

INVESTIGATING UK RENAL PSYCHOSOCIAL SERVICE PROVISION

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Declarations

The findings from this thesis have been used in the publication of one report (Seekles et al., 2018) and two peer-reviewed articles (Appendix 1 and Appendix 2):

- **Seekles, M.L.,** Ormandy, P., & Coyne, E. (2019). Mapping the renal psychosocial workforce: the first comprehensive workforce survey. *BMC Nephrology*, DOI:10.1186/s12882-019-1287-0
- **Seekles, M.L.,** Ormandy, P., & Kamerāde, D. (2020). Examining patient distress and unmet need for support across UK renal units with varying models of psychosocial service delivery: a cross-sectional survey study. *BMJ Open*, DOI: 10.1136/bmjopen-2020-036931

I was the lead author on both publications and undertook the design of the study, analyses and interpretation of findings and drafting of these articles, under supervision of and/or with support from the co-authors, who also completed revisions to the articles.

Abbreviations

AT: Anxiety Thermometer	KCUK: Kidney Care UK
AngT: Anger Thermometer	LA: Local Authority
BASW: British Association of Social Workers	LTC: Long-term condition
BRS: British Renal Society	MDT: Multidisciplinary team
CAB: Citizens Advice Bureau	MR: Mandatory reconsideration
CBT: Cognitive behavioural therapy	NCCN: National Comprehensive Cancer Network
CD: Clinical Director	NHS: National Health Service
CI: Confidence Interval	NHSCCS: NHS and Community Care Act
CKD: Chronic kidney disease	NICE: National Institute for Health and Care Excellence
CNSW: Council of Nephrology Social Work	NSF: National Service Framework
DepT: Depression thermometer	ONS: Office of National Statistics
DH: Department of Health	OR: Odds ratio
DSM-V: Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition	PC: Problem Checklist
DT: Distress Thermometer	PD: Peritoneal Dialysis
DWP: Department of Work and Pensions	PIP: Personal independence payment
ET: Emotional Thermometer	RRT: Renal replacement therapy
ESRD: End-stage renal disease	RSW: Renal social worker
FTE: Full-Time Equivalent	SSD: Social Service Department
IAPT: Improving access to psychological therapies	UK: United Kingdom
(IC)HD: (In-centre) haemodialysis	UKRR: UK Renal Registry
IDWG: Interdialytic weight gain	US: United States of America

Abstract

Background: Internationally, emerging evidence of psychosocial problems in patients with end-stage renal disease has led to increasing calls for collaborative renal care models that include psychosocial services. In the UK, there is a dearth of empirical studies and clear policies to guide the implementation of these services. *Methods:* This thesis used a critical realist, mixed-methods approach to examine processes and outcomes of psychosocial service delivery, specifically focusing on the renal social worker role. First, an audit of the UK renal psychosocial workforce was completed. Then, a cross-sectional survey (n=869) captured and compared distress, psychosocial issues and need for services of in-centre haemodialysis patients across seven units. Focus groups (n=4) and in-depth interviews (n=6) with health professionals added a deeper understanding of processes of service delivery. In addition, diaries (n=15), questionnaires completed before and after social worker involvement (n=161), and a focus group brought insight into the renal social worker role. *Results:* Findings highlighted variation in psychosocial staffing patterns, with recommended benchmarks significantly exceeded. Overall, almost 50% of patients experienced distress. Multivariable logistic regression analysis showed that patients in units with better psychosocial staffing ratios [odds ratio (OR) 0.33 (95% CI 0.14-0.77); p= .01] and specifically better renal social work ratios [OR 0.15 (95% CI 0.05-0.45; p= .001) were less likely to experience distress, even after controlling for demographic variables. Nurses were found to play an important part in the process of psychosocial service delivery, yet experienced barriers in their ability to fulfil this role. Differences were found in funding arrangements and in the degree to which services were proactive and process oriented. The role of renal social worker was found to be poorly defined; and problems with their integration into renal teams and threats for the future of the role from Local Authorities were exposed. *Discussion:* The novel findings implicate a need for an increase in the renal psychosocial workforce. To ensure equitable access across the country, renal policy documents should make dedicated psychosocial care an unambiguous requirement and offer clear standards of practice and staffing recommendations. Renal units should explore processes, such as psychosocial education for clinical staff and distress screening, that can be put in place to ensure that a focus on psychosocial wellbeing is a standard part of renal care. To guide practice and further research, this thesis proposes a stepped-care model, putting renal social work at the heart of psychosocial service provision.

Chapter 1: Introduction

A growing number of studies have shown that psychosocial problems in patients with end-stage renal disease (ESRD), and particularly those receiving dialysis treatment, can result in reduced quality of life and adverse clinical outcomes, such as increased hospitalisation and mortality (1–3). This emerging evidence-base has led to an acceptance that a focus on the psychological and social needs of patients should be included in the provision of comprehensive renal care (4).

In times of growing financial and service pressures on the UK National Health Service (NHS), Kidney Care UK (KCUK), a national renal charity, has supported the NHS with the provision of renal psychosocial therapies through funding posts such as psychologists, social workers and counsellors. Since 2010, the charity has spent around £4 million on supportive funding through their seed funding model, of which internal evidence suggests that about 70% of posts were taken on by Trusts as substantive posts. Yet, it has no robust evidence on which to base future strategic funding decisions. KCUK sought out a partnership with the University of Salford and a Knowledge Exchange project was designed, commencing in February 2017. KCUK, as the research funding body, initially requested that the research focused on identifying and implementing ways to evaluate the role of the renal social worker (RSW). It soon became evident that a lack of understanding about the RSW role reflected a much wider lack of understanding about the provision of UK renal psychosocial services in general. In response, further funding was obtained to expand the project into a PhD. This allowed for a wider interrogation of the organisation of renal psychosocial services described in this thesis. Whilst KCUK mandated the initial focus of the study and were routinely updated about the progress of the study, they had no further involvement in its design, data collection, analysis or writing.

The state of the renal psychosocial workforce was last assessed by the National Renal Workforce Planning Group, over 15 years ago, in 2001. This group also prepared the only available document that sets out recommendations about renal psychosocial staffing levels in the UK, the Renal Workforce Plan (5). Over the past 15 years, the UK has been hit by austerity and considerable changes in the way health, mental health and social care are

provided have since taken place. It is unclear how psychosocial services are currently delivered, with the workforce plan out-dated and no clear guidelines or pathways for renal units to refer to when considering psychosocial staffing allocations. The lack of guidelines reflects a wider lack of UK scientific literature on the provision of renal dedicated psychosocial services. Generally, care providers have now been charged with achieving more care outside of the hospitals and in the community (6). It is unknown what this apparent move to more generic services as opposed to specialised services would mean for renal patients, particularly those receiving in-centre haemodialysis (IHD) treatment.

In response to these current gaps in knowledge, this thesis aims to gain a deeper understanding of UK renal psychosocial service provision. Since this is such an unexplored area of research, the study takes a broad, exploratory approach. A mixed-method approach, comprising of two studies, is adapted to study different models of renal psychosocial care and investigate the RSW role. Both studies use patients' experience of distress as an outcome of service delivery.

Research on psychosocial issues in ESRD patients has often focused on psychological problems such as anxiety disorder and depression, either as prevalence or outcome measure (4,7). Importantly, the current study also included the social aspect of psychosocial care. Research in other chronic conditions has described a wider issue caused by the biopsychosocial impact of a disease: distress. It has been studied in conditions such as oncology and diabetes (8–11), but has rarely been mentioned in relation to ESRD. Researchers stating that they have measured distress in ESRD patients, have usually actually measured depression and anxiety (12,13) rather than the broader array of patient responses to life on renal replacement therapy (RRT). The importance of a focus on the wider impact of the disease was also recognised by a research team at the University of Birmingham, whose findings of research on lower-level support needs and mild-to-moderate distress in UK renal patients were published towards the end of the current study (14–16), allowing for interesting comparisons.

This study applies a critical realist approach to understand processes and organisation of renal psychosocial service provision; capture experiences of staff and patients; and evaluate service

delivery, in particular that of RSWs. It uses the Distress Thermometer (DT) and Problem Checklist (PC) as a tool to identify distress and need for psychosocial services in the renal population.

To achieve this aim, the study had five objectives:

- To map the current provision of renal psychosocial services across the UK and examine how this has evolved since the last workforce mapping in 2001.
- To explore distress, psychosocial issues and need for support of ICHD patients.
- To investigate differences in distress and psychosocial issues across renal units with different models of psychosocial service provision.
- To generate an understanding of processes of service delivery within different models of renal psychosocial care.
- To gain a deeper understanding of the RSW role.

1.1 Overview of the thesis

To achieve the study aims and objectives, the thesis begins in Chapter Two with a general background of CKD and its prevalence. The current context in which renal psychosocial services are delivered across the UK is described, focusing on the state of health, mental health and social care systems for people living with chronic conditions. A critical overview of literature on psychosocial issues in patients living with ESRD is provided, after which the methods and results of the psychosocial workforce audit, undertaken to address objective one are detailed. Together with existing literature, the findings of this audit formed part of the rationale and direction of the PhD study. Therefore, even though they are part of the new knowledge created in this study, the decision was made to present this audit early, separate from other investigations.

In response to findings of the workforce mapping, which identified a lack of a generic UK model for psychosocial service delivery, Chapter Three and Chapter Four interrogate UK policies and international scientific literature for guidance on what such a model could look like. Chapter Three presents an overview of pertinent policies that shaped service provision at the intersect of health and social care for chronic conditions and describes how in recent

years psychological services have become part of this policy landscape. A critical examination of renal specific policy then explores guidance on which to base a renal psychosocial service.

Chapter Four presents the results of a systematic literature search of published research over a period of 15 years, in an attempt to uncover evidence as to what constitutes an appropriate psychosocial workforce composition. The search returned meagre results, insufficient to build any recommendations for practice. Therefore, the scope of the search was widened, and the Chapter provides an overview of scientific and grey literature related to renal psychosocial service provision in other countries, the state of research into renal psychosocial services and the delivery of psychosocial care in other long-term conditions (LTCs).

With the rationale and direction of the research now well established, Chapter Five examines the philosophical and theoretical considerations underpinning the methodology. There is a particular focus on adapting a biopsychosocial approach to distress and the way it is measured, given that the study uses distress as an outcome of psychosocial service delivery. Guided by the principles of critical realism, the Chapter outlines the research design, the data collection techniques and instruments. In addition, operational aspects of the research and ethical and analytical considerations are discussed.

The study findings are reported in three sequential chapters. Chapter Six focuses on distress, Chapter Seven is engaged with different models of psychosocial care, and Chapter Eight presents an in-depth exploration of the RSW role.

Chapter Six explores the concept of distress in ICHD patients combining qualitative findings with the themes derived from existing literature. Quantitative findings are integrated to identify the prevalence of distress, psychosocial issues and need for support in this patient group. Qualitative data are used to explore distress in the context of the systems of service delivery that patients are engaged with, or are attempting to be.

Chapter Seven draws on quantitative data to compare distress levels, psychosocial issues and need for services across seven units with different models of service provision, specifically exploring how variations in psychosocial staffing levels relate to differences in outcomes.

Qualitative data are used to contrast relationships, processes and funding of service delivery, generating a comprehensive understanding of possible underlying mechanisms to adequate psychosocial service provision and reduced distress.

The RSW profession is explored in Chapter Eight, providing insight into the necessity and scope of this unique, specialised type of social work. Factors within the Local Authority and the renal unit that restrict RSW practice and that could be detrimental to the future of the profession are exposed.

The final chapter of this thesis, Chapter Nine, brings together the key research findings described in Chapters Six to Eight and generates discussion in the context of insights obtained through investigations in Chapter Two to Four. The strengths and weaknesses of the study are highlighted. Recommendations for practice, policy and future research that emerged throughout the chapter and are summarised, followed by concluding remarks.

Chapter 2: Contextualising and mapping renal psychosocial services

2.1 Introduction

After providing a general background of chronic kidney disease (CKD), this chapter describes the current context in which renal psychosocial services are delivered across the UK. Taking a birds-eye view to focus on health, mental health and social care systems for people with chronic conditions, the challenges that services face and to which they must continue to adapt are described. After exploring the interplay between these systems, the chapter concentrates on psychosocial issues in adult renal patients, specifically exploring the concept of distress. Finally, the chapter describes the psychosocial services available, presenting the results of a renal psychosocial workforce audit (pertinent to the first study objective).

2.2 Chronic kidney disease and end-stage renal disease

CKD is a worldwide public health problem, with increasing incidence and prevalence, high costs, and poor outcomes (17). CKD is defined as 'abnormalities of kidney structure or function, present for more than 3 months, with implications for health' (18). The disease is typically progressive and divided into five stages of increasing severity, with treatments based on these stages. For a small, but significant percentage of people, CKD progresses to end-stage renal disease (ESRD), which is reached in the fifth stage of the disease (CKD stage 5). At this stage, which is irreversible, the kidneys are no longer able to function, and renal replacement therapy (RRT) -dialysis or transplantation- becomes necessary to maintain life (19,20). CKD is common, but frequently unrecognised, because it is largely asymptomatic in the first stages and often exists with other conditions (20). In England, the most recent population prevalence for CKD stage 3-5 (using data from the 2016 Health Survey for England) is around 7% of people aged 35 and older. This prevalence was found to increase with age, with 34% of people aged 75 or over classed as having moderate to severe CKD (21). According to the latest UK Renal Registry (UKRR) report, at the end of 2018, there were 66,612 patients receiving RRT in the UK. Of those, 38.6% were on in-centre haemodialysis (IHD). The number of people receiving RRT has grown by almost 3% between 2017 and 2018 and about 45% during the past decade (22). Forecasted further growth in the prevalence of the disease together with predicted reductions in the nephrology workforce requires forward planning to ensure appropriate management and access to services (23,24).

Living with CKD, and especially ESRD, provides many ongoing physical, emotional, financial and/or social challenges throughout an individual's renal journey. Particularly ICHD therapy, one of the RRT options, has a great impact on an individual's vocational, social and physical functioning, mainly due to the intrusiveness of the treatment. An average HD treatment lasts about four hours and is repeated three times a week, with missed treatments associated with increased mortality (25,26). Time-intensity of the treatment aside, many dialysis patients are required to assume strict diets due to their inability to process food products with high levels of potassium and phosphorous, and a need for sodium restrictions. They are also unable to effectively produce urine, and therefore many have very strict fluid restrictions. Adequate self-management, with ESRD patients playing a role in their own care by attending their treatment sessions and adhering to diet and fluid restrictions is expected and essential for patient survival (26). Patients with ESRD often have a range of comorbid conditions. Some of these, such as hypertension and diabetes, are risk factors for renal disease. Others, such as coronary heart disease, are often co-prevalent because of shared risk factors (27). The physical and psychosocial consequences of the disease and its comorbidities make patients' access to expertise in the medical, surgical, nursing, dietetic, pharmacological, psychological and social issues essential (28). This means that patients often access many different services, thereby crossing the boundaries between health care, social care (including welfare provision) and mental health care. As a result, renal care is complex, multifaceted and, in the current health care system, often fragmented across different specialities (27).

2.3 Health and Social care under pressure

In 2018, the NHS celebrated its 70th birthday, festively commemorated across the country. An equally important service – adult social care – also had its anniversary, but this was not marked in the same way. The services and support delivered in social care are not well known, even though their significance becomes evident as there are increasing indicators that unmet social care need is undermining health services (29). Both systems are currently facing unprecedented financial and operational pressures, with social care services being described as 'at tipping point' (30) and the NHS facing an 'existential crisis' (31, p.1).

The legislations that essentially laid down the current arrangements for health and social care took effect in 1948. It was then that a fault line was established between health care, which is almost entirely free at the point of use, and social care, which is heavily needs- and means-tested (29,32). These services, built on the foundations of the needs of the post-war population they were set up to serve, centred on the treatment of single, mostly infectious, diseases. Since that time, the aim of the NHS – to provide universal, equitable, comprehensive, high quality, free healthcare – has not changed (33). Neither has that of social care, which aims to provide personal or practical support to people who need help with essential daily activities or participation (e.g. work and socialising), because of age, illness, disability or other circumstances (29). This includes the provision of home care, meals, equipment and adaptations, day services, residential and nursing home care. Mechanisms for delivering these services include individual and carer assessments, adult protection procedures, personal budgets and direct payments. The profession typically involved in protecting adults and giving them access to social care, through assessments, development of care plans and management of provision of these services, is social work (34). In the 70 years that have gone by, technological advances have allowed medicine to be revolutionised and our society has changed immeasurably (32). To keep up with the changes, the health and social care services face the following key challenges: a growing and ageing population, changing disease burden, and constrained funding.

2.3.1 A growing and ageing population

The UK population is at its largest ever and is projected to continue to grow steadily (35). Whilst a larger population in general increases pressure on health and social care, the main challenge for these services is the demographic change due to an ageing population. Population ageing refers to a fundamental change in the age structure of the UK population, in which the proportion of older people is increasing. This is the result of two long-term trends, namely historically low fertility rates and falling mortality rates. Add to this a time-limited effect of historic high fertility rates – a high number of births after World War II, and a longer ‘baby-boom’ during the 1960’s, which introduced large cohorts of similar ages into the UK population – and a demographic change can be observed. One of the most important implications of this is that currently the number of pensioners is increasing faster than the number of working age people, lowering the proportion of individuals who pay taxes and

provide care for those who need it (36). The ONS (37) predict there will be more people aged over 65 than aged under 15 by 2024. Of particular importance is an increase in the number of people aged 85, reflecting increased longevity. Even though this is cause for celebration, there are implications of living longer for health services. At the age of 65, both men and women can expect to spend around half of their remaining life expectancy in good health. However, the likelihood of being disabled and/or experiencing one or more chronic and complex health conditions increases with age (38). It is observed that the Healthy Life Expectancy – an estimate of the number of years lived in ‘very good or ‘good’ general health – has not been able to keep up with the increase in Life Expectancy (39). This means that older people spend more years in poor health, resulting in a steep increase in demand and cost of healthcare services for people from around 65 years (38).

The ageing population also has implications for social care services, which include both paid (formal) care and care provided by family, friends or volunteers (informal care). Typically, social care requirements increase with age, as people become less able to self-care and live independently; in 2018/2019, around 80% of people who received social care were aged 65 or over (40). However, it is not just older people who require social care. The proportion of working-age adults (under 65) approaching Local Authorities (LAs) for support (even if they do not necessarily receive it) has grown by nearly 4% since 2015/2016, while the proportion of older people has fallen by more than 2% (41). About half of social care spending is for services for older people, such as help with every-day tasks at home, or placements in care homes. The rest is spent on working adults, mainly long-term support for people with mental health conditions or learning disabilities (42).

2.3.2 The shifting burden of disease

In the early days of the NHS, the attention of the public and service providers was largely on issues of poverty: infectious diseases, malnutrition and overcrowding. As prosperity increased, medical, technological and public health advances successfully lowered the incidence of these kind of conditions and the nation’s health improved. For those who once believed that the costs of the NHS would fall as this happened, it soon became evident that instead, the illnesses of poverty had been replaced by those of affluence and of longevity (43). Indeed, ‘diseases of old age’ – LTCs with a strong age gradient such as CKD, dementia and

Parkinson's disease – that were rare many years ago, are now much more common (32). Moreover, medical advances have turned some conditions, such as ESRD and heart disease, from being life-threatening into LTCs, as more people survive acute episodes of illness and live many years with their illness (44). The shift in disease pattern towards LTCs is not only due to the ageing population. Better health and social care has also improved the life expectancy of younger people with physical and/or learning disabilities (45). Many LTCs, including CKD, have a strong age gradient and part of their disease burden can be attributed to a small number of risk factors: tobacco use, harmful drinking, unhealthy diet, low physical activity and most notably obesity (46). In the past years, the public have made lifestyle and behavioural changes, such as less people smoking cigarettes, which have overall improved the nations' health. However, there has been a significant increase in alcohol consumption over the past three decades, in addition to obesity levels rising alarmingly (47,48). These new trends are threatening to halt or even reverse gains in life expectancy for the next generation (48).

