concept, first introduced by Parsons in 1951. According to Parsons, the ‘sick role’ requires individuals to fulfil a number of obligations such as; seeking medical advice, co-operating fully with healthcare practitioners and having a will to get well as soon as possible. In return, a person is allowed to cede responsibility for their social obligations. The ‘sick role’ creates and perpetuates passivity and dependency, fostering a person’s sense of entitlement when ill to be cared for, and a corresponding reluctance to take responsibility for decisions on treatment - a powerful psychological barrier to participation, (Faulkner and Aveyard, 2002). It has been suggested that this attitude also allows patients to have someone else to blame when things go wrong (Laine, 1997), cited by Faulkner and Aveyard, 2002. This is supported by a number of studies in Say

Anticipated regret can also influence how people make decisions. Ogden et al (2009) suggest that, ‘If an individual shows high anticipated regret (e.g. ‘If the outcome of my decision is wrong then I will regret it’) then they may welcome having their choices constrained as this may afford a diminished sense of responsibility should the outcome of their choice be negative.”

Bandura’s work on self-efficacy is also useful to reflect on here. Self-efficacy is “the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations,” (Bandura, 1995, p. 2). Self-efficacy affects how people think, behave, and feel, and as Albert Bandura and other researchers have demonstrated, self-efficacy can impact on everything from psychological states to behaviour to motivation. According to the theory, people with a strong sense of self-efficacy: view challenging problems as tasks to be mastered; develop a deeper interest in the activities in which they participate; form a stronger sense of commitment to their interests and activities, and recover quickly from setbacks and disappointments. Conversely, people with a weak sense of self-efficacy: avoid challenging tasks; believe that difficult tasks and situations are beyond their capabilities; focus on personal failings and negative outcomes; and quickly lose confidence in their personal abilities (Bandura, 1994).

It seems reasonable to hypothesise therefore that people willing to take a greater role in treatment decision-making are likely to have higher levels of self-efficacy. For renal patients, it also seems reasonable to hypothesise that people with higher levels of self-efficacy are more likely to be comfortable with considering self-care dialysis options.

Ford et al (2003), note that while sharing decisions may be desirable on humanistic grounds alone there is also empirical evidence that involving patients in this way can result in improved psychological and clinical outcomes (see also Schofield and Butow, 2004; Cameron, 1996; Deadman, 2001; and Street and Voigt 1997). Benefits can be found in improved satisfaction, treatment compliance, increased confidence in healthcare recommendations, symptom resolution and better psychological adaption to illness.

Ford et al cite Stewart’s (1995) work which concluded that the provision of clear information, the opportunity for patients to ask questions, a willingness to share and discuss decisions from both parties, and agreement between doctor and patient about the problem and the plan, were related to positive patient outcomes such as emotional health, symptom resolution, function and physiological health.

Hack et al’s (2010) research involving 1057 Canadian patients with either breast or prostate cancer, suggests those who took a more passive role in their treatment decisions experienced greater distress (depression, anxiety, confusion, fatigue and anger) and reduced quality of life (physical well-being, social/family well-being, emotional well-being, and functional well-being. The authors also cite Folkman’s framework (1997) on the coping process for cancer patients, whereby involvement in treatment decisions, “…may be regarded as a coping response to the perceived threats, challenges and harms associated with … treatment and its associated side effects,” (2009, p. 607).
Hack et al’s previous research (2006) with 205 women with breast cancer, also found that those women who had reported an active involvement in choosing their surgical treatment had significantly higher overall quality of life at follow up (three years later) than those women who had reported a more passive role. Actively involved women were reported as having higher physical and social functioning and less fatigue.

However, when and how often patients are able to take part in shared decision-making is variable, depending on the nature of the health condition and the number of interventions with healthcare it requires. Joosten et al’s systematic review of 11 Random Controlled Trials (RCTs) comparing the effectiveness of shared decision-making (SDM) interventions with non-SDM interventions concludes that, “SDM can be regarded most appropriately as a collaborative process rather than one or two isolated events, and it is therefore not surprising that individual decisions have no significant measurable effect on factors that SDM might be expected to influence,” (2008, p224). This research suggests therefore that unless there are ongoing opportunities for collaboration and decision-making, a one-off decision is unlikely to have much impact on the patient outcomes described above.

Sihota and Lennard (2004) state that shared decision-making is dependent on patients understanding both their condition and how to manage it, and the range of treatment options available to them and the advantages and disadvantages of each option. Shared decision-making, the authors suggest is most important when the following conditions exist:

- When trade-offs exist between near-term and long-term outcomes
- Where there is a small risk of an extremely negative outcome
- When treatment options appear to have minimal differences
- Where there are dramatic differences in the kinds of outcomes offered by treatment options
- Where there are major differences in the probabilities of complications
- When a patient is risk-averse
- When a patient places extreme value on certain outcomes.

These conditions seem highly relevant in the main for renal patients, though there is perhaps less relevance for the first and fourth conditions.

Witney (2003) states that patients should have maximum ability to share in decisions when equipoise exists – i.e. when two or more interventions are approximately equal and when the decision is of personal importance to the patient. Stiggelbout et al. (2012) state that making the patient aware that equipoise exists and that there is no ‘best’ choice is the first and most important step in shared decision-making in preference sensitive decisions.

Stiggelbout et al (2012) also suggest that the patient’s preferred role should be actively explored but only once information has been provided to them, pointing to evidence that suggests patients who may be initially reluctant to take a more active part in decision-making may change their mind, once the options are presented to them. The authors also point to evidence that suggests patients may be fearful of appearing too assertive and thus jeopardising their care, and suggest that doctors must therefore actively invite patients to participate. The authors suggest clinical practice guidelines could promote decision points and suggest what information to communicate about options and how to involve patients.
Research also suggests that doctors might underestimate the amount of involvement patients want in decision-making. Bruera et al’s (2001) research involving 78 Canadian cancer patients and the use of a decision preference questionnaire, found that even after a lengthy initial consultation with a palliative care physician with special training in communication skills, there was still only concordance between physician and patient in 38% (n=30) of cases, with physicians predicting that patients preferred a less shared approach than they in fact did. This research was based on patients receiving palliative care i.e. at a final stage of disease progression, and it is possible that patients may be more inclined to prefer a more active role as their disease progresses. However, further research by Bruera et al (2002) with American women with breast cancer (n= 57) found similar results - with concordance between physicians and patients in 42% (n= 24) of cases, for women attending their first outpatient appointment with a medical oncologist. (See also Rothenbacher, Lutz and Porzsolt, 1997).

Evidence also suggests that doctors cannot accurately predict the preferences of their patients as regards treatment options (Coulter, Peto and Doll, 1994; Protheroe, 2000 and Marshall et al, 2009). The latter’s study on screening preferences for colorectal cancer, surveyed 1,588 members of a panel made up of the general public from the US and Canada and 100 physicians, and found that physicians’ assessment of patient or public preferences differed significantly from their actual preferences when it came to intervention decisions. Attitudes, opinions, emotional readiness and life experience will influence how people make decisions. Individuals will differ in what they value and the risks they are prepared to take, (Hope, 1996). Preserving quality of life and maintaining a sense of normality are also important factors in which choices people make in healthcare (Health Foundation, 2012 p. i). Sihota and Lennard (2004) state that shared decision-making should allow, “...for patients’ values, views and preferences to be made explicit and mediate the professional interpretation of the disease and disability, as well as the selection of treatment and management options. The treatment that best matches the patients’ personal values is sought,” (p.30).

Evidence suggests that preserving quality of life and maintaining a sense of normality are important aspects for renal patients too when making choices about their options for treatment, (Murray et al, 2009). Tweed and Caesar’s (2005) study, involving interviews with nine renal patients concluded that choice of dialysis modality is as much about the effect the modality has on their personal lives as medical effectiveness. The study highlights the importance for patients of maintaining their integrity i.e. normality of function and living as unimpaired as possible. This can involve issues of body image for example and whether people prefer the appearance of a fistula or catheter. The authors cite earlier studies which suggest that a patient’s choice is not always related to the statistical effectiveness of a particular treatment (Kelly-Powell 1997).
4.0 Decision-making theory

**Key Points**
- The processes by which people make decisions are varied, and complex
- People frequently use heuristics, rather than a more deliberative approach, to make decisions
- There are different opinions on whether the amount of deliberation undertaken affects the quality of the decision, with some arguing that too much deliberation reduces the quality of the decision
- Emotion plays a fundamental role in achieving efficient decision-making
- The way information is framed is also important to decision-making. An individual’s mental representation of the decision problem or decision frame can change depending on how information is presented
- Fear arousal leads to biased processing of information

There is a sizeable body of literature on the processes by which people make decisions, the quality of those decisions, and how to define a good quality decision (Bekker, 2010). Elwyn et al’s (2011) work on the theory-practice gap in designing decision support interventions provides a useful summary of the decision-making theory, which is helpful to reproduce in part here. The authors reviewed the literature and selected eight theories they considered of relevance in the design and development of decision support interventions, namely; the expected utility theory, the conflict model of decision-making, prospect theory, fuzzy-trace theory, the differentiation and consolidation theory, the ecological rationality theory, the rational-emotional model of decision avoidance, and the Attend, React, Explain, Adapt (AREA) model of effective forecasting. A brief explanation of each is given in the box below in chronological order.
**Decision-making theory**

*Expected Utility Theory – Von Neumann and Morgenstem (1944)*
Based on numerical outcomes and probabilities of these outcomes occurring, resulting in Expected Utilities (EUs) – decision with highest numerical score of EUs was the best decision.

*The Conflict Model – Janis and Mann (1977)*
A five stage model of decision-making: problem appraisal; appraisal of alternatives – averting or minimising losses; evaluation of alternatives – minimisation or satisficing are used to assess advantages and disadvantages of alternatives; commitment to decision – revealing the decision to others and building resistance to negative feedback on the option chosen; and adherence – bolstering techniques and denial of alternatives.
This theory has led to the decision conflict scale (O’Connor, 1995).

*Prospect theory – Kahneman and Tversky (1979)*
Decision-making is divided into the early ‘editing’ phase – analysis, framing and perception of options; and the ‘evaluation’ phase – the option with the highest perceived value is chosen. Individuals perceive consequences in terms of the level of change from reference points or anchors. “Decision-making is ...influenced by framing of information (gains versus losses), and by the certainty effect, that individuals are generally more risk averse when facing losses versus gains,” (p. 568).

*Fuzzy trace theory – Reyna and Brainerd (1990)*
Three stages of information processing – representation, retrieval and processing. People ‘represent’ information at different levels, from exact or verbatim to a vague ‘gist’. Memory limitations mean that people do not retrieve all the information stored in the memory and people therefore reason at an imprecise level of information.

*Differentiation and consolidation theory – Svenson (1992)*
Decisions are made by gradually differentiating and consolidating competing options, “…until one emerges as superior and able to withstand future threats and doubts,” (p.569). During differentiating, competing options are judged for their attractiveness and importance.

