

1-4-2003

Renal dialysis services in the Eastern Regional Health Authority: a review of patient satisfaction across hospitals

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Citation

Rundle K, Keegan O, McGee H. Renal Dialysis Services in the Eastern Regional Health Authority. A review of patient satisfaction across hospitals. Conducted by the Health Services Research Centre, department of Psychology, Royal College of Surgeons in Ireland on behalf of the Eastern Regional Health Authority. April, 2003

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**RENAL DIALYSIS SERVICES IN THE EASTERN
REGIONAL HEALTH AUTHORITY**
A review of patient satisfaction across hospitals



Conducted by the
Health Services Research Centre
Department of Psychology
Royal College of Surgeons in Ireland
on behalf of the
Eastern Regional Health Authority



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April 2003

Acknowledgements

This report on patient experiences of renal dialysis services was commissioned by the Eastern Regional Health Authority. The Health Services Research Centre (HSRC) at the Department of Psychology, Royal College of Surgeons in Ireland, conducted the study. The research team comprised Ms. Kay Rundle (Project Coordinator), Ms. Orla Keegan (Health Research Board Health Services Research Fellow in Patient Satisfaction Assessment) and Professor Hannah McGee (Director, HSRC). Thanks to Ms. Denise O'Shea who worked as a study interviewer.

We acknowledge the support and assistance of many individuals who cannot be named to maintain service confidentiality. Many administrative and clinical staff from participating hospitals gave their valuable time and advice to facilitate us in conducting the study. Representatives of the Irish Nephrological Society also contributed advice to the project. We are particularly grateful to those patients who, by participating, described their experiences for the benefit of future patients and services.

The authors are also grateful for the support received from Ms. Evelyn Jameson of the Monitoring and Evaluation Section, Eastern Regional Health Authority, throughout the research process.

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The views expressed in this report are those of the authors and do not necessarily reflect the views or policies of the sponsors.

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Chapter 1

INTRODUCTION

1.1 General introduction

Recent changes to the health services have initiated a consumer-oriented approach to health care. The current national health strategy in Ireland “*Quality and fairness: a health service for you*” emphasises the principles of equity and fairness, a people-centred service, clear accountability and quality of care (Department of Health and Children, 2001). A consequence of these changes is the consideration of patient views of their health care, and this is often evaluated in the form of patient satisfaction studies. There is a growing realisation that patient input can give a greater understanding of the quality of services and how best to improve them.

1.2 Background to the Eastern Regional Health Authority evaluation

The Department of Health and Children is implementing a review of current services as part of plans to introduce a national renal strategy. As demand for renal services increases, there is a need to explore the best ways to facilitate the increase. A plan needs to incorporate three main objectives: to provide dialysis services close to patients’ homes, to provide nephrology services with specialist oversight (i.e. teams headed by a consultant nephrologist), and to make available various dialysis modalities so that patients can chose to have dialysis in their own home if that is their preference and if it is advisable on a medical basis (Department of Health and Children, 2001).

The Eastern Regional Health Authority (ERHA) currently offers renal dialysis services in four Dublin hospitals. It needs to expand its renal services to cope with increased demand. In conjunction with the Department of Health and Children, the ERHA is carrying out a full review of its renal services. This will provide information about current services and will suggest how the increase in dialysis services could be

implemented to provide quality care to all renal patients. One area of this review is a survey of patient satisfaction.

1.3 End-stage renal disease

End-stage renal disease (ESRD) has been defined as an “irreversible 90-95 percent reduction in kidney function” (Binik et al, 1993). When this occurs, the kidneys no longer effectively remove waste products and they build up in the blood. Without medical intervention, terminal renal failure occurs within weeks. The medical intervention would ideally be transplantation, when a healthy kidney is taken from a donor (cadaveric or living) and surgically placed inside the ESRD patient’s body. However, there are a number of obstacles to successful renal transplantation.

Firstly, many people with kidney failure are not eligible for a transplant, often because they have other health problems which increase the likelihood of death following transplant. There are insufficient kidneys available for transplant so there are often long waiting lists. Donated kidneys also have to be matched with recipients by blood group and tissue type so those with rare blood and tissue types may wait longer for a suitable kidney. Even if one is found, there is still a risk that the recipient’s body will reject the kidney following transplantation (Cameron, 1996).

Given these challenges, it is essential that there is an alternative method of removing waste products from the blood of ESRD patients who cannot have, or are waiting for, a kidney transplant. This alternative is dialysis, of which there are two types, haemodialysis and peritoneal dialysis. These are explained next so that the differing demands on patients and locations of service delivery are clear.

Haemodialysis involves removing blood from the body and circulating it through an artificial kidney, a dialysis machine. In the dialysis machine, a semi-permeable membrane lies between the patient’s blood and dialysate solution, a fluid which approximates the healthy balance of substances usually found in blood. The waste products that have built up in the blood diffuse through the membrane into the

dialysate. The dialysate is drained out and the cleaned blood is returned to the body. This dialysis routine usually needs to be performed approximately three times per week for about four hours each time. It can be carried out in a hospital or at home (Cameron, 1996; Will and Johnson, 1994). In practice, haemodialysis in Ireland is generally provided in hospital settings.

An alternative to haemodialysis is peritoneal dialysis. Instead of using an artificial membrane in a dialysis machine, peritoneal dialysis uses a natural membrane, the peritoneum, which already exists in the body, lining the inner abdomen. The peritoneal membrane forms a cavity into which dialysate is drained. The peritoneum has a good blood supply and waste products flow from the blood, through the peritoneal membrane, into the dialysate. Dialysate containing the waste products is then drained from the body and replaced with new dialysate. Before commencing peritoneal dialysis, an operation is required which inserts a catheter into the abdomen, enabling the fluid to be drained in and out of the peritoneal cavity (Cameron, 1996; Will and Johnson, 1994).

There are two types of peritoneal dialysis, Continuous Ambulatory Peritoneal Dialysis (CAPD) and Continuous Cyclical Peritoneal Dialysis (CCPD, also known as Automated Peritoneal Dialysis, or APD). On CAPD, dialysis fluid remains in the body at all times. The patient drains the dialysate into their peritoneal cavity, leaves it for several hours whilst the waste products pass across the peritoneal membrane into the dialysate, then they drain the fluid containing the waste products, and replace with new dialysis fluid. Most patients do this about four times every day (Cameron, 1996). Hospital visits are not required outside of the usual outpatient review for this system to operate.

On CCPD, a machine carries out the fluid exchange, usually when the person is asleep, for approximately 8 to 10 hours. Again this is done without the need for frequent hospital visits. The major advantage of this method is that it allows more freedom during the day (Cameron, 1996).

1.4 Patient satisfaction

There are numerous definitions of patient satisfaction. A broad definition is the patient's 'reaction to salient aspects of the context, process and result of their experience' (Pascoe, 1983). Alternatively, Fitzpatrick (1997) suggests that patient satisfaction should be conceptualised as 'an evaluation by the patient of a received service, where the evaluation contains both cognitive and emotional reactions'. Difficulties in defining patient satisfaction may be partly due to the multidimensional nature of the concept of satisfaction. Patients may be satisfied with some aspects of their care and dissatisfied with other aspects. Dimensions of health care may include, for example, technical aspects (the actual service received, e.g. an x-ray), physical aspects (the environment, food, etc.) and the interpersonal aspects (e.g. staff attitudes) (McCarthy, McGee and O'Boyle, 2000). Whilst the multidimensional nature of satisfaction allows identification of the particular aspects which patients are dissatisfied with, and therefore highlights the areas to target with improvement strategies, it has also resulted in a wide variety of categorisations of aspects of care.

Hall and Dornan (1988) carried out a meta-analysis of 221 patient satisfaction studies. They found that the most popular aspects of satisfaction investigated in the studies were humaneness, informativeness, overall quality, competence, overall satisfaction, bureaucracy and access. They then identified an overall ranking of satisfaction with aspects of care (excluding overall satisfaction) and found that overall quality, humaneness, competence and outcome had been given the highest ratings of satisfaction throughout the studies.

Alternatively, Cleary and McNeil (1988), in their review of the patient satisfaction literature, found the aspects of care most frequently measured were 'personal aspects of care, technical aspects of care, accessibility and availability of care, continuity of care, patient convenience, physical setting, financial considerations, and efficacy'.

Wilde et al (1993), in an effort to develop a model to understand quality of care, identified four dimensions of patient perception of quality of care: 'the medical-technical competence of the caregivers, the physical-technical conditions of the care

organisation, the degree of identity-orientation in the attitudes and actions of the caregivers and the socio-cultural atmosphere of the care organisation’.

Patient satisfaction studies have become an important part of the evaluation of the quality of health care, providing information on problem areas to be targeted for improvements and enabling the measurement of changes in patient evaluation of their experiences following interventions. Studies have illustrated that another reason for the importance of measuring patient satisfaction is its relationship with other aspects of health care (Fitzpatrick, 1997). Patients are more likely to adhere to medical regimes (Korsch et al, 1968; Kinsey, Bradshaw and Ley, 1975; Fitzpatrick and Hopkins, 1981) and more likely to re-attend if they are satisfied with their care (Hall, Roter and Katz, 1988; Calnan, 1998).

A number of studies have illustrated a relationship between satisfaction and health outcome; healthy patients are generally more satisfied with their health care. There are a number of suggested explanations. Patients may be directly dissatisfied because their health is not improving with treatment. Since less satisfied patients adhere less to medical regimes, perhaps their poor health outcome is a result of their dissatisfaction through lack of adherence (Fitzpatrick, 1997).

Wilkin et al (1992) suggest another reason for the importance of patient satisfaction studies, i.e. as health services develop a consumer-oriented approach, the patient is usually still limited because they do not have a choice of alternative places to obtain their health care.

1.5 Patient satisfaction and renal dialysis

There are specific issues and challenges for ESRD patients and their families. Renal failure necessitates life changes to accommodate the dialysis routine and major dietary changes. Previous studies of the quality of renal dialysis services assessed physical aspects of dialysis care and mortality rates. The care and services were then planned around what was found to be ‘normal’. It is often assumed that a lack of

clinical problems leads to increased patient satisfaction and a better quality of life. However analyses of patient satisfaction literature illustrate a greater variety of determinants of satisfaction than health outcome alone (Hall and Dornan, 1988; Cleary and McNeil, 1988).

There is a growing realisation that patient input can give a greater understanding of services and how to improve them. Since dialysis has such an impact on the life of the patient, the patient's views of the care they receive should be essential. One reason that patient satisfaction is particularly relevant in ESRD patients is because satisfied patients are more likely to adhere to medical regimes (Harris et al, 1995; Milas et al, 1995). It is particularly important that renal dialysis patients adhere to dietary restrictions since non-adherence decreases long-term survival rates. McGee et al (1998) found that non-adherence to dietary restrictions was common in Irish renal patients.

Measuring patient satisfaction of the quality of care in renal dialysis services necessitates a consideration of the dimensions to be measured. There are issues relevant specifically to ESRD patients. Patient satisfaction studies have investigated which aspects of care are most important to dialysis patients. Alexander and Sehgal (1998) studied patient ratings of the quality of care received from various medical staff. They used six aspects of care: 'availability of doctor, technical skill, personal manner, explanations provided, amount of time spent, and how much patient was helped', as well as an overall satisfaction rating. They found the areas of lowest satisfaction ratings were explanations provided and amount of time spent with medical staff.

Rubin et al (1997) studied the aspects of care that patients rate as most important. They identified 18 dimensions of dialysis care and found the areas rated as most important by dialysis patients were the care given by nephrologists, other doctors and nurses and patient education and training.

Dialysis patients may have different priorities depending on which dialysis modality they use. Rubin et al (1997) found that, compared with priority ratings of haemodialysis patients, peritoneal dialysis patients rated as more important the

accuracy of instruction from doctors, information provided regarding diet, nurse ability to answer their questions, and nurse and doctor cleanliness when dealing with dialysis access site. Wuerth et al (2000) investigated patient satisfaction with peritoneal dialysis services. The main areas of satisfaction were the information received from staff, the clinic atmosphere, the efficiency of delivery services and the primary nurse availability. All patients stressed the importance of the interaction with the nurse.

Research has found no differences in patient survival rates for haemodialysis and peritoneal dialysis (Little et al, 2001). Some patients do not have a choice of type of dialysis because peritoneal dialysis requires greater responsibility by the patient and may not be suitable for patients with particular health problems. However, other patients may not have a choice of dialysis modality because of a lack of hospital facilities. Some hospitals do not offer peritoneal dialysis. Many hospital haemodialysis units are being stretched to accommodate the numbers of haemodialysis patients. In an American study, Szabo et al (1997) compared patients who had had the opportunity to chose peritoneal dialysis with patients who had been forced to take peritoneal dialysis, and found that patients who did not have a choice rated their quality of life as significantly lower than patients who had chosen peritoneal dialysis. The planning of dialysis facilities in the future should enable freedom of choice of dialysis modality to patients, when this is medically possible.

1.6 Methods of measuring patient satisfaction

As patient satisfaction studies become more popular, a reliable tool of measurement becomes ever more crucial. There are many methods to measure patient satisfaction, the most popular being the questionnaire (McCarthy, McGee and O'Boyle, 1998). There are a number of concerns about the weaknesses of this method.

Firstly, there are concerns that questionnaires typically find high levels of satisfaction. It has been suggested that this is due to methodological problems, for example the wording of the questionnaire. However, these high levels of satisfaction

are reported throughout different health care services, different countries, and using different research methodologies, so this may simply indicate an overall satisfaction with care (McCarthy, McGee and O'Boyle, 1998). Alternatively, these high levels of satisfaction may be due in part to patient dependency on health services and their lack of alternative health care options with which to compare services (Batchelor et al, 1994).

Ross et al (1995) suggested that participants are biased towards agreement with questions, known as acquiescent bias. This bias can lead to higher levels of satisfaction being reported when positively worded questions are used and lower levels of satisfaction if wording is negative. They recommend neutrally wording questions. Another criticism of patient satisfaction questionnaires is that they are often quite basic, using simple rating scales of satisfaction or dissatisfaction. It has been suggested that a greater level of understanding could be reached by using qualitative methods (Coulter and Fitzpatrick, 2000; Calnan, 1998).

The acceptance of low response rates may give an inaccurate picture of patient satisfaction. Barkley and Furse (1996) compared patient satisfaction data for two groups; the first 30% of respondents and all respondents. They found significant differences between the two groups, suggesting that a low response rate of approximately 30%, which has been accepted by some patient satisfaction studies, does not give a full representation of patient satisfaction.

Wensing et al (1994) looked at 40 general practice patient satisfaction studies and found that postal questionnaire methods generally produced higher non-response rates compared with other methods. Harris, Weinberger and Tierney (1997) illustrated a higher response rate among inner-city hospital patients when using telephone interview with a follow-up by post compared with a mailed questionnaire followed-up with telephone interview. The telephone interview also yielded more complete data.

Many studies have measured patient satisfaction but few of these have focused on developing a reliable instrument for measurement that enables the study to be repeated at a later date to make comparisons of quality of service following

interventions. Arnetz and Arnetz (1996) developed an instrument to measure satisfaction and demonstrated improvements in the patient ratings of satisfaction following changes to services.

In the U.S., Carey and Seibert (1993) studied the quality of hospital services by developing inpatient and outpatient questionnaires which measured patient satisfaction on a number of specific dimensions of hospital services. They emphasised questionnaire reliability and validity since quality surveys are increasingly being used to assess changes in patient quality ratings following changes made to services. Carey and Seibert's outpatient questionnaire was adapted to the Irish setting by McCarthy, McGee and O'Boyle (2000) and used to investigate general adult outpatient services. Renal dialysis services will typically be provided on an outpatient basis and their measure was adapted for use in the present study.

Because of the possibility of improved response rates, the present study also adopted a telephone interview based on the standardised questionnaire. It used neutrally worded questions to avoid acquiescent bias. The telephone method also allowed qualitative reporting of experiences or clarification of responses, which may provide a more complete picture of patient views.

While many dialysis patients are in hospital on a regular basis, the dialysis setting was deemed not conducive to face-to-face interviews because of lack of privacy, patient discomfort or fatigue or the clinical demands of the setting. CAPD and CCPD patients would also not be easily accessed by such an approach. A telephone survey was thus considered more confidential, with the possibility of increased response rates, and serves to overcome problems such as low literacy and misunderstanding of questions. It was felt that particular patient concerns could be more readily recorded in a short telephone survey than through a self-completion questionnaire.

1.7 The present study

The present study investigated the multidimensional concept of patient satisfaction among patients using renal dialysis services provided by the ERHA.

The study was conducted in the context of planning for an increase in renal services and the aim to ensure equitably distributed and high quality services throughout the ERHA. The objective was to determine patient experiences, in particular levels of patient satisfaction, with various dimensions of their care in the hospitals providing renal services to the ERHA. Feedback to hospitals was aimed to inform them of the relative strengths and weaknesses of their own particular system alongside information on the population overall, which could be of value in service planning. It also provided an opportunity to describe the population being served at this point in time. Finally, it will provide a baseline from which future studies can monitor improvements at the level of patient satisfaction.

Chapter 2

METHODOLOGY

2.1 Introduction

All hospitals providing renal dialysis services in the Eastern Regional Health Authority (ERHA) were approached to participate. Of the four eligible hospitals, one declined participation. All adult renal dialysis patients from the remaining three hospitals were invited to take part. Children were not included in the study because the small number of children receiving dialysis meant that their anonymity could not be guaranteed and because the issues to be addressed were likely to require separate study.

The study received overall ethical approval from the RCSI Research Ethics Committee and from the ethics committees of the three participating hospitals.

2.2 Procedure

2.2.1 Pre-survey consultation

The study design included a consultation process in each hospital to collect the views of consultants, junior doctors, nurses and administrators on the proposed questionnaire and procedure. Consultant nephrologists also signed consent forms to allow contact of his/her patients. In addition, a pilot study of the questionnaire provided an opportunity for input from patients in the final design of the measurement instrument.

2.2.2 Invitation to participate

All adult renal patients received correspondence comprising an introductory letter from their consultant (Appendix 1 – Letter from Consultant), a patient information sheet explaining the purpose of the study (Appendix 2 - Patient Information Sheet) and a consent form (Appendix 3 – Patient Consent Form). They were asked to return the consent form, indicating whether or not they agreed to participate in a telephone interview. If agreeing to participate, they were asked to sign the consent form, enter a suitable time for telephone interview and confirm their telephone number. Patients who did not return their consent form received a reminder telephone call to enquire if they wished to participate in the study.