2.3.3 Funding constraints

The above trends have played out at a time of public spending austerity, with both health and social care services facing an unprecedented period of financial constraint as a consequence of the banking crisis that began in 2008 (44,49). For the NHS, this has meant a significant slowdown in funding growth: since 2009/2010, the NHS funding has grown by slightly more than 1% a year. This is far below the historic yearly average increase of 3.7% since the NHS was established and, more importantly, the 4.3% a year growth rate that is needed to cover current demand (50). This decline in growth occurred at a time when the NHS is treating more patients than ever before. It has seen NHS pay growth constrained, staffing shortages grow, waiting times rise markedly and provider deficits escalate (42,50,51). In June 2018, the government announced increases in NHS funding over five years, beginning in 2019/2020. It was envisaged that thanks to this funding commitment, the NHS can regain core performance and has the financial security to develop a 10-year plan, prioritising quality of care; prevention; transformation of cancer care; better access to mental health services; and better integration of health and social care (52). The emphasis on the latter two is of importance to this study and is discussed in the following paragraphs.

Whilst the NHS has been affected by austerity, it has been relatively protected, with the coalition government pledging to protect NHS budget from reductions in funding (44). Instead, LAs – who pay for publicly funded social care – felt the effects of budget cuts most strongly, as financial support to LAs from the government decreased by 40% between 2010 and 2015 (53). To manage this fall in funding, LAs have spent less money on social care by tightening the eligibility criteria. The ‘means test got meaner’ (41), with thresholds in England – accounting for inflation - now 12% lower than in 2010/2011 (29). As a result, the number of people receiving publicly funded social care has fallen rapidly, and care has become more focused on those with very high levels of need. In 2006, 53% of councils supported people with ‘moderate’ levels of need, yet by 2010, only 25% said they planned to do so in the future (49).

There are important differences in the way publicly funded social care is accessed across the UK. In all countries, people face both needs and means testing, yet thresholds and generosity vary. In Wales, the upper asset threshold is £40,000, compared to £23,250 in England and Northern-Ireland. In Scotland, the means test for personal care for people over 65 years has been removed, making it free of cost for people with appropriate needs. The Scottish government committed to extending free personal care to those under 65 years by 2019 (54). This variation has led to differences in spending per adult across England, Northern Ireland, Scotland and Wales. Scotland has the highest public spending and its funding has risen by an average of 0.3% per year between 2008/2009 and 2015/2016. During the same period, funding per head has fallen in England and Wales by an average of 1.6% and 0.8% a year respectively. In England, spending per head is the lowest of all countries, followed by Wales, then Northern Ireland, which saw its spending rise with an average of 1.5% a year since 2011/2012 (29).

There is now growing concern about the negative impact of the reductions in funding for social care on a broad range of outcomes, such as unmet need leading to poor quality of life of users of social care, or the physical, mental and financial burden on informal carers. Reductions in the availability of social care have led to increased use of Accident and Emergency services (55) and delays in discharges from hospital, negatively affecting patient flow (29,56). In recognition of the overlap between health care and social care, there have

been significant transfers of money from the NHS to social care, through the so-called Better Care Fund. In addition, in 2016, the English government introduced a 'social care precept' (57). This gave LAs the opportunity to raise additional income through an annual rise in council tax, between 2016 and 2020. Moreover, the government made extra funding available over a period of 3 years. As a result, public spending on adult social care services is expected to rise again, but it continues to lag behind growth in demand. Since 2015, LAs have seen a 5.7% increase in requests for social care support, yet fewer people (a 1.7% decrease) have received it. Particularly the number of older people receiving long-term care has fallen with 7% since 2015, despite an increase in older people over that period (58). The injections of money will not be able to stop the funding gap from growing (29,49). Plans to reform funding and service delivery in social care have been promised, yet there is still no sign of the much anticipated and delayed Green Paper on Social Care, which was supposed to present these plans in the summer of 2017. Despite two decades of attempts by successive governments, there remains no clear long-term plan for reform and no clear path for developing one; social care policy is 'the zombie of modern policy debate, stumbling unsteadily around in circles' (59, p.1).

2.4 Multi-morbidity and mental health in chronic conditions

The current fiscal climate is not conducive to the provision of good quality care, but even if the funding situation was comfortable, the rising numbers of people with LTCs would still present a challenge to the care systems. People managing LTCs often have complex needs, for which they need to access many different services. They account for around 50% of GP appointments, 64% of outpatient appointments and 70% of hospital bed days (60). In addition, around 70% of total health and social care expenditure in England is attributed to people with LTCs, with a similar picture across the UK (31,60). LTC care is further complicated due to multi-morbidity becoming the norm. Increasingly, rather than having a single condition, people suffer from two or more LTCs. In the UK in 2015, 54% of people aged 65 years or over had two or more conditions; this was 68.7% for people aged 85 years and over, predicted to rise to 68.7% and 90.5% respectively by 2035 (61). In older people, multi-morbidity is largely due to higher rates of physical health conditions, whereas in younger people and people from less affluent areas, multi-morbidity is often due to a combination of physical and mental health conditions (62).

The link between physical and mental health issues is strong, and the relationship between untreated depression and anxiety disorders and poor physical health is complex and likely bi-directional (63). Around 30% of all people with a long-term physical condition in England also suffer from a mental health concern such as anxiety or depression. Conversely, around 46% of people with a mental health problem have a LTC (64). If left untreated, mental health problems can have a significant impact on the person's physical health, lowering the person's likelihood of engaging with treatment; reducing ability to self-manage; increasing the likelihood of unhealthy behaviours and the chance of premature mortality (63). Coexisting mental and physical health problems have been linked to significantly higher healthcare costs, through increased use of physical health services, including higher number of consultations, increased rates of hospitalisation and repeat attendance (63). There is growing evidence that supporting the psychological and mental health needs of people with LTCs more effectively can lead to improvements in both mental and physical health. However, existing health care provision often fails to realise these opportunities, due to a hard-wired separation of mental and physical health within institutional arrangements, payment systems and professional training curricula (64).

2.5 Social determinants of health

Once ignored and regarded only as distant or secondary influences on chronic disease, the role of social determinants in fostering illness and disability has been increasingly recognised. Social determinants can include social practices and conditions (such as lifestyles, living and work situations, environmental pollution etc); social economic status (income, education, and occupation); stressful circumstances; and racial discrimination, along with economic, political, and religious factors that affect the health of individuals, groups, and communities—either positively or negatively (65). The association between socioeconomic status and other social determinants of health and prevalence of chronic diseases is now well established (66,67). An investigation by Barnett et al. (66) of prevalence of multi-morbidity in Scotland found that the absolute number of people with comorbidity was, surprisingly, higher in those younger than 65 years. A substantial difference in prevalence of multi-morbidity between areas was found, with young and middle-aged adults living in the most deprived areas having the same prevalence as people aged about 10-15 years older living in more affluent areas (66). Financial difficulties, unemployment and debt are not only shown to impact physical health - they also

have a negative impact on people's mental health and form a hindrance for interventions (68). Around 25% of people with a mental health problem are in debt (69). The overlap between financial issues and mental and physical health problems can cause vicious circles, in which financial problems negatively affect health (70) and poor health affects the ability to generate income or resolve financial problems (68).

In the UK, people with LTCs can access financial support provided by the welfare system to alleviate financial difficulties, depending on their needs. Support can be split into those benefits that cushion the incomes of people unable to work for health reasons – principally employment and support allowance and universal credit – and those that help to meet extra costs associated with disability – personal independence payment (PIP) for people of working age and attendance allowance for people above 65 years (71). In an attempt to cut spending on working-age adults, in 2013 PIP was introduced as 'a more dynamic, fair, transparent and objective assessment' (72) to replace the previous Disability Living Allowance (DLA), moving most people from indefinite to fixed term awards (71,72). Spending has though continued to rise significantly with PIP costing around 15 to 20% more in 2017/2018, with rollout only around two-thirds complete (71). The entitlement for PIP is assessed by considering the impact of a person's condition, rather than the diagnosis that they have. So far, the claimants' responses about the claim process have been mostly negative, with people stating that the process was very stressful, too long and that Health Professionals conducting the assessments lacked understanding of the condition (72). An independent review of the PIP assessment highlighted that PIP was a 'complex claim process' and articulating the functional impact of their disease effectively was challenging for many patients (72). Data on award levels of PIP raises questions as to the effectiveness of the assessment. The most recent data (73) showed that PIP award rates were 44% for new claims and 72% for DLA reassessment claims in January 2019. Claimants who wish to dispute a decision on the PIP claim can apply for a 'Mandatory Reconsideration' (MR), to ask DWP to reconsider the decision. Of claims disallowed, 69% were reconsidered: 19% of new claims MRs and 24% of reassessed DLA MRs resulted in an awarded benefit (73). If claimants also want to dispute the MR decision, they can appeal and present their case in front of a tribunal. By the end of December 2018, there were 375,000 PIP appeals lodged, which meant that more than 9% of all initial PIP claims went to tribunal. In 2018, 72% of appeals cleared were in favour of the appellant (74). Concerns about the ability of the

contractors to conduct accurate assessments have been voiced (75). In addition, a lack of insight and ability of the claimant to describe the impact of their condition was a possible reason for an initial assessment that gathered insufficient evidence (72). Input from advocacy or support organisations had a significant positive influence in the outcome of a claim. Pressures on these organisations meant that choices had to be made about whom to support and at what stage of the claim, which meant that usually support is only available once the claim reaches appeal phase (72). In renal services, this advocacy role appears to be mainly taken on by RSWs and/or benefits advisors – where available in the unit – and voluntary or charitable organisations, such as Kidney Care UK.

2.6 Psychosocial issues in ESRD

Research into psychosocial factors, quality of life and psychological disorders in CKD has developed rapidly over the last 30 years, focusing mainly on ESRD patients. ESRD has a heavy disease burden and the intrusiveness of the treatment, particularly dialysis, provides patients with multiple disease-related and treatment-related psychosocial stressors that affect their everyday life (19). Many patients face psychological challenges such as trying to adjust to and cope with the illness and treatment regime; medical complications and problems; issues related to pain, palliative care and end-of-life care; changes in their social roles (familial, social and vocational); diminished quality of life; and body image issues (26). In addition, many have to deal with social challenges due to numerous losses, such as loss of financial security, employment, health, libido, strength, independence, mobility, schedule flexibility, sleep, and freedom with diet and fluid. These challenges could result in psychosocial problems (7,26). A recent systematic literature review highlighted a dearth of published research which provides insight in social care issues in CKD patients. Acknowledging that it is an incomplete picture, the authors provide examples of the common social care needs of people with CKD that were often articulated as being unmet (76):

- at home support for domestic and personal care
- support with taking medications at home and completing home treatments such as dialysis,
- accessible transport systems,
- welfare and housing support,

- help with renal diet and exercise regimes,
- counselling to underpin decision-making,
- general wellbeing support,
- social integration and avoidance of loneliness and social isolation,
- age-appropriate social events
- support for family members and unpaid carers.

These social issues affect patients' quality of life and have been linked to issues with self-management, behavioural compliance and treatment adherence, resulting in negative health outcomes (26). During the last 20 years, multiple prospective studies have also demonstrated an association between psychological issues and adverse clinical outcomes, such as increased hospitalisation, mortality and increased withdrawal from dialysis (2,77–80).

The most frequently reported psychological issues in ESRD patients are depression, anxiety, and adjustment disorders (4,7,81). Determining the prevalence of depression and anxiety within ESRD patients has proved complicated and research has come up with inconsistent results due to methodological issues (1). Zalai and colleagues (12) identified several studies undertaken between 1980 and 2008 that produced data derived from small, non-representative samples, using variable definitions of depression, and without using disease specific-validated assessment tools. This resulted in a variation in reported prevalence rates of 5% to 75%. More recently, reliable general depression scales have been validated against clinician-administered structured interviews in HD patients (12). These tools have been used in several large and well-conducted research studies, which have confirmed increased rates of clinical depression among those with ESRD, with meta-analysis suggesting the summary prevalence of interview-defined depression in ICHD patients to be 22.8% (82). This is higher than the prevalence of depressive disorders in the general population (7%) and in those with other chronic diseases including cancer (11%) (7,83,84) Clinician and self-reported levels of depression in dialysis patients were generally higher at approximately 40% (82). Anxiety disorders, characterised by a range of symptoms such as excessive worry and fear, were frequently comorbid with depressive disorders and ESRD (7). There is limited evidence on the incidence of anxiety among ESRD patients and research in this area is confounded by methodological issues, comparable to those in the study of depression. Nonetheless, the

available evidence indicates anxiety being experienced by a significant proportion of patients, similar to the prevalence of depression, with prevalence ranges reported from 38% to 53% when using self-reported questionnaires (1,3,7,80).

Research in other chronic conditions has described a wider issue caused by the biopsychosocial impact of a disease: distress. In the United States (US) cancer literature, distress is often defined as ‘a multifactorial unpleasant emotional experience’, based on guidelines from the National Comprehensive Cancer Network (85, p.2), which has also guided the conceptualisation of distress in the current study as described in the next paragraph. The NCCN introduced the term ‘distress’, as measured by the Distress Thermometer (DT), since it felt that it would be perceived as less stigmatising and more acceptable to patients and consultants. It was meant to encapsulate a broad, unpleasant state associated with a diagnosis and the effects of disease and treatment (85). Distress has been studied in conditions such as oncology and diabetes (8–11), but has rarely been mentioned in relation to ESRD. Researchers that state that they have measured distress in ESRD patients, have usually actually measured depression or anxiety (12,13); rather than the broader array of patients’ responses to life on RRT that distress is meant to encapsulate.

2.6.1 The concept of distress

Whilst there is a large body of research on distress in diseases such as cancer, the concept is rarely unpacked (86) and there are differences in how distress is defined across disciplines. In health care literature, distress is sometimes used to express physical discomfort. For example, Chiou (87) developed a Physical Symptom Distress Scale, which is a self-report tool that assesses distress in dialysis patients by measuring physical symptom intensity, ignoring sources of psychological distress. Gamondi et al. (88) describe distress as the response to experiencing physical pain. However, it is often described as a psychological phenomenon (89), certainly within the literature across the fields of psychiatry, psychology and sociology. Yet, since there are epistemological differences regarding the nature of mental illness between these fields (90), the way distress is conceptualised again varies across disciplines. Following a biomedical model, psychiatric nosology assumes that mental disorders are caused by biological abnormalities located in the brain. Behaviours that deviate from the norm are explained on the basis of disordered somatic processes and as such, treatment for these

'diseases' should entail targeting underlying biological dysfunctions (91). Within psychiatry/psychology literature, the status of distress is ambiguous and the way it is conceptualised often depends on the empirical question. In some cases, distress is viewed as the same thing as a clinically diagnosed mood disorder such as depression or anxiety disorder, with the terms being used interchangeably (92). Concrete categorical boundaries are provided to distinguish those with a mental disorder from those without. In order to diagnose patients and determine who is 'sufficiently ill' to justify treatment, clinicians use a symptom-based classification system called the Diagnostic and Statistical Manual of Mental Disorders – fifth Edition (DSM-V) (92). The DSM-V, however, lists distress not as a disorder, but as a diagnostic criterion, for example in the case of major depressive disorder: '*Criterion B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning*' (93). A definition of distress in the DSM-V is lacking and there are no criteria for determining when distress becomes 'clinically significant', yet it implies that the concept of distress is distinct from disorder. Moreover, it suggests that distress is a result of the occurrence of symptoms of a disorder (such as sadness, fatigue, trouble concentrating). This approach seems to eschew social causation of distress and instead focuses on the consequences of distress (94–96). Whilst it is acknowledged that some renal patients may suffer from distress caused by biological abnormalities in the brain, distress in this study is not seen as an equivalent to a clinically diagnosed mood disorder, nor is it necessarily a sign that someone is suffering from a disorder.

In sociological literature, one of the main tenants of the stress paradigm is Horwitz (97), who argued that stressful social arrangements can produce two fundamentally distinct outcomes, namely mental disorders and distress. He defines mental disorders in line with the DSM as an internal psychological disfunction and describes distress as a normal human emotion, a '*natural response that non-disordered people have to stressful conditions*'; it is expectable and transient and subsides if the stressor disappears or as people adapt to their circumstances (97, p. 275). Importantly, this definition creates room for social causation of distress. However, and this is where the author disagrees, Horwitz argues that treatment for distress is often not necessary, as it likely to remit over time without professional intervention. Whilst this could be true for some patients and Horwitz argues that it could help resist inappropriate medicalisation of 'normal emotions', it may not be appropriate in the context of renal

psychosocial service delivery. Namely, although Horwitz does not specify what he means with 'professional intervention', his argument about overmedicalisation implies that he refers to psychiatric and/or psychological interventions. Even though he is a sociologist, he seems to thereby fail to recognise the possible role that interventions of social workers play in reducing distress, something that will be explored in this thesis. Distress in the context of renal failure could be completely expectable, yet might not be transient due to the chronicity of the disease. Distinguishing between distress and disorder based on chronicity to determine whether someone receives treatment might not be in the best interest of the patient or their treatment. For example, a psychologist may decide that a CKD patient is a current 'case' when someone is distressed because they have just been told they need to start dialysis, to ensure a smooth transition and risk further complications, instead of waiting to decide whether it is a real disorder based on whether someone gets better when they have been on dialysis for a long time (94). Similarly, distress can be expected in a patient who just got the news that they have only got three months to live, yet following Horwitz' reasoning they should not be receiving any help to come to terms with this. Not offering a renal psychosocial intervention because the distress is 'natural' and patients might eventually adjust (or find help elsewhere), would be unjustified and could cause unnecessary suffering, particularly for distress related to social care issues.

Alternative views suggest distress is related to two forms of disorder - depression and general anxiety disorder - and *'is not transient, moderate or necessarily normal'* (94, p.306). Instead, distress has a continuous nature with a range from lower to higher levels of severity which can be tied to an underlying likelihood of certain disorders. Whilst sharing the view that distress has a continuous nature, the author does not agree with Wheaton's implicit conceptual difference between distress and disorder. Instead, the underlying study perspective sits closer to *'distress exists in the minds of those who suffer it. Disorder exists in the minds of those who define it'* (98, p.301). In this sense, distress is the umbrella term, an unpleasant subjective state, which takes two major forms of symptoms, namely anxiety, such as feeling afraid, worried, or tense; and depression, such as feeling sad, lonely, or unhappy (99,100). Distress is opposite of well-being on a single continuum, which means that if distress goes up, well-being goes down (100). In this sense, *'disorder is nothing more than an artificially constructed cut-off point of severe distress'* (99, p.215).

The ideas from Mirowsky and Ross relate closely to the concept of distress used in this study, as defined by the National Comprehensive Cancer Network which designed the DT:

'Distress is a multifactorial, unpleasant experience of a psychologic (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.' (85, p.2).

It is a deliberately broad term - the concept of distress is intended to be more inclusive and less stigmatizing for patients than terms such as depression or poor quality of life. It recognises that the causes of distress can be manifold, and the advantage of the DT is that it is designed to work with whatever definition of distress each patient deploys, without challenging them on that definition (Alston, 2018). This definition was found appropriate because this study will provide information on how distress presents in ICHD patients and whether screening for distress can be used as an *indication* of a need for psychosocial services. These services do not only include psychology and counselling, but also social work and benefits advice. The aim therefore is not to solely determine whether distress is an indication of diagnosis of depression or anxiety or another problem that would warrant psychological treatment. Instead, it is the severity of feelings of suffering, in the widest sense of the word, the causes of this suffering and the patient's desire for professional support that are of interest. Distress does not have to be indicative of a clinically diagnosable psychological problem to have a negative influence on disease progression and health outcomes.

To date, there are only two UK studies that explored distress in an ESRD population with the DT, which is also the measurement tool of the current study. The first study, by Alston (86) identified a prevalence of distress in 42.7% of HD patients within one renal unit. Damery et al. (15) studied mild-to-moderate distress in pre-RRT and RRT patients across four hospital sites. They classed around 35% of HD patients as mild-to-moderately distressed and 12.3% of all patients as severely distressed, suggesting that distress is highly common amongst ESRD patients.