Different strategies may be used during differentiation such as the conjunctive, disjunctive, satisficing or lexicographic rules. A conjunctive strategy involves the identification of the option that has all, or most, of the attributes considered important; a disjunctive option means ranking of options on the basis of prioritising only one or two important attributes; the lexicographic strategy means making choices based on the presence or absence of the most highly rated attribute.
Elwyn et al make the distinction between prescriptive or normative theories - how people should make decisions i.e. the expected utility theory; and descriptive theories – how people actually make decisions i.e. ecological rationality. The authors note that Bekker et al’s (1999) earlier review concluded that most decision support interventions, when employing theory, use prescriptive or normative theories. Elwyn et al’s work also considers the relevance of theory on two aspects of decision support interventions – the ‘information components’ i.e. the nature of the options available and the ‘deliberation components’ i.e. how people are helped to deliberate on their choices. The authors note caution however regarding the latter and point to the existence of differing opinions on whether the amount of information presented to the decision-maker in such a way as differentiation is facilitated. For example, data may be organized into head-to-head comparisons. Additive or additive–difference rules are used to make comparisons. According to Elwyn et al’s summary, ‘The Additive rule compares options in terms of global comparison, after deliberating about the sum of their attributes. The additive-difference rule requires a comparison at the level of attributes...’ (p.569, cites Feldman-Stewart et al, 2006).

Ecological rationality – Gigerenzer (1996)
People make decisions under constraints, whether these are time constraints, knowledge constraints, or computational ability, using the Darwinian-inspired idea of the ‘adaptive toolbox’. Decision-making is based on heuristics – people discover or learn for themselves by trial and error or loosely defined rules. The recognition heuristic is regarded as one of the most simple rules – when it is applied to information seeking, it means that people will make a decision based on only one piece of information i.e. recognition – the knowledge that many others have chosen the same treatment for example. There is no need to consider trade-offs between different attributes – it is ‘one reason’ decision-making.

Elwyn et al (2011) note that there is concern over people using heuristics, rather than a more deliberative approach to make decisions, especially in new situations.

Rational-emotional model of decision avoidance – Anderson (2003)
Decision avoidance is motivated by the need to regulate negative emotions, such as ‘anticipatory’ emotions - being afraid, or worried, or ‘anticipated’ emotions – guilt or remorse. This arises because of selection difficulty. ‘When the best option is clear, people do not feel compromised. However, if options concurrently have highly negative and highly positive attributes, or when all attributes are negative, then trade-offs lead to distress. Decision avoidance or postponement is adopted in the hope that other solutions will appear....On the whole people tend to associate action with more regret than inaction, ” (p. 570).
of deliberation undertaken affects the quality of the decision, with some arguing that too much deliberation reduces the quality of the decision.

Elwyn et al suggest that, “…basing the design of decision support interventions to support patient decision-making on narrowly focused cognitive theories may not be the ideal way in which to make progress in this field,” (p. 571). They conclude that, “Given the increasing understanding that emotion plays a fundamental role in achieving efficient decision-making, these two models (rational-emotional and AREA) will need to be operationalized into both information and deliberation components (of decision-making interventions),” (p. 571).

An interesting study based on the differentiation and consolidation theory, using a discrete choice experiment, has been written up by Cheraghi–Sohi et al (2007). In the researchers’ study, 20 volunteers were given a number of primary care scenarios and were asked to make their choices between two options using a ‘think aloud’ protocol i.e. verbalizing their decision-making process. Their findings build on previous research into the issues, including the impact of the ‘halo effect’ - a cognitive bias towards one attribute which affects the judgement against others and a willingness to trade attributes and also highlighted how participants ‘went beyond the information given’ in order to make their decisions, leading to what might be termed ‘irrational decisions’ by objective observers.

Harcourt and Rumsey’s (2004) study of 93 women due to undergo a mastectomy in three UK hospitals, examined how the women had decided whether to opt for or against immediate breast reconstructive surgery. The authors identified three decision-making styles as follows: instant/immediate (number of women opting for this style = 76); information seeking (n= 14); and indecisive (n=3). Harcourt and Rumsey suggest that patients in the first category of styles make decisions rapidly while in consultation, use information selectively to confirm their choice, appear as positive and concerned in terms of mood and have certain confidence in their decision. Women in the second category make decisions quickly once information has been obtained and studied, use information to facilitate their decisions, accessing an extensive but selective range of literature, and also appear as positive and concerned and have certain confidence in their decision. Women in the third category spend a long time arriving at a decision – up to the point of surgery itself, find information confuses their decision-making and leaves them feeling conflicted, they appear highly anxious in terms of mood and lack confidence in their decision.

For the first group of women, the instant/immediate style, salience was a strong sub-theme – with the patient immediately identifying one aspect of the decision as of particular importance to them and using this to create a template for the decision – for example, for those choosing immediate reconstruction, not wanting to see themselves without a breast was enough of a reason to make the choice. For others safety was the salient factor. This reflects Gigerenzer’s (1996) ecological rationality model of decision-making and the ‘one reason’ decision, with women using heuristics to reach a decision.

Harcourt and Rumsey also note the importance in their study of information framing and note how women were influenced to some extent by the language health professionals used to discuss their options, such as using emotive words to describe someone’s appearance after a mastectomy i.e. ‘disfigured’, or ‘deformed’, (2004, p. 110).
The ‘protection–motivation’ theory (Rogers, 1975 and 1983) in relation to how people deal with information that is fear-inducing, such as a woman being told that a mastectomy will leave her deformed, or a renal patient being told that RRT is now necessary, is potentially useful here. Fear arousal is said to have two effects, it will either act as a motivator to people engaging with processing the information, or it induces a defense motivation which leads to biased processing of information. So, the defense motivation effect leads people to confirm the validity of their preferred position and disconfirm the validity of their non-preferred position, rather than an assessment of the validity of all relevant information to achieve a valid position, (de Hoog et al, 2005).

Bekker et al (2010) also write about the importance of information framing in relation to decision-making. They refer to research which indicates that an individual’s mental representation of the decision problem or decision frame changes depending on how information is presented and that the ‘packaging’ of information can ‘leak’ other information which influences the decision. An example is provided of women being offered the opportunity to take part in a trial as opposed to a choice between usual treatment and taking part in a trial – the former resulting in more women taking part in the trial.
5.0 Socio-demographic differences in decision-making

Key Points

- The evidence for factorial associations such as age, gender, level of education, marital status, socio-economic status and health status with a patient’s preference for involvement is inconclusive.
- However, associations between younger and better educated people wanting to take a greater part in decision-making and older people favouring a more traditionally ‘paternalistic’ approach retain some currency.
- Evidence suggest there may some link between ethnicity and participatory medical encounters.
- People may conceptualise their involvement in decision-making in different ways, depending on their level of education and functional health literacy.
- Passivity may be a result of emotional distress.
- Patients with strong religious beliefs may be unwilling to discuss these with their doctors because they assume their religious values will be undermined or misunderstood.
- A patient’s preference for involvement can change over time as a result of a number of factors.

Age, gender, educational attainment and social support may also affect the decisions made by individuals. There is some evidence to suggest that younger and better educated people want to take a greater part in decision-making and older people favour a more traditionally ‘paternalistic’ approach but this is not necessarily a universal experience. (Degner and Sloan, 1992; Degner et al, 1997; McKinstry, 2000; and Henderson and Shum, 2003 – all cited by Florin et al). Hubbard et al’s (2008) systematic review of the literature about patients’ preferences for involvement in cancer treatment decision-making found that the evidence for factorial associations such as age, gender, level of education, marital status, socio-economic status and health status was inconclusive.

In the authors’ review of 31 papers, 11 studies found no association with age, five indicated that younger people were more likely to prefer a collaborative role, while one concluded that younger women wanted their doctors to make a recommendation. Three studies reported no association with gender, though one found that women were more likely to prefer an active role. No studies identified an association between race/ethnicity and role preference, nor between level of income and role preference. Six studies reported an association between higher levels of education and a more active role, though eight studies found no such association. The authors note the limitations of sample sizes in the majority of studies included in their review, and hence the generalisability of their findings.

Research by Beaver et al (2008) involving 375 colorectal cancer patients in the UK found that women had more positive opinions on decision-making than men and were more likely to prefer active decision-making roles. The authors note that women in general are more likely to access healthcare information but that research also shows that when men with prostate cancer were provided with the information they needed, they assumed a more active role in decision-making. Earlier research in Canada (Deber et al, 2007), involving 2754 participants across a full range of health conditions, showed no statistically significant difference by gender in terms of decision-making role preference.
Say et al (2006) conducted a quantitative and qualitative review of 33 articles investigating the influence of different factors on people’s preference for involvement in decision making. The authors found that in spite of differences across the studies in terms of the patients involved or the type of decisions they were making, 17 out of 22 studies investigating the association with age found that younger people preferred a more active role in decision-making, than older people. Five out of eight studies found that women were more likely than men to prefer a more active role, while 16 out of 20 studies found that people with a higher education preferred greater involvement. Smith et al’s (2009) study of education and functional health literacy, involving 73 Australians, found that people conceptualise their involvement in decision-making in different ways, depending on their level of education and functional health literacy. Higher education participants described their role as ‘sharing the responsibility’, and were more confident in challenging healthcare professionals, while participants with a lower level of education considered their involvement as consenting to an option recommended by the doctor.

In Hack et al’s (2010) study of cancer patients, the authors postulate that this specific factorial difference may be a result of a diminished sense of personal agency in affecting change in treatment course and health outcomes and hence, “...a lack of confidence in ability to personally manage ones cancer affairs may breed resigned acceptance of fate in the hands of particular oncology service providers,” (p.615). The authors also suggest however that people with an anxious-reserved personality, who have developed a learned avoidance response to stress, can actively withdraw. Therefore, they argue, health professionals should consider passivity as a risk factor for emotional distress as well and should be prepared to address this by providing tailored, supportive interventions.

Ethnicity was a factor in one out of seven studies in Say et al’s review, with white patients more likely to want to be involved than black patients. Evidence from England suggests health professionals sometimes use cultural differences between patients to justify not involving minority groups as much in shared decision making. A study undertaken by Davies et al (2009) examining the ways in which 13 midwives, obstetricians and GPs perceive Arab Muslim women’s participation in decision-making in pregnancy, found that professionals considered them unable and unwilling to use information in decision making because of a preconception of their dependent position in the family. Participants judged these women to be more passive and less rational in decision making and ‘less deserving of the support required for participation in decision-making’ by not seeking to take control of their bodies and their care. The authors conclude that such stereotyping, “...has serious implications for developing trust, information exchange and patient education. It is entirely incompatible with attempts to encourage patient participation in decision-making,” (p. 47).

The results of Sheppard et al’s (2011) research into the experiences of 49 black women in the US with breast cancer suggest that though patients believed they had shared in decisions regarding their treatment, communication was dominated by physicians and that the study’s subjects were not actively presenting physicians with questions about their options but selecting an option from the ones presented to them. The authors claim that this supports other studies (Cooper and Rotter 2003 and Cooper, Rotter and Johnson 2003) that have found black patients do not have participatory medical encounters.
Mir and Sheikh’s (2010) three-year ethnographic study on UK Pakistani Muslim patient decision-making found that practitioners (n=7) and patients (n=31) are unwilling to enter into discussions about religious influences on patient decision-making and that these patients consequently do not receive the support they may need to consider these influences appropriately. Apart from the obvious communication barrier of language, the authors found that though religious beliefs influenced their decision-making, patients were unwilling to discuss these with their doctors because they assumed their religious values would be undermined or misunderstood. Examples of competing demands between religious observances and aspects of healthcare included the effect of medication and illness on activities such as mosque attendance, reading the Qur’an, ritual prayers, ablutions and fasting. “Religious values could thus set boundaries for possible decisions and be an important determinant of behaviour,” (p.333).