When consent was received, telephone interviews were conducted using the Renal Patient Satisfaction Questionnaire (Appendix 4 – Patient Satisfaction Questionnaire). Interviews were conducted from a customised telephone call setting at the Health Services Research Centre, Department of Psychology, Royal College of Surgeons in Ireland.

2.3 Measures

Most renal dialysis services are delivered as outpatient services. The outpatient satisfaction questionnaire developed by Carey and Seibert (1993), and previously

adapted by McCarthy, McGee and O'Boyle (2000), was used in the present study. It was thought to be the most appropriate assessment method for the measurement of ongoing quality improvement. This measure was developed further following consultation with literature on renal dialysis services and discussion with consultant nephrologists and ERHA administrators, to address evaluation issues specific to renal dialysis services.

The questionnaire examined multiple dimensions of patient satisfaction using five-point rating scales. It also incorporated open-ended questions, allowing for patients' qualitative experiences of renal dialysis services. The questionnaire contained some questions relating specifically to haemodialysis and some relating only to peritoneal dialysis (CAPD and CCPD).

2.4 Sample

Study information packs containing study information and consent forms were initially sent to a total of 363 patients in three hospitals. Of these, 35 patients were excluded from further participation: 12 patients were deceased, six were transplanted, three were transferred to a different dialysis unit, and 14 were deemed not contactable (no known postal address, telephone disconnected or in long-term hospital care). This resulted in a total potential population of 328 patients.

Consent forms from 167 participants were returned by post prior to a follow-up telephone call (i.e. an initial response rate of 51%). The remainder then received one telephone reminder and 20 patients subsequently returned consent forms. During telephone follow-up reminders, a further five participants requested, and subsequently returned, postal questionnaires. Thus of a possible sample of 328 patients, there were 192 participants (response rate 59%). Table 2.1 shows a breakdown of response rates by hospital. The number of patients who participated from each of the three hospitals was 114, 59 and 19 participants. The hospital from which 19 patients participated has a small haemodialysis unit and the separate results for this small group should be treated with caution.

Table 2.1. Response rates for the three hospitals

	Response rate %
Total	59
Hospital 1	73
Hospital 2	62
Hospital 3	50

As a relatively new form of survey for patient studies, the opportunity was taken to assess the acceptability of a telephone research interview. At the end of the interview, participants were asked the following question:

“Have you found it acceptable to be interviewed over the telephone?”

In total, 98% of participants said they had found it acceptable to be interviewed over the telephone. Participants were also asked the following:

“We don’t have any plans to contact you again, but if we were to do a follow-up study in a few months time or longer, would you be willing to be contacted again? You could of course say ‘no’ to participation at that point.”

In response to this question, 97% of all participants agreed that they would be willing to be contacted again.

2.5 Statistical analysis and data presentation

A Filemaker Pro database was used to store data. It was analysed using the Stata statistics programme. The results are displayed as percentage of patients across all hospitals, and also presented by individual hospital.

For questions involving patient satisfaction with services, satisfaction was rated as 1 (very dissatisfied), 2 (dissatisfied), 3 (neither satisfied or dissatisfied), 4 (satisfied)

and 5 (very satisfied). In illustrating results, satisfaction questions have been collapsed from five categories to three categories, i.e. 'dissatisfied', 'neither' and 'satisfied'.

In displaying summary statistics, the range (lowest value and highest value) and the median have generally been used to illustrate results. Because many of the questions are answered in a statistically skewed manner, the median score is given instead of the average score. The median identifies the point at or above which 50% of scores lie.

Chapter 3

RESULTS

3.1 Demographic profile

3.1.1 Age and gender profile

In all three hospitals, there were more male than female participants, reflecting the general dialysis patient profile. Participant age ranged from 17 to 88 years, with a median age of 58. Over one third of the sample (37%) were aged 65 years or older. Table 3.1 summarises participant age and table 3.2 shows gender and age profiles across the three hospitals.

Table 3.1 Age profile of study participants

	Median (years)	Range (years)
Total	58	17 – 88
Hospital 1	66	31 – 80
Hospital 2	60	17 – 88
Hospital 3	52	20 – 79

Table 3.2. Gender and age profile of participants

	Gender %		Age %			
	Male	Female	16-35 years	36-50 years	51-65 years	+65 years
Total	60	40	13	20	30	37
Hospital 1	63	37	10	0	32	58
Hospital 2	65	35	12	20	27	41
Hospital 3	51	49	13	29	36	22

3.1.2 Occupational profile

One fifth of all participants were in paid employment and 32% were retired. The remainder were not employed, with 20% of all participants stating that they were unable to work due to their renal condition (this is 32% of those below the state retirement age of 66 years). Figure 3.1 illustrates the employment status of all participants and table 3.3 shows a breakdown of employment status by hospital.

Figure 3.1. Employment status of all participants

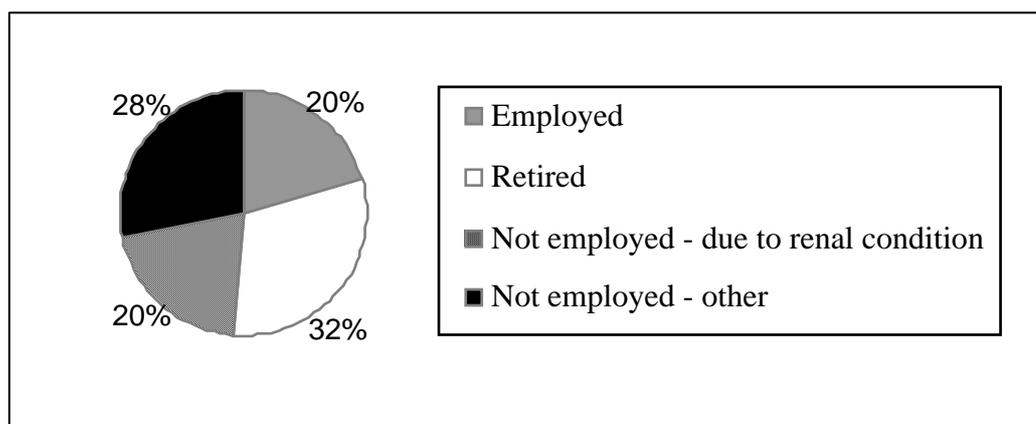


Table 3.3. Employment status by hospital

	Employed %	Retired %	Not employed – due to renal conditio n %	Not employed – other reasons %
Total	20	32	20	28

Hospital 1	16	48	10	26
Hospital 2	19	32	19	30
Hospital 3	24	24	25	27

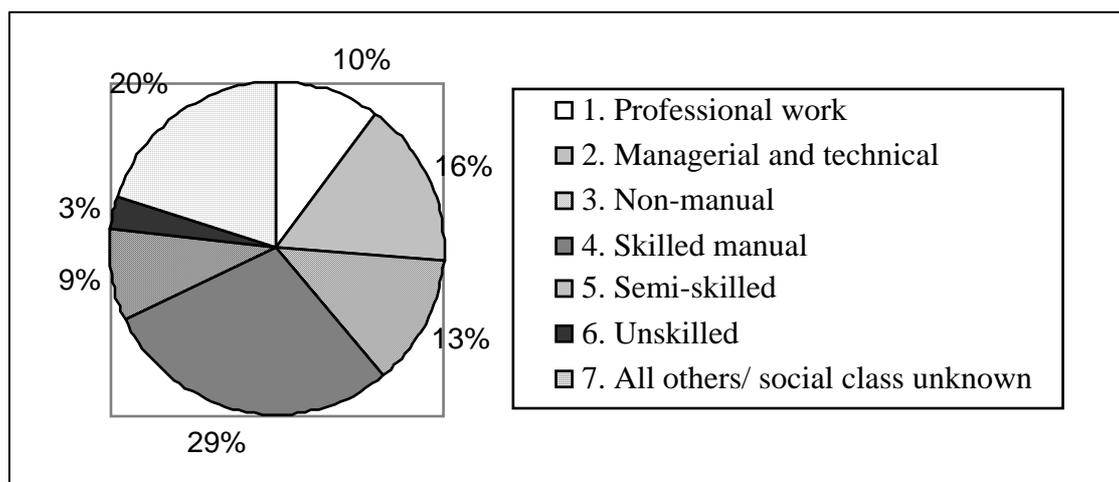
Participant employment status for each dialysis type was considered, since haemodialysis patients are constrained by regular hospital visits for dialysis every week whilst peritoneal dialysis patients can carry out their dialysis in a wider range of settings. However, percentages of participants in the various employment categories were similar for the two types of dialysis (table 3.4).

Table 3.4. Employment status by dialysis type

	Employed %	Retired %	Not employe d – due to renal conditio n %	Not employed – other %
Total	20	31	20	29
Haemodialysis	19	32	19	30
Peritoneal Dialysis	24	27	24	25

Participants were classified in terms of their social class, determined by the occupation of main household earner, or previous occupation if retired. Figure 3.2 illustrates the percentage of participants in each social class.

Figure 3.2. CSO Social class of participants



(From Social Class Definitions, CSO 1991 Census)

3.1.3 Profile of participant distance from home to hospital

Participants were questioned about the distance from their home to the hospital they attend for dialysis services, and about the county and health board in which they lived. Overall, participants lived a median of 8 miles from the hospital they attended, with some variation across hospitals (table 3.5).

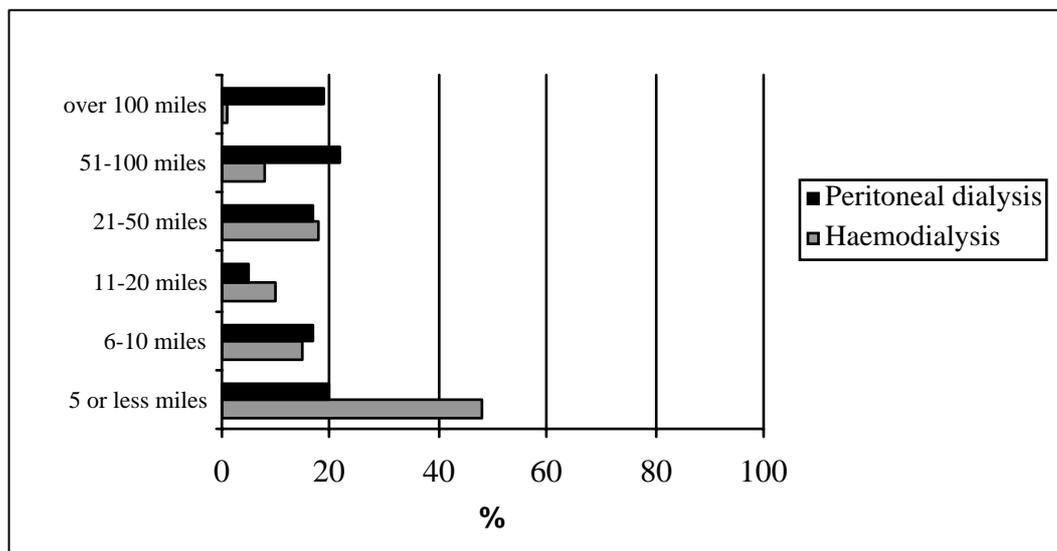
Table 3.5. Distance from participant home to hospital

	Median (miles)	Range (miles)
Total	8	0.5 – 200
Hospital 1	5	1.25 – 50
Hospital 2	12	0.5 – 200
Hospital 3	7	1.25 – 180

While a number of participants travelled long distances for dialysis services, a more useful breakdown of the information is by dialysis type, since haemodialysis patients must travel to hospital two to four times per week, while peritoneal dialysis patients generally travel to hospital less often for more typical outpatient appointments.

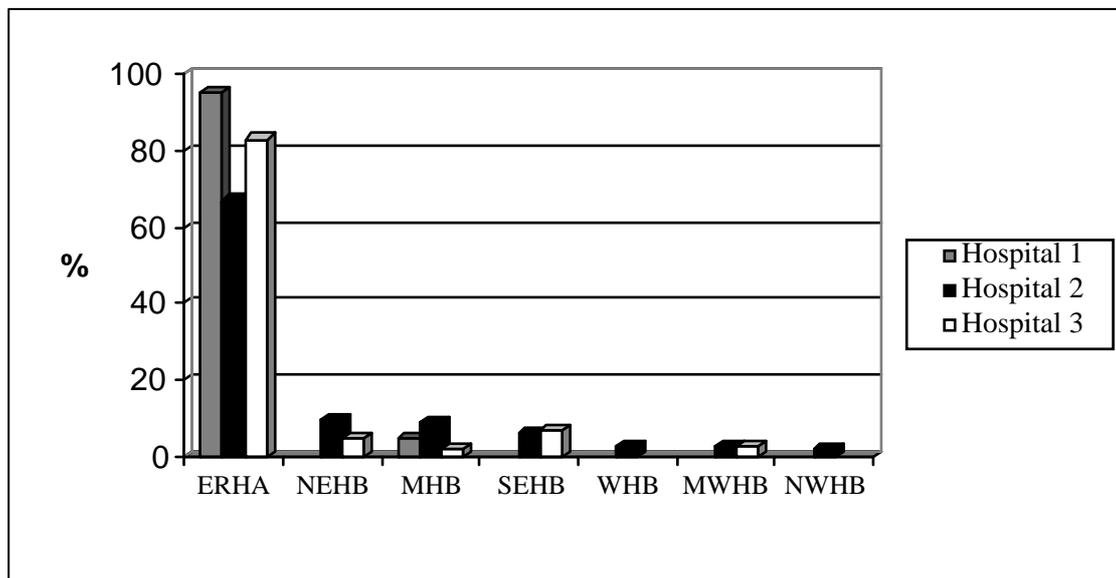
Figure 3.3 illustrates the distance from hospital to home for patients availing of haemodialysis and peritoneal dialysis. Haemodialysis patients lived a median 5.5 miles (range 0.5-150 miles) and peritoneal dialysis patients a median 40 miles (range 1-200 miles) from treating hospitals. Thus, the patients who live farthest from the hospital are generally peritoneal dialysis patients, who usually travel to the hospital for dialysis services less often than haemodialysis patients. While most haemodialysis patients live relatively close to hospital, 9% live over 50 miles away from a service they need two to four times weekly.

Figure 3.3. Distance from patient home to hospital for haemodialysis and peritoneal dialysis patients



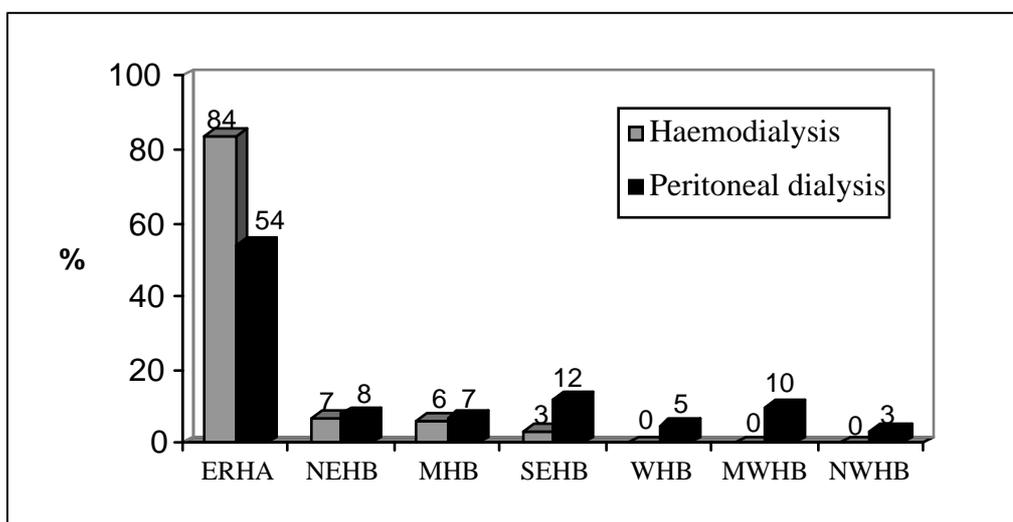
All three hospitals discussed in the present study are in the Eastern Regional Health Authority (ERHA) geographical area. However, when asked in which health board area they lived, 25% of participants reported that they travelled from other health board areas to use dialysis services in the ERHA. Figure 3.4 illustrates the health board areas from which participants originate.

Figure 3.4. Health board area of participants by hospital



Non-ERHA participants were asked why they travelled to an ERHA hospital for dialysis services. The major reason stated was that there were no dialysis services locally. Figure 3.5 illustrates the distribution of haemodialysis and peritoneal dialysis patients across the health boards.

Figure 3.5. Health board residence of haemodialysis and peritoneal dialysis study participants attending ERHA services



It is notable that more non-ERHA patients were on peritoneal dialysis (46% of peritoneal dialysis patients were non-ERHA while only 16% of haemodialysis patients were non-ERHA (and all of these resided within three health boards directly adjoining the ERHA (i.e. SEHB, NEHB and MHB)). Whether patients eligible for peritoneal dialysis are in some way 'directed' to ERHA centres providing these services or whether services faced with the challenge of geographical distance are more likely to consider peritoneal dialysis is not clear from this data.

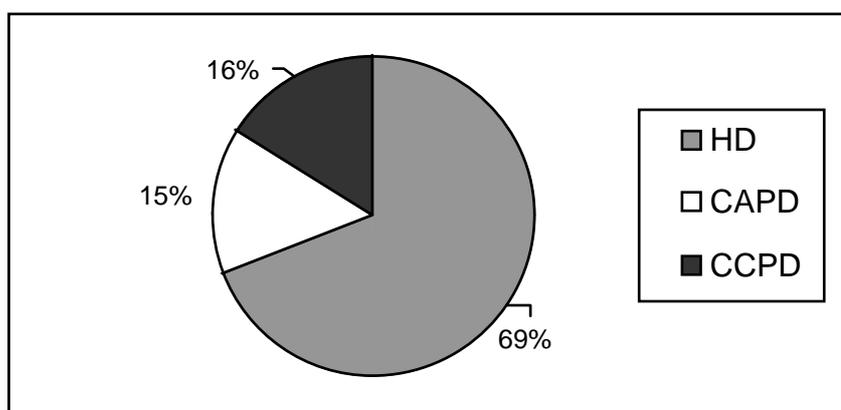
3.2 Patient dialysis profile

Section A of the dialysis questionnaire investigated patient dialysis profiles, including types of dialysis currently and previously availed of, length of time on dialysis and transplant profile. Section E considered information about kidney disease provided by the hospital and section F explored participant understanding and patient choice of dialysis type. All 192 participants were asked all questions in sections A, E and F, providing a full representation of overall patient dialysis profiles.