2.7 Mapping the renal psychosocial workforce

2.7.1 Recommended psychosocial care for renal patients

Despite the negative impact of mood disorders on patient quality of life and health outcomes, symptoms of depression and anxiety in dialysis patients are often underdiagnosed and untreated (101,102). Still, emerging evidence of psychosocial issues has led to an acceptance that a focus on the emotional and psychosocial needs of the patient should be included in the provision of comprehensive renal care (4). The only document that provided insight into the extent to which such comprehensive care was provided, was the report of the last audit of the entire UK nephrology workforce, completed in 2001. The results of this audit were published together with recommendations for establishments and staffing levels across each professional group involved in renal healthcare (5). It was recommended that the psychosocial aspects of renal care should be provided by renal-dedicated psychologists, counsellors and social workers. The Kidney Health Advisory Group (28) reiterated this advice, explaining that these members of staff have different, but complementary roles. The role of the renal psychologist includes the delivery of psychological assessments and interventions for renal patients dealing with complex mental health issues, in addition to developing and supervising the delivery of appropriate routine psychological care by all renal staff. The work of renal counsellors involves crisis management; counselling related to emotional distress; bereavement and loss; and enhancing patients' ability to understand in order to make informed decisions. Generally speaking, a counsellor tends to focus on what is happening to patients in the present and work with people that are mentally in a better state than those seen by the psychologist. Finally, the RSW role includes caring for the needs of patients at the interface of health and social care, addressing the practical, economic, and social problems of patients and carers, which often also takes emotional issues into account; helping those with ESRD to cope with chronic disease, disability and eventually death and bereavement (5). Whilst the lines between these professions might appear blurred, it is important to recognise that there are differences in training and in perspectives that these members of staff bring to renal care. A psychologist will have undertaken a minimum of six years of training to doctorate level; a counsellor or psychotherapist will have a minimum of an undergraduate diploma, but may have a bachelor's degree or postgraduate qualifications; a RSW will have at least a bachelor's degree in social work and/or a post-graduate social work qualification.

Psychologists and counsellors draw upon several perspectives, like behavioural and cognitive theories, although broadly speaking the focus of their interventions is on the individual. Simply put, psychological therapy entails exploring thoughts, feelings and behaviours in order to solve psychological problems (103). Social workers, on the other hand, often adopt a person-in-environment perspective, drawing from theories about systems, empowerment and social change, to explore how a patient functions in their social environment. In practice, psychology and social work are intrinsically linked and often combine ideas from several theories to produce a style of work (104).

The 2002 workforce report provided recommendations for psychosocial staffing ratios, which appear only partially complete and lack a clear evidence-base. Figure 1 shows the recommended levels of social workers and psychologists for RRT patients, with psychology recommendations dependent on whether RSW recommendations are met. With regards to dialysis patients, recommendations were only given for social work and were set at 1 Whole-Time Equivalent (WTE) per 70 patients (5). Recommendations for counsellors were lacking altogether.

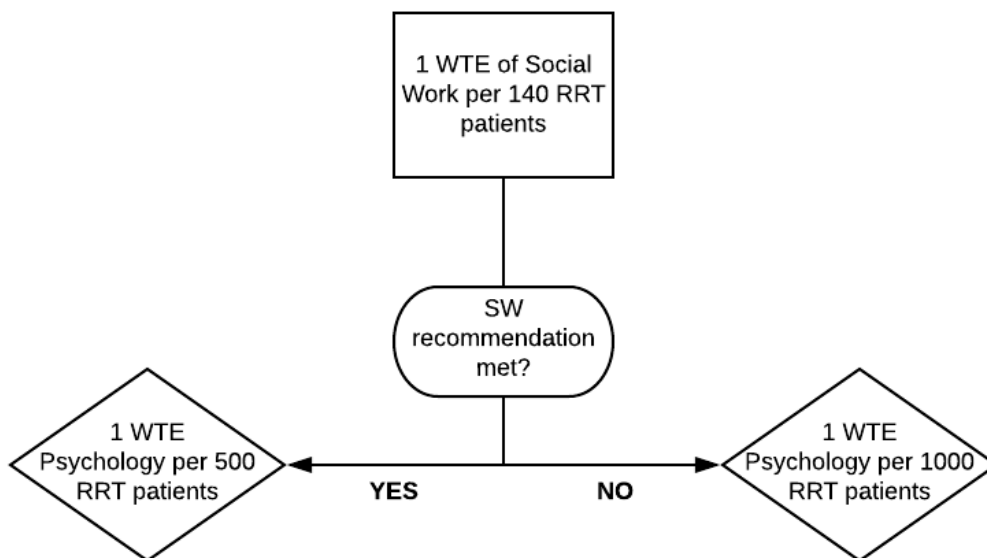


Figure 1. Schematic recommendations for renal psychosocial staff

2.7.2 Mapping the renal psychosocial workforce in 2017

To achieve the first objective of this study and expand the rationale on which to base the subsequent phases of this research, a mapping of the renal psychosocial workforce was completed. Findings of this mapping were published in a report (105) and/or peer-reviewed article (106) (Appendix 1) and referenced as appropriate.

Renal psychosocial services were defined as psychological and/or social care provided by psychosocial staff to meet patients' informational and emotional needs. The focus of the investigation was only on renal unit staff specifically recruited to provide psychosocial support to renal patients. Therefore, this mapping did not capture information on wider provision of services provided through other channels such as the GP, community teams or voluntary organisations.

The data collection process for this mapping was creative and iterative. Initial data were collected through separate initiatives by a number of collaborating organisations and then combined and cleaned by the author. First, in 2016, the British Renal Society (BRS) asked Clinical Directors (CDs) of all renal units in England, Wales and Northern-Ireland to complete an excel file, based on the Scottish Renal Association's staffing survey (107). This workforce survey, used in Scotland for several years, asked for details on all renal staffing and facilities in the unit, including psychosocial staff. Despite numerous reminders, the response rate to the questions about psychosocial staff was only 64.8%.

Coinciding with the BRS survey, an online questionnaire was designed jointly by the British Psychological Society Renal Network, Renal Psychological Services Group and British Association of Social Workers Renal Special Interest Group. The link to this questionnaire was distributed through the above networks late 2016 and was envisaged to be completed by all individual members of renal psychosocial staff in the UK (including Scotland). Psychosocial staff were asked to provide a wide range of information about qualifications, Full-Time Equivalent (FTE), type of interventions provided, time in post, employment agreements, funding of post and concerns about the service, among others. Since the overall number of psychosocial staff members was not known, response rates were hard to define. However,

104 professionals returned the questionnaire, which, based on current findings, would mean a response rate of 55.3%.

Upon combining these data sources, conflicting information was found, with renal psychosocial staff contradicting information provided in the BRS workforce survey. To increase the reliability of data through data triangulation, Freedom of Information (FOI) requests made to 84 hospitals, asked only for details about the type, number and FTE of renal staff. The response rate was high, with 96.4% of units replying to this request within the end date of the data collection period. Email contact between the author and renal staff took place to ask for clarification of data. Eventually, 100% of the units provided information through at least one of the data collection methods. Finally, all CDs were asked to confirm accuracy of the findings; 82% of CDs adhered to this request.

The data were managed in Excel and a selection of data - number and FTE of staff – was analysed using Stata 14 software for summary and descriptive statistics. To calculate staff-to-patient ratios, adult CKD and RRT patient number data were obtained from the 19th UK Renal Registry Report (Hamilton, Braddon, et al., 2017; MacNeill & Ford, 2017). Every attempt was made to collect complete data in the current investigation, however, there was some missing data, with not all FTEs provided for all staff. This had consequences for the calculations of totals and ratios. Namely, the total FTE per profession with more than 10 staff identified was calculated based on assigning the average FTE to the missing data. An average was calculated for three out of 68 social workers and three out of 64 psychologists. Staff-to-patient ratios were only calculated for the units that employed psychosocial staff and provided information on FTEs of staff.

Whilst the psychosocial mapping included adult and paediatric services, for the purpose of this research, only relevant results related to adult services are reported in the following sections. Table 1 shows the identified staffing levels in adult renal services as per July 2017. The numbers of psychosocial staff available to renal patients in a unit varied from zero to seven (Mdn = 2.37, IQR = 1 – 3.75).

Twelve units (16.9%) had no renal dedicated psychosocial service. In the other units, different members of staff worked together in varying combinations. For example, in one unit a social worker worked together with a psychiatrist, whereas in another unit a psychologist worked together with a counsellor and a welfare advisor. Some units employed non-traditional members of psychosocial staff, such as a cultural and health liaison officer or staff from external companies, such as Auriga and Citizens Advice Bureau (CAB) (Seekles et al., 2019). In 2001, it was reported that, based on total numbers, social workers made up the majority of psychosocial staff in adult services, followed by counsellors/psychotherapists and then psychologists (National Renal Workforce Planning Group, 2002). This majority has reduced, as can be seen in Table 1.

Table 1. Number, FTE and proportion of renal psychosocial staff in 2017

Profession	2001			2017		
	N	FTE	% of total N	N	FTE	% of total N
Social work	73	55.0	76.1	58	44.6	36.3
Psychology	7	2.5	7.3	51	27.2	31.9
Counselling/Psychotherapy	16	Unknown	16.6	28	15.0	17.5
Youth work	-			9	6.5	5.6
Welfare advisor	-			3	2.2	1.8
Social care practitioner	-			1	1.0	0.6
Assessment & support coordinator	-			1	0.85	0.6
Cultural & health liaison officer	-			1	0.8	0.6
Trainee cognitive behavioural therapist	-			1	0.4	0.6
Psychiatrist	-			2	Unknown	1.3
Psychology assistant	-			2	Unknown	1.3
External company	-			3	Unknown	1.8
Total	96	Unknown	100	160	Unknown	100

The results demonstrate an interesting trend: the combined psychology and counselling/psychotherapy workforce has become almost the same size as that of the RSWs. Due to limited data in the 2002 report, changes in the workforce since 2001 could only be calculated for renal psychologists and social workers. The total FTE of renal psychologists has increased almost tenfold, by 1088%, from 2.5 to 27.2 FTE. Instead, the adult RSW FTE has decreased by 19%, from 55.0 to 44.6 FTE. In 2001, patients in 86% of renal units had access to an RSW, in

2017 this had reduced to 51.7%. Taken together, the adult workforce of these psychosocial professions has increased by almost 25% over the past 15 years. Yet, the RRT population has increased by over 50% over the same time.

Table 2 shows the median and dispersion of adult patients per 1 FTE staff per unit, for psychologists, social workers and counsellors/psychotherapists. The number of dialysis patients includes all dialysis modalities; the number of RRT patients includes transplant patients. In addition, the table highlights the proportion of units that meet the benchmark ratios as recommended in the 2002 workforce report (5). None of the units meet the social work requirements. This meant that the psychology requirement for all units was 1 FTE per 500 RRT patients; only four units met this requirement, three of which were in Wales. Some units that employ psychologists also offered a counselling service. Taking the counselling and psychology provision together would mean that one additional unit has a provision of 1 FTE psychologist and counsellor for less than 500 RRT patients. It is however not specified in the 2002 recommendations how the presence of counselling services in a unit affect the psychology requirements (106).

Table 2. Ratio of adult patients per 1 FTE staff per renal unit

	No. of units	Mdn	Q1	Q3	IQR	Proportion of units meeting benchmarks (95% CIs)
Psychology	33					
Dialysis		675	368	1290	922	No benchmark available
RRT		1392	838	2665	1827	4.7% (1.3-11.7)
Social Work	32					
Dialysis		311	195	385	190	0
RRT		614	396	929	533	0
Counselling	15					
Dialysis		591	298	905	607	No benchmark available
RRT		1358	905	2035	1130	No benchmark available

Notable variations exist between the staff to dialysis patient ratios across different units. For social work, the unit with the best staff ratio per dialysis patient had a ratio of 1:104, exceeding the benchmark with 48%. This was 1:165 for psychology and 1:171 for counselling. The worst ratio for social work was 1:1895. This was 1:4430 for psychology and 1:7390 for counselling. Figure 2 provides an overview of the ratios of psychology and/or social work across all UK units that provide these services (106).

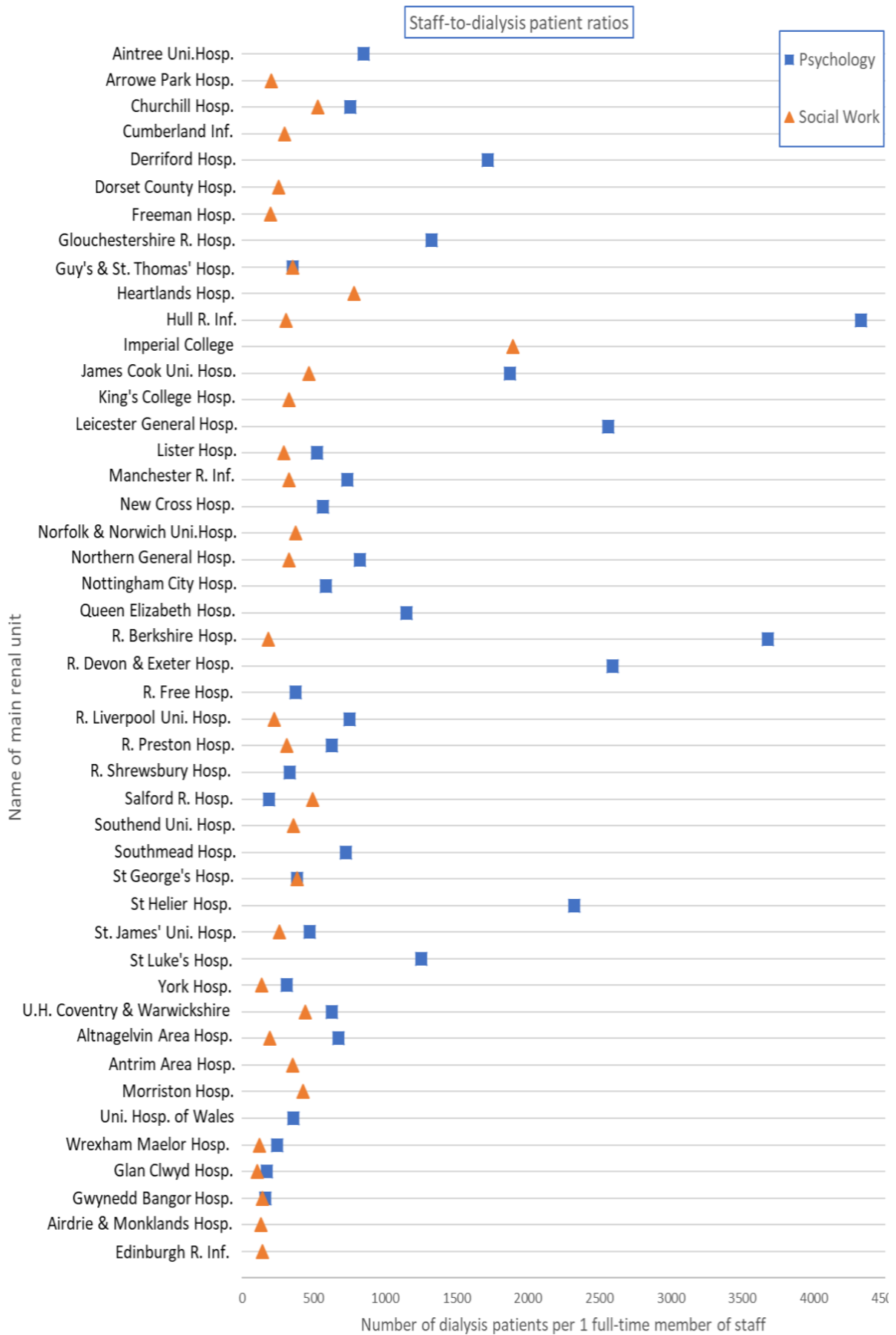


Figure 2. Ratios of renal psychology and social work in UK renal units

The 2002 data did not allow for a comparison of ratios based on units that employed psychosocial staff. Instead, the ratios of staff per total RRT population across all units, regardless of whether they employed psychosocial staff, were provided; a comparison of that data with the 2017 establishment is provided in Table 3 (106).

Table 3. Average 1 FTE adult staff- to- patient ratios for all units

	RRT	
	2001	2017
Renal Psychologists*	1: 15233	1: 2252
RSWs	1: 693	1: 1373

*When taking psychology and counselling/psychotherapy services together, the 2017 establishment is 1:668 for dialysis patients and 1:1429 for RRT patients.

2.7.3 Psychosocial staff employment and funding

The questionnaire sent out to psychosocial staff also requested data on staff employment and funding arrangements. Part-time contracts were very common among psychosocial staff: 44.2% of the social workers, 17.4% of counsellors/psychotherapists and only 13.3% of psychologists reported working full-time. Table 4 presents data on employment arrangements for these three main professions. Most psychologists and counsellors are employed through their hospital trusts. This was different for the social workers, of whom almost half were employed through the LA.

Table 4. Employment arrangements for main renal psychosocial staff

Profession	Employer	N	%
Psychologist	Acute hospital Trust	46	88.5
	Mental-Health trust	6	11.5
Social Worker	Acute hospital Trust	18	52.9
	LA	15	44.2
	Mental-Health trust	1	2.9
Counsellor/ psychotherapist	Acute hospital Trust	15	83.3
	Self-employed	2	11.1

For all three professions, the main sources of funding are either the renal or the acute hospital budget (Table 5). The LA is involved in the funding for approximately 20% of the social workers.

Table 5. Funding arrangements for main renal psychosocial staff

Profession	Funding body	N	%
Psychologist	Renal budget	22	41.5
	Acute hospital budget	19	35.8
	Charity	3	3.8
	Externally funded by CCG	3	5.7
	Mental health services	2	5.7
	Other	4	7.5
Social Worker	Renal budget	16	44.4
	Acute hospital budget	9	25.0
	LA	4	11.1
	Joint funding: renal + LA	3	8.3
	Charity	2	5.6
	Other	2	5.6
Counsellor/ psychotherapist	Renal budget	10	62.5
	Acute hospital budget	4	25
	Charity	2	12.5

2.7.4 Evidence-based decision making

The results of the mapping indicate that RSWs have traditionally been responsible for the provision of renal psychosocial services. However, in recent years, a shift has taken place, with an increased number of psychologists and counsellors now making up the renal psychosocial team. The reasons for units deciding to employ certain members of staff are unknown, but this shift could be related to the lack of high-quality studies that could form an evidence base of renal social work. In this economy of managed health care and cost-benefit, policy makers, such as healthcare commissioners, are encouraged to adopt evidence-based decision making. This means that they increasingly draw on academic research that presents outcomes in the field of health and social care to assess cost-effective alternatives and make the best use of limited resources (110). An extensive knowledge base, resting on a substantial body of research evidence, is central to a discipline's strength. As a profession, psychology is characterised by its focus on empirical investigation (111). This has resulted in a sizable evidence base for the profession to draw on, with the efficacy of a broad range of psychological interventions established through hundreds of randomised controlled trials and meta-analyses (112,113). Instead, social work is described as a 'practice-based discipline' (114) and it is in the early stages of developing tools for measurements of practice effectiveness (115). This early childhood stage of evidencing fits within a perceived general

deficit in social work research (116). Policy makers and practitioners find it difficult to access good quality evidence on the effectiveness of social work interventions (117). There is an inadequate knowledge base in social work and a need for a fundamental step change in breadth, depth and quality of the UK research base in social work (118). The UK's Chief Social Worker for Adults reiterated this when she highlighted the need to strengthen social work's evidence base in the years to come (117).

2.8 Summary and conclusion

This chapter provided an explanation of CKD and the complexities of the care that come with it. It has described the pressures that the health and social care systems need to respond to, namely a growing and ageing population; a shift towards chronic conditions and significant constraints in funding. There is an increasing recognition that physical health, mental health and social status are linked. ESRD and its treatment can cause a wide array of issues that could disturb the balance between these areas, leaving ESRD patients not only in need of medical intervention, but sometimes also requiring psychological and/or social work support. Recommendations on the renal workforce stipulate that psychological and social support should be provided in-house, by renal dedicated staff.