The authors also found preconceived ideas about Pakistani women as oppressed Muslim women and about people holding fatalistic health beliefs, and failing to prioritise their health - the latter potentially preventing the negotiation of treatment and discussion of risks. Where health practitioners were viewed as holding positive perceptions of patients, this enabled a more participatory engagement. The authors warn that if a Pakistani Muslim patient’s faith is ‘invisible’ to practitioners, it can have adverse consequences for their treatment and self-care. Practitioners are advised to have higher expectations of their dialogue with Pakistani Muslim patients and to initiate dialogue themselves.

A number of studies in Say et al’s review found that the experience of being a patient reduced the patient’s preference for involvement in decision-making. However studies also showed that people’s preference may change as they progress through their illness, though there were contrasting results here, so that in some instances, people newly diagnosed preferred greater involvement, while other studies showed patients preferring greater involvement further into their disease progression, (Butow et al, 1997; Degner et al, 1997; Mansell et al, 2000; Thorne and Paterson, 2001) For example, a study by Butow et al. (1997) of 80 cancer patients found that patients were more likely to want increased involvement, if their follow up appointments were regular reviews, as opposed to a follow-up to discuss a significant change to their condition. However the review’s authors note that Butow’s longitudinal research only allowed for two consecutive consultations, so could not demonstrate changes in preference over a longer time period and further disease progression.

The salient point here however, is that a patient’s preference for involvement can change over time as a result of a number of factors. Given that renal patients are likely to have been in the care of the same medical team for a long time – years in most cases, it is perhaps helpful for health professionals to re-check patient preferences on an ongoing basis.

Morton et al’s (2010) systematic review of 18 qualitative studies of decision making and choice for dialysis, transplantation, or palliative care, reports the experiences of 375 patients and 87 carers, from the United States, Canada, Denmark, Australia, Hong Kong, and Taiwan. The authors’ findings suggest that older patients may be more likely to choose palliative care rather than make necessary changes to lifestyle to accommodate dialysis and to reduce ‘burden’ on family members.
A UK-based study reinforces the findings of Morton et al. Chanouzas et al’s (2012) research involved 118 patients from a single renal unit responding to a questionnaire in which they were asked to rate factors which affected their treatment choice. The authors determined that there was a strong correlation between age and modality choice, with a mean age of 55 of those patients choosing PD, compared to 68 for HD and 84 for conservative management (CM). The degree of co-morbidity was also linked to modality choice, with patients with lower scores on the Charlson Index choosing PD and those with higher scores choosing CM. Other demographic factors such as being married, having a job, and having support at home were linked to choosing PD. The results were as follows: Being married - 95.7% of those choosing PD were married, compared to 53.8% on HD and 41.7% on CM 41.7%; having a job – 33.3% of those on PD had a job compared to 11.5% on HD and 0% choosing CM 0%; having support at home – 100% of those on PD had support at home, compared to 69.5% on HD and 50% choosing CM. The authors suggest that there is an overwhelming association between having a strong social support network and being functionally able, with choosing PD as a modality.
6.0 The influence of healthcare professionals on decision-making

Key Points

- Trust and respect are important aspects of the physician-patient relationship
- The relationship should also be characterised by openness and negotiation
- The physician’s communication style is the strongest indicator of patient involvement
- Patients are more likely to want to be involved in decision-making, if they feel their physician actively encourages them to do so
- The area of psychological care is poorly understood by health professionals
- Training for professionals in shared decision making can improve skills and knowledge but don’t necessarily lead to better outcomes for patients
- Patients may receive different information about the relative merits of different options, depending on their clinician’s skills, knowledge and dispositions
- Doctors’ recommendations can lead people to make decisions that go against their own preferences
- The way information is framed by clinicians will influence patients’ decision making
- The ability for a more open dialogue to occur between nurse and patient can facilitate the patient taking a more active role in decision-making
- Patients may deem the information and advice given by nurses as of less value than that given by doctors.

It is beyond the scope of this literature review to consider concepts such as power, trust and negotiation with regards to doctor/patient relationships or nurse/patient relationships in any depth. However, it is worth reminding the reader that these concepts underlie all encounters between health professional and patients. For example, Forsyth et al (2011) note that both a physician’s technical mastery and their social power are present within the consultation and suggest that the latter is why patients consent to treatments – not because they understand the medical reasoning but because of their faith in the physician as a representative of their profession. They go on to suggest that this act of trust sustains the patient-physician relationship.

It is also perhaps useful to provide a definition of negotiation here in order to consider the interaction between the patient and healthcare professional with regards to shared decision-making. Stoddart and Bugge (2012) in their exploration of the interaction between nurses and patients in community settings cite Strauss (1978) when describing negotiation as, “the process that individuals embark upon in developing shared meanings, understandings and agreements…”.

Lown et al’s (2008) work in the US considers patient behaviours that facilitate shared decision-making and the influence of patients and physicians on each other. The study of 41 primary care physicians and 44 patients with serious or chronic health conditions came up with 26 physician behaviours and attitudes and 18 patient behaviours and attitudes that influence and facilitate shared decision-making. These include; the importance of trust in one’s physician, the ability of both parties to show respect and empathy towards each other, the ability of patients to express their fears and anxieties, discussing information in a
way that enables both parties to ask questions and to clarify responses, acknowledging areas of agreement and disagreement, sharing control and negotiating a decision.

6.1 Physician skills and competence

There is a significant body of literature on doctor-patient communication (see Ong et al, 1995 for a review of the literature) and it is beyond the scope of this review to consider this in detail. However it is important to consider the influence a physician’s communication style has on the patient in terms of shared decision-making. Street et al’s (2005) study of 279 physician-patient interactions in the US found that other than clinical setting, the strongest indicator of patient involvement was the physician’s communication style - whether it was marked by supportive talk such as praise, reassurance and empathy, and whether it encouraged partnership building,” (cited by Hack et al, 2010, p. 614).

Adams et al (2001), cited by Say et al (2006) found that patients were more likely to want to be involved in decision-making, if they felt their physician actively encouraged them to do so. Interviewees in Beaver et al’s (2007) research into the views of health professionals with regards to participation in decision-making with patients with colorectal cancer, reported that doctors with poor communication styles, or that are considered to be aloof or autocratic were considered as unlikely to be able to articulate options clearly and to encourage participation. Caution must be expressed with these findings however, as they relate to health professionals commenting on other colleagues’ attitudes and attributes, and it is not possible to determine what other influences may lead them to make such observations of colleagues’ practice.

However, those interviewed, (35, across a range of healthcare professions) also suggested that providing information on risks or uncertainties, was not always appreciated by patients, as it suggested professionals were indecisive. The authors also note that the area of psychological care was poorly understood by health professionals and that this was an area where health professionals may need more guidance and information on what psychological support services are available to patients. Health professionals taking part in the study were also reported as making assumptions about the level of participation patients wanted in decision-making based on their age.

Elwyn and Charles (2000) identified a sequence of professional competences as important features of a consultation aimed at patient involvement in treatment decisions as follows:

- Problem definition
- Patient involvement (implicitly or explicitly)
- Exploration of ideas, fears and expectations, possible treatments
- Portrayal of options
- Convey equipoise (where two or more possible directions are available, and each could reasonably be chosen)
- Identify preferred format and provide tailor-made information
- Check process: understanding of information and reactions
- Acceptance of process and preferred role in decision-making
- Make, discuss or defer decision
- Arrange decision review.
The MAGIC (Making Good decisions in Collaboration) programme in the UK is a skills development programme for health practitioners, funded by the Health Foundation. It also addresses patient skills in shared decision-making through the use of posters in waiting rooms, asking patients to think of three questions to ask their clinician: What are my options? What are the benefits and harms? How likely are these? (Stiggelbout et al, 2012).

Training for professionals in shared decision making can improve skills and knowledge but don’t necessarily lead to better outcomes for patients. In examples of three separate studies in Germany, with patients with hypertension (Deinzer et al, 2009), fibromyalgia (Bieber et al, 2008) and depression (Loh et al, 2007), patients were either provided with information only interventions (the control groups) or information and shared decision making interventions with a doctor trained in these competencies. Those patients receiving both information and shared decision making interventions reported improved interactions with their doctors but there were no reported impacts on clinical outcomes. The reasons for this were not explored by the studies (Health Foundation, 2012a, p11).

In addition to the skills and competence in undertaking the process of shared decision making, clinicians may have varying technical skills between different procedures. Entwistle et al (2006) raise this in relation to surgeon’s skills with hysterectomy variants, citing Garry et al, 2004, and suggest that patients may receive different information about the relative merits of different options, depending on their surgeon’s skills and dispositions.

A similar limitation on options may arise for renal patients as the knowledge clinicians have regarding particular modalities will be affected by the exposure they have had to them during their clinical training, or subsequent practice. It is entirely possible that while on rotational placements, doctors may not have experienced all forms of dialysis modality, and this may therefore limit their ability to discuss the full range of options with patients. A similar situation arises with nursing staff who may have only experienced the delivery of dialysis care to patients in one setting during their careers. So, for example, staff working in in-centre dialysis units may have little or no experience of home dialysis, while those supporting people in the home will conversely have little or no experience of in-centre dialysis. This limited experience may affect the way by which they frame discussions about options with patients.

This limitation is noted by a participant in a focus group in Denmark, “When I restarted in dialysis I wanted it home again, but I had moved in the meantime and at the [new] hospital they did not know anything about home heamo dialysis,” (Lee et al, 2008, p3956). In Sheu et al’s (2012) study, a focus group participant notes that they started on PD because that was the modality their nurse told them about and that was the only modality they were ever shown, (p.1001).

6.2 Physician preferences

Research suggests that doctors’ recommendations can lead people to make decisions that go against what is best and against what they would otherwise prefer (Gurmankin et al, 2002). In the authors’ US study, 102 volunteers responded to a web-based questionnaire which presented medical scenarios in which the treatment choice which maximised health was clear. The authors altered the scenarios to provide a) examples where physicians
supported the choice that maximised health, b) examples where physicians didn’t support that choice and c) where physicians made no recommendations. Where participants went against the choice that maximised health as a result of physician recommendations, reasons given included; the doctor knows best type response, ‘the doctor must be party to some additional information I don’t know’, and the wish to maintain a good relationship with their physician.

However, writing in the American Journal of Kidney Disease, Mendelssohn et al’s (2001) findings suggest that physician preference, often cited as the primary selection driver of modality in the US, may not be a major factor in reality for renal patients. An email survey, responded to by 240 nephrologists, suggests a physician preference for 30%–40% of new patients to start dialysis using PD. This figure is significantly higher than the actual rates of PD in the States, (less than 8% - Burkat, 2008) which leads the authors to make their conclusion that it is not the preference of physicians against PD which is resulting in low take up.

Respondents from studies in Morton et al’s (2010) systematic review referred to decisions being made by physicians on their behalf, though it was recognised by the authors that in part this would be due to clinicians excluding a particular treatment because of medical contraindications such as the inability to create a vascular access – according to the literature 36% of patients with end-stage renal disease may have contraindications to either HD or PD (Prichard 1996, Jager et al 2004 and Heaf 2004). However, there was reference to decisions being made as a result of the clinician’s own preferences, though what these are and how they have been arrived at are not explained within the review.