3.2.1 Type of renal service used

Of a total sample of 192 renal patients, 69% availed of haemodialysis while 15% used CAPD and 16% used CCPD (figure 3.6).

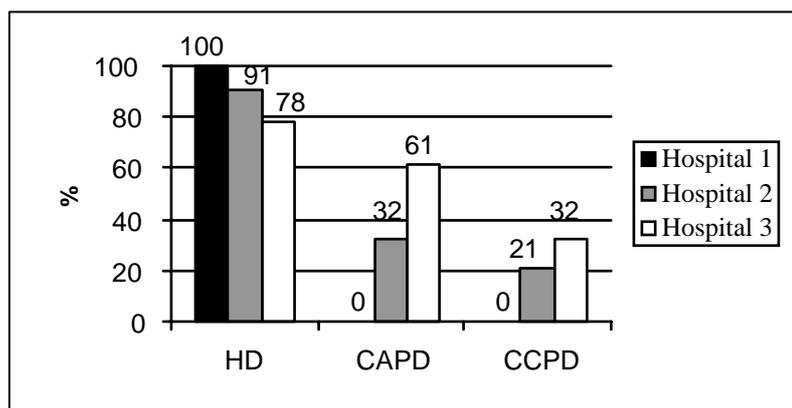
Figure 3.6. Type of dialysis currently used by total sample



There were variations across hospitals with one hospital providing no CAPD or CCPD services, another having half of their patients (51%) on CAPD or CCPD and the third hospital having 74% of participants using haemodialysis and 26% using CAPD or CCPD.

Participants were also questioned about the types of dialysis they had previously used. Figure 3.7 illustrates the percentage of participants who had ever used each type of dialysis in each hospital. In total, 88% of all participants had used haemodialysis at some point, 38% had used CAPD and 23% had used CCPD at some time.

Figure 3.7. Types of dialysis ever used by participants at each hospital



3.2.2 Length of time on renal dialysis

Participants were asked when they started dialysis. For patients who had received a kidney transplant but whose transplant had since failed and who were again on dialysis, the length of time on dialysis was counted as length of time on continuous dialysis (i.e. since their most recent transplant failure). It was considered that length of time of continuous dialysis would be more useful data since a transplant patient may have originally begun dialysis a number of years ago, but for only a short period before transplantation. Table 3.7 shows summary statistics of length of time on dialysis. Participants had a median 24 months on continuous dialysis with a variation from 18 months in one unit to 26 months at another unit.

Table 3.7. Summary statistics for number of months on dialysis

	Mean (months)	SD (months)	Median (months)	Range (months)
Total	31.7	29.5	24	0.5 – 163
Hospital 1	18.8	12.3	18	3 – 42
Hospital 2	32.9	30.9	24	0.5 – 163
Hospital 3	33.5	30.1	26	3 – 155

3.2.3 Renal transplantation profile

Participants were questioned about their kidney transplant history. Of the 192 participants, 54 (28%) had previously had one or more kidney transplants (table 3.8).

Table 3.8. Number of participants who had one or more kidney transplants

	%
Total	28
Hospital 1	5
Hospital 2	32
Hospital 3	27

When asked whether they were currently on the transplant waiting list, 65 participants (34%) said they were on the list, 122 (63%) said they were not on the list, and the remainder were unsure whether they were on the transplant waiting list (table 3.9).

Table 3.9. Profile of participants on the transplant waiting list

	Yes %	No %	Don't know %
Total	34	63	3
Hospital 1	5	84	11

Hospital 2	37	61	2
Hospital 3	37	61	2

Analysis of participant comments suggested a number of reasons for not being on the transplant waiting list. Many participants believed that medical reasons made them permanently unsuitable for a transplant, or they were currently unsuitable due to recent surgery or illness. A number of participants thought they were too old to receive a kidney transplant. Many respondents were still waiting for tests in order to be added to the waiting list, and some felt that they did not want to be on the waiting list for a transplant.

Responses from participants of Hospital 1 suggested that only 5% were on the transplant waiting list, with 84% stating that they were not on the list. Over a third of respondents at this hospital who were not on the transplant waiting list stated that they did not know why they were not on the list.

The 65 participants who had stated that they were on the transplant list were then asked how long they had been on the waiting list (figure 3.8 and table 3.10). While the median waiting time to date was 12 months, 15% reported they were then waiting longer than two years for a transplant.

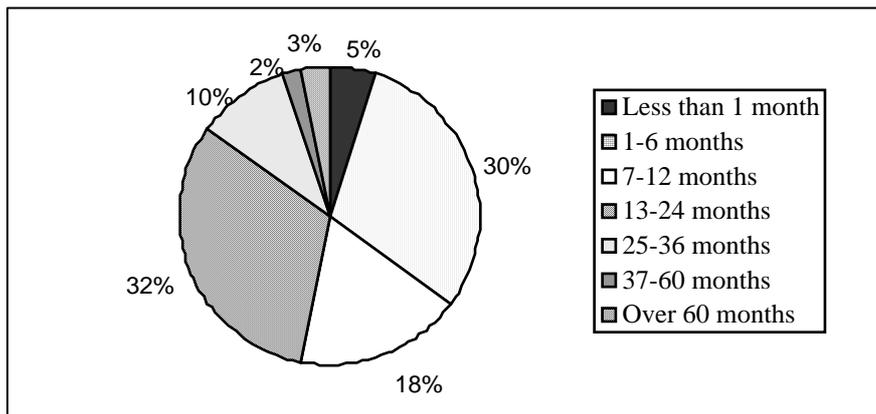


Figure 3.8. Length of time participants had been on transplant waiting list

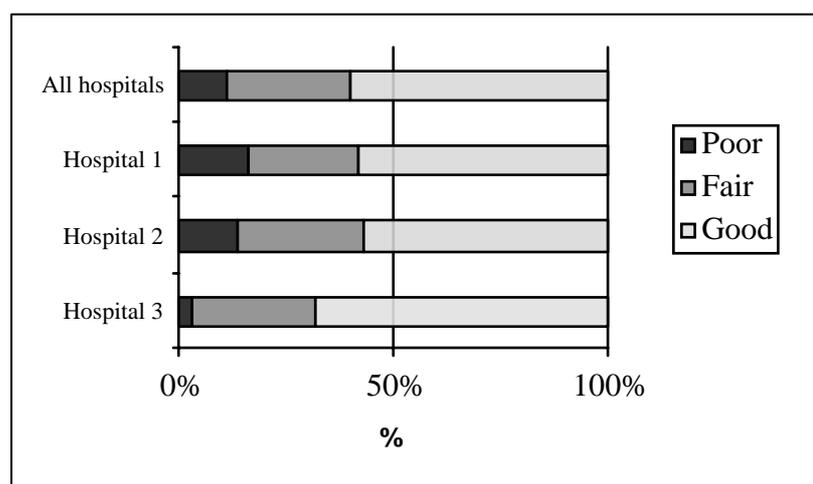
Table 3.10. Length of time on transplant waiting list by hospital

	Mean (months)	SD (months)	Median (months)	Range (months)
Total	16.1	18.3	12.0	0 – 100
Hospital 1	-	-	15.0	NA
Hospital 2	17.2	18.4	14.5	0 – 100
Hospital 3	14.2	18.8	9.0	1 – 84

3.2.4 Health status

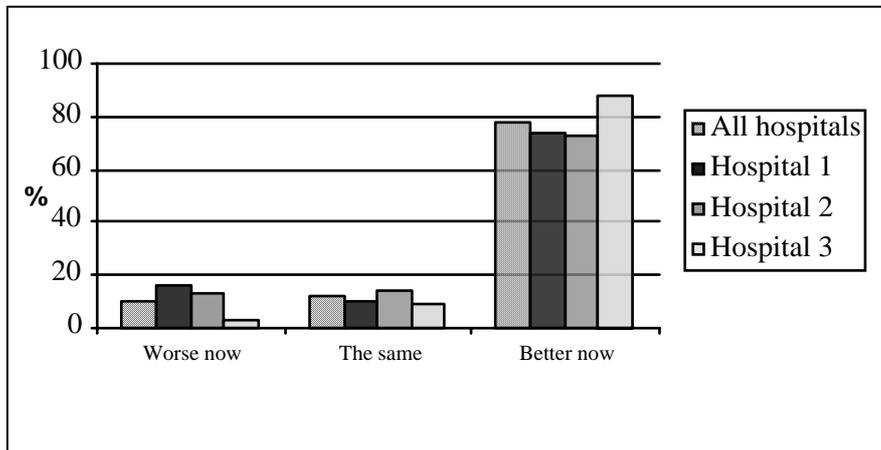
Participants rated their “current general health” (figure 3.9) and their “health now compared to when they were first referred for dialysis” (figure 3.10).

Figure 3.9. Current health rating



In total, 60% of participants rated their current health as good or very good, with small variations across hospitals (figure 3.9). Over three-quarters (78%) of participants reported that their current health was ‘much better’ or ‘somewhat better’ than their health when they were first referred for dialysis (figure 3.10).

Figure 3.10. Current health rating as compared with when first referred for kidney dialysis



3.2.5 Satisfaction with type of dialysis provided and with choice of dialysis type

Participants were asked if they knew why they were treated with their current type of dialysis (table 3.11), and if they felt they had a choice of which dialysis type to be treated with (table 3.12).

Table 3.11. “Do you know why you are on your current type of dialysis?”

	Yes %	No %
Total	76	24
Hospital 1	37	63
Hospital 2	78	22
Hospital 3	84	16

Table 3.12. “Did you have a choice of which type of dialysis to have?”

	Yes %	No %
Total	65	35
Hospital 1	21	79
Hospital 2	73	27
Hospital 3	62	38

Over three quarters (76%) reported they knew why they were assigned to their particular type of dialysis. There were clear differences between Hospital 1 and the other hospitals. Fewer of Hospital 1 participants knew why they were on their current type of dialysis. While two thirds (65%) felt they had a choice of type of dialysis, fewer of Hospital 1 participants felt they had a choice of which dialysis type to use. These results must be interpreted cautiously and in the context that Hospital 1 did not offer peritoneal dialysis.

However, analysis of participant comments also highlighted differences between hospitals. Firstly, most respondents from Hospital 2 and Hospital 3 who felt they had not had a choice of dialysis type explained further that other dialysis types were not possible due to medical reasons. For example, some haemodialysis patients were not suited to peritoneal dialysis due to previous surgery, or because previous use of peritoneal dialysis had resulted in infection difficulties. Other reasons given by respondents from hospitals where peritoneal dialysis was available were that they had needed to start haemodialysis in an emergency due to serious illness or that they were restricted due to disabilities.

Conversely, analysis of comments from participants of Hospital 1 who felt they had not had a choice of dialysis type suggested that a higher proportion do not know about alternative dialysis types. A number of respondents said they knew nothing, or very little, about peritoneal dialysis.

Participants were then asked to rate their level of satisfaction with the type of dialysis currently used. Table 3.13 illustrates levels of satisfaction across hospitals and table 3.14 shows satisfaction levels across different dialysis types. High levels of satisfaction were recorded across all hospitals (97%) and for all dialysis types (97%).

Table 3.13. Satisfaction with current type of dialysis by hospitals

	Satisfied %	Neither %	Dissatisfied %
Total	97	1	2
Hospital 1	100	0	0
Hospital 2	99	1	0
Hospital 3	93	0	7

Table 3.14. Satisfaction with current type of dialysis across dialysis types

	Satisfied %	Neither %	Dissatisfied %
Total	97	1	2
Haemodialysis	97	0	3
CAPD	100	0	0
CCPD	97	3	0

The possibility of dialysis type preference was explored. Participants were initially asked, all things being equal, which type of dialysis they would prefer. Of all haemodialysis participants, 81% stated that their preference was for haemodialysis, essentially stating that they were currently availing of their preferred dialysis type. Of CAPD participants, 89% said their preference was for CAPD, and 94% of CCPD participants said they would prefer CCPD. Thus it appears that a high majority of patients (84% in total) were availing of their preferred dialysis type. However, an important consideration is again the level of knowledge of alternative types of dialysis. Participants were therefore asked to rate their level of knowledge of different

types of dialysis. Figures 3.11, 3.12 and 3.13 suggest that level of knowledge of CAPD to some extent, and CCPD to a greater extent, is fair or poor for participants not using these dialysis types.

Figure 3.11. Participant ratings of their level of knowledge of haemodialysis

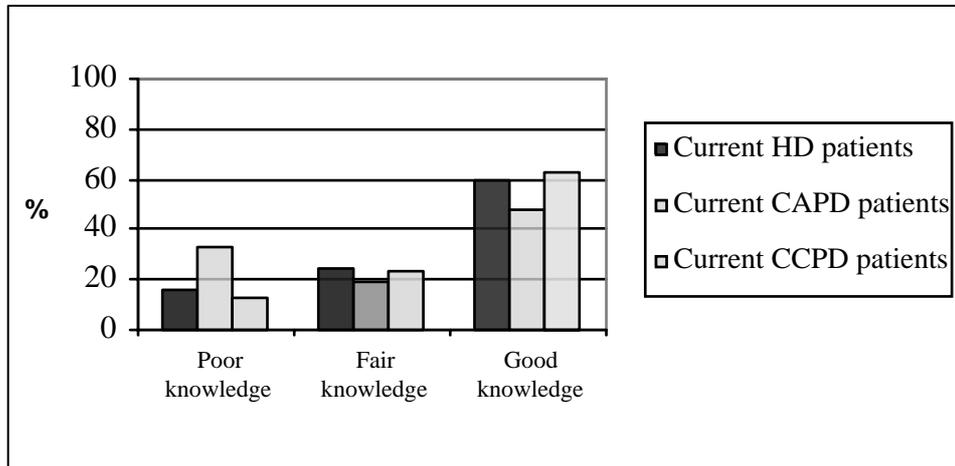


Figure 3.12. Participant ratings of their level of knowledge of CAPD

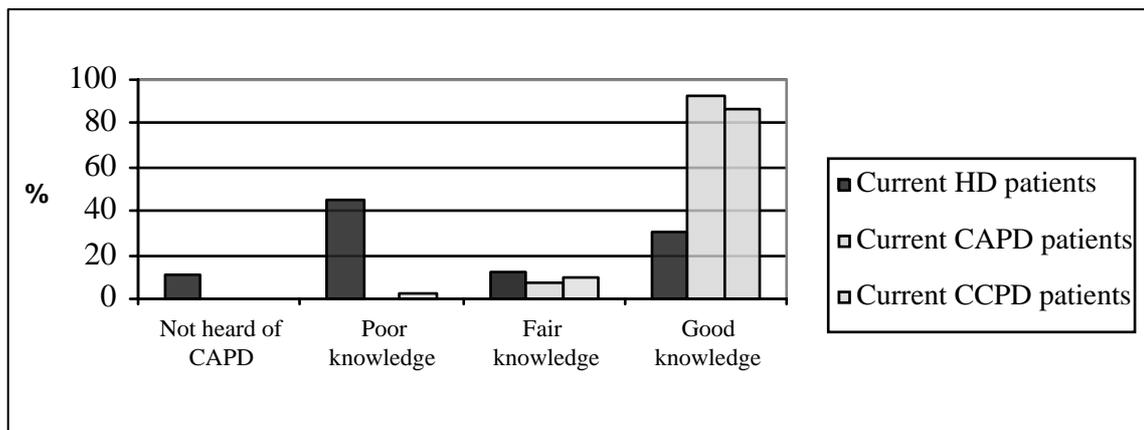
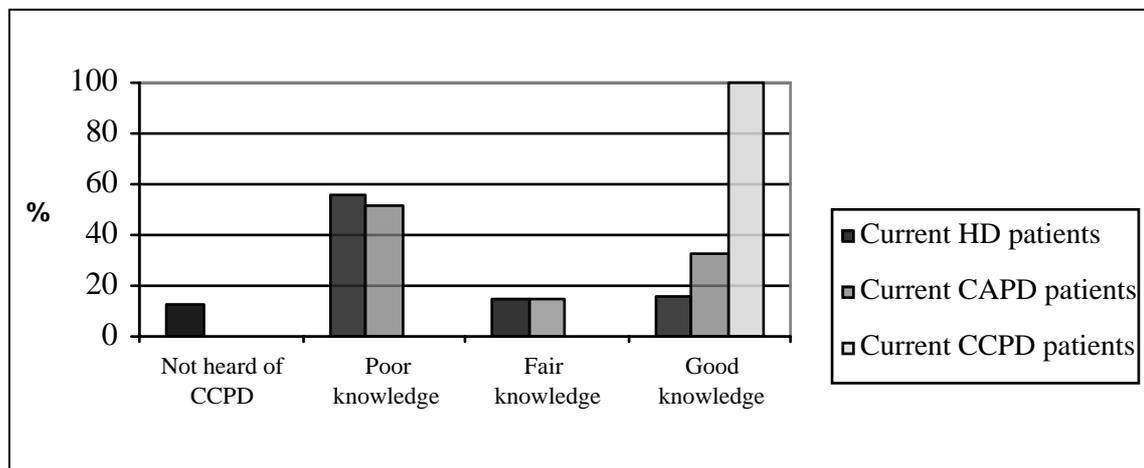


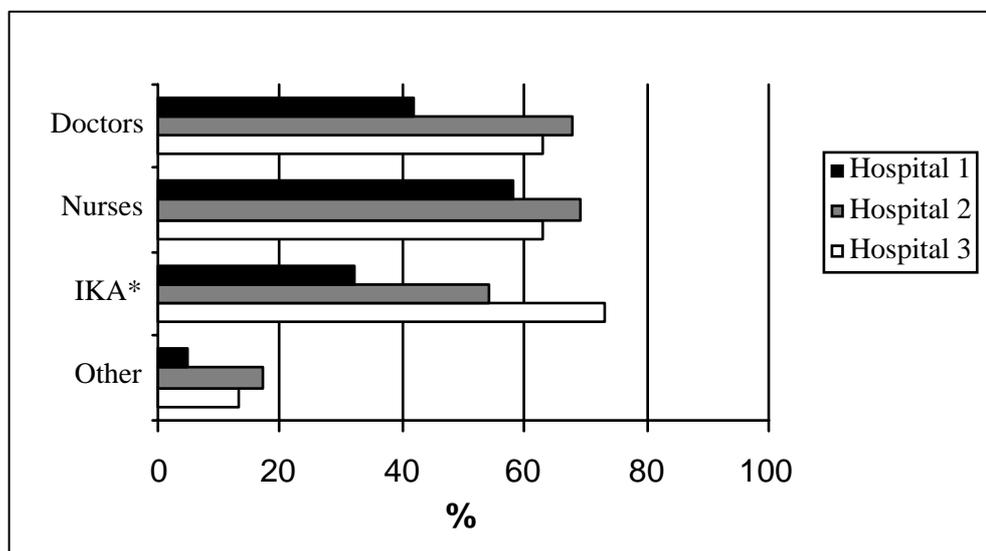
Figure 3.13. Participant ratings of their level of knowledge of CCPD



3.2.6 Information about kidney disease

All participants answered section E of the dialysis questionnaire, regarding the information they had received about kidney disease and their kidney condition, and from whom they had received information (figure 3.14). Participants were asked to name all sources of information so figures shown are percentages of the total participants for each hospital.