This chapter further presented the findings of an exploration into the psychosocial workforce (Box 1), which showed that renal units have created their own models of psychosocial service delivery. The arrangements that might have contributed to the development of these varying models are currently unknown. Patient access to renal dedicated psychosocial services is unequal and based on a 'postcode lottery'. It is unclear what the consequences of this are for patient access to psychological support and social care services available in the community and ultimately, for the psychosocial wellbeing of patients. Furthermore, it can be wondered whether the apparent lack of psychosocial services influences the ability of psychosocial staff to adequately fulfil their tasks, and how the large variations in staffing ratios affect the breadth and depth of their roles across units.

Research into the psychosocial needs of renal patients lies at the heart of the answer to many identified questions. Moreover, these questions highlight a need to investigate current processes of psychosocial service delivery and identify useful practices in addressing patient needs.

Box 1: Key findings related to objective one

Objective 1: To map the current provision of renal psychosocial services across the UK and examine how this has evolved since the last workforce mapping in 2001

- Large variability in models and availability of psychosocial services across the UK, with different combinations of staff employed across different units.
- Since 2001, psychology services increased almost tenfold; RSW services reduced by 19%. An overall increase of 25% in renal psychosocial staff is not in line with an increase in RRT patients of more than 50% over the last 15 years.
- Renal dedicated psychosocial staff are lacking; recommended staffing levels are not met.
- Differences were found in funding and employment arrangements, particularly for RSWs.

Chapter 3: Policy context

3.1 Introduction

The mapping of psychosocial staff identified many different models of renal psychosocial service provision across the country, and a significant reduction in RSWs over the past 15 years. In response to those findings, the current chapter will focus on interrogating general and renal specific policies to determine whether they provide any guidance on the delivery of renal psychosocial care. It provides a history of relevant policies and reforms in health and social care that have influenced and shaped adult social work as a profession today. It will also take a broad approach to examine how policies have framed the provision of psychosocial services within care for LTCs, describing how the management of LTCs emerged as a key strand of policy around 30 years ago, with similar objectives since. The final sections of this chapter will examine renal specific policies.

3.2 A history of health and social care for LTCs

This overview brings us back to the creation of the post-war Welfare State, which signified the firm establishment of state intervention in service provision and the economy. The major institutions of this Welfare State were created when the Labour Party came to power in 1945. These consisted of a system of national insurance, topped up by means-tested national assistance and underpinned by full employment, a national health service and family allowances, proposed in the Beveridge Report (1942). At this time, most social workers worked in separate departments in LAs, with some working in organisations, such as hospitals or charities (119). Already in the 1950s, the policy priority in health services was saving money in the hospital sector, by emphasising short-stay provision and containing the number of beds for the chronically ill. A shift was envisaged from long-term hospital care to community-based alternatives provided by the LAs, drawing the NHS boundary more tightly around an acute care-only hospital (120). However, in the National Assistance Act (121), the responsibilities of the LA were largely concerned with residential provision and did not specify any remit for promoting community well-being (122). This led to a struggle over responsibilities between the two institutions, which was detrimental to service development for people with LTCs (120).

In the late 1960's, growing concerns about the increasing numbers of older people served as one of the catalysts for the establishment of the Seebohm Committee, which was set up to 'review the organisation and responsibilities of the LA personal social services in England and Wales' (123). The findings exposed inadequacies in the amount, range and quality of service provision and problems of access, co-ordination and inflexibility. Underlying causes included a lack of resources; lack of research and knowledge about social needs and the most effective responses; and the fragmented responsibilities between the different departments. In addition, the education of social workers was provided by different bodies and funded by a specific service, which was seen as an impediment to a generic education (123). The report led to the implementation of the Local Authority Social Services Act (124), which meant that generic Social Service Departments (SSDs) would be established at LAs. At a national level, the British Association of Social Workers (BASW) originated and a generic Certificate of Qualification in Social Work was launched (replaced by the Diploma in Social Work in 1989, which was replaced by the Degree in Social Work in 2003). There was a unified organisation, a unified professional body, unified training and social work in SSDs was initially well resourced: it was considered to be the 'high tide' of social work (125). Then, in 1979, a Right Wing Conservative Government under the leadership of Margaret Thatcher argued that the welfare state created dependency and that the limits of taxations were reached; the influence of the state had to be rolled back in order to give people more freedom in making their own choices (125). In this climate, there was a call for a new emphasis on community social work, with social workers working in partnership with local people to support and build on community strengths (126). Although some SSDs experimented with using community social workers, it was the changes that came about through reforms in community care in the 1990s that meant a fundamental transformation of social work. The key processes of these reforms were marketisation and managerialisation, with care management as the method of practice (125). Care management was implemented as a passage of the NHS and Community Care Act (127) and is described as a process involving assessment of service-user needs, purchase of services to meet those needs and review of the delivery of those services. The intention of this care management model of service delivery was to meet individual need, provide services in and by the community (rather than in large permanent institutions), provide a wider choice of services and secure better value for money. It is argued that care management has fundamentally altered social work as practised in SSDs through fragmentation of the generic

casework role, the increasing commodification of services and increased managerial surveillance of social work activities (128). LA social services were broken-up into separate departments for children and adults. In this way, the central and local government structures today actually resemble the pre-Seebohm situation (119).

The changes made under the implementation of the NHSCCA 1990 and the introduction of care management have profoundly impinged on the profession's identity and role. Social workers turned in to resource managers, who would 'match categories of need to available services and predetermined procedures; compile 'packages' of services sourced across the 'care market', where these were judged to be necessary, available and affordable; record performance targets achieved within defined limits; and move on' (129). As such, the primary role of the social worker entailed rationing, to ensure that LAs can manage cash-limited budgets (128,130). There was an imposition of prescriptive forms and paperwork, time limits and authorisation to spend, which reduced the feeling of professional discretion for many practitioners (128). This increase in bureaucratisation, form filling and financial assessments is said to have brought an end to the traditional, 'real' activities of social work such as counselling, advocacy and user empowerment through personal contact to facilitate change (131,132). Whilst this shows how the implementation of community care has transformed social work, or rather, changed the purpose of social work, many government documents lacked detail about the roles and tasks that social workers might occupy under the new arrangements. Increasingly, the New Labour government of 1997-2010 used its power to create an environment focused on targets, performance indicators and inspections, and created of a whole new range of regulatory agencies (133).

It was not only social care that underwent changes in the 1990s; the NHS was also about to embark on a series of major reforms for which the reasons were linked to social care's increased focus on community services. Waiting times in hospitals were rising and it had become evident that there was a need to improve the management of patients with LTCs outside of the hospital, to reduce emergency hospital visits and inpatient stays (134). In the late 1990s, improving care for people with LTCs became prominent in NHS policy (135). It was the system of National Service Frameworks (NSFs) that became the centrepiece of government policy to improve chronic care in the late 1990s and early 2000s (135). The NSFs

set out to define best practice and establish national standards of care for a range of common chronic conditions and selected patient groups (135,136). To facilitate the implementation of standards of LTC management in general practice, the Quality and Outcomes Framework (QOF) (137) was adopted in 2004. This placed a focus on paying general practice for achieving targets in the identification and management of people with LTCs. Even though the overall impact of the QOF is contested, its presence showed an increased importance attached to the role of GPs in managing people with LTCs (134). Other NSFs subsequently emerged, including for renal disease (138,139) which were initially implemented in isolation for each condition.

However, there was a growing recognition of the need to integrate services for people with multiple complex problems and take a more systematic and proactive approach to chronic disease management (140). Since 2004, new policies started to emerge that attempted to address this need, heavily influenced by models developed in the US. The publication of The NHS Improvement Plan (141) placed the needs of those with LTCs at the centre of the government's reform plans. This plan, and further policies, were derived from the 'Chronic Care Model' developed by Wagner in 1998, which demonstrated how patients, health care providers and community organisations can interact to deliver better systems of care (142). The NHS Improvement Plan set out three tiers for intervention. It envisaged help with self-management for those able to look after their conditions on their own; disease management for those people whose conditions could be looked after by regular contact with a nurse, doctor or other professional; and intensive case management for those with the most complex needs (140,143). To support case management, the government proposed to employ 3000 community matrons across England by 2008. The introduction of the community matron came at a time when the political and public image of social work was damaged, because of two high profile child abuse tragedies. There were growing concerns about social services for adults, the nature of public services more generally and the high threshold for LA support for adults (Dickens, 2010). The community matron role included the combined assessment of physical, mental and social care needs and co-ordination of care from all providers, in addition to the provision of clinical care. The aim was to ensure that patients' multiple health and social care needs were met and so enable them to remain at home (134,140,142,144). Policy documents contained no references to specific funding allocations, or expectations as to which resource streams would fund them (145). The potential

duplication of other health professional roles, such as the GP and district nurse, raised questions over the concept of the community matron. LAs suggested it overlapped with the work of social workers or other social care providers who used the similar concept of care management in their practice (145). The introduction of the community matron role was not a success. The target numbers were not achieved, and it was found that the costly unplanned hospital admissions had not been reduced by intensive nurse input. Within two years, the role had disappeared from policy documents and after three years, the central monitoring target removed (145). Although the role still exists today, there are no plans for a major expansion of the service.

Mental health assessments were identified in the role description of community matrons. However, the main framework for service delivery at that time, *'the NHS and Social Care Long-Term Conditions model'* (141, p.9), contained little mention of offering support to patients to cope with the psychological and social consequences of living with a LTCs, especially for those with a lower complexity of needs. The integration of mental and physical health services remained low on the policy agenda. Instead, the NHS Improvement Plan (141) emphasised the need for health and social care to work together, and for services to be more personalised. This was reiterated by the NSF for LTCs (146), a ten-year plan, presented as the key tool for delivering the government strategy. It aimed to work collaboratively with people with LTCs to deliver integrated, person-centred services. Three key areas formed the core mandate: improving quality of life, supporting people to self-manage their symptoms; and enabling people to live as independently as possible (147). It was the publication of the White Paper *'Our Health, Our Care, Our Say'* (148) that set commitments in these areas. By 2008, (former) Primary Care Trusts and LAs were supposed to have joint teams in place to care for people with complex health and social care needs and by 2010 everyone with a LTC should have a care plan. This commitment was reinforced in the *'NHS Next Stage Review'* (29,149). The concept of personalisation was introduced in adult social care, a key element of which has been the development of *'individual'* or *'personal'* budgets to extend the autonomy and choice of service users (119,130). Much like government documents on community care, there was a lack of clarity about the role of social workers within the delivery of the personalisation agenda. It was only clear that different people, with different skills and education, could be in a position to do so. A replacement of qualified social work staff by

unqualified employees was an ongoing component of the care management labour process and wider personalisation remit. Consequently, the boundaries between the types of work that qualified or unqualified staff could undertake were blurred (130,150). Fears were expressed that by increasing the number of non-qualified staff, unqualified bureaucrats would be created who would be cheaper to employ and easier to manage and control (151). Seen as detrimental to service users, these new 'professionals' could be more willing and able to tick choice-denying boxes rather than support users to achieve the best quality of life open to them, even if it is more expensive for the public purse (151).

A Social Work Task Force (SWTF), established in 2008 to advise the government on a 'comprehensive reform programme' for social work, concluded that the changes to implement care management and personalisation processes had left social workers demoralised. Several issues were identified, namely that social workers felt overburdened by staff vacancies, high caseloads, excessive bureaucracy and unrealistic expectations in their first year; that they required better IT systems, supervision and training for the realities of practice; lacked a strong national voice for the profession and had no effective performance management systems (119,152). To implement changes proposed by the SWTF a Social Work Reform Board (SWRB) was established. However, the hope that the NHS and social care would work more closely together to deliver integrated and personalised care to those with complex needs had not been realised (143). In 2010, a mid-point review for the NSFs was cancelled by Ministers after the general election (153) and while the SWRB was working on developing and implementing reforms within social work education and practice, the government was designing plans for the biggest reforms of health and social care in 60 years (154).

The Health and Social Care Act (155) and the Care Act (156) formed the centrepieces of the reforms, which were set out to clarify responsibilities and accountabilities, empower people and communities and focus on the evidence of what works. In addition, the need to achieve better results with less money was an undercurrent to the entire health and social care reforms, driven by the government's aim to reduce their budget deficit (154). It was promised that the Care Act would overturn a disempowering, 'one-size fits all' approach to care, to create a system built around each person: '*what they need, how they can best be cared for, and what they want*' (157, para 7). It would mean a shift away from a top-down, reactive model of care, to one which centred on wellbeing, prevention and early intervention, helping

to reduce crisis and demand for acute services (117). The Act places a clear responsibility on LAs with regards to social care as they must carry out an assessment of who appears to require care and support, regardless of their likely eligibility for state-funded care. There was great optimism among key observers of social work when the Act was passed, not only for the prospects it held for people in need of care and support. The new Act was seen as having liberating implications for adult social work practice (129). More recently, the Department of Health launched a strategy to raise the quality and status of social work with adults. It has placed social work practice at the centre of adult social care under the new Act with the aim *'to raise awareness and understanding of the invaluable role that social workers play in adult social care and health'* (158, p.2). This strategy, however, looks highly compromised, dependent on the future support of national and local government, making the path to liberation not only long, but politically winding (159).

3.2.1 Triple integration

It is now 2020, and health and social care services are far from integrated, with integrated care becoming a *'policy sacred cow ... repeatedly proving impossible to deliver in practice'* (160, p.1). Moreover, Naylor et al. (161) argued that *'integrated care initiatives have paid insufficient attention to the relationship between physical and mental health'*. In terms of funding and policy, mental health has not had the priority awarded to physical health, has been short of qualified staff and has been deprived of funds for decades (162). Recent years have seen a focus in English national policy on achieving parity of esteem for mental health, with the *'Five Year Forward View'* (2014) making the case for *'triple integration'*: integration of health and social care, primary and specialist care, and physical and mental health care (161). The Five Year Forward View makes a clear commitment towards improving integrated care for LTCs in all three areas:

'Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the long term rather than providing single, unconnected 'episodes' of care ... Services need to be integrated around the patient. For example, a patient with cancer needs their mental health and social care coordinated around them.' (163).

The key arguments are that more attention should be given to prevention and public health; patients and communities should have far greater control of their own health and care; and barriers in how care is provided should be broken down through greater integration of services. The emphasis is on future services being provided out of the hospitals, with *'far more care being delivered locally, but with some services in specialist centres, organised to support people with multiple health conditions, not just single diseases'* (163). The current policy plan, The NHS Long Term Plan (2019), reconfirms this focus and commits to a series of community service redesigns, with real terms funding for primary and community health services guaranteed to grow faster than the NHS budget overall, for the first time in history (164). The new investments will fund expanded community multidisciplinary teams, consisting of a network of GP practice, which will comprise a range of staff such as GPs, pharmacists, district nurses, geriatricians, and allied health professionals such as physiotherapists, joined by social care and the voluntary sector. Offering a wider scope of services, this model is particularly suited for the management of frail older people and people with multiple LTCs (163). Outpatient services will also be redesigned, using digital technologies, thereby avoiding patients having to travel to unnecessary appointments (164). By including specialists currently based in hospitals in their memberships, the practices could shift the majority of outpatient consultations and ambulatory care out of hospital settings, taking over the running of local community hospitals. In turn, these hospitals would then be able to expand services such as dialysis and chemotherapy (163,165). Whilst specific guidance is lacking, this suggests that dialysis patients will still fall under the care of hospitals.

3.2.2 Provision of psychological services

The need to develop more integrated approaches to mental health has also been reinforced by 'The Five Year Forward View for Mental Health' in 2016 (162). This report, which marked the first time that a shared national ambition for mental health had been set, made 58 recommendations on prevention; improving the quality and accessibility of care; innovation and research; workforce; data and transparency; incentives, levers and payment; and regulation and inspection (166). The Long Term Plan makes a renewed commitment to grow investment in mental health services faster than the NHS budget overall for the coming years (164). This includes ambitions to expand the Improving Access to Psychological Therapies (IAPT) programme. The IAPT programme, established in 2008, was a systematic way to

organise and improve the delivery of evidence based psychological therapies for people with common mental health problems (167). IAPT spans primary and secondary mental health care, but has a strong link with primary care and community services that enable most of the face-to-face therapy to be provided in local settings, easy for people to access (such as GP practices, community settings and voluntary organisations). Recently, commitments have been announced to expand IAPT to provide better care to people with common mental health problems who also have LTCs (63,167). To achieve this, an IAPT-LTC model has been developed, to be co-located and integrated with physical healthcare services; encourage physical healthcare staff to use mental health screening tools in routine practice; and have close and effective links with the wider system, including liaison mental health services and clinical and health psychology services in the hospitals. In 2016/2017, an IAPT-LTC pilot started with early implementer sites for several conditions such as cancer, diabetes and COPD, but not CKD (168).

3.3 Psychosocial support in renal care policies

Renal care policy documents, linked to national policies, were interrogated to examine if they provided any guidance on the position of psychosocial support within renal care. The majority of documents emphasised the need to consider psychosocial issues in renal patients, but the guidance on how to address these issues, is vague. References are made to the psychological and social aspects of CKD in the NSF for Renal Disease (138,139). Standard One in Part One of the NSF aims to optimise the role that people with CKD can play in the management of their own care and recognises that patients can encounter physical, psychological and socio-economic problems. People need information, advice, education and support, if they are to be full partners in care and this could positively improve psychological and social outcomes. It highlights the importance of a multi-skilled renal team and an agreed care plan to identify health and social care needs. The standard specifically mentions how the care plan *'can set out the social work support required to help patients with problems relating to benefits, work and family matters, and can highlight the need for psychological support and recognition and management of depression'* (138, p.19). Standard Two in Part One aims to provide coordinated care to patients approaching established renal failure, in order to timely inform the patient about RRT. In this standard, *'a referral to a multi-skilled renal team, where possible*

at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation', is seen as a marker of good practice (138, p.23). The NSF's place an emphasis on social aspects of health and seem to suggest a role for social work and psychology services, yet they do not specify whether these professions are part of the 'multi-skilled team'. It is unclear if the introduction of the NSF and its focus on renal psychosocial support led to an increase in renal psychosocial staff in the mid-2000s. The NSF's, originally designed as ten-year plans, are now superseded by the NICE guidelines, discussed below.

The current service specification for assessment and preparation for RRT (including establishing dialysis access) (169) is based on the NSF standards. It states that *'patients with progressive CKD shall have access to a multidisciplinary team which will include trained nephrologists, ... renal pharmacists. The provider shall also provide access to other support including (but not limited to) clinical psychology, counsellors and social workers/welfare advisors with specific expertise in the problems encountered by patients with kidney disease. ... Where these services are not available at the provider's facility, information should be provided about how, and/or arrangements should be made, to access them'* (169, p.5). This specification is ambiguous: it calls psychosocial staff 'other support' and not part of the multidisciplinary team, but at the same time says patients need access to professionals with 'specific expertise', thereby not suggesting a generalist role. The service specification for ICHD patients states that *'the provider will offer patients access to social work advice/psychological services as required'* (170, p.9). Both specifications are vague and open to interpretation, and do not imply a strict duty of care. It is unclear whether offering patients 'access to' services 'as required' means services should be provided, in the renal unit, and by whom. For example, where these services are not available at the provider's facility, a simple leaflet for patients with phone numbers of available services could be interpreted as sufficient 'access to' provision.