Patients from nine of the 18 studies reviewed by Morton et al obtained an understanding of treatment options from their nephrologist or renal nurse. The authors note that, ‘The way this information was framed influenced their decision making,’ (p5), providing an example of one patient who dismissed transplantation as an option after being told it was a highly risky six hour operation. The review suggests that patients may willingly accept a physician led choice of modality, when the rationale is explained to them.

This attitude is also demonstrated in Mendick et al’s (2010) UK-based research involving 20 patients with breast cancer and nine surgeons. In the study, surgeons made most decisions and only explicitly offered choice where treatment options were clinically equivocal. However patients were reported as feeling as though they had ownership of the decisions because surgeons had provided justification for their decisions and patients felt that they could always refuse. When faced with actual choice, patients reported feeling a lack of trust in their own decisions and usually sought guidance from their surgeons.

6.3 The consultation and the physician/patient dynamic

Research of an experiential nature undertaken by the Health Foundation (2012b) provides a helpful exploration of conceptual themes with regards to other aspects of the patient/clinician dynamic, some of which are explored in detail below. The research is based on the data gathered through a series of interviews and workshops involving over 120 patients, clinicians and managers. The analysis of the data was subsequently refined through a series of further workshops with more than 20 policy and change programme experts.
The consultation process itself exerts its own very powerful dynamic between the doctor and patient. Consultations will look, mean and feel differently according to their organising principle or ‘higher’ purpose, whether that be determining a diagnosis, delivering a diagnosis, or exploring options for ongoing treatment (Health Foundation 2012b). And yet as the authors of the Health Foundation’s report note, “... the methods and resources available to clinicians to vary the consultation are not as complex as the potential variation in the consultation itself... (and clinicians do not) develop a range of consulting styles that would be truly fit for multiple purposes,” (p. 10).

The authors suggest there are two dimensions at play within the consultation - the first is the extent to which the priorities of doctor and patient are shared. In some situations there may be complete agreement on desired outcomes and how to achieve them. In others, the medical priority might suggest one course of action while the patient has another set of priorities against which the medical priority needs to compete. The second dimension concerns the difference between ‘tame’ versus ‘wicked’ problems, that is those problems which are complex but solvable and may not offer alternative courses of action, and those for which there may be no obvious solution, or a number of potential options for courses of action.

The authors suggest that these two dimensions suggest four possible ‘principles’ around which a consultation might be organised as follows:

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<th>Shared priorities</th>
<th>Competing priorities</th>
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<tr>
<td>Tame problem</td>
<td>Co-ordination</td>
<td>Competition</td>
</tr>
<tr>
<td>Wicked problem</td>
<td>Co-evolution</td>
<td>Negotiation</td>
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The implications of this for pre-dialysis patients, is that the ‘problem’ they face is ‘wicked’ but priorities are shared in that for those who choose dialysis, the desired outcome is the prolonging of life, even though the means of achieving this may offer a number of alternatives. The approach to the doctor-patient relationship may therefore be said to best involve co-evolution.

The authors also suggest that the primary driver of the doctor–patient dynamic is fear or anxiety and that this applies to both parties. This fear can be categorised in three ways: Existential anxiety – for the patient this is the fear of the consequences of having or not having treatment, while for the doctor, this is the fear of not making a diagnosis correctly; interaction anxiety – for the patient, the fear of being made to feel foolish, while for the doctor, it is the fear of being swamped by a patient’s needs or disappointing their expectations; and entitlement anxiety – the fear of using resources unnecessarily and inappropriately – which is possibly as much of an anxiety now for doctors as for patients.

For CKD patients, the implications of this might be that entitlement anxiety is playing a role in their decision-making processes – perhaps because they feel terribly grateful they are still alive and being cared for, they also feel that they cannot ask for too much else in terms of the additional information they may want on different options, the time of a health professional to talk it through, or the additional time required to make a decision.
6.4 The nurse/patient dynamic

Research by Millard et al (2006) on the interactions between community nurses and patients in the UK, suggests that the social dimension of the relationship serves to establish each party as equals, and while this equalisation begins in the social dimension, it carries over to the professional dimension, allowing for a more open dialogue between nurse and patient which facilitates the patient taking a more active role in decision-making. Millard et al suggest that by establishing this social dimension, the nurse is acknowledging that the patient is an individual and not simply a ‘task’ or a ‘condition’. Sahlsten et al (2005), cited by Lyttle and Ryan suggest that if the nurse gets to know the patient as a person, it is more difficult for them to act in a paternalistic manner but the authors also note that participation must be purposeful, otherwise a paternalistic approach will be maintained.

Florin et al's (2006) work on the nurse-patient dynamic, involving 59 nurse-patient dyads, in an in-patient setting in Sweden found that a majority of nurses over-estimated the extent to which patients wanted to participate in decision-making. In the study 61% (n=46) patients preferred a more passive role, whereas nurses perceived that only 24% (n= 18) of the patients preferred that role. Despite this gap, 41% of patients experienced being even less active in decision-making than they preferred. The study also refers to earlier research (Scott et al, 2003), which found that nurses over-estimated the participation opportunities presented to patients. The authors also note that other research (Lam et al, 2003) concludes that patients are most satisfied with their level of involvement in decision-making when their actual involvement concurs with their preference for involvement, regardless of the level at which this is based.

Sihota and Lennard (2004) writing for the National Consumer Council’s guide to health literacy discuss the concept of nurses as patient champions or advocates drawing on the literature to provide the defining attributes of such nurses as valuing, apprising, and interceding. Nurses are described as able to: “(Develop) a therapeutic nurse-patient relationship in which to secure patients’ freedom and self-determination; promot(e) and protect... patients’ rights to be involved in decision-making and informed consent; (and) act... as an intermediary between patients and their families and between them and healthcare providers,” (p.38)

The authors note however that little is known as to how such a role is interpreted by nurses in practice and question whether nurses possess the authority to challenge doctors or the healthcare system more generally. “Doctors have felt threatened by nurse advocacy because deference to doctors is the unwritten rule of nursing culture. An important point is that this leads patients to perceive nurses as being powerless as representatives,” (p38).

This leads to a hypothesis that patients may therefore value the information and advice given by nurses as of less value than that given by doctors. This might, if borne out, affect renal patients who while interacting more frequently and for longer duration with specialist nursing staff for one-to-one support, counselling, information and advice, may change their views and opinions of treatment options if information and advice presented by their doctor is at odds or variance, from that given by nursing staff.
The authors note that the literature focuses on justifications for the role of nurses as advocates, and refer to an earlier review of the literature on advocacy in nursing (Mallik, 1997) which argues that there are multiple interpretations of the role of nurse advocate and therefore there is no clarity over how the role should be formalised and operationalised. The authors suggest that, “...the concept of nurse advocacy is just as complex and fraught with dilemmas as it is for doctors... Advocacy is a potentially risky role to adopt, and support systems are inadequate,” (p.38).

6.5 Inter-professional contribution to decision-making

‘Most studies and models of shared decision making do not account for inter-professional work or the need for multiple professionals to interact with patients about their decisions,’ (Stacey et al, 2010, cited by Health Foundation, 2012a, p33). Sheu et al’s (2012) study, which is the only one of direct relevance to renal patients to comment on this specific factor, notes the importance of professionals from a range of disciplines such as dieticians and nurses being involved in education and assisting shared decision-making, to help patients understand the impact on their daily lives of different modalities.
7.0 Systemic issues – barriers and facilitators

Key Points

- Systemic barriers to involvement in decision-making may include a paternalistic healthcare culture, the attitudes of patients and professionals, and the structure of consultations
- Facilitators may include strong leadership, changing patient and professional roles, motivated patients and professionals and appropriate infrastructure
- Time constraints are the most frequently reported problem in involving patients in decision-making
- The health system is composed of invisible structures and patients, carers and staff ‘bump up’ against these structures, which may lead to confusion and frustration when dealing with the impact and effect of these structures
- There is a crucial mismatch in energy and focus between the doctor and patient through the period of the consultation – the doctor is focused on diagnosis, while the patient is focused on prognosis
- The ability and confidence of patients to ask questions within the consultation is an important aspect of shared decision-making but patients face a range of cognitive and affective barriers in doing so.

Systemic issues within organisations may act as barriers or facilitators towards the provision of and execution of patient choice over modality. With regards to the former, these may include a paternalistic healthcare culture, the attitudes of patients and professionals, and the structure of consultations, while the latter might include strong leadership, changing patient and professional roles, motivated patients and professionals and appropriate infrastructure (Health Foundation, 2012a, p.iv). As a separate and distinct issue, Morton et al (2010) note that resource constraints do limit the options offered from one centre to another. Ten studies in their review reported that resources formed the basis of the treatment decision – whether these were space in a satellite dialysis unit - a consistent reason for choosing home dialysis or PD, or available kidneys for transplantation.

A systematic review (Gravel et al, 2006) of 38 studies investigating health professionals’ views of the barriers and facilitators to shared decision-making found that time constraints were the most frequently reported problem, followed by a perception that shared decision-making was inappropriate or not worthwhile for certain patients or in certain circumstances. The most commonly mentioned facilitators were professional motivation, and evidence of positive impacts on the clinical process or patient outcomes, (cited by the Health Foundation, 2012a, p. 32).

Sihota and Lennard (2004) make reference to a 2003 survey which though based on the impact of the English Expert Patient Programme is nonetheless illuminating in terms of professional perspectives on the well-informed patient. According to the survey, 63 per cent of doctors thought that, in the long run, better informed patients would require more of their time, a higher proportion than nurses at 48 per cent (p39).

The Health Foundation’s (2012a) report makes the point that, “... putting shared decision making into practice will not be achieved through policy statements: active steps to change
the behaviour of both healthcare professionals and patients are central to its successful
delivery,” (p. i).

7.1 Invisible structures throughout the system

The Health Foundation’s research in the patient/doctor dynamic (2012b) suggests that in
addition to the physical structures which are visible and apparent, the healthcare system is
also comprised of structures which are invisible but all pervasive. These invisible structures
include; the relations between individual staff, team members, departments and other
organisations; and the logics and processes which guide decisions and actions. Patients,
carers and staff themselves ‘bump up’ against these structures and may all experience a
sense of confusion and frustration when dealing with the impact and effect of these
structures on their receipt or delivery of care.

As a result of the socialisation and training process doctors undertake, the way they talk can
be quite different to the way patients talk. Their interactions with patients are normally
always also formalised in events such as consultations, ward rounds, clinics etc and codified
by tasks such as ‘taking the history’, ‘giving a diagnosis’ etc. This is in contrast with nursing
where interaction is much more fluid and the language used is much closer to that of a lay
person. (Health Foundation, 2012b) The authors go on to suggest from their research that
there is, “... a consistent disconnection of the consultation and the doctor’s sense of
responsibility from the rest of the system,” (p15) as a result of this distinction and
separateness. In other words, the authors seem to be suggesting that the consultation
process while part of the overall invisible structure of the organisation, is not always well
connected or matched to other aspects of the organisational structure, which leaves
patients potentially confused and disorientated by such differences in styles, attitudes and
approaches.