Figure 3.14. Source of information about kidney disease



[* IKA = Irish Kidney Association]

There are clear differences across hospitals in the percentages of participants who stated they had received any information from each source. Differences in information received by doctors and nurses may reflect local practices and/or the extent to which each dialysis service is delivered by nurses or doctors. However, 32% of respondents from Hospital 1 stated they had received information from the Irish Kidney Association (IKA), compared with 54% and 73% of respondents from Hospital 2 and Hospital 3 respectively. The main source of information making up the 'Other' category was information from the Internet, with other sources mentioned including medical texts, libraries and family members.

Those participants who had stated that they had received information from doctors,

nurses and the IKA were then asked to rate how useful the information was from each source. All information received by participants was rated highly, with 89% of participants who had received information from doctors stating that the information was ‘good’ or ‘very good’. Of all participants who had received information from nurses, 93% rated the information as ‘good’ or ‘very good’. Similarly, 88% of participants who had received information from the IKA rated it as ‘good’ or ‘very good’.

Participants from all hospitals were then asked to rate their overall level of satisfaction with information provided and available about their kidney disease (table 3.15).

Table 3.15. Patient satisfaction with information provided and available about their kidney disease

	Satisfied %	Neither %	Dissatisfied %
Total	84	8	8
Hospital 1	83	6	11
Hospital 2	86	7	7
Hospital 3	81	9	10

Again, high levels of overall satisfaction (84%) were observed across all hospitals, despite variations in source and extent of information. Participants were finally asked to recommend improvements in the provision of information. From respondents of all hospitals who were both satisfied and dissatisfied with the information provided, the most frequently expressed recommendation was to provide more information. Areas in which the hospitals were seen as capable of providing more information included the cause of patient’s kidney disease and original kidney failure, how the patient’s dialysis is progressing, and transplantation.

Respondents made suggestions of how the hospitals could provide more information. Some suggestions were to make more leaflets available, provide more detailed

information, update booklets and provide holiday information. Examples of suggestions are listed below:

“They could have a leaflet stand in the dialysis unit.”

“A wider range of information should be available, especially on the ward and in the unit.”

“A lot of the information you get from other patients. They could give you other information, especially about transplants. They don’t tell you about the psychological side, only about the medical side.”

“Maybe if there was more information leaflets about the different kidney conditions left in the waiting area. Also information listing website addresses to look at because there’s lots of information on the Internet so it’s a matter of finding the right information.”

“More information about mobility and holidays. I looked it up on the Internet and found quite a lot of information which should be available for all patients who may not be able to access Internet information.”

“More updated booklets – they’re very dated. Medicine is moving on.”

“To have a proper little book that isn’t all doom and gloom, with some humour. They have one that’s quite basic and has no humour.”

A major area of improvement suggested by many participants from Hospital 2 and also some participants from Hospital 3 was to provide more information at the start: at the time when patients are first diagnosed with kidney failure and when they first begin dialysis. The following comments are examples of views expressed by many

participants:

“When starting dialysis, it would be a great idea to speak to someone who’s already on dialysis or who’s been on dialysis, to give you an idea of what to expect.”

“Was extremely frightened at the start – it’s hard to make a decision at the start of which type of dialysis to go on.”

“If they told you at an early stage what was wrong and what to expect. It was a bit disappointing because I wasn’t given a lot of information. There wasn’t a word about dialysis - it just came out of the blue. They could have forewarned me and told me as I went along.”

“They tell you on a need to know basis rather than keeping you informed. Also, before they take out your kidney, they should tell you what’s going to happen with dialysis. They should tell you more from the start – should have things like counselling.”

Respondents also suggested that the IKA could have more involvement in the provision of information to patients, for example:

“The IKA could get more involved with their patients – they should have somebody to come to the hospital as a contact person who we can go to if we have problems.”

“We don’t see [the IKA] in the dialysis unit. The IKA should come into the dialysis unit, should sit down with staff at the hospital and work out what the IKA’s role is going to be. The IKA should become more involved in the social area of patients lives, should give you information about getting dialysis abroad on holidays. They could organise patients holidays around Ireland or abroad. Information about what the IKA is about, what they do, where their money is spent, research areas.”

3.3 Haemodialysis services

Section B of the patient satisfaction questionnaire (see Appendix 4) investigated satisfaction with haemodialysis care, in particular the care received within the haemodialysis unit of each hospital. All participants who had stated that their current type of dialysis was haemodialysis (n=133) were asked these questions.

3.3.1 Haemodialysis profile

Participants were asked about their haemodialysis profile, including how often and for how many hours they have dialysis, and about the days and times of dialysis. Participants' most recent visit for haemodialysis was between zero (today) and four days ago, with a mean of 1.18 days ago. Table 3.16 shows summary statistics for the number of sessions per week and table 3.17 shows summary statistics of length of each dialysis session.

Table 3.16. Participant number of dialysis sessions per week

	Mean	SD	Median	Range
Total	2.8	0.4	3	2-4
Hospital 1	2.7	0.5	3	2-3
Hospital 2	2.9	0.4	3	2-4
Hospital 3	2.8	0.4	3	2-3

Table 3.17. Participant number of hours of dialysis per session for each hospital

	Mean (hours)	SD (hours)	Median (hours)	Range (hours)
Total	3.4	0.5	3.5	2.5-4
Hospital 1	3.1	0.3	3	3-4
Hospital 2	3.5	0.5	3.5	2.5-4
Hospital 3	3.4	0.4	3	3-4

A median three sessions per week were being used by patients in all hospitals. Length of time of dialysis session ranged (median) from three to three and a half hours. Table 3.18 illustrates whether participants felt they were given a choice of days and times of dialysis sessions. While the majority of participants in all hospitals felt they were not given a choice of days (62%) or of times (60%), overall satisfaction with days and times was high (89%) (table 3.19).

Table 3.18. Participant choice of days and times to have dialysis

	Choice of days		Choice of times	
	Yes %	No %	Yes %	No %
Total	38	62	40	60
Hospital 1	21	79	32	68
Hospital 2	38	62	40	60
Hospital 3	48	52	45	55

Table 3.19. Participant satisfaction with times and days of dialysis

	Satisfied %	Neither %	Dissatisfied %
Total	89	3	8
Hospital 1	95	5	0
Hospital 2	89	2	9
Hospital 3	86	3	11

3.3.2 Travel arrangements

In all hospitals, the most common mode of transport to the dialysis unit was health board taxi (average 77%; Hospital 1, 68%; Hospital 2, 78%; Hospital 3, 79%).

Participants were asked how long it took to travel to the hospital for dialysis (table 3.20). This was a median 22 minutes, with little real variation across hospitals.

Table 3.20. Length of time taken to travel to hospital for haemodialysis

	Median (mins)	Range (mins)
Total	22.5	2-165
Hospital 1	17.5	2-105
Hospital 2	22.5	5-165
Hospital 3	25	5-150

There were high levels of satisfaction with travel arrangements (92%), as illustrated in table 3.21.

Table 3.21. Satisfaction with travel arrangements to dialysis unit

	Satisfied %	Neither %	Dissatisfied %
Total	92	0	8
Hospital 1	95	0	5
Hospital 2	92	0	8
Hospital 3	90	0	10

While there were high levels of satisfaction with travel, participant comments further highlighted issues surrounding travel arrangements. All respondents who stated they were dissatisfied with travel arrangements at Hospital 2 had been availing of the health board taxi service. Examples of their comments are listed below:

“I used to travel to haemodialysis with others on a bus but it was changed to a taxi with four of us in. Travelling to dialysis is very uncomfortable – travel with three in the back.”

“I have to wait for two hours to get home after dialysis.”

“Very often they’re late. A number of taxi drivers smoke and I think that’s dreadful.”

Other issues arising from respondents of Hospital 2 who had stated they were satisfied with the travel arrangements follow:

“I use my own car because I wasn’t happy with the taxi service – I was waiting after dialysis for one and a half hours for the taxi.”

“Sometimes the taxi can be late to collect you or late to pick you up after dialysis and you wait in the hospital when you just want to leave.”

“If another person who is sharing your taxi is ill after dialysis, we all have to wait for two hours or more.”

Comments made from a small number of respondents from Hospital 3 who were both satisfied and dissatisfied with the travel arrangements are:

“I’m dissatisfied but there’s not much you can do. The fact that they supply the taxi is good – removed that burden.”

“I wish there was a unit near me – it’s the travelling that’s the difficult part.”

“There’s a bit of a wait between arriving at the hospital and getting on the machine – could be waiting an hour and you get tired. They could coordinate the times I’m collected with the hospital so that you arrive and go straight onto the machine.”

Those participants who had indicated that they travel to the dialysis unit by car rated the parking convenience. While only 25 participants across all hospitals indicated that they had travelled by car, there were clear differences between parking convenience ratings across hospitals, as illustrated in table 3.22.

Table 3.22. Participant rating of parking convenience

	Good %	Fair %	Poor %
Total	56	4	40
Hospital 1	75	0	25
Hospital 2	33	7	60
Hospital 3	100	0	0

The majority of respondents from Hospital 2 considered the parking convenience to be poor or fair, whilst respondents from Hospital 1 and Hospital 3 generally rated the

parking convenience as good. Illustrative comments given by respondents from Hospital 2 who had rated the parking convenience as poor are listed below:

“They have designated dialysis spaces - if I was there during the daytime, dialysis ambulances park there so I would have trouble parking. And the general public and staff ignore the designated parking spaces. They should be better policed or patients given a pass into the barrier parking.”

“There are dialysis spaces with ‘Dialysis’ written on but I have to drive around the hospital finding a space. There are too few dialysis parking spaces.”

Conversely, all respondents from Hospital 3 rated parking as good or very good, and commented:

“There is special parking for the dialysis unit and I have a special card for the special dialysis parking area.”

“I have access to the dialysis parking facility.”

Respondents from Hospital 1 who had rated the parking convenience as good or as poor made the following comments:

“Sometimes I can’t get a space in the dialysis parking area. The parking is very stressful. The main car park would be €9 a time.”

“The new car park is filled up with doctors and hospital staff and is supposed to be for disabled patients, who are queuing up for spaces in the afternoon.”

3.3.3 Dialysis unit

Participants rated various aspects of the dialysis unit, including physical aspects such as comfort, and practical issues surrounding the running of the unit. Table 3.23 summarises views on physical aspects of the unit.

Table 3.23. Participant rating of space and comfort of dialysis unit

<i>“What is your view of...”</i>	Good %	Fair %	Poor %
<i>... the space available in the dialysis unit?</i>			
Total	74	16	10
Hospital 1	84	11	5
Hospital 2	79	13	8
Hospital 3	55	28	17
<i>... the comfort of the dialysis unit?</i>			
Total	84	9	7
Hospital 1	100	0	0
Hospital 2	82	11	7
Hospital 3	80	10	10

Three quarters (74%) were satisfied with space at the unit, with Hospital 3 reported as less satisfactory. Similarly, most (84%) found the unit comfortable. Many

respondents commented on lack of space at dialysis units. For example, the following comment was made by a respondent who had rated the space available at Hospital 2 as good:

“The one with the four beds is grand – the other one is a bit overloaded, slightly cluttered. They could do with another unit.”

Respondents from Hospital 2 who rated the space available more negatively made the following comments:

“It’s very cramped. For the amount of patients in there now, you’re basically on top of each other.”

“It’s really quite crowded and cramped. There’s not much space between beds.”

Whilst 45% of respondents at Hospital 3 rated the space available as poor or fair, qualitative analysis of their comments highlighted the same issues as for the other hospitals, for example:

“I was disappointed. It could have been twice as big. Beds farther apart would have given more privacy.”

“Waiting room is very cramped, the unit is small and in summer is very stuffy.”

In relation to the comfort of the dialysis unit, a number of respondents from Hospital 2 commented on the air conditioning, for example:

“It’s freezing cold. There’s something wrong with the air conditioning and it’s blowing cold air all the time.”

In Hospitals 2 and 3, respondents commented that there was a selection of beds and chairs but the chairs were not very comfortable. For example:

“They should put in more comfortable chairs instead of beds – the type of chairs that you can move yourself by remote control to find a comfortable position.” (Hospital 2)

“They could have a few more beds instead of chairs – it feels like everyone is fighting over the beds.” (Hospital 3)

“The electric automatic beds are great.” (Hospital 3)

There were general suggestions about the comfort of a dialysis unit:

“It could be a little bit more comfortable – less like a hospital, more like a lounge, especially for those patients who aren’t as ill (some do need beds). Psychologically it would be better for patients not to be in such a hospital environment.”

Table 3.24 illustrates respondent views of aspects of the functioning of the dialysis unit. High levels of satisfaction with aspects of the dialysis unit were generally recorded. Some aspects showed great variation across hospitals and qualitative analysis suggested differences. For example, 42% of respondents at Hospital 3 rated the amount of time they waited for a dialysis machine to become available as poor or fair. A number of these participants commented that they could wait one to one-and-a-half hours for the dialysis machine to become available, particularly those having dialysis sessions in the afternoon. Examples of comments from Hospital 3 participants follow:

“You are waiting too long. When you arrive you have to wait for an opening and the machine to be cleaned.”

“First shift is brilliant. The others are late – other patients have to wait.”

Conversely, respondents at Hospital 1 and Hospital 2 more typically reported an occasional wait for the machine due to machine malfunction or problems with previous patients.

Table 3.24. Participant ratings of aspects of dialysis unit

<i>“What is your view of...”</i>	Good %	Fair %	Poor %
<i>... the amount of time you have to wait for a dialysis machine to become available?</i>			
Total	86	9	5
Hospital 1	95	5	0
Hospital 2	94	5	1
Hospital 3	58	21	21
<i>...the opportunity to rest and recover following treatment?</i>			
Total	81	14	5
Hospital 1	94	0	6
Hospital 2	80	15	5
Hospital 3	76	17	7
<i>... the opportunity to ask questions?</i>			
Total	86	9	5
Hospital 1	94	6	0
Hospital 2	87	7	6
Hospital 3	79	14	7
<i>... the general atmosphere in the dialysis unit?</i>			
Total	88	8	4
Hospital 1	95	5	0

Hospital 2	87	11	2
Hospital 3	86	4	10
<i>Overall how good do you think the running of the dialysis unit is?</i>			
Total	89	10	1
Hospital 1	100	0	0
Hospital 2	95	4	1
Hospital 3	62	35	3

The majority of participants at all hospitals commented that they did not feel it necessary to rest or recover after dialysis, and preferred to leave the hospital immediately. However, some at each hospital commented that there was nowhere to rest or that they had to leave because other patients were waiting to use the machine or their taxi was waiting. For example:

“There’s not much space in the unit for people to recover. There should be an area set aside for recovery, but where the nurses could observe.” (Hospital 2)

“There isn’t any opportunity [to rest and recover] because the turnover is so quick. There are always patients waiting to go on dialysis. You could wait in the waiting room but then you’re delaying the taxi man.” (Hospital 3)

“They ring for a taxi and you’re afraid he may be waiting for you so you’re anxious to get out to him. There’s no problem with resting in terms of the hospital, but it’s more in terms of being anxious about the taxi waiting for you. The whole taxi business can make you very anxious, even sometimes he’s late to collect me and that makes me anxious. It’s no complaint against the taxi

company, it's more the degree to which we depend on them and the way they're affected by other forces.”(Hospital 1)

The opportunity to ask questions and the general atmosphere in the dialysis unit were rated highly by the majority of participants in all hospitals. Ratings of the overall running of the dialysis unit were mostly positive. However 38% of respondents at Hospital 3 felt that the overall running of the unit was poor or fair. Comments from participants suggest a reason for this was the wait for the machines to be available:

“Sometimes there are backlogs from previous patients so you're later going on and coming off dialysis.”

“There are too many nurses. They should have technicians in to set up the machines and then the nurses could be nursing, and if it was all set up you could get patients onto machines more quickly and nurses would have more time with the patients.”

“It's not as good as it was. There was a sister there that hasn't been replaced. It started at 7am when she was there.”

3.3.4 Dialysis unit privacy

The majority of participants (79%) rated the respect shown for their privacy as good (table 3.25) and were satisfied with the opportunity to speak privately with a doctor or nurse (77%) (table 3.26).

Table 3.25. Participant rating of the respect shown for their privacy in the dialysis unit

	Good %	Fair %	Poor %
Total	79	12	9
Hospital 1	88	6	6

Hospital 2	84	11	5
Hospital 3	61	18	21

Table 3.26. Participant satisfaction with opportunity to discuss something privately with doctor or nurse

	Satisfied %	Neither %	Dissatisfied %
Total	77	6	17
Hospital 1	84	5	11
Hospital 2	78	5	17
Hospital 3	67	11	22

Analysis of comments from participants who rated these aspects negatively illuminated one particular issue at all hospitals, i.e. that any discussion carried out with patients in the unit could be overheard by other patients. A number of participants from each hospital also mentioned the lack of separate rooms for speaking privately with staff:

“There’s not much privacy – if someone has the doctor beside them, everyone can hear what he’s saying.”

“There isn’t any privacy. If the doctors are talking to any patients, I can’t help but overhear. Perhaps the doctor shouldn’t do a consultation until you’ve finished on dialysis, and should go into a separate room.”

While ratings for aspects of privacy at Hospital 3 received more negative responses, qualitative analysis of participant comments did not reveal specific or different issues other than those mentioned above, which apply to all hospitals.

3.3.5 Occupying time during haemodialysis

Participants were asked how they usually occupy their time during dialysis. Popular responses were reading, listening to music, sleeping and watching the television. Respondents then rated their satisfaction with how their time is occupied during dialysis (table 3.27).