NICE provides national advice to improve health and social care, by developing guidance and quality standards. In renal services, NICE currently has two quality standards: Chronic Kidney Disease in Adults (20) and Renal Replacement Therapy Services for Adults (171). The previous CKD quality standard (2014) included the following quality statement regarding psychosocial services, which in the updated guideline was no longer considered a national priority for improvement: *'people with established renal failure have access to psychosocial support*

(which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances' (20, p.3). It is unclear why this statement was removed, but it appears that the NICE guidelines have reduced the importance of psychosocial support presented in the NSFs. The quality standard for RRT services also makes no specific mention of psychosocial services, although it does state that a person-centred, integrated approach is required to coordinate care across all relevant agencies. Linked to this quality statement is the RRT and conservative management guideline (171, p.7), which recommends that patients have *'psychosocial evaluation, preparation and support'* starting one year before RRT. It recommends that further assessment, by a clinical psychologist or psychiatrist is considered, for adults worked up for a transplant if risk factors for poor outcomes have been identified. The importance of recognising the psychological impact of RRT and psychological/behavioural symptoms (such as anxiety, depression, sexual dysfunction, body image concerns and mood disturbances) and discussing the psychological support available is reiterated (171). There is no specific mention of social workers or provision of social care, although it was recommended that patients receive information about how RRT may affect their lives, which included the impact on things such as work, travel and social interactions; home alterations; transport; or additional support or services (171). The guideline does not state that support should be offered by renal dedicated staff, nor does it offer guidance on staffing types or levels of who should offer such support.

3.3.1 IAPT for renal patients

The NCCMH (168, p.28), in their IAPT-LTC implementation guidance, seem to imply that the organisation of IAPT services might be different for dialysis patients than other patients: *'The delivery of psychological therapies for depression and anxiety disorders in people with LTCs ... can be affected by ... the complexity of the physical health interventions delivered and the settings in which they are provided, such as if the person is undergoing renal dialysis.'*

Discussions with psychologists in the initial stages of this thesis clarified that IAPT-LTC services are currently not appropriate for people who have conditions that require them to spend many hours at the hospital. The IAPT services work on an outcomes-based payment approach, which means that patients whose survival is limited affect the cost-effectiveness of the service since they do not produce outcomes. If they do not attend or cancel two appointments,

patients are discharged. The psychologists identified this as a significant issue for dialysis patients, who often fluctuate in health and require more flexibility to fit treatments around their dialysis times and not on their days out of hospital. Moreover, many of the IAPT services use group therapies, which do not provide this flexibility, but also mean that a generic approach to therapy is used. Research on the effectiveness of IAPT-LTC services is still underway, but initial findings showed that it was difficult to translate such generic services to fit the needs of individuals with complex problems (172). Although for patients with one single condition managed by the GP, who had mild to moderate problems, the IAPT-LTC services were effective, it was questioned whether these patients would not be better served by GP based IAPT services. It was said that individuals with multiple co-morbidities and complex needs may be better served by hospital-based integrated psychology services (172), such as renal psychology services. Further research into IAPT services for dialysis patients is required, as it is not clear whether their psychological care is best provided by integrated specialist Clinical Health Psychology services or in the community by GP IAPT services. The current configuration of IAPT services does not allow for the integrated way of working that is suggested by many guidelines (172).

The issues with IAPT illustrate the challenge of translating national policies to better integrate health, social, and mental health care into practice for ESRD patients. National policies have increasingly emphasised the availability of more community-based services for patients with LTCs, led by community-based clinicians such as GPs. This seems useful for patients with conditions such as diabetes or earlier stages of CKD managed in primary care, but it is unclear what this means for dialysis patients who receive their treatment outside of the community, in secondary care. There is a risk of these patients falling between the cracks, if psychosocial support is increasingly offered through GPs instead of through the specialised renal care pathway.

3.4 Chapter Summary and Conclusion

The profession traditionally involved in the provision of UK renal psychosocial services, is social work (5). This chapter has shown that many reforms that have taken place within the social care system have caused long-standing tensions about general social workers' role and purpose, which have largely been unresolved. During an informal discussion in the lead up to

this study, a consultant said that in their experience, patients do not need social worker, all they need is someone to give them welfare advice. Statements like these might be an indication that sentiments voiced in general social care, of unqualified staff being just as able to support service users, might have also reached the renal world. The story for mental health services seems slightly more positive. Public attitudes towards mental health have improved and funding for psychological therapies is increasing. It is unclear how and if these tensions and public images of both professions have played a role in the replacement of RSWs by psychologists and counsellors observed in the workforce audit.

Patients with CKD often access many different services, crossing the boundaries between health care, social care and mental health care. Increasingly, policy makers have realised that problems in one system can create impact on and increase demand in the other systems. There is growing recognition that to achieve the best quality of life for patients and create the most effective arrangement of service delivery, these different systems need to work together in an integrated way. Over the last 70 years, driven by economic and political influences, many reforms and changes have taken place that influence how these organisations operate and work together. These reforms encourage the development of varying local approaches to provision of care. General policy seems to suggest that care for LTCs, including psychosocial care, be provided outside of hospitals, in the community through families, GPs and community teams. Whilst this may be appropriate for patients in early stages of CKD, it is unclear what this means for patients who have to attend the hospital regularly, like ICHD patients. Although they emphasise the need for a focus on psychosocial issues in kidney patients, current 'no-rules' renal policy documents are ambiguous and do not provide much specific guidance on how psychosocial support for these issues could best be delivered. They appear to be shifting focus away from dedicated renal psychosocial support, whilst at the same time saying that patients need advice and assessments that require renal knowledge. These policy documents do not present any evidence, nor do they offer any comparisons with other LTCs, on which to base a staffing model for renal psychosocial service delivery. There is no information that could help build or oppose a case for renal dedicated support as opposed to generic services. This evidence-base is the subject of investigation in the next chapter.

Chapter 4: Searching for evidence-based, international, renal psychosocial service provision models

4.1 Introduction

The psychosocial workforce audit demonstrated that a general renal psychosocial service provision model in the UK is lacking (Chapter 2), linked to the lack of clear policies on which to base staffing allocations (Chapter 3). The only available UK recommendations on renal psychosocial staffing levels, from a twenty-year-old workforce report, were generated from a very limited and vague evidence base. The benchmarks were only set for social workers and psychologists, yet the findings showed that in practice, other professions, such as counsellors, support workers and welfare advisors, are increasingly used to provide psychosocial services. These findings raised questions for which literature searches presented in this chapter aimed to provide answers. The first section of this chapter presents the results of a systematic literature search to identify studies that could serve as an evidence base for future psychosocial service delivery models, providing information on what type and number of staff are able to best support patients with psychosocial needs. It specifically searched for original research articles of comparative studies that provided an answer to the following questions:

- Which types of staff are best positioned and qualified to offer psychosocial services (e.g. psychology versus counselling, social work versus support work)?
- What patient-to-staff ratio is needed to offer adequate psychosocial services?
- Do renal dedicated psychosocial staff achieve better outcomes than generic psychosocial services?

The results of this search were extremely meagre. Therefore, the second section of this chapter continues with a wider exploration of scientific and grey literature, including non-original research articles, reports and quality standards. These documents allowed for the creation of an overview of current and relevant themes within renal psychosocial service delivery internationally, that also offered possible explanations for the lack of research studies found in the original search. Finally, this chapter also offers insight into how psychosocial services are delivered in other LTCs, particularly oncology, stroke and diabetes.

4.2 Search strategy

4.2.1 Search terms

The systematic literature search took place in July 2017. Seven searches were done, using possible terms related to renal psychosocial staffing models. Words related to 'CKD' such as 'kidney disease', 'renal' and 'nephrology', combined with Boolean operators 'AND' and 'OR', with terms related to 'psychosocial' were used. These were further combined with words related to 'service', 'team', 'staff' and 'multidisciplinary'. Finally, the Boolean operator 'NOT' was used combined with 'children', and 'oncology'. These steps were repeated in the same way for each of the databases using matching key words. A final search combined all seven searches.

4.2.2 Search of databases

Publications were identified by searching six databases (Academic Search Premier, Medline, Cinahl, Psycinfo, ProQuest Social Sciences, Cochrane). The first five databases were selected because they covered all relevant areas related to renal psychosocial service provision: namely medical, nursing, allied health, psychology and social work. The final database, Cochrane, was used to identify whether there was already a systematic literature review available on this topic. Each search was limited by date (Jan 2002 – July 2017).

4.2.3 Inclusion Criteria

Studies were considered for inclusion in the review if they focussed on adult patients with CKD and provided comparative evidence for recommendations on renal psychosocial service provision, for example by exploring outcomes of psychosocial care related to different staffing levels or types. Only studies that were fully available and written in English were included in this systematic review.

4.2.4 Exclusion Criteria

Articles were excluded if they focused on the effectiveness of an intervention rather than on which member of staff delivered the intervention. In addition, articles were excluded if they

only recommended psychosocial services, without giving a rationale or an evidenced example of what would be the most appropriate way to deliver these services.

4.2.5 Types of studies

Original research studies and systematic reviews were considered in the review.

4.3 Results

The final search identified a total of 322 articles across the different databases (Figure 3). These were transported into Endnote for evaluation and after removing non-English articles and duplicates, 263 articles remained. Based on the title, 106 articles were excluded. The author read 157 abstracts, after which another 154 articles were excluded. For the remaining 3 articles, the full text version was studied with great attention, but eventually only one article was found to meet the inclusion criteria.

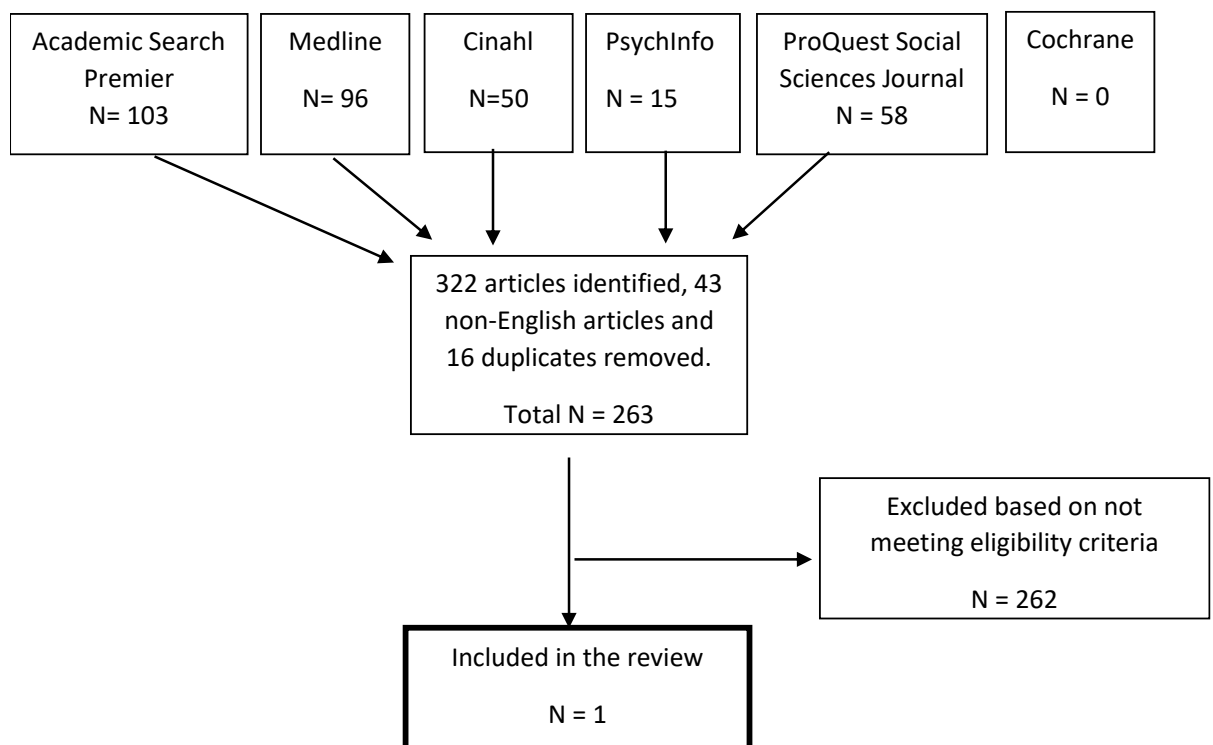


Figure 3. Initial systematic search diagram

The systematic search identified only one article that focused on investigating patient outcomes in relation to differences in the provision of psychosocial care. This article, by Beder

(173), presented a study on the impact of differences in RSW contact due to staffing patterns. The RSW did not work on Saturdays, which meant that patients on the Tuesday-Thursday-Saturday shift had a third less routine contact with the RSW. The findings showed that patients on this shift had significantly poorer quality of life and showed significantly higher levels of depressive symptomatology than patients who dialysed on Monday-Wednesday-Friday. The statistical power of this study's design was limited by its small sample size (N=62).

The other two articles that were excluded after reading the full article, both had titles that seemed promising and related to the search question. The first article was titled 'The Psychosocial Experience of Patients with End-Stage Renal Disease and Its Impact on Quality of Life: Findings from a Needs Assessment to Shape a Service'. The authors stated that they 'created an evidence base' for health psychology services, and the study led to funding being secured for a health psychologist and a clinical health psychologist in their English renal unit (84). The findings of this study were qualitative, and while they provided useful insights into the psychological burden along the renal pathway, they did not offer any indications on which to build a service, like the number of patients that might be in need of psychological support, for example.

The second article was titled 'Establishing Evidence-Based Renal Social Work Practice Guidelines'. The author explored patient files to examine whether the system implemented and practiced by the RSW, to ensure that all patients in a Canadian 'Renal Management Clinic' (pre-dialysis clinic) were assessed before they started treatment, was working (174). It was found that 80% of all patients were assessed before commencing treatment. The study did not provide any further comparative data of outcomes of patients who had received an assessment and who had not, and was therefore excluded.

The lack of studies identified through this search showed that evidence on which to base staffing models is currently insufficient or the question asked too narrow, so a wider scoping review was undertaken.

4.4 Scoping review of international models and evidence of renal psychosocial care

The scoping review did not aim to produce a critically appraised and synthesised answer to a particular question, but rather aimed to provide an overview of the current state of practice and research within renal psychosocial services. The next sections present the results of this review, showing relevant themes within renal psychosocial care internationally. Furthermore, the provision of psychosocial services in other LTCs in the UK were explored, to identify whether they could offer any useful insights for the renal context.

4.4.1 Challenges to the literature search

The search that led to the identification of the articles and documents used in this review was by no means straightforward or easy. The results of the original search were used as a starting point for this review. All abstracts were re-read and 30 full-text articles were explored for any useful insights into the delivery of services in the country of study origin. References to other articles, policy documents or guidelines that appeared relevant were further investigated. Appendix 3 provides an overview of the review process, detailing articles that were read and any useful information or additional documents that were found as a result. Many of the identified papers, although peer-reviewed, were low in quality (small sample sizes, descriptive, poor reporting of results) and published in small journals (such as *Nephrology News & Issues* and the *Journal of Nephrology Social Work*) with low impact factors.

In addition to this search, other strategies were employed to obtain relevant information. The author was familiar with Dutch and German, in addition to English. To widen the scope, Google searches in these languages were done to explore how psychosocial services are delivered outside of the UK: websites of hospitals or renal units, national psychosocial networks, kidney guidelines and renal charities across many countries were investigated to look for any clues that might lead to useful documents. Emails were sent to American and Dutch nephrology social work networks, without response. An email was sent to the UK's Chief Adult Social Worker with a question if she could provide any scientific literature related to social work in the context of chronic diseases. Unfortunately, they only came back with an article about a day in the life of a renal social worker. Eventually, the searches identified articles and documents that together painted a picture about the state of research into

psychosocial services, and also provided an explanation for the lack of comparative studies found in the initial search, as will be discussed.

4.4.2 The provision of renal psychosocial services outside of the UK

In Europe, detailed information about the renal psychosocial team was found only in The Netherlands. There, the key person for psychosocial care in the renal unit appears to be the social worker, trained to Bachelor's level. The Dutch Association of Nephrology Social Workers has developed quality standards (175) which recommend a ratio of 1 full-time RSW on 85 patients in the renal failure stage or already established on HD or PD. It is recommended that RSWs initially work supply-oriented, offering education and psychosocial assessments to each patient in the pre-RRT phase and as they move along the renal pathway. This includes psychosocial screening for transplant recipients and donors, home visits for pre-dialysis patients and support for patients who choose conservative care or those reaching the end-of-life stage. After the initial contact, it is recommended that the RSW routinely contacts the patient twice a year to offer their services, in addition to being available to patients on a demand-oriented basis. The quality standards offer a detailed calculation, based on average time spent per patient following this pro-active way of working, to provide the rationale for the recommended ratios. Importantly, the calculation also includes time for 'indirect non-patient related activities', such as training, supervision, management meetings and networking activities organised by the association of nephrology social work. Box 2 shows a translated excerpt from the calculations to illustrate the expected time spent per year for a patient on HD/PD. The increments that are added after the sub-total reflect the recognition that about 20% of HD/PD patients will require extra social work input, for example when changing therapy modality, or in case of carer issues, vulnerable elderly patients, bereavement, coping issues or relational problems. In addition, an extra time investment of 10% is added to account for patient groups that often require more intensive and long-term social work involvement, for example those with dementia, learning difficulties, (illegal) migrants, addiction and/or psychiatric disorders (175).

Box 2: Translated excerpt from Dutch RSW formation guidelines (175, p.26)

Haemodialysis and peritoneal dialysis	
Conversations:	180 minutes
Short-term support:	145 minutes
Multidisciplinary team meeting:	160 minutes
<i>Sub-total:</i>	<i>485 minutes</i>
Increment 20% extra support:	97 minutes
Increment 10% complex background:	48 minutes
Total HD/PD per patient:	630 minutes per year

The Netherlands operates an insurance-based healthcare system, which means that social worker involvement will be recorded meticulously. In 2016, 'only a few hospitals' employed RSWs in line with the recommended staffing levels (175). Detailed information on the Dutch RSW workforce could not be found. Limited information from Flanders, Belgium suggests that a similar model is followed, with several hospital information leaflets about dialysis listing social workers, but not psychologists, as part of the renal team (176). No information was retrieved on recommended or current staffing levels in Belgium.

Outside of Europe, information was found on renal psychosocial staff in the US, Canada and Australia. Again, the social worker appeared to be mainly responsible for dedicated renal psychosocial support within the renal unit. In the US, the RSW is in a special position, since ESRD is the only disease for which the country's federal Conditions for Coverage Mandate requires a clinical social worker on every interdisciplinary team in dialysis and transplant units (26). An important difference with the RSW in the US compared to those in the UK and The Netherlands, is that the US requires their RSWs to be Master's level trained. The additional hours of specialised, clinical training, on top of the Bachelor's degree, prepare the RSW to provide interventions such as assessment, education, and individual, family and group therapy. Importantly, the RSW is trained to use validated tools, such as the SF36 and KDQOL, to improve care and independently monitor the outcomes of their interventions. Currently, dialysis social workers in the US must assess all patients for depression and quality of life as part of the care planning process (26). A toolkit has been developed by the US Council of Nephrology Social Workers (CNSW) to guide facilities and RSWs in complying with this requirement (177). Jackson (178) explains that in the US, RSWs have the knowledge and skills

to provide counselling interventions, such as cognitive behavioural therapy, for patients who experience depression or a poor quality of life.

As of 2012, no nephrology social work ratios had been mandated by federal authorities, yet the Conditions for Coverage indicate that every dialysis unit needs to make sure that all professionals have caseloads that allow them to fulfil their duties. The CNSW, in their standards of practice, recommends an acuity-based RSW-to-patient ratio of maximum 75 dialysis patients per full-time member of staff. This recommendation is based on providing every patient with a psychosocial assessment and continuous follow-up (177). A recent investigation in RSW caseloads among 931 US dialysis social workers found a median caseload of 1 full-time RSW on 120 patients in 2017. Caseloads were found to vary largely, from 13 to 1500. Whilst the authors report that the median caseload is 60% higher than recommended, they do not provide a percentage of RSWs that have caseloads that are within the recommended levels (179).

In Canada, dedicated social workers are required to be available to all patients on dialysis, and reimbursement takes this into account (180). The Canadian Association of Nephrology Social Workers (CANSW) has also developed a document outlining their standards and scope of practice and RSW staffing recommendations (181). These vary widely by treatment modality and reflect recommended RSW involvement across varying renal services, from pre-dialysis clinic, to acute care, to post-transplant clinic. The recommendations for ICHD patients are similar to those in the US: 1 FTE Master's-level trained RSW per 75-100 patients, proactively providing assessments to all patients (181). These recommendations are however often not mandated, and a perceived shortage of sufficient social workers is reported, although further details are not provided (180).