7.2 The structure of the consultation

The Health Foundation’s research (2012b) raises a number of interesting points about the
invisible structure of a clinical consultation specifically. It suggests firstly that there is a
specific point within the consultation when a patient’s contribution is welcome and that, “... patients may only sense there is a structure when they realise they have ‘missed their slot’; that there was a moment or opportunity to say something which is actually now gone. Imperceptibly, the doctor has moved on to another stage in the structure and that contribution is no longer sought or welcome,” (p 28).

The research also suggests that there is a crucial mismatch in energy and focus which occurs
through the period of the consultation. The authors contest that the focus for doctors is
getting to a correct diagnosis - taking the history and the differential diagnosis, while the
patient’s focus is on the future and what will happen to them. ‘... they may be quite passive
through the process of history taking, because their energy and anxiety rises at the point of
diagnosis, just at the point at which it drops for the doctor.” (p. 29)

Patient participants in the research also spoke of their confusion when the consultation or
conversation did not follow the expected structure. ‘If you ... have a loose pattern in your
head about what has happened before, but the doctor suddenly says, ‘so what would you like to do about this then?’, your structure, such as it is, is thrown. That is not what doctors are supposed to do; it is not what you have learned that doctors do,” (p. 31). This last quote is an interesting reflection on the expectation of what doctors ‘do’ and perhaps has its basis in a subconscious fulfilment of Parson’s sick role (1951), whereby patients are not expected to contribute to their care in this way.

An experimental study by Kidd et al (2004) of 202 patients attending diabetic outpatient appointments in UK evaluated the effectiveness of three different interventions designed to increase the ability of patients to ask questions in consultations. Their study built on earlier work by Roter which identified enabling, predisposing and reinforcing factors as predictors of patient question asking. The authors suggest that disabling barriers can be divided into two categories - cognitive and affective. Cognitive disabling factors include; the patient’s perceived lack of ability to ask questions, their perception of time barriers within the consultation, perceiving that it is unacceptable to ask questions and forgetting the questions they wanted to ask. Affective barriers relate to patients being too embarrassed to ask questions or feeling that they will be humiliated if they do so. The study also showed some demographic differences with non white patients tending to ask fewer questions in their consultations and those aged 45 plus asking more questions than younger patients.

The ability and confidence to ask questions within the consultation is clearly an important aspect of shared decision-making but disappointingly the study found that those patients in the intervention groups did not ask any more questions than those in the control groups. And although levels of self-efficacy were measured as higher in those patients in the interventions groups three months after taking part in the study, there was no difference in clinical outcomes between the groups in terms of diabetic control, suggesting no change in patient behaviour.

7.3 Meta-conversations

The Health Foundation (2012b) research also considers the impact of what it refers to as ‘meta-conversations’ between the patient or carer and the health service as a whole. The entirety of interactions between the patient and the health system is conceptualised as one ongoing experience or ‘conversation’. This includes all face-to-face conversations such as those between patient and receptionist or patient and nurse, all other forms of communication such as appointment letters and all other interactions such as tests, scans and admission processes etc. The difficulty for patients comes when their contribution to one part of the conversation is not ‘heard’ and considered in the next part of the conversation.

“...patients expect the meta-conversation to follow the same kinds of rules as an individual face-to-face conversation. In particular, they expect that each contribution they make will be heard and will be used to inform the reply – the next consultation or the next engagement they have with the health service,” (p36).

The authors of the Health Foundation’s report suggest that a ‘break’ in the conversation, whereby the conventions are not followed, can have negative emotional consequences for patients. “If they are not ‘heard’ – their notes are missing, or what they said to their GP has
not been communicated well to (or is being ignored by) the consultant, or promises are not kept – patients will feel ignored, demeaned and insulted at a deep level,” (p36). The authors go on to note that what is ‘said’ at each point in the conversation can affect how patients respond to the next part of the ‘meta-conversation’. They give the examples of missing notes and a poor experience at outpatients’ reception as dysfunctional parts of the conversation which can cause frustration and annoyance and can have a negative impact on the next ‘conversational’ interaction if patients disengage from the process, and feel ‘unheard’ and neglected.
8.0 Provision of information

**Key Points**
- Lack of information provision is the most frequent source of patient dissatisfaction
- Doctors underestimate the amount of information that patients want particularly in relation to prognosis
- Healthcare practitioners must elicit patient preferences for decision-making and information provision as two separate entities
- Literature from renal units is often difficult to understand, rarely includes information on risks or treatment limitations, and is not clear on the purpose of the information
- Low levels of health literacy exist in the UK and present considerable challenges for health services and professionals when communicating healthcare information to patients and/or carers
- Presenting the most important information first, ensuring information is concise, avoiding jargon, explaining medical terms, personalizing messages, encouraging questions and checking on understanding, can increase patient understanding and recall

- There is a lack of information available to patients about all modality options
- Good quality, easily understood information for renal patients should focus on areas such as lifestyle preservation, and self-efficacy
- Narrative-based text, illustrations and pictographs can reinforce textual messages and help patient recall by providing more memory jogs
- Healthcare professionals should be prepared to direct their patients to appropriate online information, in order to avoid them becoming overwhelmed or confused by conflicting information
- Information should be provided and re-provided at different stages in a patient’s disease progression and care
- Patients will experience different emotions at different times following diagnosis or a significant change in health status and will have differing levels of capacity to absorb information
- The medically ill have trouble thinking clearly when presented with complex treatment choices
- Much medical information is forgotten immediately by patients and half is remembered incorrectly
- The more information given, the more is forgotten
- Discrepancies exist in what information patients and doctors think has been provided and discussed in a consultation

According to Coulter (2003), a lack of information provision is the most frequent source of patient dissatisfaction, coming top of the list of complaints in patient surveys and acting as the underlying cause of many complaints and legal actions against healthcare providers. There is evidence to suggest that doctors underestimate the amount of information that patients want (Gaudagnoli and Ward 1998, cited by Say et al, 2006, particularly in relation to prognosis (Gaston and Mitchell, 2005). Beaver et al (2008) warn practitioners against assuming that patients who display a more passive attitude towards decision-making, don’t want information. Their research, based on 375 questionnaire responses from colorectal
cancer patients, suggests that healthcare practitioners must elicit patient preferences for decision-making and information provision as two separate entities. Their research also found that patients had a slightly better understanding of written information than verbal information – with 31 of 353 patients agreeing with the statement that they did not understand the written information given to them, whereas, 61 of 368 patients agreed with the statement that they did not understand the words used by doctors about their treatment.

The literature summarises patient information needs as follows:
• Understand what is wrong, with clear explanations
• Understand the processes and likely outcomes of tests and treatments
• Gain a realistic idea of the prognosis
• Learn about available services, including options and alternatives
• Engage in self-care
• Identify further information and self-help groups
• Help others around them (family, friends, carers) to understand
• Help them identify other sources of information.
(Source: Sihota and Lennard, 2004)

As regards written information, good quality literature should be accessible, readable, accurate, balanced, updated and evidence-based and many guidelines for designing, writing and testing patient-friendly information materials have been produced over the years (Gal and Prigat, 2005).

Winterbottom et al’s (2007) study reviewed the literature provided from 67 renal units and charities. All those that provided dialysis leaflets were asked to forward copies – 32 out of 47 responded resulting in 31 different leaflets. These 31 leaflets were assessed for quality and content using a coding frame. From completed questionnaires, it was apparent that the services that responded to the study provided patients with large amounts of information in several media such as leaflets, meetings with nurses and patients, videos etc, though computers were not used frequently.

Most leaflets from the units were found to be difficult to understand, rarely included information on risks or treatment limitations, and were not clear on the purpose of the information. Individual needs of patients such as literacy levels were also not taken into account. In spite of the production of guidelines produced over the years, Winterbottom et al note that there is, as yet, no centralised system for literature development for renal units, or formal guidelines, and that each appears to be doing its own thing.

8.1 Health literacy

Research over the years has identified problems with the readability and understandability of patient information leaflets in general (Gal and Prigat, 2005). The scale of the problem is significant. Smith et al’s (1998) work reviewing 178 leaflets on asthma, provided by general practices in Southern England illustrates this. They found that only 3% of leaflets were written at a reading grade that could be understood by the majority of the population.
The ‘quality’ of information is therefore as much about pitching the material at the right level to ensure individuals have the skills to make sense of and use the information as it is about the content of the materials themselves. In other words, good quality information must take into account the ‘health literacy’ of patients and carers.

The concept of ‘health literacy’ emerged in the 1970s and is described as: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,” (Institute of Medicine, 2004). This builds on an earlier definition by The World Health Organisation (1998) which states that: “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.”

Health literacy incorporates the skills of; health knowledge, reading, numeracy, writing, speaking and listening, critical appraisal and decision making. People with low health literacy tend to have poorer health status; are at greater risk of hospitalization; have longer hospital visits; have higher rates of admission to emergency services; are less likely to adhere to prescribed treatments and self-care plans; have a poorer understanding of diseases and treatments; have more medication and treatment errors; are less likely to engage in health-promoting behaviours; make less use of preventive services; and incur substantially higher healthcare costs (Sihota and Lennard, 2004).

In the US, it has been estimated that almost half of the adult population – some 90 million people – have inadequate health literacy (Institute of Medicine, 2004). A study of patients at two American hospitals found that one third could not read and understand basic health-related materials, 42% could not understand directions for taking medicine on an empty stomach and 60% could not understand a standard consent form (Williams et al, 1995). Other studies have found that two thirds of patients do not understand terms such as orally, terminal and biopsy, (List et al, 1994 and Davis et al, 2001, cited by Mannings and Dicken, 2006).

In the UK 16% of adults lack basic literacy skills and 47% of adults lack basic numeracy skills (UK population Skills for Life survey, 2003). The groups most likely to be affected are older people, ethnic minority groups and people classed as socially deprived (Sihota and Lennard, 2004). However, many people may underestimate their need for help with literacy and may be embarrassed to ask (Mannings and Dicken, 2006).

Research indicates that patients also find it difficult to assess information relating to risk – the probability of an adverse outcome, when they have no experience of the potential consequences, (Kenny et al, 1999, cited by Say et al, 2006). Politi et al. (2011) comment that little is known about how to communicate scientific uncertainty to patients and whether doing so actually helps patients make decisions, or whether it confuses and overwhelms them. Nexoe et al. (2007) suggest that risk information is not helpful at the individual patient level because variation in risk across patient groups can cause unfounded anxiety. The authors note that for patients, decisions related to risk will involve more than an assessment of the probability of an adverse event occurring and a valuation of the potential outcomes, as perceptions of risk may also be influenced by factors such as dread, control, choice, the nature of the risk, awareness and trust, (p. 649).
For renal patients on PD for example, infections are the major risk - either in the catheter exit site or more significantly in the abdomen wall - peritonitis. Peritonitis is treated with antibiotics and in severe cases the patient may need hospital admission for a few days. The infection can be so severe that the catheter has to be removed. The latter is rare but the fear of such a severe infection may detract from its statistical probability for some patients.