Table 3.27. Satisfaction with how time is occupied while on dialysis

	Satisfied %	Neither %	Dissatisfied %
Total	86	7	7
Hospital 1	95	5	0
Hospital 2	90	6	4
Hospital 3	64	11	25

While the overall levels of satisfaction with how time on dialysis is occupied were high (86%), Hospital 3 produced considerably lower satisfaction levels, with 36% of patients reporting that they were either ‘very dissatisfied’, ‘dissatisfied’ or ‘neither satisfied or dissatisfied’ with how they occupied their time. Analysis of comments from respondents of this hospital illuminated the main issue – televisions had relatively recently been removed from the unit. Many respondents suggested an improvement would be to return the televisions to the unit. For example:

“Put the televisions back – with your own headphones. In a unit in England, everyone had their own television and a headset. You could watch whatever you wanted.”

“Would be better if the televisions came back because it passes the time fairly quickly.”

When asked to suggest improvements in ways to occupy their time, participants suggested that there could be more televisions, larger televisions and remote controls and headphones. There were also suggestions there could be a library or supply of newspapers or magazines. For example:

“Maybe if there were more televisions – now there’s one per three beds. They could provide newspapers and magazines.”

3.3.6 Medical and nursing care

Ratings of the quality of care from consultant (table 3.28) and availability of consultant (table 3.29) in the dialysis unit showed most patients (92%) felt they received a high level of care and were satisfied with the availability of their consultant when needed (83%).

Table 3.28. Participant views of quality of care from consultant in the dialysis unit

	Good %	Fair %	Poor %
Total	92	3	5
Hospital 1	95	5	0
Hospital 2	90	3	7
Hospital 3	91	0	9

Table 3.29. Participant satisfaction with availability of their consultant if they need him/her

	Satisfied %	Neither %	Dissatisfied %
Total	83	7	10
Hospital 1	94	6	0
Hospital 2	80	9	11
Hospital 3	81	4	15

Ratings of quality of care from doctors (other than consultants) (table 3.30) and overall ratings of medical care in the dialysis unit (table 3.31) were generally high (92% and 88% respectively).

Table 3.30. Participant views of quality of care from doctors other than consultants in the dialysis unit

	Good %	Fair %	Poor %
Total	92	6	2
Hospital 1	94	6	0
Hospital 2	94	4	2
Hospital 3	86	11	3

Table 3.31. Participant rating of the overall medical care in the dialysis unit

	Good %	Fair %	Poor %
Total	88	10	2
Hospital 1	100	0	0
Hospital 2	89	10	1
Hospital 3	79	17	4

Participants rated nursing care based on the quality of care, the amount of time spent with nurses (i.e. the amount of time nurses had available to spend with patients) and the overall nursing care (table 3.32). Nursing care ratings were generally high, with some variability across hospitals.

Table 3.32. Participant ratings of nursing care in the dialysis unit

	Good %	Fair %	Poor %
<i>What is your view of the quality of care you receive from the renal nurses in the dialysis unit?</i>			

Total	95	4	1
Hospital 1	100	0	0
Hospital 2	95	5	0
Hospital 3	90	3	7
<i>What is your view of the amount of time you spend with the renal nurses in the dialysis unit?</i>			
Total	91	6	3
Hospital 1	100	0	0
Hospital 2	93	5	2
Hospital 3	79	14	7
	Good	Fair	Poor
	%	%	%
<i>Overall, how good do you think the nursing care is the dialysis unit?</i>			
Total	96	2	2
Hospital 1	100	0	0
Hospital 2	97	1	2
Hospital 3	90	7	3

3.3.7 Other hospital services

Participants were asked whether they see any other specialist in the same hospital. Altogether, 38% (N=51) of haemodialysis patients said they did see another specialist. Given the major demands of a median three visits per week to hospital for haemodialysis, any further reasons for visiting a hospital pose a significant additional burden. Satisfaction ratings for the coordination of appointments between attendance for dialysis and attendance for other appointments are shown in table 3.33.

Table 3.33. Satisfaction with coordination between attendance for dialysis and attendance for other appointments

	Satisfied %	Neither %	Dissatisfied %
Total	76	4	20
Hospital 1	100	0	0
Hospital 2	74	6	20
Hospital 3	70	0	30

While three quarters (76%) were satisfied, over a quarter of respondents at both Hospital 2 and Hospital 3 were ‘very dissatisfied’, ‘dissatisfied’ or ‘neither satisfied nor dissatisfied’ with the co-ordination of dialysis and other appointments. Analysis of participant comments suggests these respondents were dissatisfied because they had experienced a lack of co-ordination of appointments, sometimes because the other appointments were for clinics which run on different days to their dialysis and sometimes because it appeared that no effort was made to co-ordinate appointments:

“They have clinics on Monday and Wednesday, I have haemodialysis on Tuesday, Thursday and Saturday.”

“Nobody cares about when you have other appointments. I have loads of blood counts done in different departments because the different departments can’t access each other’s computer systems.”

3.3.8 Patient recommendations concerning improvements

Participants were asked what aspect of the present haemodialysis service could be improved most (and how). The major area of improvement as suggested by respondents of Hospital 2 involved physical aspects of the unit. Participants suggested the unit could be bigger and brighter, with more comfortable beds and

better air-conditioning. Examples of typical comments concerning the physical aspects of the unit at Hospital 2 are presented:

“The location of the dialysis unit is very poor – it’s very dark and there are not enough windows. It can be quite depressing. Also the television doesn’t have a remote control so you always have to ask the nurse to change the channel. And they have headphones but often the radio doesn’t work. They could have a television for every bed, with a remote control.”

“Maybe it could be less like a hospital, a more relaxed atmosphere. In Majorca they had recliner chairs, it looked less like a hospital, relaxed atmosphere. Each patient had a television facing them and a remote control. In Hospital 2 there’s only four televisions.”

Another common suggestion for improvement at Hospital 2 was to have more dialysis machines, thus reducing waiting time if a patient becomes ill:

“If somebody is ill on the machine in the morning, it holds everyone up all day. There should be a few spare spaces for spare machines so when there’s been a hold-up, you’re not delayed all day.”

A small number of respondents at Hospital 2 also suggested it should be possible to chose the time and days that they have dialysis. Other comments concerned staffing: the most common comment being to increase the number of nursing staff. Other suggestions were to have the doctor or registrar in the unit more often, and to improve communication between staff and patients.

Respondents at Hospital 1 also recommended improvements to physical aspects of the unit. Suggestions included having a larger unit, with more dialysis machines, more televisions, a recovery area and an area to consult with doctors in private.

Another area of improvement at Hospital 1 was to provide more parking or to better police the parking area:

“It seems that hospital staff are using the patients’ parking. There are only three disabled parking spaces and it’s not enough. Security should be down there and not let people who won’t pay for the big car park to park in dialysis or disabled spaces.”

Another important issue raised concerned patient support:

“It would be good to have someone to speak to about it – sort of a counsellor or maybe more of a support person. You can feel isolated and the ongoing nature of the dialysis can affect you – it can feel a bit devastating at times.”

The most common suggestion for improvement at Hospital 3 concerned waiting time for dialysis machines. It was felt that there should be better co-ordination between arriving for dialysis and actually starting on the machine, because the machines were often not ready when patients arrived. Some participants suggested ways to achieve this, including having more dialysis machines and more beds, running the unit for longer hours, or starting earlier in the morning. Examples of comments in this area are presented:

“Time between arriving at hospital and getting on the machine – it works out as more like five or six hours altogether. If they had more machines spare instead of having to wait for machines to be cleaned...”

“When we come off the machine there is a mad rush to clean the machine and your bed – if they had just two more beds it would make a huge difference.”

Some participants of Hospital 3 also made suggestions regarding staff. Some mentioned that there was a language barrier with foreign staff. Others suggested that staff could explain more to patients.

Some suggestions for improvement related to the availability of dialysis more generally and were not specific to any hospital, for example:

“Being able to travel – if we could swap with other patients in other hospitals for a few days holiday, e.g. in Galway or Cork.”

“Dialysis machines should be scattered around the country – should be a few in my local hospital. Travelling to Dublin and back is diabolical with such ill patients.”

“They should have units in most hospitals – if there was a unit in Naas, less money would be spent on taxis and it would be easier for nurses.”

3.4 Peritoneal dialysis services

Section C of the renal patient satisfaction questionnaire investigated services relating specifically to peritoneal dialysis (CAPD and CCPD). Therefore, this section only applied to participants from Hospitals 2 and 3 who were currently availing of either of these types of dialysis. [Note: Hospital 1 does not provide peritoneal dialysis services]. There were 29 respondents from Hospital 2 and 30 respondents from Hospital 3. Number of participants are small and thus when divided by hospital and type of dialysis, findings should be treated with caution.

3.4.1 Infections and hospital admissions

Overall, 23 (39%) participants stated that they had infections relating to their dialysis in the past year. Table 3.34 shows a breakdown of infection by hospital and by type of dialysis in the past year.

Table 3.34. Profile of infections relating to dialysis in the past year

	CAPD		CCPD	
	Yes %	No %	Yes %	No %
Total	22	25	17	36
Hospital 2	14	17	21	48
Hospital 3	30	33	14	23

Participants who had experienced infections relating to their dialysis in the past year were then asked how many infections they had experienced (table 3.35).

Table 3.35. Number of infections related to dialysis in the past year

	Mean	SD	Median	Range
Total	1.93	1.05	2	1 – 5
Hospital 2	1.56	0.73	1	1 – 3
Hospital 3	2.19	1.18	2	1 – 5

Those experiencing dialysis-related infections reported a median 2 infections in the past year. Participants who had experienced infections then rated their level of satisfaction with the overall management of their infection(s) by the hospital. Of the 22 people who responded to this question, 21 (95%) were ‘satisfied’ or ‘very satisfied’ with the overall management of the infections by the hospital.

3.4.2 CAPD and CCPD equipment supply

All participants were asked to rate their level of satisfaction with the service they received from their renal equipment supplier. Of the 58 participants who answered this question, 57 (98%) responded that they were ‘satisfied’ or ‘very satisfied’. Participants were asked who they would speak to in an emergency regarding their renal equipment supplies. The majority (N=52, 90%) of respondents said they would telephone Baxter (a commercial renal products company), or mentioned a Baxter emergency telephone number or contact person. A small number said they would contact the hospital (N=2) or that they did not know what to do (N=2).

When asked to rate satisfaction with the renal equipment emergency procedure, 15 (25%) participants felt unable to rate it because they had no experience of it. All others (N=44; 100%) reported being ‘satisfied’ or ‘very satisfied’ with the procedure.

3.4.3 Patient recommendations concerning peritoneal dialysis service improvements

Despite high levels of satisfaction with the CAPD and CCPD service, participants did comment regarding aspects of the service that could be improved. The major theme concerned distance to the hospital and transport arrangements. Participants commented that they lived a long way from their respective hospital and that transport to the hospital was poor. Some suggested that peritoneal dialysis services should be more widely spread throughout the country. Others were unsure that it was necessary to travel all the way to their dialysis hospital for blood tests that could possibly be carried out at a local hospital. Also, some participants suggested that the transport arrangements were stressful because they did not have their own transport. Some suggested that the hospital should provide transport for peritoneal dialysis patients. Examples of comments concerning transport and distance follow:

“CAPD should be available in Galway.”

“I have to go to my dialysis hospital for blood tests – it’s a long distance for blood tests, which surely could be done at my local hospital.”

Other suggestions of aspects that could be improved included having a facility to dispose of the waste from dialysis supplies, having home visits from renal nurses and providing an after-hours emergency service:

“Nurses should have come out to my home at the start to check the set-up, hygiene, etc.”

“The cardboard boxes that the supplies come in are very heavy and difficult to tear up for disposing of.”

“Hospital 3 seems like it’s only a 9-5 service. My blood pressure was high during the night and I was told to go to Casualty. I think I should go to the renal ward and get dialysis there because

I should have been on the dialysis machine all night.”

Participants were asked what, if anything, they worried about in terms of the provision of the CAPD/ CCPD service in the future. The major worry concerned how long they would be able to remain on peritoneal dialysis. Some expressed concerns relating to going back to haemodialysis, for example due to distance from their home to the hospital, or due to the strain on haemodialysis services:

“I worry if I had to go back onto haemodialysis, there seems to be a strain on the haemodialysis services and patients having to do haemodialysis during the night.”

“[Peritoneal dialysis] doesn’t last forever and I will have to go back on haemodialysis, and getting to the hospital is difficult from where I live.”

Other concerns included dietary worries due to lack of contact with the dietician, worries about getting the peritoneal dialysis supplies and concerns regarding after-hours emergency care.

3.5 Renal outpatient clinic services

This section relates to experiences of the renal outpatient clinic. Some haemodialysis patients were reviewed or assessed while attending for dialysis instead of attending a designated renal outpatient clinic. The distinction was made clear to patients during interview, and only those who reported having attended a renal outpatient clinic answered questions in this section.

Of the three hospitals surveyed, Hospital 1 did not generally offer patients an outpatient visit. Instead, they reviewed patients during haemodialysis visits. Their patients are therefore excluded from this section. Participants who reported they had not visited an outpatient clinic for over one year were also excluded, since an evaluation of services provided more than one year ago may now be irrelevant. Private patients were also excluded because the outpatient clinic services they avail of are provided outside of the ERHA's service and are thus not part of the present study's remit. Overall, 45% (N=87) of the surveyed participants were provided with an outpatient visit through the ERHA in the previous year.

3.5.1 Outpatient clinic appointment profile

Of those attending renal outpatient clinics, half were seen within a two month (median 61 day) period (table 3.36).

Table 3.36. Frequency of participant visit to outpatient renal clinic

	Median (days)	Range (days)
Total	61	7 – 365
Hospital 2	61	7 – 365
Hospital 3	61	14 – 365

Overall 96% of participants stated that they were satisfied or very satisfied with the frequency of outpatient renal clinic visits. The way in which appointments were arranged was also rated highly, with 94% of respondents ‘satisfied’ or ‘very satisfied’.

3.5.2 Outpatient clinic waiting time and waiting area

Table 3.37 illustrates participant rating of waiting time at their last outpatient clinic visit across the two hospitals. Since haemodialysis and peritoneal dialysis patients attended different clinics, results are presented by hospital and by dialysis type, illustrating differences across clinics.

Table 3.37. Participant rating of waiting time at last outpatient clinic visit

		Good %	Fair %	Poor %
Hospital 2	Total	65	12	23
	HD clinic	43	14	43
	PD clinic	86	9	5
Hospital 3	Total	88	7	5
	HD clinic	72	14	14
	PD clinic	97	3	0

The majority (88%) of participants at Hospital 3 rated the waiting time highly, with similar positive ratings at both peritoneal dialysis and haemodialysis clinics.

Approximately two thirds (65%) of participants from Hospital 2 rated the waiting time as good. On closer analysis by clinic, the majority of negative ratings (‘poor’ or ‘fair’) were given for the waiting time at haemodialysis clinics. Comments from participants of Hospital 2 on their experiences of the haemodialysis clinic illustrated reasons for dissatisfaction:

“Usually appointments are made for 9am. Everyone seems to come at that time. You’re lucky to be seen anything up to three or four hours later.”

“It’s a big clinic, lots of people waiting.”

Positive changes in waiting times were noted by some. A number of participants from Hospital 3’s peritoneal dialysis clinic commented on how recent changes in taking blood samples had improved the waiting time:

“I used to wait a long time for blood tests but now the procedure has been changed and the phlebotomist comes over to us, and I wouldn’t be waiting any more.”

Participants were also asked whether they felt they had waited a long time to see the consultant/doctor in the clinic at their last visit. Differences across hospitals were observed with 29% of those at Hospital 2 and 9% of those at Hospital 3 reporting they felt they had to wait a long time. Table 3.38 illustrates participant rating of waiting area by hospital. Since haemodialysis and peritoneal dialysis patients attend different clinics and in some instances may use different waiting areas, results are presented by dialysis type.

Table 3.38. Participant rating of waiting area at outpatient clinic

		Good %	Fair %	Poor %
Hospital 2	Total	52	27	21
	HD clinic	71	19	10
	PD clinic	35	35	30
Hospital 3	Total	76	12	12
	HD clinic	64	14	22
	PD clinic	82	11	7

Just over half (52%) of all respondents from Hospital 2 rated the waiting area as good, with much lower satisfaction from peritoneal dialysis patients (only 35% rating their waiting area as 'good'). Views expressed by a number of peritoneal dialysis participants from Hospital 2 clarify this dissatisfaction:

“Very, very small – something should be done about that. The CAPD waiting room is for smokers. There’s another waiting room which is bigger and no one uses it but if you did use it, the nurses probably wouldn’t come down to it.”

“There are two waiting areas – the one that’s close to where the examinations take place is very small and is for smoking. The larger one is further away but you’d be afraid to wait there in case no one knows you’re there.”

Other issues highlighted in both haemodialysis and peritoneal dialysis clinics at Hospital 3 and also haemodialysis clinics at Hospital 2 mostly concerned problems arising with the size of the waiting area when lots of people are waiting:

“Waiting in the hallway because it’s such a big clinic, there was no room in the waiting room.”

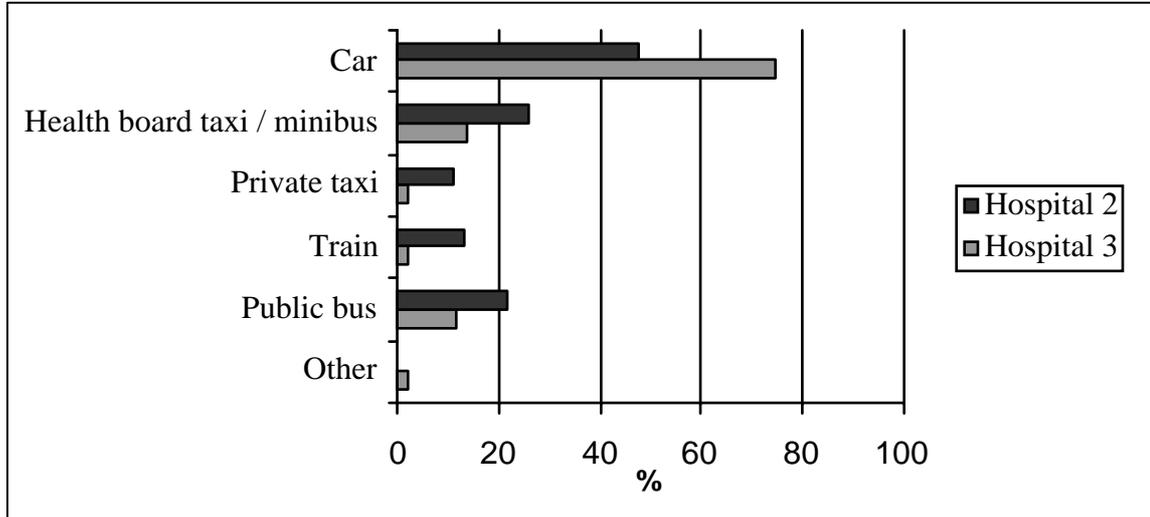
Participants were asked whether they were accompanied to the outpatient clinic, since this will affect the number of prospective waiting area spaces utilised. Nearly two thirds (63%) of participants visited the outpatient clinic alone, with 37% accompanied by one person, with similar percentages in both hospitals. Thus waiting areas need to be planned for at least one third more occupants than the expected patient numbers for a given clinic.