In Australia, variety in the availability of allied health services, including social work, between and within renal health care networks has been reported (182). An audit of allied health professionals in the region of Queensland was undertaken in 2011 (23). It found that out of 14 sites, 7 had access to renal social work and renal psychology, 5 sites had access to renal social work only and 2 sites did not have any renal psychosocial support available. The FTE of RSWs was around 4 times higher than that of psychologists. The median ratios were 1:191 for RSWs and 1:396 for psychologists. This exceeds local benchmarks stipulating a ratio of 1 RSW

per 70 dialysis patients and a ratio of 1 psychologist per 200 patients. In the absence of these members of staff, the duties they typically undertake were shifted to the existing nursing and medical staff (23). More recent, nationwide psychosocial workforce audits and quality standards or national guidelines outlining staffing recommendations were not found. Fortnum, Kinrade, Mahony, Burgess, & Maxwell (183) explained that the RSWs had begun to set up a professional group in 2014, which had 80 members in 2016. In their article, they described an effort at examining RSW caseloads across Australia, however this investigation was poorly reported. Table 6. presents an overview of information about the availability of dedicated psychosocial services in these countries, compared to the UK.

Table 6. Overview of international dedicated psychosocial care models

Country	UK	Netherlands	US	Canada	Australia (Queensland)
Type of staff	RSW (BSc) & Psychology	RSW (BSc)	Clinical RSW (MSc)	Clinical RSW (MSc)	RSW (BSc) & Psychology
Recommended HD ratios	RSW: 1:70 Psy: unknown	1: 85	1: 75	1: 75-100	RSW - 1: 70 Psy - 1: 200
Median ratios	RSW: 1: 311 Psy: 1:675	Unknown	RSW: 1:120	Unknown	RSW - 1:191 Psy - 1: 396
Benchmarks met?	No	Unknown	Partially (% unknown)	Unknown	Unknown

Finally, Osman and colleagues (184), in their worldwide nephrology workforce study, stated that 62% of 121 countries reported a shortage of social workers, with 67% reporting a shortage of psychologists/counsellors. It is unclear whether they referred to renal dedicated social work and psychology staff, or availability of general social work and psychology services. Based on the limited data on renal psychosocial staff presented in this overview so far, the latter seems to be the most likely. Recently, in their journal, the American Society of Nephrology has introduced a regular feature which provides information about how renal services are delivered across the world. So far, the countries that have featured in this 'global dialysis perspective' are Vietnam, Senegal, Argentina, Japan, Mexico, Thailand, Israel, Brazil, Korea, Canada, and Australia. Information of psychosocial services in the latter two has been discussed; reference to dedicated psychosocial support was further only mentioned briefly in the overviews from Israel, Senegal, Brazil and Japan. In Israel, Japan and Senegal, the dialysis unit is required to employ a social worker, although in Senegal patients do not have free

access to the social work service. In Brazil, a unit must also employ a psychologist, in addition to a social worker (185–188). The articles provided no further information about whether units actually employ these members of staff.

4.4.3 Evidence for renal psychosocial interventions

The initial literature search did not identify any papers that could contribute to an evidence base for the creation of psychosocial staffing models. The lack of research to provide an evidence-base for staffing recommendations has been highlighted by others (23,189). The current literature search identified that instead, research cited as the evidence base of renal psychosocial staff focuses on outcomes after specific interventions by RSWs, psychologists, or multidisciplinary teams, as opposed to comparing outcomes across different members of staff or staffing levels. Yet, excluded papers guided an investigation into available scientific evidence for RSW or psychology interventions.

Available evidence from other countries presented suggests that recommended RSW ratios are based on offering RSW support to each patient; the Dutch guidelines provided a clear rationale for the set benchmarks based on staff time and activities. Yet these guidelines cite no scientific literature to explain whether this proactive way of working is actually what patients want or need. Articles that could serve as the evidence base for RSW are mainly from the US, where there is a *'rigorous foundation of empirical support for the importance of RSWs in dialysis and transplant settings'* (190). However, a closer exploration of studies cited as part of this 'empirical support' found that this foundation seems to be mainly built on small evaluation studies done in the 1990s and early 2000s, with little research published in the last ten years. Still, Wolfe (191) claims that it has been demonstrated that *'of all subspecialties in medical care research, RSW intervention has perhaps the greatest potential for impacting outcomes and costs'*. It appears that research on the effectiveness of RSW has mainly focused on highlighting this potential, by showing the impact of RSW interventions on patient outcomes that are of value to the renal unit, as well as the patient.

Johnstone (192) and Callahan (193) described US RSW interventions designed to improve patient quality of life and self-management. The literature search identified few studies that showed how RSW patient education and interventions positively influence issues related to

non-adherence to dietary and fluid restrictions, medication and treatment regime: Johnstone & Halshaw (194) reported the results of a small pilot study (n=31) on a RSW-led 'Making Peace with Fluid (MPWF)' class, which aimed to improve patients' fluid management, as measured by interdialytic weight gain (IDWG). An improvement in fluid management behaviour was reported, which served as evidence to develop a quality of life program called 'the Social Work Intensive Program', rolled out across the country in 2012, to manage patients with self-management and coping issues. As part of this program, non-adherent patients are offered initial screening to detect barriers to non-adherence such as depression, stress, sleep disturbances, low quality of life or pain. If any of these barriers are noted, patients are offered RSW behavioural health and quality of life interventions, in addition to three MPWF classes. In a follow-up on the 2004 article, Johnstone, Li & Demaline (195) report on the results of this intervention model. The researchers highlighted reductions in percentage IDWG and fluid-related hospitalisation over a six-month post-intervention period in a group of patients who took part in the MPWF class, although the significance of these findings is not reported. Cabness, Miller, & Martina (196), in their non-randomised, quasi-experimental study, found improved motivation for treatment adherence, fewer hospitalisations and decreased missed and shortened treatments for patients in a social work intervention group (n=14). Similarly, Mazzella & Berkman (197) found significantly reduced missed treatments in the RSW intervention group (n=13) compared to a comparison group (n=8). Beder et al. (198), in their larger experimental study, found significant increases in medication compliance, physical activity and treatment attendance, in addition to decreased blood pressure levels, in the RSW intervention group (n=191). RSW interventions have also been found to reduce depression, which is linked to self-management issues (199,200).

The US literature on RSWs appears to highlight a focus of RSW interventions for patients presenting with depression or self-management issues, who are most at risk of negative health outcomes. A study in Australia found that finances and domestic assistance were also amongst the most common RSW consults (25). Generally, literature on RSW outcomes does not report on the impact of RSW interventions on more general social, vocational and emotional issues that fall within the realm of social work. This search identified no studies on outcomes of RSW involvement in the UK, literature on the subject is not much more than an article describing a day in the life of a renal social worker (201). Linked to this, in a recent

narrative review, Neukirchinger et al. (76) found a dearth of published research providing evidence on social care provision and needs for CKD patients.

Recently, more robust, randomised controlled trials have shown the effectiveness of targeted home-based interventions, which included a social worker, on improved treatment adherence (202) and increased pursuit of living kidney donors (203,204). These articles could form a part of evidence-based practice in renal social work. However, a further exploration showed that social workers are not exclusively able to deliver such interventions. For example, the intervention described by Massey et al. (204), delivered by a social worker, was built on previous studies that yielded similar results by using health educators (205) or a medical psychologist and transplant coordinator (206) to deliver the intervention. In addition, a recent meta-analysis, Wang et al. (207) illustrated that nursing interventions also led to higher compliance with dialysis treatment. This not only shows how roles within renal psychosocial service delivery can overlap; it highlights the importance of considering differences between countries in terms of professional training and context in which health care is delivered. This becomes particularly visible when exploring the literature on renal psychology. Research on renal psychology as a profession is limited and compared to research on RSW, it appears to focus less on positioning itself within the renal service. Instead, renal psychologists can draw from an evidence base consisting of systematic reviews and meta-analysis describing the prevalence of psychological issues and the effectiveness of psychological interventions in renal patients (7,82,208). In the UK, there is a renal psychology research team at King's College London, which is currently working on developing and evaluating cognitive behavioural therapy interventions to improve outcomes in dialysis patients (209). As discussed earlier, this type of intervention can be delivered by US RSWs. It is unclear if UK RSWs would get involved in the delivery of these kind of interventions, but the literature suggests that this is left to counsellors and psychologists.

4.4.4 Psychosocial services in other long-term conditions

Final searches explored the provision of psychosocial services in three other long-term conditions, which, together with renal failure, are amongst those with the highest costs for social care and hospital admissions: cerebrovascular disorder (stroke), diabetes and cancer (210). There is a large body of literature on psychosocial aspects of these conditions, yet the

aim of the following sections is to provide an overview of UK practice of psychosocial service delivery. Therefore, only documents that detail recommended or current levels of psychosocial staffing within the UK care pathways for these illnesses are included.

With regards to psychological services, guidance for all three conditions proposes psychological interventions based on a similar stepped-care approach, as recommended by NICE guidelines. Figure 4 shows this model, adapted for supportive and palliative care for adults with cancer (211). NICE estimates that around 15% of cancer patients will experience mild to moderate distress and are likely to benefit from level 3 intervention and 10% of patients are expected to experience more severe levels of distress, requiring level 4 intervention (211).

In cancer care, this type of support is available through dedicated psycho-oncology services. These are now established and increasingly available within the NHS, typically comprising of clinical psychologists, counsellors, psychotherapists, liaison psychiatrists, psychosexual therapists and neuropsychologists. A recent pan-London initiative built on the stepped care model to design a psychosocial support pathway. It estimates a yearly caseload of 120 new patients per full-time level 3/4 worker and states that a social worker, with an accredited counselling qualification, could also take on level 3 interventions (212).

Recommended model of professional psychological assessment and support			
Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Cousselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Figure 4. Psychological stepped care model (211)

Estimations for the prevalence of emotional and psychological need are also provided for diabetes care, although diabetes pyramid of psychological problems is divided into five levels. It is stated that patients in levels 4 and 5 require specialist psychological and/or psychiatric interventions. It is not specified which members of staff could offer support for level 2 and 3, which represent more severe difficulties with coping and moderate psychological problems.

Prevalence is estimated at around 60% at level 1, 40% at level 2, 20-30% at level 3, and 10-15% at levels 4 and 5. These prevalence estimates reflect that people may simultaneously have needs represented at several levels, for example, an individual with a severe mental health issue at level 4 may also have a level 1 anxiety surrounding an aspect of their diabetes management. The last investigation into the availability of psychological services was in 2008. It found that 85% of people with diabetes in the UK have either no defined access to psychological support and care, or at best only in the form of local generic services.

Where psychological services do exist, they are provided by people from a range of disciplines, with psychologists the provider in 57% of cases and liaison psychiatrists in 18% of cases. Much like the conclusion presented on renal psychosocial services in chapter 2, it was stated that there appeared to be no clear rationale for why diabetes services have developed in this manner; provision appears to be related to factors such as whether or not diabetes is a special interest of the provider (213). Currently, psychological support still appears to be a limited resource and is often provided through primary care, but information on national staffing recommendations or current workforce composition could not be found. A more recent mapping of psychological services in London found that 60% of diabetes providers had psychological services available for their patients, of which two-thirds were offered through general adult mental health services. Those with severe mental illness were often referred to liaison psychiatry and for those with moderate issues, the referral options depended on what was available locally. Options included services such as IAPT, practice nurses with psychological skills, counsellors from the voluntary sector, GPs with skills in mental health or diabetes. The remaining one third used a variety of uniquely designed integrated care models (214).

In stroke services, guidance from NICE and the Royal College of Physicians states that acute and inpatient stroke rehabilitation services should include specialist clinical (neuro)psychology within their core multidisciplinary team. The recommended level of psychology provision is currently 1 FTE per 30 stroke unit beds. However, many care arrangements do not include psychological provision, or separately commission these from another provider. A recent driver for improvement was created by the Department of Health, asking stroke services to aim for achievement on a national measure for 40% of their patients to receive psychological support within six months of a stroke (215).

With regards to the provision of social care services, guidance within these conditions is less specific and documents about the social care workforce related to these conditions could not be found. This finding supports those by Moriarty et al. (216) who, in their review on hospital social work, also struggled with a lack of data on where adult social care workers actually work.

It appears that the NHS is looking to LAs to fulfil their statutory responsibility in offering social care services for diabetes, oncology and stroke patient populations. Yet, in oncology, LAs have not traditionally perceived cancer as a social care issue. Therefore, cancer specific social care provision was rarely provided due to disagreements over funding. A large national cancer charity, MacMillan, works to address this issue and appears to be aiming to fill this gap in service provision, by funding oncology social (care) workers, placed within the oncology MDT, to ensure that patients can access support in their communities (217). Information on recommended staffing levels and NHS/LA funded dedicated oncology social workers could not be found.

In stroke services, the availability of social workers and social care features heavily, although unlike stroke psychology services, guidance does not specify who is responsible for the provision, nor does it provide workforce recommendations. Depending on severity, most patients are initially treated in hospital, in acute and rehabilitation services. NHS guidance states that in acute stroke units, the MDT should comprise of a social worker. It is unclear if this is provided through the hospital social work team or whether there are separate employment arrangements, like is the case with RSWs. The focus of this social work involvement will be on discharge, as all equipment and aids necessary to ensure a safe environment should be available at discharge. For some patients, rehabilitation can take place at home. These patients will fall under the care of the Early Supported Discharge team, which should have access to social work and psychology. After patients are discharged from the stroke unit or following ESD, they will access community rehabilitation teams, which also include social care. A requirement is that, if appropriate, patients will receive a social work assessment within 72 hours of referral. Then, adults who have had a stroke should have a structured health and social care review at 6 months and 1 year after the stroke, and then annually (218,219). No information was found on whether these requirements were met.

4.5 Discussion

The systematic literature search presented in this chapter set out to identify studies that could serve as an evidence base for future psychosocial service delivery models, providing information on what type and number of staff are able to best support patients with psychosocial needs. The complex search identified no comparative studies that explored

differences in outcomes of different methods of service delivery. It only found one study that provided some indication of the negative impact of reduced RSW staffing (173). A gap in the literature on delivery of renal psychosocial services was identified, especially in the UK and Europe more broadly. Yet, information about which members of staff were involved in providing psychosocial support could be derived from texts of excluded articles, and together with further searches, led to insights that could offer several possible explanations for the lack of comparative studies in renal psychosocial care.

Firstly, it became clear that different countries have different contexts of healthcare provision, education and regulation, which needs to be considered. It appears that in the US, the Netherlands and Canada, in the first instance, the RSW is responsible for the provision of psychosocial support for renal patients. Their clinical training makes them the key person in diagnosing and treating psychological disorders, in addition to dealing with patients' social issues. From the information extracted it appeared that in the USA and Canada, there was only one model of service provision: the clinical RSW provides psychosocial support at each unit and refers to the psychologist or psychiatrist for complex mental health intervention and pharmacological treatment if necessary. In Australia too, where only a limited input from renal psychologists is reported, the main person offering psychosocial services appeared to be a social worker (23). This might explain why there were no studies from those countries comparing different models of service provision; there were no different models to compare.

In contrast, in the UK, different types of psychosocial staff work alone or together in different combinations to provide psychosocial services. The RSWs are often bachelor-level trained and do not generally have a counselling registration. This makes them unqualified to treat psychological disorders, such as depression, which is the task of renal psychologists and/or renal counsellors/psychotherapists. Regulations that state that patients must 'have access to' psychosocial services (169,220) seem less strict and less specific than in the US. It does not necessarily mean that renal units have to employ staff to provide these services, nor does it clarify which professional staff that should be. As a result, many different models of psychosocial service provision have emerged.

The recommended ratios of RSW in the UK are similar to those in the US, yet this literature review suggests that, based on training, RSWs in the UK have a smaller remit than those in the US. It is unclear how research on US RSW interventions translates to the UK RSW role. No studies on the UK RSW were identified, yet it appears that in the UK, psychologists/counsellors might be needed to deliver the psychological interventions that are presented as part of the evidence base of RSWs in the US. Most studies on renal psychosocial issues focus on psychological problems; studies on social care issues in renal patients are notably lacking. As previously mentioned, in the UK, traditionally, the RSW was the provider of psychosocial services in renal units. However, over the past 15 years, the total of whole-time equivalents of renal psychologists and counsellors/psychotherapists has greatly increased and RSWs decreased (106) (chapter 3). This finding links to the results of this systematic search, which highlighted that evidence in renal psychosocial care is mostly related to psychological interventions, with evidence of social care interventions lacking. The employment of renal psychologists and counsellors/psychotherapists is a relatively new phenomenon in the UK, leading to the creation of new service provision models, which could explain why there are no studies comparing service provision models across the UK.

Even though in the US and Canada there appears to be only one model for psychosocial service provision, that does not mean that it is the best model. If anything, this literature review has shown that there is hardly any robust evidence on which to build models of service delivery. No articles were found that had the delivery of psychosocial services as their main focus and authors of articles on aspects of psychosocial care for kidney patients did not place these within the context of models of service delivery. In addition, guidelines stipulating psychosocial services did not provide evidence, such as data on the number of dialysis patients requiring RSW involvement or renal dedicated counselling or psychology, or whether patients could have been supported by lower qualified staff such as social support workers or welfare advisors, or general services. In the US, the medical and therapeutic ramifications of inadequate RSW staffing levels are yet to be determined by research (191).

This review further provided an overview of the practice of psychosocial service delivery for people living with cancer, diabetes or stroke, which yielded some interesting insights. It indicated that although research in psychosocial issues in these conditions is well established

- arguably more established than in CKD - much like in renal care, this has not yet been translated in widespread access to dedicated psychosocial services.

For all three conditions, psychological support is clearly stated in the guidelines and stepped-care models have been designed, along with workforce recommendations. In oncology and acute stroke care, psychological support is increasingly available through specialist hospital services, whereas diabetes patients are often advised to find this support through general services. For social care, the only clear guidelines stating social worker involvement are found in acute stroke services. However, the focus of this involvement will be more on discharge back into the community, which makes it important to recognise that there are differences between these conditions and renal disease, in terms of acuteness, longevity, intensity and location of care, which provide every illness with its own unique impact and thus own need for tailored service provision. Still, both in oncology and in diabetes care, the provision of social care seems to be hardly discussed in practice guidelines; patients appear to be heavily reliant on the charity sector to find the social care support that they need. This shows that perhaps the need for investigations to better understand the demand for and provision of social care services is not only present in renal disease, but in other long-term conditions also.

4.6 Chapter summary and conclusion

This literature review showed that scientific evidence on which to build a model of psychosocial care and staffing recommendations in the UK is extremely limited. Identified articles mainly came from the US and focused on the RSW. Dutch RSW guidelines provided a clear rationale for staffing recommendations, based on pathways of involvement and accompanying calculations of time spent per activity along these pathways. However, these guidelines were grounded in practice, instead of in scientific evidence. Overall, it appears that in renal care in other countries and other LTC guidance, the role of a social worker in provision of psychosocial support is recognised as pivotal. However, in the UK, RSW numbers have decreased, whilst the number of psychologists and counsellors have increased (Chapter 2). The results from this literature review suggest that this might be a response to the lack of studies on the UK RSW, whose role in UK renal psychosocial service provision remains unclear. The evidence base on renal psychosocial interventions mainly consists of studies that focus on psychological aspects and outcomes of care, as opposed to researching social care

provision for renal patients. Furthermore, it cannot be assumed that research from the US and the Netherlands can be translated to the UK, since there are differences between training, regulations and health care contexts between the UK and these countries. This highlights the importance of UK specific research.