These factors clearly present considerable challenges for health services and professionals when communicating healthcare information to patients and/or carers. However, research shows that even small changes can have a positive effect. For example, Mannings and Dicken (2006) cite Ley and Llewelyn (1992) who found that presenting the most important information first, ensuring information is concise, avoiding jargon, explaining medical terms, personalizing messages, encouraging questions and checking on understanding, can increase patient understanding and recall. Weiss’s (2007) guidance for clinicians to improve communication specifically to address poor health literacy provides six steps to follow. These are: Slow down – speak slowly and spend a little longer with each patient; use plain, non-medical language; show or draw pictures; limit the amount of information provided and repeat it; use the teach-back technique; and create a shame free environment and encourage questions.

The teach-back method is often employed in health-care settings to check on a patient’s understanding of information or material presented and to re-teach information if necessary. The method asks patients to explain in their own words what they need to know or do. It is intended to check how well a professional explained something rather than a ‘test’ of the patient, (Minnesota Health Literacy Partnership, 2011). Evidence shows it can improve outcomes, (Weiss, 2007).

A study by White et al (2012) with 276 heart failure patients found that the ‘teach-back’ method helped patients retain self-care educational information. Data on ability to recall educational information while hospitalized and during follow-up approximately seven days after hospital discharge were collected. The results showed that patients correctly answered 3 of 4, or 75%, of self-care teach-back questions 84.4% of the time while hospitalized and 77.1% of the time during follow-up telephone call.

### 8.2 Content of information

In Winterbottom et al’s (2007) study, sixty-two (93%) of the renal units surveyed provided written information about End Stage Renal Failure and sixty-four (96%) provided information on treatment options in general. All 67 units provided written information about Haemodialysis (HD), 97% (65/67) provided information on peritoneal dialysis (PD), while 94% (63/67) provided information on renal transplants. Two-thirds of the units (45/67) provided written information about conservative care, i.e. choosing not to receive RRT, though the units also reported providing information verbally to patients by both doctors (84%; 56/67) and nurses (94%; 63/67). Written information was also provided about lifestyle changes and fluid restrictions in 49 of the units (73%). None of the information sources in the review included techniques to assist patient involvement or shared decision-making.
A lack of information available to patients about all modality options is raised by Morton et al (2010) in their systematic review. Though none of the studies they considered were UK based, patients or their carers reported that they did not have the information they wanted on treatment options, regardless of whether transplantation, dialysis, or palliative care was preferred, in 11 out of 18 studies. Morton et al note that, “Family members of patients were especially concerned about their lack of knowledge of the different treatments available and the practicalities in managing each treatment,” (p5). Murray et al’s (2009) review of 40 studies also cites a number which highlight a lack of awareness among patients of the full range of modality options across countries.

A small focus group of six Canadian patients, three on PD and three on HHD were involved in exploratory research (Sondrop et al, 2011) to provide healthcare professionals with a better understanding of current educational materials on RRT options. When asked what would encourage them to consider self-care dialysis participants suggested educational materials should focus on specific lifestyle aspects and present these in a positive way which explains the benefits of self-care options, rather than material which provides the pros and cons of different modalities. Patients suggested that very practical aspects should be included in educational material such as the amount of space needed for storing supplies in the home, rubbish collection arrangements, limitations on swimming and bathing and the need to maintain a clean environment to prevent infection.

This focus on important personal factors such as lifestyle preservation is raised by Chanouzas et al’s (2012) research into increasing patients’ choice of PD. The authors recommend that good quality, easily understood information should focus on areas such as lifestyle preservation, self-efficacy (ability to cope) and the need for a strong support and social network, and that such information should be provided alongside an education day and that patients should be allowed plenty of time for decision-making.

**8.3 Format of information**

Randomized trials evaluating the effectiveness of simplifying existing material for gaining consent (Coyne et al, 2003) suggest that using more narrative-based text, illustrations and pictographs can reinforce textual messages and help patient recall by providing more memory jogs. Providing personal context to the information has also been found to be effective, (Flory, 2004). This may mean leaving out information that is not relevant to that individual’s own specific circumstances – it is thought that this kind of prioritisation can assist recall and understanding, (Coyne et al, 2003).

Some of the groups that are most at risk of low health literacy tend to prefer accessing information from a telephone helpline (Ellins and Coulter, 2005) and appear to engage particularly well with information delivered by digital TV (Nicholas et al, 2004). Recording consultations for patients to listen back to afterwards may also be a helpful way to increase recall and to encourage further participation, as suggested by Leydon et al’s (2000) Cochrane review of eight random control trials on the effects of giving records or summaries of consultations to people with cancer, (see also Hack et al 2003 and 2007).
A study by McGregor (2002) found that prostate cancer patients (n=11) shown an information video had an improved understanding of their condition and its treatment and felt better able to be active partners in the decision-making process. The subjects drew inferences from and developed affinity for the individuals represented in the video. Previous research also shows that older people have better recall for information delivered in a TV format, (Frieske and Park, 1999, cited by McGregor, 2002).

The internet is clearly becoming an increasingly sought source of information. Recent statistics show that the growth of internet use over the last decade has increased by 500% and 30% of the world’s population now have online access (Internet Worlds Stats, 2011, cited by Lagan et al, 2011) A study by the latter of the use of the internet to obtain information related to pregnancy by 92 women across five countries, considered the subject’s experiences of and perceptions of using the internet and its influence on their decision-making. The motivation for accessing the internet for information for most women was because health professionals had not provided enough information to meet their needs. Anonymity was also considered an important benefit of the internet as women in the study were able to ask for information and advice without having to divulge their identity. The flexibility to access it at any time was also seen as a positive feature, as was the opportunity for ‘social networking’ and sharing experiences. On the negative side, women in the study talked about being overwhelmed by the information and how it could make them feel more anxious, paranoid and frightened. This correlates with Bessell et al.’s (2002) earlier systematic review which concludes that using the internet for health information can do harm as well as good.

Most of the women in the study preferred sites supported by health or academic organisations and most recognised the need to evaluate the information in some way to assure themselves of its validity and reliability. This was achieved by either cross-checking with a range of websites, or by cross-referencing with other sources of material (see also Ziebland et al, 2004, cited by Ziebland and Herxheimer, 2008 for triangulation of internet data by cancer patients). The internet was also used to validate what they had been told by health professionals and its use was seen as empowering them - giving them confidence to speak to health professionals on an equal basis. It was also seen as aiding decision-making by giving them a greater understanding of available choices. Lagan et al conclude that as many people will access the internet as an information source as a matter of course, the onus is on healthcare professionals to direct people to appropriate online information, in order to avoid their patients becoming overwhelmed or confused by conflicting information.

In Winterbottom et al’s (2007) study of renal units, information was delivered in various face-to-face sessions over and above routine consultations. These included; meetings with a dialysis nurse (95%; 64/67); meetings with other patients on dialysis (94%; 63/67) and with transplants (84%; 57/67); home visits by the renal team (81%; 54/67); and attending workshops (70%; 47/67). Nurses reported providing more verbal information to patients than doctors.

While it was apparent from the study that information was being provided in different formats i.e. printed, face-to-face, DVDs etc., it was not clear how effective different interventions were and in what combinations. It has subsequently been reported that different formats of providing information tend to have similar outcomes, though
multimedia options can be tailored to individuals with some benefits identified, such as the ability of patients to replay specific sections of material to reinforce understanding or clarify specific issues which cannot be done with a one-to-one discussion, (Health Foundation, 2012). The patient’s ability to select and review learning content in their own time is also reported by Chio and Chung (2011) as reducing the time spent by staff on patient education.

Winterbottom et al (2012) suggest that to avoid bias in the way information is presented, balanced information should be given about all treatment options. The article suggests; ‘...using figures to illustrate the decision options and consequences, using tables to summarize decision options and attributes, presenting risk figures as natural frequencies rather than as odds or verbal descriptors, (and) using questions to elicit patient values about consequences,’(p. 326). However, they go on to note that: ‘Currently, there is little evidence, indicating which of these techniques, and/or a combination of techniques, is most effective in helping patients who are new to the decision making process for dialysis modality to make an informed choice,’” (p. 326).

8.4 Timing of information

McPherson et al’s (2001) review of different information formats for cancer patients, found that information given in advance was more helpful than that given at the time of the consultation, (cited by Gaston and Mitchell, 2005).

In Beaver et al’s study (2007), patients who were further away from diagnosis reported less understanding of information. The authors suggest that this is because attention on providing information is focused on the initial diagnosis and treatment points and therefore make the point that the provision of information should be continuous and not a one off intervention. Participants in the study suggested that appropriate and timely information, tailored to the individual could reduce anxiety, allowing patients a degree of control at a traumatic time in their lives. However, interviewees suggested that too much information could overwhelm people and be harmful. This echoes Miller’s (1987) earlier work on ‘monitors’ and ‘blunters’ - whereby monitors want information prior to decision-making, whereas blunters find too much information upsetting, (cited by Ogden et al, 2009).

Difficulties in timing emerge when considering at what point information should be provided to renal patients specifically. Participants in a Danish study (Lee et al, 2008), conducted as part of a wider programme by the Danish Board of Health to investigate the feasibility of increasing the number of patients on out-of-centre dialysis, stated their preference for information on dialysis options earlier in their disease progression, though they also acknowledged the information could be quite abstract at this stage and recognised that they would need the information re-provided at a later stage as well.

Difficulties also arise in relation to the timing of information on modalities and the timing of surgery to create vascular access. Though such surgery may be a pragmatic course of action regardless of the choice of modality to be made, some patients may understand that this has in effect made their choice for them, (Morton et al, 2010).
8.5 Capacity to absorb information

It is helpful to reflect here on the emotional and psychological state of people at the time at which they are faced with making difficult decisions about their ongoing treatment. For renal patients considering renal replacement therapy options, the inevitability of this course of action will usually have been discussed with them over a longer period of time, if their disease has followed a natural progression and their condition is not a result of sudden trauma for example. However, although these patients may have been ‘prepared’ for the inevitable, the realisation that that time has come will still cause an emotional and psychological reaction.

Kubler-Ross’s (1969) grieving cycle model might be illuminating in these circumstances. Though Kubler-Ross developed his model to demonstrate how people cope with death and subsequent grief, it has subsequently been used extensively to demonstrate how people cope with unwanted change per se. Renal patients requiring RRT will therefore be coping with unwelcome change and the grief associated with a loss of physical function and a move away from their previous state. The model explains that people will move through a number of emotional or psychological states, starting with shock, followed by denial - ‘this is not happening to me’, anger – ‘why is this happening to me?’, realisation, and depression, – ‘there’s nothing I can do’. At the nadir of their experience, individuals are said to then let go of their resistance and to begin testing out what happens next - ‘how am I going to move forwards?’. This is followed by a search for meaning, an acceptance of the new state and finally internalising the change in status.

Patients will therefore be experiencing different emotions at different times following diagnosis or a significant change in health status and will have differing levels of capacity to absorb information. Research suggests that difficulty accepting a new diagnosis of cancer may limit people’s ability to be actively involved in decision-making, (Hack et al, 1994, cited by Say et al, 2006; and Beaver et al, 2007) and it is possible to surmise that any significant change in a person’s health status may have a similar effect. Sheppard et al (2011) cite research that concurs with Hack et al that women may be so overwhelmed by their cancer diagnosis that they fail to take on board information given to them by their healthcare providers. The authors of the Health Foundation report (2012b) on patient-doctor dynamics found that social status, education, or even prior experience and knowledge of the health service do not prevent people from lacking absorptive capacity when it comes to complex information which may be emotionally difficult to take on board.