3.5.3 Outpatient clinic travel arrangements

Figure 3.15 illustrates mode of transport to outpatient clinic. Since participants could indicate using more than one mode of transport, percentages are of total participants

from each hospital. Most people (74% at Hospital 3 and 48% at Hospital 2) travelled to hospital by private car.

Figure 3.15. Usual mode of transport to outpatient clinic



When evaluating the accessibility of a service, the time taken to travel to the service, transport options and parking convenience can be evaluated. Participants were asked how long it took to travel to the hospital for outpatient appointments. Participants of Hospital 2 had notably longer travel times to outpatient clinics than Hospital 3 (median 75 vs. 22 minutes) (table 3.39).

Table 3.39. Length of time taken to travel from patient home to outpatient renal clinic

	Mean (mins)	SD (mins)	Median (mins)	Range (mins)
Total	68.6	69.1	45	5-270
Hospital 2	90.9	78.5	75	5-270
Hospital 3	44.8	47.8	22	5-270

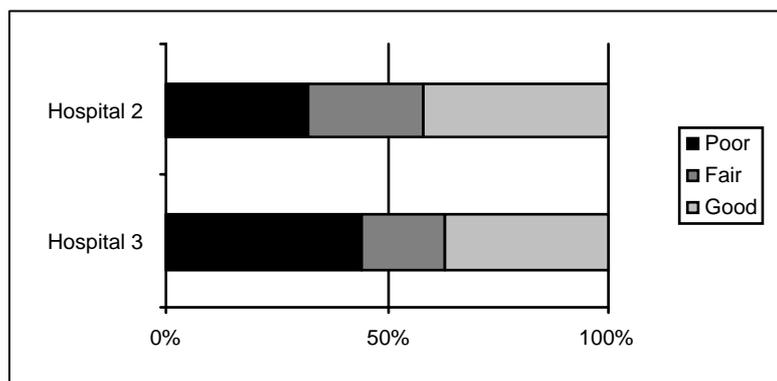
Table 3.40 illustrates patient satisfaction with travel arrangements. Despite large differences in travel time between Hospital 2 and Hospital 3, most participants in both hospitals were satisfied with travel arrangements to clinics.

Table 3.40. Satisfaction with travel arrangements to outpatient clinic

	Satisfied %	Neither %	Dissatisfied %
Total	82	8	10
Hospital 2	82	9	9
Hospital 3	81	7	12

However, more than half of participants at both hospitals rated parking convenience as ‘fair’, ‘poor’ or ‘very poor’ (figure 3.16).

Figure 3.16. Participant rating of parking convenience for renal outpatient clinic visits



Analysis of participant comments suggest two main reasons for negative ratings. Firstly, a number of participants from both hospitals mentioned having to pay for parking, with respondents from Hospital 3 also commenting more negatively about the high cost of the car park. Comments below reflect the views expressed by many respondents:

“Very poor parking because it’s so expensive. It’s a hospital and we shouldn’t have to pay that much.”

“They don’t have parking spaces for patients. The multi-storey car park is too expensive. They should have spaces for patients who attend regularly.”

The second major reason for dissatisfaction appeared to be the lack of disabled or dialysis patient parking spaces close to the hospitals. Respondents from Hospital 3 commented on the lack of disabled spaces and the distance from the car park to the hospital:

“[Car parking is] not very good. You find people park in the disabled spaces and we have to park away from the main entrance – it’s an extra stress, a long way up to the main entrance.”

“Parking is dreadful. I have a disabled sticker but there’re loads of other cars parked in disabled spaces. The car park is too long a walk.”

Participants at Hospital 2 also mentioned the distance from the car park to the clinic and the lack of dialysis parking spaces:

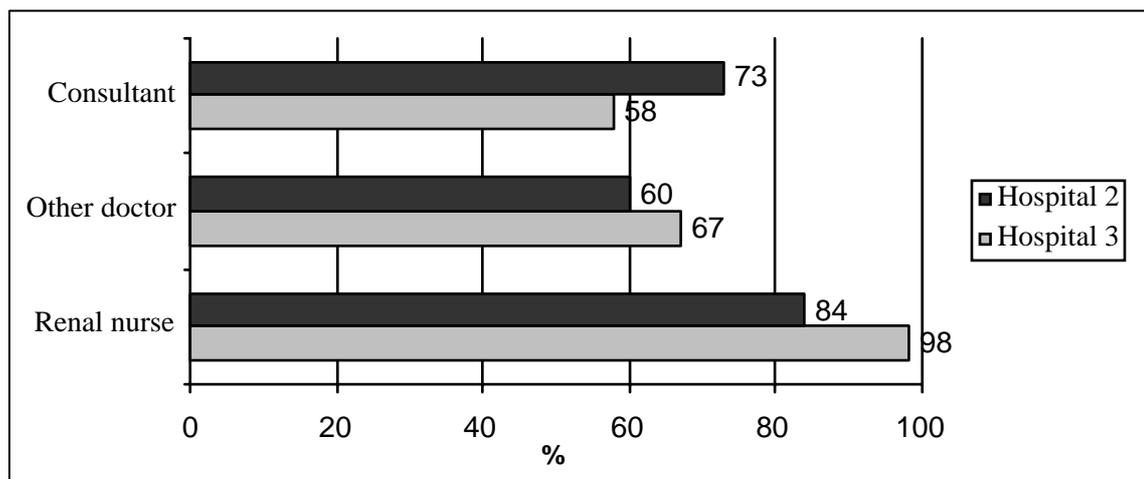
“There’s plenty of parking but not many parking spaces for dialysis patients. The public car park is expensive – there should be more provision made for patients.”

“Scandalous – other people park in the dialysis spaces and there’s not enough spaces.”

3.5.4 Outpatient clinic medical and nursing care

During outpatient consultations, patients may meet a number of different healthcare professionals. Participants were asked which medical and nursing staff they received services from at their last visit to the public outpatient clinic. Figure 3.17 illustrates the percentages of participants in each hospital who received care from consultant, other doctor or renal nurse at their last visit. In total, 68% of participants saw a consultant at their last visit, with most participants (91%) meeting a renal nurse.

Figure 3.17. Health professional staff from whom participants received care at last visit to renal outpatient clinic



Those respondents who indicated that they had received care from a consultant were then asked to rate aspects of the care from the consultant (table 3.41).

Table 3.41. Participant ratings of consultant care in the outpatient clinic

	Good %	Fair %	Poor %
<i>What is your view of the amount of time you spent with the consultant?</i>			
Total	91	5	4
Hospital 2	85	9	6
Hospital 3	100	0	0
<i>What is your view of the quality of care you received from the consultant?</i>			
Total	96	2	2
Hospital 2	94	3	3
Hospital 3	100	0	0

Almost all participants rated the amount of time spent with, and quality of care received from, consultants as good (91% and 96% respectively).

Those participants who had stated that they had received care from doctor(s) other than their consultant at their last outpatient renal clinic visit were also asked to rate aspects of the care they had received. Ratings of care were also high and similar to that from consultants (92% for time spent and 95% for quality of care received) (table 3.42). However, some participants at Hospital 3 commented that doctors were always changing and they felt they were repeating their medical background on each visit:

“Every time you go, you see a new doctor and have to explain everything again – what medication and bags I’m on.”

“The doctor has my charts in front of him but he still asks me, but I forget – I take 20 tablets a day. I’d rather he consult the charts.”

Table 3.42. Participant ratings of care from doctors other than consultants in the renal outpatient clinic

	Good %	Fair %	Poor %
<i>What is your view of the amount of time spent with the other doctor(s)?</i>			
Total	92	4	4
Hospital 2	96	4	0
Hospital 3	90	3	7
<i>What is your view of the quality of care you received from the other doctor(s)?</i>			
Total	95	3	2
Hospital 2	100	0	0
Hospital 3	90	7	3

Participants rated a number of aspects of medical care at the outpatient clinic (table 3.43 and table 3.44).

Table 3.43. Participant ratings of aspects of medical care at renal outpatient clinic

	Good %	Fair %	Poor %
<i>What is your view of the chance to have your questions answered during your visit?</i>			
Total	90	5	5
Hospital 2	89	4	7
Hospital 3	93	5	2
<i>What is your view of the doctor's advice about ways to avoid illness and stay healthy?</i>			
Total	89	7	4
Hospital 2	93	5	2
Hospital 3	84	11	5
<i>Overall, how good do you think the medical care is at the outpatient clinic?</i>			
Total	94	4	2
Hospital 2	93	2	5
Hospital 3	95	5	0

Table 3.44. Participant satisfaction with doctor's explanations of what was done for them (tests, treatment, etc.)

	Satisfied %	Neither %	Dissatisfied %
Total	90	5	5
Hospital 2	87	10	3
Hospital 3	93	0	7

Approximately nine out of ten participants rated opportunities to ask questions and health promotion advice at renal outpatient clinics as 'good' or 'very good'. Most participants (90%) reported satisfaction with explanations of treatments and tests.

Overall evaluations of medical care at renal outpatient clinics was high (94% satisfaction).

Participants who had received care from a nurse at their last outpatient renal clinic visit were asked to rate aspects of the care they had received from the nurse (table 3.45).

Table 3.45. Participant ratings of nursing care in the renal outpatient clinic

	Good %	Fair %	Poor %
<i>What is your view of the amount of time you spent with the nurse?</i>			
Total	96	4	0
Hospital 2	97	3	0
Hospital 3	95	5	0
<i>What is your view of the quality of care you received from the nurse?</i>			
Total	96	3	1
Hospital 2	95	5	0
Hospital 3	98	0	2
<i>Overall, how good do you think the nursing care is at the outpatient clinic?</i>			
Total	98	1	1
Hospital 2	96	2	2
Hospital 3	100	0	0

Similar to medical care, there were very high ratings of aspects of the quality of care provided by renal nursing staff.

3.5.5 Renal outpatient clinic attributes

Participants rated a number of clinic attributes based on their experience at their last visit to the renal outpatient clinic (table 3.46). All aspects were rated highly across both hospitals. The overall running of the outpatient clinic was also rated highly, with 81% of respondents at each hospital rating it good or very good.

Table 3.46. Participant ratings of general renal outpatient clinic attributes

	Good %	Fair %	Poor %
<i>What is your view of the respect shown for your privacy?</i>			
Total	98	1	1
Hospital 2	100	0	0
Hospital 3	96	2	2
<i>What is your view of the cleanliness of the examination room?</i>			
Total	95	5	0
Hospital 2	91	9	0
Hospital 3	100	0	0
<i>Overall, how good do you think the running of the outpatient clinic is?</i>			
Total	81	14	5
Hospital 2	81	12	7
Hospital 3	82	16	2

A number of participants commented that a major problem with outpatient clinics was waiting time. Participants from Hospital 2 commented more specifically that many people were given the same appointment time:

“The waiting time is the problem. They give the same

appointment time to so many people.”

“Patients don’t know where they are in the queue to see the doctor. If they gave you a number when you arrived so you knew roughly how long before you’d be called, then you could get a coffee.”

“Everyone seems to get an appointment for the same time – waiting two or three hours.”

3.6 Renal support services

In relation to kidney disease and dialysis, relevant support services may include dietary support, financial and social support services, and medical support. Part G of the dialysis questionnaire dealt with the availability and rating of these services.

3.6.1 Dietary-related services

Table 3.47 provides a profile of time since last consultation with a dietician by participants. About half of the group had seen a dietician in the last two months (median 61 days) with large differences across hospitals. Hospital 2 had notably longer times since last consultation than others (approximately half of their participants had seen a dietician in the last four months; median 116 days).

Table 3.47. Profile of time since last consultation with a dietician

	Mean (days)	SD (days)	Median (days)	Range (days)
Total	137.8	215.3	61	0-1460
Hospital 1	17.8	18.8	14	0-61
Hospital 2	207.5	250.9	116	7-1460
Hospital 3	49.9	100.9	21	0-730

Satisfaction with dietary support services was then addressed (table 3.48).

Table 3.48. Participant satisfaction with dietary support services

<i>“How satisfied are you with...”</i>	Satisfied %	Neither %	Dissatisfied %
<i>... the availability of information on dietary related aspects of your care?</i>			
Total	95	2	3
Hospital 1	95	0	5
Hospital 2	92	4	4
Hospital 3	100	0	0
<i>...the availability of the dietician?</i>			
Total	92	4	4
Hospital 1	100	0	0
Hospital 2	85	7	8
Hospital 3	100	0	0

Participant satisfaction with the availability of the dietician and of information on dietary related aspects of care was high across hospitals. Hospital 2 received somewhat less positive ratings concerning dietician availability. Comments regarding availability of the dietician at Hospital 2 explain this:

“I would like to see the dietician more often – it would be good if they came down to the unit.”

“She’s non-existent. The dialysis unit is too far away – detached from the renal wards – so the dietician doesn’t come down.”

“Dieticians have gone home by the time I start dialysis.”

“There should be a dietician on at night for the night-time patients.”

Respondents were asked what, if anything, would improve the dietary care they receive. Some suggested improvements in advice about diet and preparing food. Some required more detailed information, while others would prefer simple and comprehensive information:

“More imaginative recipes – a proper big recipe book should be made available to every patient. There should be more detailed information on exactly which foods to avoid.”

“A simple but comprehensive booklet, not too long – a fast reference with list of different types of food with yes/no listed.”

“They could draw up details for people on dialysis – what is and isn’t banned, what you can have in small amounts – more clear-cut information.”

“Diabetic-renal dietary advice. They should give you advice on what you can eat, be more innovative and try to collect recipes.”

A number of participants from Hospital 2 suggested increased availability of the dietician, in particular for the dietician to visit the dialysis unit regularly. Some peritoneal dialysis participants from Hospital 2 also commented on the lack of dietary care for patients who are not regularly in hospital for haemodialysis.

3.6.2 Financial advice and social services

Participants were asked about social and financial service advice (table 3.49). Over half (62%) were satisfied, with wide variability across hospitals. For instance, less than half (46%) of respondents from Hospital 1 were satisfied with the availability of information and advice on social and financial support.

Table 3.49. Participant satisfaction with the availability of information and advice on

social and financial support with regard to kidney condition

	Satisfied %	Neither %	Dissatisfied %
Total	62	13	25
Hospital 1	46	15	39
Hospital 2	58	10	32
Hospital 3	73	18	9

A number of respondents from Hospital 1 commented that they did not know about social and financial support services relating to renal failure:

“I don’t know anything about it – hospital hasn’t spoken to me about any of it.”

“I think they should have a social worker attached to, or available to, the unit. I was self-employed and had to retire... There should be a social worker to advise me about entitlements and my financial situation and tell you which forms to fill in and have the forms there for you.”

At Hospital 2, 42% of respondents were ‘very dissatisfied’, ‘dissatisfied’ or ‘neither satisfied nor dissatisfied’ with social and financial support, information and advice.

Comments below reflect the views expressed by many Hospital 2 respondents:

“Anything I know about entitlements, I learned from other patients – was never told anything from the hospital.”

“I wasn’t given any information on this area... Maybe it could be part of an information pack they could give to you early on.”

In contrast, nearly three-quarters (73%) of respondents from Hospital 3 were ‘satisfied’ or ‘very satisfied’ with the availability of social and financial support

information. This was reflected in more positive comments:

“I’m availing of anything that’s available. They make sure you’re aware of all your entitlements.”

A number of participants across hospitals commented that they would like information about holidays and dialysis units abroad.

Participants were then asked about health care personnel who could provide social and/or counseling support (table 3.50). High levels of satisfaction (90%) were reported.

Table 3.50. Participant satisfaction with the availability of a hospital social worker/ patient care coordinator/ counsellor

	Satisfied %	Neither %	Dissatisfied %
Total	90	5	5
Hospital 1	100	0	0
Hospital 2	90	4	6
Hospital 3	88	8	4

Participants were asked what, if anything, would improve the social and financial support aspect of their care. The main suggestion was to provide more information about entitlements, for example:

“[Provide] an information pack (and leaflet with financial advice) with all the information early on, especially on the financial side.”

“If they talked to you about different problems you may have and the social welfare available to you from the beginning it would be a help.”

The other main comment concerned the financial difficulties with adjusting to dialysis, particularly in relation to the expense of transport to the hospital, for example

“If some provision (e.g. travel vouchers) was made for patients travelling so far.”

3.6.3 Medical support in a medical emergency

Participants were asked to whom they would speak if they had a medical emergency relating to their kidney condition. The most common response was to contact the dialysis unit, dialysis ward or hospital. Other suggestions were to contact the Accident and Emergency Department or telephone 999, or to contact their GP or consultant. Participants were asked to rate their level of satisfaction with arrangements for support in a medical emergency (table 3.51).

Table 3.51. Participant satisfaction with arrangements for support in a medical emergency

	Satisfied %	Neither %	Dissatisfied %
Total	85	3	12
Hospital 1	89	0	11
Hospital 2	91	1	8
Hospital 3	73	7	20

While most (85%) were satisfied with the strategy they had, there was some variation across hospitals, with only three quarters (73%) of Hospital 3 participants being satisfied.

Analysis of comments in relation to satisfaction with arrangements for a medical emergency highlights some issues for ongoing consideration. Participants from all

hospitals commented that they are told to go to the Accident and Emergency Department in a medical emergency, rather than the dialysis unit or ward, and they have to wait for many hours, and may see doctors who are not renal specialists, for example:

“If I go into hospital, I have to go in through A&E and see doctors I don’t know and they don’t really understand your case.”

“Usually in Casualty they don’t have a clue what they’re dealing with (not renal specialists) and you’re left waiting.”