Chapter 5: Methodology

5.1 Introduction

The first four chapters of this thesis showed that evidence of psychological issues in renal patients has emerged over the last years, whilst social care problems were found to be largely under-researched. Still, it was identified that a growing awareness of the link between physical health and psychological and social wellbeing has led to a policy emphasis on provision of psychosocial support for all LTCs. A country-wide renal psychosocial workforce audit showed large inequalities and variation in the availability of psychosocial services across the country, with many units offering psychosocial support in different ways, or not at all. It was concluded that the policy emphasis on integrated psychosocial support has not resulted in an increase in renal psychosocial services over the past 15 years. An investigation of policy documents showed that policies are ambiguous and unclear when it comes to offering guidance for the design of a renal psychosocial service. A literature review revealed that there is a lack of scientific evidence to inform policy and future models of psychosocial service delivery. This might explain the large variation in how services are provided across the country. Furthermore, renal psychology services have increased and appeared to have slowly replaced social work services over the last 15 years. This is a process that seems to be unique to the UK, as limited information from other countries, particularly the US and The Netherlands, showed that usually the RSW appears to be the main point of contact for psychosocial care. Yet, there are no empirical studies about the UK RSW role and its impact, which might be why the profession has not been able to stand its ground in times of austerity and budget cuts.

The first four chapters of this thesis have provided a background to and shaped the rationale for this research, which will focus its investigations on these two main gaps and uncertainties:

1. Models of service provision: It is currently unclear how dedicated psychosocial service provision is organised across different units, how these services align with patients' needs and affect the experience of psychosocial distress and issues in renal patients. In addition, it is unknown if these issues are more prevalent in units where dedicated service provision is lacking and patients need to find support to general services.
2. The RSW: The role of the social worker within renal units is unclear, as is its impact on patient wellbeing.

Building on these gaps, this chapter presents the primary aim of the research study and reiterates the key research questions. Since it has become clear that UK renal psychosocial service provision is a largely unexplored area, this study will apply a broad approach to its investigation. Health services research is, by its nature, highly complex, with many interactions between social, organisational and market contexts influencing the course and outcome of service delivery (221). Researching such a phenomenon requires the application of an appropriate methodology to capture its complexity. Crucial aspects of methodological decision-making are the researcher's philosophical assumptions concerning beliefs, values, ontology and epistemology (222). Indeed, researchers bring to their research certain beliefs about what is valid and meaningful knowledge, which form their philosophical stance.

In this chapter, the philosophical stance that has underpinned the design of this study will be made explicit by exploring the ontological and epistemological perspectives of critical realism. To research renal psychosocial service provision, a mixed-method design is adopted, which capitalises on the strengths of both quantitative and qualitative approaches. An explanation of two studies, linked to the described main gaps in knowledge, will follow, and the study sites and participants defined. An overview of and rationale for the data collection and analysis methods is provided, including a description of the Distress Thermometer as a measurement tool. Finally, ethical implications considered for the study are explored.

5.2 Research aim and objectives

The primary aim of this study is to gain a deeper understanding of renal psychosocial services in the UK, by examining different models of psychosocial service provision and focusing specifically on understanding the RSW role. Applying a critical realist approach, it aims to understand processes and organisation of service provision; capture experiences of staff and patients; and evaluate service delivery – in particular that of RSWs – by using the DT to identify distress and need for psychosocial services in the renal population.

The five study objectives to achieve these aims are:

- To map the current provision of renal psychosocial services across the UK and examine how this has evolved since the last workforce mapping in 2001
- To explore distress, psychosocial issues and need for support of ICHD patients

- To investigate differences in distress and psychosocial issues across renal units with varying models of psychosocial service provision
- To generate an understanding of processes of service delivery within different models of renal psychosocial care
- To gain a deeper understanding of the renal social worker role

This chapter continues with a description of the author's philosophical position and the theoretical framework, methodology and methods used to complete these objectives.

5.3 Philosophy of science

Science can be described as the practice of gathering knowledge about reality. When doing research, it is important to consider the nature of reality and knowledge. Namely, *'every scientific (and everyday) attempt to understand and explain the world starts from our concepts of it'* (223). To provide the reader with clarity over the ways in which 'valid' knowledge is obtained and the nature of knowledge claims made in this study, the following section will focus on the philosophy that underpins this research. Philosophical literature can be *'immensely confusing, inconsistent, and at times, completely impenetrable'* (208, p.1186). Therefore, the next paragraphs will provide a brief general explanation of important concepts and views within the philosophy of science and philosophical stance of critical realism, explaining how this stance is adopted in this thesis.

5.3.1 Critical realism as a philosophical perspective

Two main branches of philosophy are important in the social sciences: ontology and epistemology. Ontology – the study of being – concerns itself with the nature of reality, what truly exists in the world about which humans can acquire knowledge. Intimately linked to ontology is epistemology – the study of knowledge – which is concerned with how people acquire knowledge, make meaningful sense of the world, and how we can know what we know (223,224). For the purpose of this thesis, it is argued that ontological theories tend to fall somewhere along the spectrum of two opposing categories, realists and relativists. Epistemological positions can also be seen as part of a continuum, often falling somewhere between objectivism and subjectivism (225). Sometimes referred to as a paradigm or worldview (226), a philosophical perspective can be defined as *'a basic set of beliefs that guide*

action' (211, p.17) and it reveals a researcher's ontological and epistemological stance. Incompatible fundamental assumptions about what should be regarded as acceptable knowledge and how society and its institutions should be characterised, have led to the so-called paradigm wars amongst researchers in the 1970's (228). It is during these wars that the stance of critical realism emerged through the work of Roy Bhaskar. It represented a broad alliance of other social theorists and researchers such as Archer (229), Sayer (230), Collier (231) and Lawson (232) trying to develop a post-positivist social science. There are many variations of critical realism across different areas of social science (233), but this section will provide the basic ideas of critical realism.

Critical realism situates itself as an alternative paradigm both to positivism and interpretivism (234), but it draws elements from both strains in its account of ontology and epistemology. One of the most important tenets of critical realism is that ontology is not reducible to epistemology (235). In other words, the knowledge about renal psychosocial services that is acquired in this thesis is only a small part of a deeper and vaster reality.

5.3.2 Reality within renal psychosocial service delivery

Ontologically, critical realism holds that there is a reality, a world, existing independently of our knowledge of it. In that sense, it agrees with positivistic realist views on ontology. In this thesis, the author is also realist about the subject matter. That is, psychosocial wellbeing and psychosocial service delivery are 'there', they are 'happening', and they exist independently of the author's investigation of it. However, a 'naïve realism' is rejected, in that an unmediated access to the Truth will not be claimed. Reality should not be limited to what can be empirically known or observed, which Bhaskar (236) referred to as the '*epistemic fallacy*'. Bhaskar (236) proposed that reality consists of three ontological domains: the empirical, the actual and the real. The empirical domain, which holds the data in scientific contexts, consists of our experiences and understanding of events in the world. This is separated from the actual domain, which contains the events as such - that what really happens – regardless of whether they are observed or experienced. This, in turn is separated from the real dimension, which is the deep dimension where one finds causal mechanisms that produce the events (223). These mechanisms may not be directly observable at the empirical level, but they are real because they cause things to happen. It is the business of science to establish the connections

between the empirical, actual and real: to observe and identify the relationship between what we experience, what actually happens, and the underlying mechanisms that produce the events in the world (223). The actual events under study in this thesis are the delivery of psychosocial services. The initial focus of this investigation will be on collecting data on patient distress and staff and patient experiences, through the use of research methods described in this chapter. This empirical data will then be used to explore the deeper causal mechanisms that have shaped the delivery of psychosocial services. Examples of these mechanisms relevant for this investigation include relationships, norms, personality, attitude and culture (223,237,238). It is acknowledged that while the author may be able to capture some of these elements, some entities may not be observable.

Further concepts of critical realism that are used to explore renal psychosocial services are those of emergence and open and unstable systems (223,230). Namely, psychosocial services are changeable, as they are made up of individuals, or agents, who act with intention and purpose. Since they form relationships and constantly change their actions and practices the system of service delivery is an open system. It is also an unstable system, in which mechanisms interact to create events, depending on numerous circumstances such as staffing levels, demands from the unit and wider policy changes (223).

5.3.3 Knowledge of renal psychosocial service delivery

Epistemologically, critical realism holds that our knowledge of reality is socially produced. Agreeing with an interpretivist account of epistemology, it posits that knowledge is generated by humans and therefore always context-, concept- and activity-dependent. Namely, for facts to be understandable, they comprise earlier every-day and/or scientific conceptualisations. This means that although there is a reality independent of human consciousness, there is no observer-independent access to it (223,230,239). In relation to the observable element of distress under study, the adopted research methods can only capture the distress and causes for distress that the patient wishes to express. The distress that a patient reports is subjective and can be influenced by many interacting factors, not the least the patient's willingness to share personal information, response to the author's interview technique and understanding of the questions. Moreover, patients can interpret and experience distress differently (86). Differences in people's abilities and strategies to cope means that the exact same issue can

leave some patients feel extremely distressed, whereas others would not experience this (240). A simple linear relationship between psychosocial service delivery and distress is therefore not expected. Although a comparison of distress levels across units will take place, the main goal is not to identify generalisable laws by determining which model of service delivery 'works better'. Instead, in order to develop deeper levels of explanation and understanding, the focus of investigation is on how the services were shaped, enabled and/or constrained by interaction between their agents and their local context. This is explored by capturing the experiences of patients and staff. When capturing the process of service delivery in this way, the author can only know things that participants decide to share. The information received depends heavily on the questions that are asked and what participants think is relevant and useful to elaborate on. Since there is no observer-independent access to reality, it is impossible to fully apprehend psychosocial service delivery, making the knowledge obtained in this thesis in fact fallible, relative, and open to adjustment (at least to some degree). However, within critical realism, not all knowledge is equally fallible, as some researchers will have more valid explanations that approximate the truth with more accuracy than others (223,230,239). Since the choices made during the design of the methodology and processes of data collection and analysis influence what is known, in this thesis, emphasis is placed on the design of a methodology in line with the principles of critical realism to come to the most valid explanation of the truth as possible.

5.4 A biopsychosocial approach to distress

To ensure that this study captures social care issues in addition to psychological issues, this study will follow a biopsychosocial approach to refer to the interaction between the physical, psychological and social factors influencing renal patients' distress. The Biopsychosocial Model was first elaborated by Engel (241), who argued that:

'to provide a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness' (225, p.132)(241).

The prevailing model at that time, the biomedical model, was found to be too narrow and left no room for social, psychological and behavioural dimensions of illness. Engel's model offered a holistic alternative and was championed not only as a scientific proposal, but also as a fundamental ideology that tried to reverse the dehumanisation of medicine and disempowerment of patients (241,242). Anderson & Armstead (243), in an attempt to bring attention to the relationship between social economic status and health, advanced the biopsychosocial model to encompass many categories of variables that may interact to determine health status. These stratifications included sociodemographic (e.g. age, gender); economic (e.g. income, occupation); social, environmental, and medical (e.g. social support, access to healthcare); behavioural and psychological (psychological distress, health damaging behaviour); physiological (e.g. cardiovascular, weight), and health outcome variables. They illustrated numerous and complex interactions that may occur both within and across these categories (243).

In the context of CKD, Bruce et al. (1) adapted a similar perspective when describing their heuristic model (Figure 5) of the associations between social environment, psychosocial factors, behavioural factors, CKD risk factors, and CKD progression and complications. This model clearly highlights some of the social determinants of mental health (including distress, which would fit under the header of psychosocial factors) and physical health. An unhealthy social environment (e.g. poor residential conditions and economic deprivation) affects psychosocial risk factors for CKD such as depression, anxiety and lack of social relations. These factors, in turn, could affect behavioural factors such as smoking, unhealthy diet and low physical activity, which are said to increase the chances of hypertension, diabetes and obesity, all risk factors for the development and progression of CKD (1). Yet, the model paints an incomplete picture, with the causal impact of CKD on socio-economic factors and psychosocial factors not reflected. It does not present a vicious circle and lacks an illustration of the reciprocal relationships between distress and the other factors. Researchers have clearly described how CKD, its treatment and associated demands, have a great impact on patients' physical and emotional wellbeing and interfere with patients' social roles. Especially patients with CKD who are being prepared for, or receive RRT often experience difficulties in

participating in various domains of life, such as paid work, sports and other social and leisure activities (19,244).

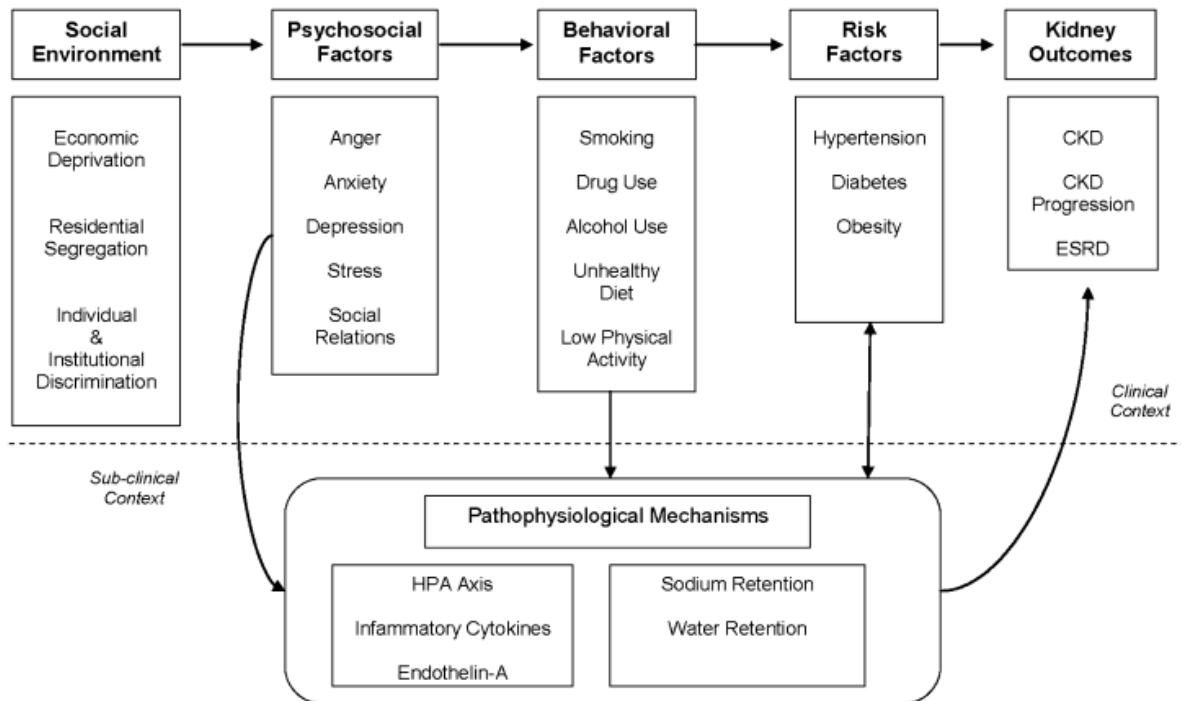


Figure 5. Heuristic biopsychosocial CKD model. Reprinted from ‘Social environmental stressors, psychological factors and kidney disease’, Bruce et al., (1, p. 584).

This impact of CKD treatment is described by White and Grenyer (245) who developed their model of biopsychosocial links in ESRD (Figure 6). Whereas ESRD was the endpoint of the model of Bruce and colleagues, White and Grenyer took ESRD as the starting point. It shows clear circular interactions between biological, psychological and social effects of RRT, showing how psychological distress can both be the cause and result of biological and/or social effects. However, their model also is incomplete, since it does not take any social and/or psychological issues into account that might have been present pre-treatment.

This thesis does not aim to identify causal relationships between issues and health outcomes, yet both models are considered to be important when determining a cause of distress and subsequent need for provision of psychosocial services, before and during dialysis treatment. Namely, one patient might have social and/or psychological issues before starting treatment, whereas the other might develop them as a result of the treatment. In line with the biopsychosocial approach, the most appropriate model for this study would be a combination

of both, which acknowledges the individual patient and their context and allows for a varying directional nature of interacting factors.

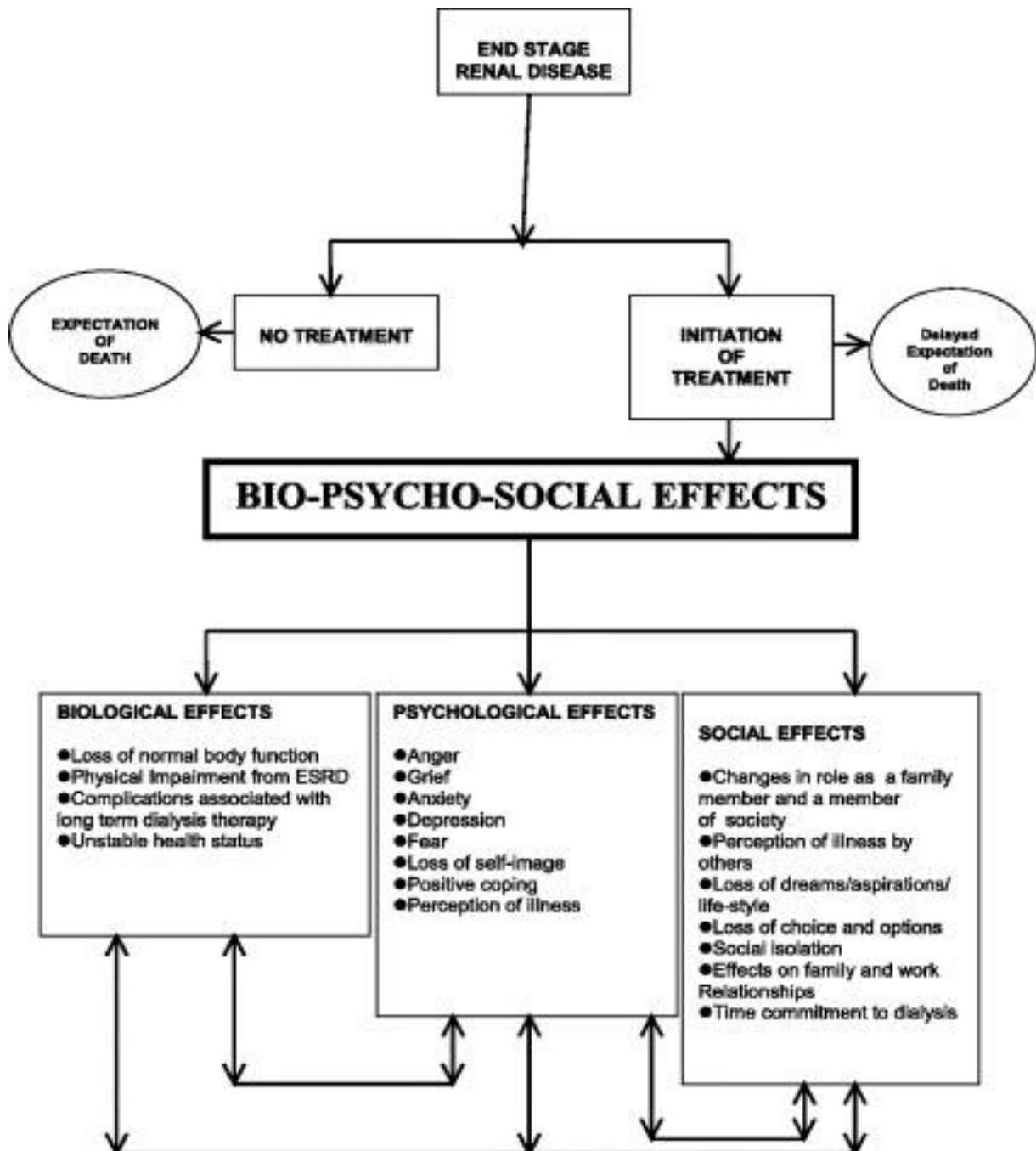


Figure 6. A conceptual model of the biopsychosocial links in ESRD. Reprinted from 'The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners', White & Grenyer, (229, p.1314).

5.5 Rationale for mixed methods research

Methodologically, the '*ontologically bold but epistemologically cautious*' (246) assumptions of critical realism have several implications. Firstly, the stratified ontology of critical realism holds that there is a deeper level of reality where the structures and powers of things may not be observable. Therefore, perceptions of empirical reality (events that can be observed and experienced) should be studied to identify the mechanisms that gave rise to that reality.