Healthcare professionals interviewed for the Health Foundation’s study (2012b) also talked about the difficulties for patients who were acutely unwell to absorb information, especially when there may be limited time to think about choices, ‘... even if we have the time to speak with them I think they don’t actually assimilate the information, they can’t really discuss it at length with their relatives or think about it, it’s very difficult for patients to think of questions on the hoof,’ (p32). This is borne out by research which has shown that the medically ill have trouble thinking clearly when presented with complex treatment choices, (Cassell, Leon and Kaufman, 2001 cited by Myers Sorger et al 2007), as a result of the stress of illness and the confusion exacerbated by the healthcare environment. The elderly ill may be particularly vulnerable to a lack of absorptive capacity. Myers Sorger et al’s (2007) research comparing 43 elderly terminally ill patients in the US with 35 healthy, elderly
subjects showed severe impairments in cognitive functioning in the elderly terminally ill patients, compared to the healthy subjects who were, on average, three years older.

For renal patients this absorptive capacity is exacerbated by deteriorating health status in the run up to dialysis, with increased likelihood of anemia, hypertension and uremic malnutrition (Thomas et al, 2008), which all potentially have an impact on cognitive functioning and the ability to take part in shared decision-making.

Impairments in functioning due to depression are another aspect of absorptive capacity and involvement in decision-making to consider, though the research is not equivocal on its effect. Myers Sorger et al (2007) refer to a number of studies which are inconclusive, though Vogel et al’s (2008) more recent research with newly diagnosed breast cancer patients (n=137) in Germany showed correlation between a passive decision-making role and higher scores for depression.

Both healthcare professionals and patients involved in the Health Foundation’s research noted the common patient response in consultations of the ‘rabbit in headlights’ described as, “...a paralysis and inability to focus, to ask questions or to hear properly what is being said by the doctor in the consultation,” (2012b, p. 32). Patients in the study described their experiences of distortions in their perception of time, so that the consultation seemed to pass by in a flash and left them feeling dazed and confused about what has happened and what has been said.

A study by Ley in 1988, found that half the research subjects forgot most of the information given to them within minutes of the consultation, (cited by Mannings and Dicken, 2006). Other research suggests that 40-80% of medical information is forgotten immediately by patients (Kessels, 2003), almost half of information provided is remembered incorrectly (Anderson et al, 1979) and the more information given, the more is forgotten (McGuire, 1996). Further research also shows discrepancies in what information patients and doctors subsequently think has been provided and discussed in a consultation, (Meropol et al, 2003, cited by Cox et al, 2006).

With this in mind, information and education need to be re-provided to patients throughout their disease progression and treatment. As a consultant who took part in the Health Foundation’s research notes, ‘There is a real difference when you can see patients more than once, divided by a length of time when they can discuss with their relatives and friends and they can assimilate the information and they come back for a second time [and] you can have a much more fruitful conversation with them,’ (2012b p. 32).
9.0 Decision aids

Key Points

- Decision aids can improve people’s knowledge of treatment options, create realistic expectations of the benefits and harms, reduce difficulty with decision-making, and increase participation in the process.
- No one theory of decision-making can provide a comprehensive framework to address all the design requirements of a DSI.
- Decision aids should contain both an information component – to provide factual information and a deliberative component – to support people to make decisions.
- Evaluations of decision aids should measure the extent that they enable patients to undergo treatments that agree with their values as well as measuring treatment decisions, patient’s knowledge and the decision-making process.
- Clinicians may have reservations about information overlap, information overload and about inappropriate content.
- Little is known about how people make decisions across the trajectory of CKD and not just in relation to RRT modalities.

The function of a decision aid is to provide facts about a patient’s condition, options for treatment and care and evidence-based outcomes – the information component. They should also help patients clarify their own values and consider what is most important to them, helping people think through the pros and cons of different options – the deliberative component, (Elwyn et al, 2010). Good communication is the basis for good decision-making in consultations and tools designed to help patients communicate can also help them to describe their health concerns, organise their needs and questions and be more proactive.

Elwyn et al (2009) state that decision support interventions (DSIs), “... help people think about choices they face, they describe where and why choice exists, they provide information about options, including, where reasonable, the option of taking no action. These interventions help people to deliberate, independently, or in collaboration with others, about options, by considering relevant attributes; they support people to forecast how they might feel about short, intermediate and long-term outcomes which have relevant consequences, in ways which help the process of constructing preferences and eventual decision-making, appropriate to their individual situation,” (cited by Elwyn et al 2010, p. 566). The authors go on to note that these are complex interventions therefore and cannot simply be accomplished by the provision of a leaflet, video or signposting to a website.

At the time of writing their guide for the National Consumer Council, Sihota and Lennard (2004) record that over 400 decision aids for patients had been registered by a Cochrane Collaboration review team. They note that a Cochrane review concluded that decision aids could improve people’s knowledge of the options, create realistic expectations of the benefits and harms, reduce difficulty with decision-making, and increase participation in the process (O’Connor et al, 1999 and 2003). Examples of decision support aids include the Wiser Choices tools, developed by the Mayo Clinic in the US, which provide graphical representations of risk for different treatment options and Option Grids, developed in...
Cardiff, which are brief summaries of options with frequently asked questions, (Stiggelbout et al, 2012).

The positive impacts of decision aids for women with breast cancer have been reported recently. In a German trial, women with newly diagnosed breast cancer were split into two groups, one group was provided with ‘usual care’, while the second was provided with a 20-minute interactive decision aid and brochure prior to their planning consultation. According to the trial, the women who had received shared decision support had better long-term body image outcomes and coping strategies, one year after the intervention,” (Vodermaier et al, 2011, cited by Health Foundation, 2012). Reports from the USA suggest that a computerised decision aid to help women with breast cancer make decisions about reconstructive surgery, resulted in women reporting a greater role in choosing the type of reconstruction, having more reconstructive options offered to them, and were more satisfied with the amount of information they were provided with, (Lee et al, 2010, cited by Health Foundation, 2012).

Other research however is more ambivalent about the impact of decision aids on affecting the choices made. A different randomised trial of the use of a decision aid for women with suspected breast cancer in Germany concluded that the decision aid, “…improved knowledge but did not increase patient satisfaction, decrease conflicts when making decisions, or influence treatment uptake,” (Vodermaier et al, 2009, cited by Health Foundation, 2012).

Kennedy’s (2003) systematic review of randomised control trials, evaluating the effects of decision aids, found that there was little consensus on what the aims of decision aids should be. The review found that the most commonly used measures were treatment decisions, patient’s knowledge and the decision-making process. “None of the trials attempted to measure the extent to which the decisions made were consistent with patient’s values. It recommended that, if there are choices to be made, evaluations of decision aids should measure the extent that they enable patients to undergo treatments that agree with their values,” (cited by Sihota and Lennard, 2004, p41).

The most effective way to implement decision aids for people with CKD is unclear. In a systematic review, Murray et al (2009) considered 40 studies and decision support tools that involved adults with CKD and a focus on decision-making needs and/or barriers and facilitators to shared decision-making, published between 1998 and 2008. The authors noted that studies typically focused on the provision of information by healthcare professionals rather than decisional conflict and supporting people to make decisions. The review found no studies that assessed the effect of decision support interventions on decision quality measures such as improved knowledge, decreased decisional conflict, more realistic expectations and decisions congruent with patient values. The review also noted that little is known about how people make decisions across the trajectory of CKD and not just in relation to RRT modalities.

Elwyn et al’s (2010) work examining the gap between decision-making theory and its use in decision support interventions suggests that no one theory of decision-making can provide a comprehensive framework to address all the design requirements of a DSI, and that where theory is used in their design, this tends to focus on cognitive aspects, rather than
supporting people to make decisions, in collaboration with others, in real-world situations. “How the decision is made visible, by who and how the supporting interactions with both professionals and others are integrated, are crucial elements of a decision support model,” (p. 572).

9.1 Professionals’ views of decision aids

Interviews with 24 breast surgeons in England regarding online decision support interventions (DesIs) for women choosing between mastectomy and breast conservation surgery for breast cancer found that many, “...did not have a working knowledge of DesIs and were ambivalent or sceptical. Many expressed conflicting opinions: they noted the potential benefits but at the same time expressed reservations about information overlap, overload and about content they considered inappropriate. Many wanted access to DesIs to be always under clinical supervision. (They were) particularly concerned that DesIs might induce patient anxiety and replace their role,” (Caldon et al 2011, p. 133).
10.0 Pre-dialysis education

Key Points
- Appropriate and timely education and professional support are thought to be important in encouraging greater use of out-of-centre modalities
- A combination of individual intervention and group education appears to have particular benefits for patients facing difficult and complex treatment decisions
- Enhanced education initiatives are thought to result in improvements in knowledge, reduction in uncertainty and reduction in decision regret

Lee et al’s (2008) Danish study found that appropriate and timely education and professional support were important to encourage greater use of out-of-centre modalities. The study which involved 24 dialysis patients, three pre-dialysis patients and 18 relatives found that those participants who had not attended an educational programme wished they had done so, “If the information had been better, I might have chosen differently and not have missed almost a year of my life,” (p. 3956).

A combination of individual intervention and group education appears to have particular benefits for patients facing difficult and complex treatment decisions. For example, a systematic review of 15 initiatives to promote informed decision making about cancer screening found that individual counselling and group education improved patients’ knowledge about their conditions and the pros and cons of treatments (Briss et al, 2004, cited by the Health Foundation, 2012, p 19). Initiatives with renal patients (Manns et al, 2005 and Owen et al, 2006, cited by Key, 2008; Chio and Chung, 2011), discuss such a combination positively though the effect on modality choice is not always clear from this body of research.

Manns et al’s Canadian controlled, randomized study involved two groups of 35 patients each receiving their clinic’s standard teaching about kidney disease, which included dietary advice and detailed information about modalities, in a three-hour one-to-one interaction, involving a nurse, social worker and dietician. The control group then received no further education, while the other group received two further educational sessions. The first enhanced educational session presented self-dialysis as a ‘desirable, life enhancing and attainable skill’. Patients also received manuals and videos of each self-care modality. The second intervention, two weeks later, was a small group problem-solving session, lasting 90 minutes. Using case studies, the session was intended to help participants overcome barriers to self-care.

The results from the study showed no difference in the control group participants planning to start self-care, at study completion, compared to baseline. In the enhanced education group, there was no statistically significant difference in the proportion of those planning to start self-care after the first educational intervention, using booklets and videos. However, after the second group problem solving intervention, 82% of those participants in the enhanced education group planned to start self-dialysis, compared to 50% in the control
group. Though these results are favourable, it must be acknowledged that they are based on intention rather than behaviour, so actual numbers starting on self-dialysis may differ.

Owen et al’s Australian initiative relates to an enhanced educational programme with small classes of between three to six patients and their families. The first group session provides an overview of their condition and modalities, followed by an individual medical review. The second group session three weeks later provides an insight into dialysis lifestyles and the support required for each. This is followed by a second medical review when the patient chooses their modality. Plans are then made for specific modality training and the appropriate medical access is arranged and visits to HD or PD training units are undertaken. The authors are unable to provide data on the take up of HD or PD prior to the initiative but in the four years since the initiative was introduced, 80% of patients have initiated on in-centre HD and 20% on home-based PD.