Another major complaint was that if patients telephoned 999 in an emergency, an ambulance would take them to their local hospital which did not have dialysis services, for example:

“If I had a medical emergency, the ambulance would take me to my local hospital, which doesn’t have dialysis provisions. Then I’d have to be transferred to the hospital that treats me for dialysis – it’s an unnecessary waste of time.”

“It could be a lot better. I can’t phone for an ambulance – they just take you to the closest hospital who don’t know about my condition and don’t have dialysis services.”

Related to this was the concern of long distances from patients’ homes to their dialysis hospital, particularly if no hospitals nearby provided dialysis services:

“They can only say to come to the hospital but I’m 200 miles away. They can’t send me anywhere else because nowhere else caters for home dialysis.”

Chapter 4

DISCUSSION

4.1 General discussion

4.1.1 Negotiating a patient satisfaction survey

The present study encountered a number of challenges during its early stages and these should be noted for future patient satisfaction measurement studies. The research was commissioned by the Eastern Regional Health Authority (ERHA), to be conducted by an independent research group (Health Services Research Centre, Royal College of Surgeons in Ireland (RCSI)). Ethical approval for the overall study was granted by the RCSI Research Ethics Committee. Procedures for individual ethical approval in each hospital had also to be undertaken. These differed in information needed and took considerable time to negotiate. Since there is currently no nationally accepted format for gaining ethical approval for studies, or clarity on acceptable methods for contacting patients or releasing patient details to a third party (in this case a research agency commissioned by and acting on behalf of the ERHA), future studies of this type are likely to experience similar delays. National guidelines for ethical approval procedures and gaining access to patients would clarify the situation.

A second notable factor related to the concerns of hospital staff about patient satisfaction studies. There were concerns regarding motives for and possible uses of findings, e.g. that results may be considered in isolation such as being used without a context of staff or facility shortages. Services or service providers could thus risk being considered as poor or inadequate when they were simply under-resourced. This suggests that the process of commissioning such research needs to incorporate consultation with key stakeholders (staff) to clarify what is being done, why it is being done, and what will happen following the study. Greater transparency and stronger links between hospitals and health authorities may assist in the conduct of service evaluations and interventions based on patient and staff experiences.

4.1.2 Survey responses and response rates

Previous research has generally reported high levels of patient satisfaction with hospital services. In the present study, satisfaction was rated as 1 (very dissatisfied), 2 (dissatisfied), 3 (neither satisfied or dissatisfied), 4 (satisfied) and 5 (very satisfied). On closer analysis of participant comments, there were differences between positive satisfaction ratings and positivity in patient comments, i.e. patients often rated themselves as satisfied on the above satisfaction rating scale, but analysis of their qualitative comments showed a greater degree of negativity. Thus, while ratings are important, patient qualifiers and other comments are also important in orienting staff to the most pressing areas needing change in an ongoing quality assurance system.

The overall survey response rate of 59% is considered sufficient to permit generalisation to the wider dialysis population. A major reason for refusal to participate (as observed during telephone reminders) appeared to be illness, with a number of patients who received telephone reminders stating that they were too ill to take part. This was anticipated since the population consisted of long-term chronically ill patients. However, it means that a sub-group of more seriously ill patients may be under-represented in the present study. The issue was addressed as far as possible by the option of postal questionnaires to these sicker patients, where they felt they could complete the questionnaire at home with assistance. Generally, an overall response rate of 59% is considered more than satisfactory for this patient group.

4.2 Demographic profile of service users

Over a third of participants (37%) were over 65 years. Thus present dialysis services face the challenges of providing care to many older people. Challenges including co-morbidity and transport problems are thus likely to be increased given this group profile. Similarly, 32% of all participants were retired, with only one-fifth in paid employment. Overall, 20% of participants (32% of those under the State retirement age of 66 years) stated that they were unable to work due to their renal condition.

While all three hospitals in the present study fall within the Eastern Regional Health Authority (ERHA), one quarter of all participants travelled from other health board areas to avail of dialysis services in the ERHA. Comments from respondents suggested that the main reason for this was a lack of local dialysis services. While nearly half (46%) of all peritoneal dialysis participants lived outside of the ERHA, their hospital visits would generally be less frequent. However, with 41% of peritoneal dialysis participants travelling more than 50 miles to avail of dialysis services, questions about national and equitable access to the service are raised. Similarly, while only 16% of haemodialysis participants lived outside the ERHA and 8% travelled more than 50 miles to avail of services, the question of accessibility of dialysis services must be addressed since these patients travel to hospital for haemodialysis a median three times per week. The Department of Health and Children's National Health Strategy (2001), lists an objective 'to ensure that regional dialysis centres are adequately resourced to give patients access to services close to their own home'. These results question the extent to which this target is currently being met.

4.3 Dialysis profile and choice of services

In total, 69% of participants used haemodialysis, with 15% using CAPD and 16% using CCPD. Since Hospital 1 offered only haemodialysis, all participants from this hospital were currently using haemodialysis and none had used peritoneal dialysis previously. Half (49%) of participants from Hospital 3 were using haemodialysis, compared with 74% of participants from Hospital 2. Similarly, more participants from Hospital 3 had previously used peritoneal dialysis at some point. It was not possible to address reasons for these differences across hospitals in the present study. It may reflect, for example, differences in patient profiles across hospitals, or hospital resources and expertise or professional preferences. An objective listed in the National Health Strategy is for various dialysis modalities to be made available so that, for example, patients can chose to have dialysis in their own home, if that is their preference and is in line with medical suitability, or can chose to receive their dialysis

in hospital. Thus, it is important that choices about peritoneal dialysis or haemodialysis are not constrained by readily amenable factors.

Three-quarters (76%) of participants reported that they knew why they were assigned to their particular dialysis type, with only 37% of participants from Hospital 1 reporting that they knew why they were on their current dialysis type. Similarly, two-thirds (65%) of all participants felt they had a choice of type of dialysis, but only 21% of Hospital 1 participants felt they had a choice. Hospital 1 does not offer peritoneal dialysis services. However, analysis of patient comments suggest that most respondents from Hospitals 2 and 3 did not have a choice of dialysis modality due to medical reasons, whereas Hospital 1 participant comments indicated a lack of awareness of alternative dialysis types. These findings suggest that important information on core options is not available to all patients. The National Health Strategy principle of choice, which works towards the availability of various dialysis modalities so that patients can choose their dialysis modality (in line with medical suitability) cannot be achieved without adequate information provision to patients.

Similar differences between hospitals were seen in participant understanding of core information regarding transplantation. Most (84%) of Hospital 1 participants reported that they were not on the kidney transplantation list, compared with 63% of all participants. Participants of Hospital 2 and Hospital 3 gave a variety of reasons (e.g. medical unsuitability or personal choice) for not being on the list, whereas over a third of participants from Hospital 1 did not know why they were not on the transplant waiting list.

Recommendations for service improvements include increasing the availability of core information for all patients on their transplantation and dialysis modality options.

4.4 Service satisfaction

4.4.1 Satisfaction with haemodialysis services

The most satisfactory dimensions of services, as evaluated by haemodialysis patients, related to the quality of care provided by medical and nursing staff. The high quality of patient encounters with medical and nursing staff is very reassuring. Credit for such high quality ratings should be clearly conveyed to those concerned. Less satisfactory aspects of care related to the physical environment and waiting times for haemodialysis sessions. Over half (60%) of participants at Hospital 2 rated the parking as poor, and comments from participants of all hospitals highlighted the importance of good parking facilities to relieve this otherwise expensive and stressful experience.

Most haemodialysis patients visited the hospital a median three times per week for a median three and a half hour haemodialysis session. Since patients spend this amount of time in a dialysis unit, the comfort of the unit is particularly important. Generally participants rated the space available (74%) and the comfort (84%) highly. Analysis of comments highlighted the importance of maintaining a comfortable surrounding and improvements were suggested, including larger, brighter dialysis units. Future planning of dialysis units could take note of patient comments and suggestions, possibly in relation to the development of haemodialysis units which are less like a hospital. Simple changes, such as the removal of televisions from one dialysis unit, led to strongly negative evaluations of experiences while on dialysis and highlighted the importance of providing ways for patients to occupy their time during these lengthy dialysis sessions.

Another area that received high ratings of dissatisfaction was the time patients had to wait for a dialysis machine to become available for them. Levels of dissatisfaction with scheduling of dialysis sessions should form a focus for planned improvements in the future.

In the evaluation of accessibility of a service, the distance travelled to avail of the service and satisfaction with travel arrangements should be considered. The National Health Strategy states an aim to provide dialysis services close to patients' homes. Since haemodialysis patients travel to hospital two to four times each week, a satisfactory mode of transport to hospital is essential. Throughout all hospitals, the most common mode of transport to the dialysis unit was health board taxi, with between 68% and 79% travelling by health board taxi/minibus in all hospitals. While satisfaction with travel arrangements was high (92%), participants travelled a median 22.5 minutes, with a range of two to 165 minutes travelled.

4.4.2 Patient satisfaction with peritoneal dialysis services

Peritoneal dialysis services (excluding outpatient clinic services, covered in section 4.5) were generally rated highly. An issue raised in peritoneal dialysis participant comments was the accessibility of hospital services, relating to the distance to hospital and transport arrangements. It was suggested that peritoneal dialysis services should be spread throughout the country and that hospital transport should be available to those patients who have difficulty travelling to the hospital.

A notable point was the variation in individual requirements and support of peritoneal dialysis patients. Some patients manage their peritoneal dialysis with little need for assistance, while other patients, in being so removed from the hospital setting, require greater support from medical staff. For example, some participants stated that they had never received a renal nurse home visit but that they were not necessary, while others reported occasional renal nurse home visits, but felt they would prefer more regular visits. Similarly, some patients had difficulties with transport arrangements for hospital visits, and would prefer greater hospital involvement, for example the provision of transportation by the hospital. Thus the degree of involvement by the hospital in each peritoneal dialysis patient's care needs to be planned according to individual patient needs.

4.5 Patient satisfaction with outpatient clinic services

As observed in ratings of haemodialysis services, the highest satisfaction ratings for outpatient clinic services were again seen in relation to care provided by medical and nursing staff. Areas rated included the quality of care provided, amount of time spent with, and advice and information provided by medical and nursing staff. All areas received high satisfaction ratings.

Lower satisfaction ratings again related to the physical environment such as waiting area and waiting times for outpatient appointments. Analysis of satisfaction levels for each hospital and for each clinic (i.e. where haemodialysis and peritoneal dialysis clinics were held separately) gave an indication of the source(s) of problems with waiting times and waiting areas. With these data, problems relating to waiting times and waiting areas for specific clinics can be addressed. Many problems appeared to concern the number of patients attending for particular clinics, both in terms of increased waiting times due to clinic numbers and also waiting areas which were not large enough for clinic numbers.

Another area of the physical environment which received lower satisfaction ratings was parking convenience for outpatient clinics. Problems were generally related to two issues, firstly the expense of parking, and secondly the lack of disabled or dialysis-specific parking spaces close to the hospital.

The profile of satisfaction findings in this evaluation are broadly similar to those found in other studies. Previous Irish work on outpatient satisfaction has found that the most satisfactory aspect of hospital care is the one-to-one quality of care provided by health professionals, e.g. for hospital inpatient and outpatient clinic services (McCarthy et al, 2000) and for outpatient ENT services (Doyle et al, 2002). Similarly, findings of problems with appointment scheduling (delays; many patients having the same outpatient appointment time) have been documented in other settings. A staff focus on sources of delay to scheduled treatment times is necessary in each centre in order to identify the main cause(s) of difficulty and the most feasible strategies for addressing such difficulties for a particular centre. Staff are often best positioned to

identify difficulties and the strategies which are likely to be most effective in addressing them. Within hospitals, staff discussion to address such issues needs to be conducted in an open and trusting system if the main sources of delay are to be addressed. For instance, in an outpatient system evaluated some years ago by this research team, delays to consultation time from the scheduled appointment time were found to be much longer for early morning appointments than at any other time during the day. Numbers of patients scheduled early in the morning were no higher than at other times in the day. Thus the most plausible explanation for the variable delay was late starting of the outpatient clinic. Consideration of this possibility was beyond the data available to researchers and could only be considered by hospital staff interested in adopting strategies for improvement.

4.6 Support services

With regard to support services for patients, two points summarise the findings. Firstly, practical resources such as dietary, social support and financial entitlement information are seen as a necessary and important aspect of hospital services. Secondly, some hospitals had better patient ratings for aspects of these services than others. There is clearly an opportunity for hospitals to learn from each other and to share resources which benefit patients. For instance, dietary, financial and social support advice and information resources could be developed either by a joint group across hospitals or by one hospital with a commitment to sharing with others, or conjointly with other interested groups such as the Irish Kidney Association. Many participants made the useful suggestion that the hospital could provide an information pack containing dietary information, financial entitlement leaflets and social support information when they are first referred for dialysis.

Chapter 5

RECOMMENDATIONS

5.1 General recommendations about this survey

Recommendation 1. The findings of the survey be circulated to staff working with renal patients.

Recommendation 2. Alongside feedback on survey findings, a mechanism for consultation to prioritise targets for improvements should be established in each hospital based on its own feedback. This should be inclusive of varying levels (senior and front line) and types of staff (administrative and health professional) who can contribute to renal patient care.

Recommendation 3. Consultation among staff within hospitals should happen in parallel with ERHA and individual hospital consultation meetings. These meetings between ERHA and representatives of participating hospitals (including administrative and health professional staff) should discuss study findings in conjunction with other aspects of the renal review in order to plan for a systematic and joint approach to investment in quality improvement.

Recommendation 4. Study results should be communicated back to patients, to encourage an environment within which patients can contribute (and can see that they can contribute) to improvements in services. Suggestions include a summary display of study findings within hospital dialysis areas. This may include an outline of issues agreed to be addressed in a quality assurance system by hospital and health board staff.

5.2 Specific recommendations

5.2.1 Medical and nursing care

Recommendation 5. The high levels of patient satisfaction with care from medical and nursing staff should be clearly conveyed and acknowledged to those providing care.

5.2.2 Physical environment

Recommendation 6. Haemodialysis units need to be evaluated in terms of acceptability of space, comfort and means for patients to occupy their time while on dialysis.

Recommendation 7. Parking facilities for those patients needing services, including policing of disabled/dialysis parking where necessary, need to be ensured.

Recommendation 8. The capacity of outpatient clinic waiting areas to accommodate numbers waiting should be considered. This should be considered in tandem with Recommendation 9.

5.2.3 Time to treatment for dialysis

Recommendation 9. The scheduling of haemodialysis appointment times and outpatient clinic appointments should be reviewed in each hospital and strategies developed to reduce waiting times where necessary.

Recommendation 10. The distance to travel for current patients should be considered and recommendations made about the most equitable and accessible service locations (while balancing efficiencies and expertise development) for the future.

5.2.4 Provision of information to patients

Recommendation 11. Patients need clear information about their current clinical status, and options for them regarding transplantation and dialysis. Where a choice of dialysis modality is possible, this choice should be given to the patient.

Recommendation 12. Printed dietary information and regular contact with a dietician should be available to patients.

Recommendation 13. Social service and financial entitlement information should be available to all patients. Information packs for patients newly referred for dialysis should be considered.

5.3 Recommendations for future patient satisfaction studies

Recommendation 14. Hospitals should consider re-surveying patients at an approximate future date to evaluate changes based on hospital changes and on other influencing factors. The instrument used here was extensively tailored, with support of renal service staff, for the purposes of assessment in the Irish system. It is available for reuse by individual centres as and when they chose to do so.

Chapter 6

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Appendix 1. Letter from consultant

[Date]

[Patient name]

[Patient address1]

[Patient address2]

[Patient address3]

Dear [Patient name],

The hospitals in the Eastern Regional Health Authority are carrying out a survey of their renal dialysis services as part of a quality improvement strategy. Patients' views and experiences are an essential part of the survey and I write to ask if you would consider taking part.

The survey is being conducted by an independent researcher from the Royal College of Surgeons. It is completely separate from the medical care you receive from this hospital and you are under no obligation to take part. However, I hope you will consider taking part as the information they gather will be used to improve renal dialysis services in the future.

I have enclosed an information sheet which gives you more details about the project. A consent form is also enclosed. Please complete and return the consent form, indicating whether or not you wish to take part in the survey. The form should be returned to the Royal College of Surgeons in the prepaid envelope enclosed.

Thank you for your consideration of this request.

Yours sincerely,

[Consultant name]

Consultant Nephrologist

Appendix 2. Patient Information Sheet

Patient views of renal dialysis services

The Eastern Regional Health Authority, as part of its service improvement activities, wishes to review renal dialysis services in hospitals in the region. A very important part of this review is the views of people who use the services. Patients receiving dialysis services are invited to take part in this study of patient views and experiences. Information collected will be used in planning to improve services in the future.

An independent survey

The Eastern Regional Health Authority have organised for a survey to be conducted of all patients using dialysis services in the region in the coming weeks. The survey is being conducted by independent researchers from the Royal College of Surgeons in Ireland.

Taking part in the survey

You will find enclosed a CONSENT FORM and freepost envelope along with a letter from your consultant asking if you will take part in the survey. Please return the consent form even if you do not want to take part – putting a tick in the box you choose means that you will not be contacted unnecessarily. It is entirely your choice, you do not have to participate. We would however greatly appreciate your participation – it is only by hearing from service users that we can best improve current services.

If you decide to take part, and we hope you do, a member of the research team will telephone you to arrange to interview you about your experiences of dialysis services. The interview will take about 20 minutes by telephone and can be completed then or at a more suitable time for you. The researcher will ask you questions about your experiences using the service. The interview is strictly confidential. Your name will not be written beside any comments you make and no one except the researcher will know the answers you give. Hospital staff will not know whether or not you took part in the survey. All of the interviews will be compiled into an anonymous report and the results will be reported back to the hospital. These results will help shape future developments in dialysis services in the Eastern Region.

Further information

If you would like to ask some questions about this survey you are welcome to contact the researchers directly at the Royal College of Surgeons. You can telephone XXXXXX at the Health Services Research Centre on XXXXXX.

Appendix 3. Patient Consent Form

**Royal College of Surgeons in Ireland
Health Services Research Centre,
Department of Psychology,
Mercer Building, Dublin 2, Ireland.**

QuickTime™ and a
Graphics decompressor
are needed to see this picture.

PATIENT CONSENT FORM

Renal Dialysis Services

Please enter your name below and tick one of the boxes to indicate whether you wish to participate in the renal dialysis survey. Please return this form to the Royal College of Surgeons in the prepaid envelope enclosed.