Using a quasi experimental design (Chio and Chung 2011), a control group of 20 patients and another group of 20 patients receiving an enhanced education intervention of a multimedia interactive DVD and follow up phone calls to clarify learning were studied. Improvements in knowledge, reduction in uncertainty and reduction in decision regret were observed in the enhanced education group. However, the study did not suggest there had been any shift in modality choice from participants in either group from their pre-study state.
### 11.0 What factors influence the choices patients make?

**Key Points**
- Research suggests 50% of patients who could freely choose dialysis modality would choose PD and 25% would choose HHD, with the remaining 25% choosing HD.
- The impact of a modality choice on quality of life is more important than clinical outcomes.
- Preferences for PD focus on greater privacy, freedom and flexibility.
- Preferences for CHD focus on a planned schedule, regular social contact and a sense of security in health professionals.
- Patients are seldom inclined to change modality, once started on one.
- Other people’s experiences are an important part of the evidence that renal patients use to make decisions.
- Information presented in the first person as the patient’s account, is more than twice as likely to influence other people’s choices than information presented in the third person.
- Decision-making is a social, relational activity which must take account of the influence of family and community.
- The opinions of friends and families can be influential on renal patients, particularly in relation to the support that would be required to facilitate certain choices.

Lee et al (2008) estimate that about two-thirds of patients should have a real choice over modality. A cohort study (Prichard, 1996), cited by the authors, showed that half of the patients who could freely choose dialysis modality chose PD and the other half chose HD, of whom half chose HHD.

The desire to maintain pre-existing lifestyles as far as possible by minimising disruption to usual activities and interests is a strong factor in the choices patients make, with the impact of a certain therapy on quality of life generally more important than clinical outcomes. Patient preferences for PD are centred around greater privacy, freedom and flexibility, whereas patient preferences for HD are based on a planned schedule, regular social contact and knowledge of the therapy, (Morton et al, 2010).

Lee et al’s (2008) Danish study suggests the following themes are important when choosing modality:

**Maintenance of a normal life** -
Patients in the study noted the importance of distinguishing between the person and the illness and separating their illness from the rest of their life. Dialysis could be coped with by normalizing the rest of their lives. Those on CHD and self-care CHD distinguished between days on dialysis (being an ‘ill person’) and days without dialysis (not being an ‘ill person’), preferring fewer, though longer dialysis sessions. For those patients on PD and HHD, avoiding hospital altogether was a way of normalizing everyday life.

**Flexibility and independence** -
With CHD, patients have dialysis-free days and can therefore plan around these and maintain a routine. A home life free of the artefacts of illness can be seen as advantageous. However, some patients find the travel involved in, and experience of, in-centre dialysis
exhausting and noted frustration around the inflexibility of this option for special occasions and holidays. For patients on HHD or PD, and their relatives, the flexibility provided by planning dialysis times themselves is appreciated, particularly in relation to maintaining work commitments.

**Sense of security** -
Patients on CHD and aAPD gain a sense of security from the involvement of health professionals in their dialysis. Fear of incompetence was spoken of as a barrier to choosing a self-care modality and the involvement of family and carers in decision-making was an important consideration in providing reassurance. Relatives of those on HHM, and who are not with patients during home dialysis, expressed their nervousness about things going wrong in their absence at the start of treatment. For patients on HHD, PD and aAPD, the importance of 24-hour telephone access for advice and instructions, and a technician to visit when needed were critical concerns.

**Physical space and noise** -
The machines, bags and other equipment required by HHD and APD take up a lot of space in people’s homes and are described by some as unsightly. The noise of the machines and their alarm noises are also described as irritating, especially for partners, if dialysis is taking place overnight.

### 11.1 Changing modality

Once on a dialysis modality, patients are seldom inclined to change modality (King, 2000, Little et al, 2001 and Bass et al, 2004). The latter’s study found that patients were more likely to accept a higher dose of dialysis in their current mode rather than change mode. 75% of the cohort of 188 U.S. patients studied would choose a higher dose to increase survival by 20%, compared to 30% who would not switch modality even if survival increased by 100%.

This reluctance could be due to a number of factors such as lack of knowledge about alternative modalities, the difficulties of doing so from a system perspective, the sense of security obtained from familiarity, the change to daily routines and fear of disrupting the status quo (Lee et al, 2008 and Morton et al, 2010).

### 11.2 Peer influence – patient stories

Ziebland and Herxheimer’s (2008) research on the contribution of patients’ experiences to decision-making found that other people’s experiences are an important part of the evidence that people use to make decisions. The authors suggest that people are naturally drawn to other people’s stories, as they add salience and make facts more memorable and palatable. “...patients often feel that only others who have been through what they are going through can really understand and guide them,” (p. 439). A different aspect of this is Hedrick’s (2005) claim that comparing oneself to another to see how well you are doing is a common coping strategy (cited by Lagan et al, 2011).

Studies note the strong influence of other people’s experiences on the treatment choices made by renal patients, (see Tweed and Ceasar, 2005 and Morton et al, 2010). In the former’s interviews with renal patients, participants spoke of strongly identifying with specific patients who came to speak to them about treatment options - matching their
circumstances to others to help them make decisions. “Peer comparison was utilized to... instil optimism that they would be able to cope with their future treatment,’’ (p. 662). In Morton et al’s research, similar views were expressed by participants who spoke of being inspired to carry out dialysis themselves after talking to other patients. Similarly, patients also spoke of being put off a certain treatment because of someone else’s poor experience.

Winterbottom et al (2012) refer to their earlier research (2008) which found that information presented in the first person as the patient’s account, was more than twice as likely to influence other people’s choices than information presented in the third person e.g. the doctor talking about the patient’s experience. The authors do not necessarily view this as a positive phenomenon however and urge caution on those services providing opportunities for patients considering dialysis modality to speak to others on dialysis. They argue that such patients may use only a limited range of considerations to make that choice by judging another patient’s experience and do not therefore systematically appraise all of the pros and cons of each option.

11.3 Peer support

Emerging findings from an ongoing companion WMC HIEC study (Taylor, 2012) on overcoming barriers and facilitating access to peer support, show that while informal support might occur naturally and is welcomed, a range of emotional and practical barriers constrain interest in taking up more formalised support. The study sample included 12 CKD patients and 10 carers, at different stages along the kidney disease pathway. Participants identified benefits of peer support over and above that support which can be provided by family and friends, or health professionals, noting that peers can better understand the patient’s own feelings and can empathise with their experience.

Taylor notes that a patient’s receptivity to peer support can vary across time and across the disease trajectory and is associated with emotional readiness, with patients needing to overcome complex psychological hurdles such as acknowledging the need for support. Practical barriers include a lack of awareness of its availability, and time and illness constraints. In order to foster greater uptake, Taylor makes several suggestions, including the suggestion that healthcare professionals could offer greater ‘permission to engage’ and promote peer support as an intervention for everyone, not just more ‘needy’ patients. Such support, it is argued should also be made available across the CKD pathway.

11.4 Involvement of relatives, carers and friends in decision-making

Forsyth et al (2011) talk about the ‘crowded room’ in decision-making, meaning that patients cannot be disassociated from their relational counterparts, such as family and friends, in decision-making arenas. “…patients’ preferences for treatments are embodied, and evolve through the various roles they assume in social interactions and the way they position themselves in relation to health professionals, family members, and community members,’’ (p. 1261). The authors conceptualise decision-making as a relational, interactive process, occurring over a period of time, as opposed to an individual, linear, cognitive process. Although Forsyth et al’s research was based on a small sample of only 16 patients undergoing bone marrow transplant in Australia (together with their significant others and healthcare professionals (n=42)), all patients spoke of making decisions on the basis of not
letting people down and meeting obligations – whether to family, friends or other social support networks, such as workplaces or faith groups. The authors argue that decision-making support interventions must take account of the influence of family and community, as decision-making is an ‘inherently social, relational activity’, which occurs over time and within different spaces to just the consulting room.

Concern for others is an important aspect in a relational perception of patient autonomy, (Mackenzie and Stoljar, 2000, cited by Gilbar and Gilbar, 2009). The authors expand as follows, “Such a perception of autonomy means that the interests of close others, such as family members, who are affected by a choice made by one of them, are taken into account when making decisions,” (p. 185, citing Donchin, 2000).

In Gilbar and Gilbar’s (2009) study of the similarities and differences in shared decision-making between 57 Israeli breast cancer patients and their husbands, 84% (n= 95) stated that the participation of the husband was important and 89% (n=101) stated that the husband’s agreement with the wife’s decisions was important. The study also found that both patients and their husbands preferred a shared decision making approach rather than paternalism or autonomy-based.

Gilbar and Gilbar (2009) note that the shared decision making model of Charles et al (1999) does allow for the participation of family members, though this relates to the process being shared rather than the ultimate decision itself, which in reality can only be made by one person. The authors note that there have been few studies concerned with the family’s involvement in medical decision-making but that these have indicated a number of potential consequences. On the positive side it could promote patient autonomy and strengthen and enhance the doctor-patient relationship. More negatively, it could lead to conflicting preferences, resulting in undue pressure on the patient to acquiesce to family members’ preferences, or family members could question the authority of the doctor thus harming the patient-doctor relationship.

Morton et al (2010) note that the opinions of friends and families can be influential on renal patients, particularly in relation to the support that would be required to facilitate certain choices. This is articulated in Sheu et al’s (2012) study with one patient describing how his wife’s preference affected his choice of modality, ‘Me and my wife went to all the classes and everything, and they showed us all the options and everything, but I wanted to do the home dialysis right, but my wife refused, so I came to dialysis because I thought I could handle that,’ (p 1001).

In Tweed and Ceasar’s (2005) small study, participants report making decisions for themselves, but receiving non-directive support from family and friends in the role of sounding boards. This theme is also echoed in Sheu et al’s (2012) study where focus group participants talk of their role as being supportive and shared, helping patients weigh up the advantages and disadvantages of the options and providing reassurance on decisions.

There is some indication that demographics may play a part in the influence of family and friends. According to Murray et al’s (2009) review, one study indicates that while older patients are more influenced by the opinions of family members, younger patients gain information from other health professionals and patients.
12.0 Decisional Quality

Elwyn and Miron-Shatz (2010) note the existence of tools to measure different aspects of the decision process such as decision conflict, decision satisfaction and decision regret. But while there is a significant body of literature on how to define a ‘good decision’ (see Bekker, 2009; Fischhoff, 2009; Fischhoff, 2002; Hammond, 2007; O’Connor, 2003; and Ratliff et al, 1999) they point out that describing and measuring decision quality is an inherently complex and difficult task. They suggest that developing a better response to this task would help improve the support provided to patients to take part in shared decision-making, would improve doctor-patient communication and would improve the decision-making process. The authors make a point of emphasising the importance of the deliberation process rather than the decision’s end results – the outcome, in assessing decision quality, as does Bekker (2010).

Bekker references Frisch and Clemen’s (1994) definition of a good decision as one that is based on an awareness of the consequences of each available option, assimilates that knowledge with the individual’s existing knowledge and beliefs, accurately assesses the risks and benefits of each option, makes trade-offs between the consequences of each available option and can reason about the choice made, with reference to these assessments.
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