NAME _____

I agree to take part in a survey of renal dialysis services

I have read the accompanying information sheet. I understand that
I can change my mind and refuse to take part at any time.

TELEPHONE No. _____

BEST TIME TO CALL _____

SIGNED _____

I do not agree to take part in a survey of renal dialysis services
(You will not be contacted again and we thank you for your time)

Questionnaire for patient satisfaction with dialysis
services provided by ERHA hospitals
(for telephone administration)

PATIENT ID CODE _____

HOSPITAL ID CODE _____

DATE OF INTERVIEW _____

Introduction to telephone call

Good morning / afternoon etc. Can I speak to _____
Hello, my name is _____ and I'm a researcher from the Royal College of Surgeons.
You recently received a letter from your hospital asking you to take part in a survey on
renal dialysis services.

I would like to thank you for returning the consent form and agreeing to take part. I was
wondering if we could do the survey now? It will take approximately 30 minutes. If you
want to stop at any time, just tell me and, if appropriate, we can arrange a time to
continue on another day. Is now a good time?

If 'no', schedule another suitable time. End call.

Date agreed ____ / ____ / 2002

Time agreed ____: ____

*If 'yes', Okay, I'll start with some questions about the type of
dialysis you use. Please remember that this survey is confidential
and your name will not be recorded with the answers you give.*

[Note time of start of interview ____: ____]

Dublin 2.

00-353-1 4022428

Section A: Patient dialysis profile

1. What type of dialysis are you *usually* on?

- HD **haemodialysis** (approx 3 visits a week to hospital for 3-4 hours on dialysis machine and no other home interventions)
- CAPD **continuous ambulatory peritoneal dialysis** (approx 4 fluid bag changes and sterilizations at home with fewer hospital visits; storage of fluids at home)
- CCPD **continuous cyclical peritoneal dialysis** (nightly connection to dialysis machine; storage of fluids & equipment at home)
Also known as **APD (automated peritoneal dialysis)**

2. When did you first start dialysis? _____ months, _____ years ago
OR _____ / _____
(month) (year)

3. What types of dialysis have you been on since then (*tick all that apply*)? HD CAPD CCPD

4. Have you always attended your current hospital for dialysis (excluding brief holidays)?

Explain

5. Have you ever had a kidney transplant? Yes No

How many times?

6. Are you currently on the transplant list?

How long have you been waiting?

Explain why not

7. In general, would you say your health at the moment is; Very Good Good Fair Poor Very Poor N/A

8. Compared to when you were first referred for kidney dialysis, how would you rate your health in:

Much better now Somewhat better now About the same Somewhat worse now Much worse now

Go to Section B (current HD) or C (current CAPD / CCPD)

Section B: for current HD patients only

i. Haemodialysis Profile

1. When was your last visit for HD at this hospital? _____ days ago
2. How many dialysis sessions per week do you have?

3. How many hours per session do you have?

4. What days of the week do you usually have haemodialysis and at what time do you usually start haemodialysis each day (24 hour clock)?

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<input type="checkbox"/>						
:	:	:	:	:	:	:
5. Did you have a choice of which days of the week you have haemodialysis?

	Yes	No	Don't Know
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. And did you have a choice of which times of the day you have haemodialysis?

	Yes	No	Don't Know
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How satisfied are you with the days and times that you have dialysis?

Explain

ii. Travel Arrangements

8. Does anyone ever accompany you to the dialysis unit?

	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
9. If yes, how satisfied are you with the facilities available for them (e.g. waiting space, canteen, toilets, etc.)

Explain

10. How do you usually travel to the haemodialysis unit (tick all that apply):

Ambulance	Car	Public Bus	Health Board Minibus	Train	Hospital Taxi	Private Taxi	Walk	Other
<input type="checkbox"/>	_____							

11. How long does it take to travel to the hospital for haemodialysis?

12. How satisfied are you with these travel arrangements?

Explain

If travel by car How would you rate the parking convenience?

13.

iii. Staff Attitudes / Interpersonal

14. When was the last time you received care from your consultant in the dialysis unit?

15. What is your view of the quality of care you receive from your consultant in the dialysis unit?

Comments

16. When was the last time you received care from any other doctor in the dialysis unit?

17. What is your view of the quality of care you receive from the other doctor in the dialysis unit?

Comments

18. What is your view of the quality of care you receive from the renal nurses in the dialysis unit?

Comments

19. What is your view of the amount of time you spend with the renal nurses in the dialysis unit?

Comments

iv. Other hospital services within the hospital at which you receive dialysis care

20. Do you need any other service, or need to see anyone else **in relation to your kidney condition** but find that you cannot see the person/ get the service when at the hospital for haemodialysis?

Yes

No (Go to Q23)

21. (If yes) who do you need to see / what service do you need?

22. Why can't you see/use them?

23. Do you see other /any specialist in the same hospital **in relation to any other health**

pr Yes

No (*Go to Q25)

If yes, specify type of specialist(s)

24. How satisfied are you with co-ordination of appointments between your attendance for dialysis and your attendance for these other appointments?

Very Satisfied

Satisfied

Neither

Dissatisfied

Very Dissatisfied

N/A

Comments

v. Dialysis Procedure

I'm now going to ask some questions about how you feel about various aspects of the actual dialysis procedure.

25. What is your view generally of the amount of time you have to wait for a dialysis machine to become available?

Very Good

Good

Fair

Poor

Very Poor

N/A

Comments

26. What is your view of the opportunity to rest and recover following treatment?

Very Good

Good

Fair

Poor

Very Poor

N/A

Comments

27. Generally, what is your view of the opportunity to ask questions?

Very Good

Good

Fair

Poor

Very Poor

N/A

Comments

28. What is your view of the space available in the dialysis unit?

Very Good

Good

Fair

Poor

Very Poor

N/A

Comments

29. What is your view of the comfort of the dialysis unit?

- Very Good Good Fair Poor Very Poor N/A

Comments

30. What is your view of the general atmosphere in the dialysis unit?

- Very Good Good Fair Poor Very Poor N/A

Comments

31. What is your view of the respect shown for your privacy?

- Very Good Good Fair Poor Very Poor N/A

Comments

32. If you need to discuss something privately with the doctor or renal nurse, how satisfied are you that you would have an opportunity to do so?

- Very Satisfied Satisfied Neither Dissatisfied Very Dissatisfied N/A

If problem, specify

33. How satisfied are you generally with the availability of your consultant if you need him/her?

- Very Satisfied Satisfied Neither Dissatisfied Very Dissatisfied N/A

Comments

34. During the dialysis procedure, how do you occupy your time?

35. How satisfied are you with the way in which you occupy your time whilst on dialysis?

Explain and suggest improvements

vi. Overall Satisfaction

Overall, how good do you think the **nursing care** is at the HD unit?

Comments

36.

37. Overall, how good do you think the **medical care** is at the HD unit?

Comments

38. Overall, how good do you think the **running** of the HD unit is?

Comments

vii. Comments

39. In terms of the care you receive for haemodialysis, what do you feel is the aspect of the present service that needs to be improved most (and how)

40. What, if anything, do you worry about in terms of the provision of the HD service in the future? _____

GO TO SECTION D

Section C for current CCPD and CAPD patients only

i. Home Visits

1. How often does the renal nurse make a home visit (*If less than once a month or never, Explain*)? _____

(*If never, go to Q4*)

2. How satisfied are you with the last visit you received from the renal nurse?

Explain

3. How satisfied are you with the frequency of renal nurse home visits?

Explain

ii. Infections and Hospital Admissions

4. **In the past year**, have you had infections related to your dialysis? Yes No (Go to Q7)

5. (If yes) how often? _____ times (approx. if a lot)

6. How satisfied are you with the overall management of these infections by your hospital?

Explain

iii. Equipment Supply

7. How satisfied are you with the service you receive from renal equipment suppliers – the people who supply your fluids and other needs?

Very Satisfied

Satisfied

Neither

Dissatisfied

Very Dissatisfied

N/A

Ask for comments and suggestions for improvements

8. Who would you speak to in an emergency regarding your renal equipment supplies?

9. How satisfied are you with this emergency procedure?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Satisfied | Satisfied | Neither | Dissatisfied | Very Dissatisfied | N/A |
| <input type="checkbox"/> |

Comments

x. Comments

10. In terms of the care you receive for CCPD / CAPD from your hospital, what do you feel is the aspect of the present service that needs to be improved most in the future (and how)

11. What, if anything, do you worry about in terms of the provision of the CAPD/CCPD service in the future?

Section D: Outpatient Clinic

I am going to ask you some questions about your experience of the renal outpatient clinic when you go for an assessment relating to your renal condition. [To haemodialysis patients only: This **does not** refer to any review or assessment you may receive during a haemodialysis session]

i. Outpatient Clinic Appointment Profile

1. When was your last visit for an appointment at the OPD renal clinic in this hospital?

1a. (If attended more than 2 months ago or never attended):
Why haven't you visited the OPD renal clinic for more than 2 months?

IF NEVER ATTENDED, go to Section E.

1b. Did you visit the public OPD renal clinic at your hospital or did you visit a private renal clinic at your hospital?

Public Clinic

Private Clinic

IF PRIVATE CLINIC, ask Questions 2, 3 and 4, then go to Section E.

2. Did you see your consultant at your last visit to the renal clinic?

When did you last see you consultant at the renal clinic?

3. How often do you visit the renal clinic? Every

How satisfied are you with the frequency of your attendance at the renal clinic?

4.

Explain

If NOT ATTENDED FOR MORE THAN ONE YEAR, go to Section E

IF ATTENDED PRIVATE CLINIC, go to Section E

5. How satisfied are you with the way in which appointments are arranged?

Explain

ii. Outpatient Clinic Waiting Time/ Waiting Area

These questions relate to your last visit to the OPD

6. How would you rate the waiting time at the clinic?

Explain

7. How would you rate the quality of the waiting area?

Explain

If last appointment was more than 2 months ago, go to Question 13

8. What was your appointment time (24 hour clock)? _____: _____
(i.e. what was your appt. time **with the consultant**)

9. What time did you arrive at the outpatient clinic? _____: _____

10. What time were you seen by the consultant? _____: _____

11. What time did you leave the clinic?
_____: _____

12. Did you feel you had to wait a long time to see the consultant in the clinic?

Comments

vi. Outpatient Clinic Travel Arrangements

13. **Do you usually** Alone Accompanied (By how many people? _____)

14. How do you usually travel to the outpatient renal clinic (tick all that apply)?

Ambulance	Car	Public Bus	Health Board Minibus	Train	Hospital Taxi	Private Taxi	Walk	Other _____
<input type="checkbox"/>								

15. How satisfied are you with the travel arrangements?

Very Satisfied	Satisfied	Neither	Dissatisfied	Very Dissatisfied	N/A
<input type="checkbox"/>					

Comments _____

16. How long does it take you to travel to the hospital for your outpatient appointment?

17. *If travel by car* How would you rate the parking convenience?

Explain _____

iii. Outpatient Clinic Staff Attitudes/ Interpersonal

18. How many of the following people provided you with services at your last visit to the clinic (tick all that apply)?

Consultant (nephrologist)	Other doctor(s)	Nurse(s)	Other _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. What is your view of the amount of time spent with the Consultant?

Good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Poor	<input type="checkbox"/>	<input type="checkbox"/>
------	--------------------------	--------------------------	--------------------------	--------------------------	------	--------------------------	--------------------------

Comments _____

20. What is your view of the quality of care you received from the Consultant?

Very Good	Good	Fair	Poor	Very Poor	N/A
<input type="checkbox"/>					

Comments _____

If received services from other doctor(s)...

21. What is your view of the amount of time spent with the other doctor(s)?

Very Good	Good	Fair	Poor	Very Poor	N/A
<input type="checkbox"/>					

Comments _____

22. What is your view of the quality of care you received from the other doctor(s)?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

If received services from a nurse...

23. What is your view of the amount of time spent with the nurse?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

24. What is your view of the quality of care you received from the nurse?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

iv. Outpatient Clinic Attributes/ Privacy

And now some general questions about your last visit to the renal clinic...

25. What is your view of the chance to have your questions answered during your visit?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

26. your privacy?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

27. What is your view of the cleanliness of the examination room?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

28. What is your view of the doctors advice about ways to avoid illness and stay healthy?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Good | Good | Fair | Poor | Very Poor | N/A |
| <input type="checkbox"/> |

Comments

29. How satisfied were you with the doctor's explanations of what was done for you (tests, treatment, etc)?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Satisfied | Satisfied | Neither | Dissatisfied | Very Dissatisfied | N/A |
| <input type="checkbox"/> |

Comments

v. Outpatient Clinic Overall Satisfaction

30. Overall, how good do you think the **nursing care** is at the outpatient clinic?

Comments

31. Overall, how good do you think the **medical care** is at the outpatient clinic?

Comments

32. Overall, how good do you think the **running** of the outpatient clinic is?

Comments

[Check patient] Are you okay to continue?
[If No, agree date and time for callback

Date ____/____/ 2002 Time ____: ____

Section E: Information about your condition

1. Have you received information about kidney disease and your kidney condition (e.g. leaflets, verbal info) from: (tick all that apply)?

Comments

- | | | | | | | |
|--|---------------------------------------|----------------------------------|----------------------------------|----------------------------------|---------------------------------------|---------------------------------|
| 2. How would you rate the usefulness of the information from doctors? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | N/A
<input type="checkbox"/> |
| 3. How would you rate the usefulness of the information from nurses? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | N/A
<input type="checkbox"/> |
| 4. How would you rate the usefulness of the information from the IKA (Irish Kidney Association)? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | N/A
<input type="checkbox"/> |
| 5. How would you rate the usefulness of the information from the internet? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | N/A
<input type="checkbox"/> |

6. How satisfied overall are you with the information provided and available about your kidney

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Satisfied | Satisfied | Neither | Dissatisfied | Very Dissatisfied | N/A |
| <input type="checkbox"/> |

7. Do you have any recommendations for improvements in the provision of information?

Section F: Type of dialysis

Different types of dialysis suit different people.

1. Do you know why you are on the particular type of dialysis you are on (rather than a different type of dialysis)?

Explain

2. If yes, was the reason explained to you by your medical team or by others?

Yes

No

3. I know this is not always possible, but did you have a choice in which type of dialysis to have?

Explain

4. How satisfied are you with the type of dialysis you are currently on?

Explain why

5. In an ideal situation, if there could be a choice, which type of dialysis would you prefer (explain each type in case they know type but don't know name)

HD *haemodialysis* (approx 3 visits a week to hospital for 3-4 hours on dialysis machine and no other home interventions)

CAPD *continuous ambulatory peritoneal dialysis* (approx 4 fluid bag changes and sterilizations per day at home with fewer hospital visits; storage of fluids at home)

CCPD *continuous cyclical peritoneal dialysis* (nightly connection to dialysis machine; storage of fluids & equipment at home) (also known as APD)

6. Overall, how would you rate your level of knowledge of haemodialysis?

Very Good

Good

Fair

Poor

Very Poor

Not heard of it

- | | | | | | | |
|---|---------------------------------------|----------------------------------|----------------------------------|----------------------------------|---------------------------------------|---|
| 7. Overall, how would you rate your level of knowledge of CAPD? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | Not heard of it
<input type="checkbox"/> |
| 8. Overall, how would you rate your level of knowledge of CCPD/APD? | Very Good
<input type="checkbox"/> | Good
<input type="checkbox"/> | Fair
<input type="checkbox"/> | Poor
<input type="checkbox"/> | Very Poor
<input type="checkbox"/> | Not heard of it
<input type="checkbox"/> |

Section G: Support Services

Dietary-Related Services - A part of kidney disease is managing dietary and fluid restrictions.

- How satisfied are you with the availability of information and advice on dietary related aspects of your care?

Explain

- When did you last see the dietician? _____ weeks ago
- How satisfied are you with the availability of the dietician?

Explain

- What, if anything, would improve the dietary related aspects of your care?

Social / Financial Services - Kidney disease and its treatment can result in many costs – leaving work or reducing working hours, transport to hospital, house and family readjustments.

- How satisfied are you with the availability of information and advice on social and financial support available to you, with regard to your kidney condition (e.g. social workers, financial assistance)?

Explain

- If you needed to speak to someone in an emergency regarding social support for yourself, who would you contact?

- How satisfied are you with this arrangement?

Explain

8. When did you last see a social worker or patient care coordinator or counsellor at your hospital? _____

9. How satisfied are you with the availability of the hospital social worker/ patient care coordinator/ counsellor?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Satisfied | Satisfied | Neither | Dissatisfied | Very Dissatisfied | N/A |
| <input type="checkbox"/> |

Explain

10. What, if anything, would improve the social and financial support aspect of your care?

Medical Support

11. If you had a medical emergency relating to your kidney condition, who would you contact?

12. How satisfied are you with this arrangement?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Satisfied | Satisfied | Neither | Dissatisfied | Very Dissatisfied | N/A |
| <input type="checkbox"/> |

Explain

Section H: Personal Details

Now some last questions so we can describe who we spoke to in the survey. Please remember that this survey is confidential. We will not record your name on the questionnaire and we will not identify you to doctors or in the final report.

1. Are you; Male Female

2. What is your age? _____ years of age

3. Are you currently employed? Yes No

If no, are you :

Retired

Unable to work - **due to renal problems**

Unable to work - **not due to renal problems**

Other

4. What is (or was) the main household occupation?

_____ (If farmer, how many acres farmed?)

5. How many miles do you live from the hospital OPD/ renal unit? _____ miles

6. Is the area that you live in part of the Eastern Regional Health Authority? No Don't Know Yes

What is the name of the health board for your area?

What is the name of your nearest town?

Why do you travel to an ERHA hospital for dialysis services?

7. What is your postcode? _____

(If Co Dublin) Is that in the North or South?

North

South

(If different county) Which county do you live in?

7b. Do you have a Medical Card?

Yes

No

Don't Know

Medical Card

8. Is there anything else you would like to say – anything we may not have covered or something you would like to add or ask?

9. Have you found it acceptable to be interviewed over the telephone?

Yes

No

Thank you very much for your help. By getting patient views of their experiences, we can best plan how to improve services in the future.

10. We don't have any plans to contact you again, but if we were to do a follow-up study in a few months time or longer, would you be willing to be contacted again? You could of course say 'no' to participation at that point.

Yes

No

Thank you again very much. Goodbye.

Interviewer Notes

Time interview finished _____: _____