One of the most distinctive features of critical realism is its view on causality (230), referring to the relationship between an action or thing (cause) and the outcome (effect) it generates (247). In the open systems of the social world, the same causal power can produce a different outcome. For example, budget cuts in two hospitals can cause psychosocial teams to reorganise in the one, but disappear in the other. Alternatively, different causal mechanisms can produce the same result (230): for instance, people can feel distressed due to a variety of reasons. It is through identification and description of these causal mechanisms that causal knowledge can be obtained (247). In practical terms, this position on causality means that a different strategy of inference needs to be adopted in order to explain events by identifying its generative mechanisms (239). This strategy is called 'retroduction', which is largely a creative process for the researcher in which multiple explanations are proposed which describe a causal mechanism, set within a social structure, that produces the observed events (247). This retroductive approach to research and the wider principles of critical realism are potentially applicable to a wide range of methodologies and methods.

Critical realism is quite unique because it validates and supports key aspects of both quantitative and qualitative approaches (226), allowing a mixed-methods approach. Mixed methods research is defined by Tashakkori & Creswell (248) as '*research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry (p.4)*'. This type of research allows the researcher to view the object of investigation from different angles, using multiple ways of seeing, hearing and sense-making (249). Some go as far as to say that the use of different methods and perspectives is required in critical realism (247).

Accepting a critical realist view does come with some limitations. Particularly, it changes the role of quantitative methods from that as used in positivist studies, where the main focus is on event regularities (239). Focusing exclusively on the identification of strictly defined patterns of observable events (regularities) in order to make causal statements would be at odds with the stratified ontology of critical realism (239). For example, suggesting that a correlation between the use of a psychosocial screening tool and an increase in referrals to the psychosocial service means that screening causes more psychosocial problems may be an inappropriate leap of causation when in fact screening has simply improved the accessibility and visibility of the service. Therefore, in critical realist studies, quantitative methods are largely viewed as appropriate to develop reliable descriptions and accurate comparisons, which are particularly useful in the exploratory phase of an investigation. In this phase, the strength of quantitative methods is in its ability to identify patterns and associations. These patterns, or demi-regularities, can play a significant part in focusing the research design as it allows for the development of hypotheses about existing causal mechanisms which can be further investigated through qualitative and comparative inquiries (239,250). In this study, the value of this role of quantitative methods in uncovering patterns in distress levels and psychosocial issues among patients across different case studies was recognised. These patterns were then used to guide qualitative research to uncover the processes of psychosocial service delivery that produced the outcome observed. Qualitative methods were found appropriate for this final phase, since they are open ended, allowing themes to emerge during the course of inquiry that could not have been anticipated in advance (250). Indeed, qualitative methods can help to illuminate a web of interactions and relationships within psychosocial service delivery that is unlikely to be captured by quantitative methods, such as standardised questionnaires with set response categories. As such, a mixed-methods research design is found to be most appropriate for this study. This realisation that no one method in isolation will suffice to create knowledge fit for the complex reality of health service delivery is echoed by the Medical Research Council. Their framework for researching interventions has put mixed methods as a research design in the spotlight, showing that the field of health services research has begun to recognise the necessity of using innovative methods such as mixed methods to help understand health care phenomena like renal psychosocial service provision in a more in depth-manner (251).

5.6 Research design

The research comprised two linked studies, which both used mixed-methods: Study I examined different models of renal psychosocial service delivery and Study II focused on the role of the RSW and its ability to reduce patient distress (Figure 7).

To decide on what type of mixed-methods design to use, it was necessary for the author to take a standpoint regarding some key decisions. These included the level of interaction, the timing, relative importance and procedure of mixture of each method in a study (226). Study I used a sequential explanatory design, run in two distinctly separate phases. The quantitative methods occurred first; then qualitative methods followed to help gain a deeper understanding of the results of the comparison of patient's distress levels and psychosocial issues across units undertaken in the quantitative phase (226). As such, the design was interactive, with methods mixed during data collection. Although the use of quantitative and qualitative methods was pre-determined and planned at the start of the research process, making the design fixed (226), the design also contained emergent aspects, as the details of the data collection in the qualitative phase emerged after interpretation of the quantitative phase. Both strands were perceived equally important to achieve different research objectives.

Study II followed a convergent parallel design (226). Quantitative and qualitative data were collected simultaneously with equal priority. Some strands were integrated during data analysis, whilst the data from the focus group were integrated during the interpretation of the results. Through this process of triangulation both quantitative and qualitative methods were used to achieve the same research objective.

Study II is linked to Study I, focusing on the RSW as a component of the wider psychosocial service delivery (Figure 7). If relevant, result emerging in one study informed further investigations in the other. Findings from both studies were interrogated together in the discussion chapter (chapter 9) where appropriate.

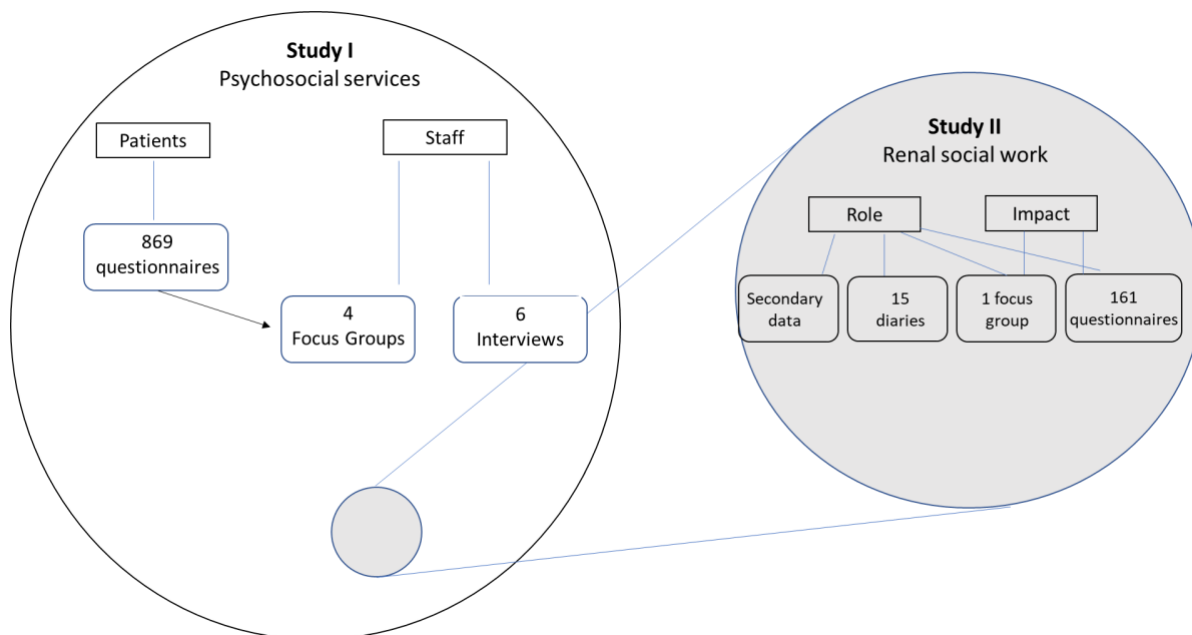


Figure 7. Research design

5.7 Overview of study sites

5.7.1 Study I – Models of psychosocial service provision

Study I focused on investigating different models of psychosocial service provision and initially included five study sites across England, Wales and Scotland. In response to demi-regularities identified after the initial analysis, it was decided to add two additional study sites (unit E and G) (explained further in Chapter 7). A non-probability approach to sampling was taken, with all sites purposively selected based on the outcomes of the mapping of services and location (Chapter 2), to ensure a representation of different models of psychosocial service provision and countries.

To protect the anonymity of the participating renal units, exact characteristics that could lead to identification cannot be provided. Instead, Table 7 provides an overview of indicators of unit size, in addition to the psychosocial provision model. Throughout this thesis, the units have been ordered based on psychosocial staff-to-patient ratio, with unit A having no dedicated psychosocial staff available and unit G having the highest psychosocial staffing levels compared to patient numbers. The staffing ratios were entered into Stata as a numerical value, calculated as one divided by the number of RRT patients per one FTE of staff,

multiplied by 100 (for example, the number entered for 1 FTE RSW per 80 patients would be $(1/80) \times 100 = 1.25$).

Table 7. Study site size indicators

Unit Name	No. ICHD patients	No. RRT patients	No. satellite units	Psychosocial staffing model
Unit A	0-250	501-750	6-8	No dedicated staff
Unit B	251-500	1001-1250	3-5	Psychology
Unit C	251-500	1001-1250	3-5	Counselling and welfare advice
Unit D	251-500	751-1000	3-5	Psychology, counselling & social work
Unit E	251-500	751-1000	3-5	Social work & psychiatry
Unit F	0-250	251-500	0-2	Psychology & social work
Unit G	0-250	0-250	0-2	Psychology & social work

The study population was made up of ICHD patients and members of the MDT within these study sites. The decision was made to focus on ICHD patients only, as opposed to the whole range of RRT patients, because of the homogeneity of this group in terms of time spent in the renal unit, in proximity to renal psychosocial staff. Pre-dialysis patients and transplant patients can also experience significant psychosocial issues (82,252), and renal psychosocial staff are often involved in their care, yet their access to psychosocial services might be different than ICHD patients due to differences in the type, intensity and frequency of care they receive. Whilst this is important to consider and requires further investigation, it was outside of the scope of the current study. In addition, the ICHD patient group is easily accessible, and questionnaires could be handed out to this group in person, which was hoped would increase the response rate.

5.7.2 Study II – Examining renal social work

Study II aimed to examine and evaluate the role of the adult RSW. The psychosocial workforce mapping (Chapter 2) identified 58 adult RSWs, who were all eligible to participate in the study. Emails with invitations to take part and several reminders were sent via the professional network of the RSWs, called the British Association of Social Workers Renal Special Interest Group (BASW-RSIG). RSWs that expressed an interest to participate were provided with an invitation letter and information sheet and were given at least 48 hours to digest the study information and decide whether or not to take part. Eventually, written informed consent to

participate was obtained from 15 RSWs: eight from England, four from Wales and three from Scotland. Six of these social workers belonged to MDTs participating in Study I.

5.8 Overview of research methods and data collection process

To capture the complex and dynamic nature of the service delivery process, a wide range of methods, data sources, and materials was utilised (Figure 8). Both studies used the same methods, albeit in slightly different ways.

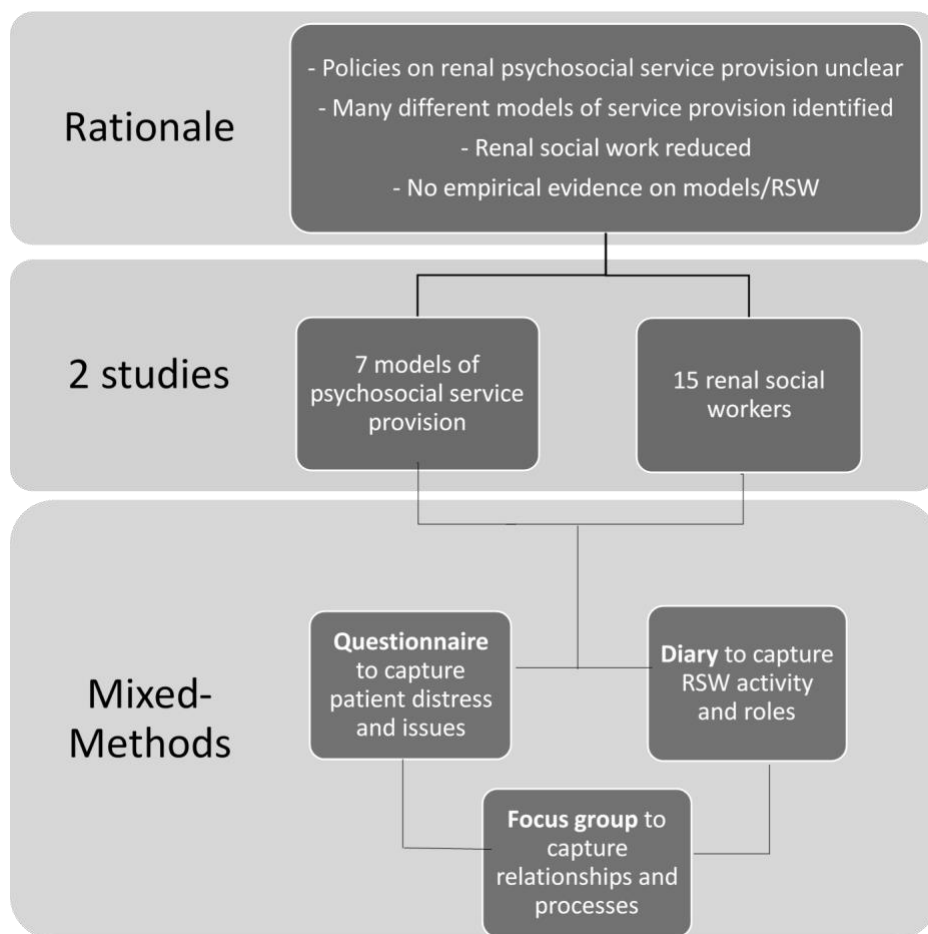


Figure 8. Overview of research methods

5.8.1 Questionnaires

The use of self-administered questionnaires was seen as an appropriate method to gather information on patient distress, patient issues and need for support. This method was chosen because it has the potential to produce a large dataset with quantifiable data that allowed for comparisons between units and events. Practically, it meant that the data could be collected without the author present (253), which was an advantage since this study covered large

geographical areas and several study sites. Moreover, the use of questionnaires allowed for a large sample size more representative of the unit population in a more time-efficient manner than other methods like individual interviews would. However, a disadvantage of this method was that the questionnaire did not offer the respondents the ability to elaborate on answers, thereby capturing more information on why patients chose a certain answer as other qualitative methods would (253).

Three similar questionnaires were devised and used to assess different types of patients at varying instances:

- A needs-assessment questionnaire (Appendix 4) to capture quantitative information on distress, psychosocial issues and self-reported need for services of haemodialysis patients (to form part of the investigation in Study I)
- A pre-intervention questionnaire (Appendix 5) to capture quantitative and qualitative information on distress, psychosocial issues and expectations of psychosocial service users before the start of RSW intervention (Study II).
- A post-intervention questionnaire (Appendix 6) to capture quantitative and qualitative information on distress, psychosocial issues, results and satisfaction of psychosocial service users at the end of RSW intervention (Study II).

The main instrument that made up the base for all three questionnaires was the DT, as primary measure of distress. The DT was paired with the PC, on which patients could select any practical (social), emotional (psychological), spiritual and physical problems they experienced in the last week.

Initially developed by Roth et al. to screen for distress in cancer patients, the DT has been validated for use in the UK renal population (254). It is a simple one-item screening tool, designed to be part of health professionals' daily practice, which asks patients to rate their distress on a scale from zero (nothing) to ten (extreme). For analysis, distress was examined through a binary variable of distress 'caseness', with DT scores of ≥ 4 denoting distress (255).

In addition to the DT, other emotional thermometers on anxiety, depression, anger, pain, burden of disease and health (256) were added to the questionnaire, to allow for more

detailed identification of emotional difficulties. Tick-box data were collected on patient demographics: age, gender, employment situation, living situation, time on dialysis and ethnicity. Patients were also asked whether they had received any help with completing the questionnaire.

For the needs-assessment in all units within Study I, the base questionnaire was extended to include further tick-box questions on whether patients were currently in receipt of psychosocial support and by whom; whether they were on a waitlist for psychosocial support; and if not, whether they would like to receive this support. For the pre-intervention questionnaire, the base questionnaire was expanded with open-ended questions about why the patient required support and what result the patient expected. For the post-intervention questionnaire, the base questionnaire was expanded with open-ended questions about what problems the patient had received support for and what the result was, in addition to tick-box questions about satisfaction with the result, approach and service provided.

5.8.2 Rationale for the use of the DT

Various other tools were identified in the literature and considered for implementation in this study. These included more established tools, such as the Beck's Depression Inventory (BDI) and the Hospital Anxiety Depression Score (HADS). An advantage of these tools is that they are said to be reliable measures, validated for use with renal patients (257). However, it was felt that, with their focus on detecting depression or anxiety, they might not illuminate social issues that can be the target of psychosocial intervention. Health Related Quality of Life instruments would perhaps be able to take such a broader approach to psychosocial difficulties, and the SF-36 and the Kidney Disease Quality of Life scale were considered. The SF-36 is a very thorough questionnaire, but is rather long (36 questions) and therefore has a high non-completion rate, particularly in elderly patients (86)(Alston, 2018). The shorter form SF-12 could have been considered, however, both the SF-36 & SF-12 have an emphasis on the ability to work and carry out physical tasks, which was not considered appropriate considering the age and high levels of disability of most ICHD patients. Similarly, the KDQOL scale was found to be too long and emphasised too much on limitations due to kidney disease that could not necessarily be resolved through psychosocial intervention.

Studies using the DT in renal care are limited, but a meta-analysis of studies in oncology patients found a good balance between pooled sensitivity (0.81, 95% Confidence Interval (CI): 0.79–0.82) and pooled specificity (0.72, 95 % CI: 0.71–0.72) at the cut-off score of 4 when comparing the DT to other diagnostic tools, such as the Hospital Anxiety and Depression Scale and Beck’s Depression Inventory (258). For the current study, this is less relevant since the DT was not used to identify patients with diagnosable mood disorders, but to determine the prevalence of distress as an unpleasant emotional state and allow for comparisons across units.

5.8.3 Data collection

For the need-assessment in Study I sites, all ICHD patients over 18 and with capacity were invited to take part in the study. Since most patients have a 3-day dialysis schedule of either Monday-Wednesday-Friday or Tuesday-Thursday-Saturday, data collection for the needs-assessment was spread over two days per renal unit. Data were collected in the first unit in March 2018 and in the last unit in March 2019. A week before the distribution of questionnaires, renal nurses provided all patients with an information sheet. At the day of data collection, the research was explained to the patients again and all patients willing to participate were given a questionnaire. The author completed the data collection process in the main units and five of the satellite units. In the other satellite units, the questionnaires were distributed by the nurses. Patients were encouraged to complete the questionnaire in the unit, but a small number of patients preferred to take the questionnaire home. These patients were given the opportunity to return the questionnaire at a later time through post, using a pre-stamped return envelope. Only one patient took up this option. Consent was assumed upon completion of the questionnaire. Patients who were unable to read English and did not have anybody available to translate were excluded from the study. Many patients asked for assistance with completion of the questionnaire because they had a fistula restricting their arm movements or had forgotten their reading glasses. The author helped by reading out the questions and answer options and writing down the answers. Patients were in no way coerced, prompted or asked to provide further details and were told that they did not have to share any information they did not feel comfortable with. Most patients appeared more than happy to discuss issues and some thanked the author for offering a listening ear. Field notes of comments were taken with permission. In the main unit of unit C,

questionnaires were initially distributed by nursing staff, who had limited time to assist patients. The response rate was much lower than in units where the author was present to help patients with completion of the questionnaire. It was therefore decided to repeat the data collection in this unit; the response rate increased from 29% to 76% as a result.

To determine the association between RSW involvement and patient outcomes as part of Study II, newly referred patients who were over 18 and had capacity to provide consent were invited to take part in the study. Each RSW was asked to recruit a maximum of 30 new patients on a consecutive referral basis. All patients were sent or given an invitation letter and information sheet by the RSW, who also completed the process of obtaining informed consent. The RSW kept a record of newly referred patients (using initials or a research code), their psychosocial issues and whether they took part in the study. The RSW provided the patient with the pre-intervention questionnaire before or during the first appointment. The questionnaire was completed either with or without the RSW. At the end of the intervention, the RSW gave the participant the post-intervention questionnaire and a pre-paid return envelope. The completed post-intervention questionnaire was sent directly to the author by the patient, without the RSW being able to see the answers. To increase response rates, all participants that did not complete the post-intervention questionnaire were sent one reminder and/or re-sent the questionnaire one time. Data collection for the evaluation started in February 2018 and the recruitment phase closed in December 2018. The last post-intervention questionnaire was distributed in June 2019.

5.8.4 Diaries

Diaries were used as a method to gain insight in the activities, roles and relationships of RSWs. Alaszewski (259) defines a diary as *'a document created by an individual who has maintained a regular, personal and contemporaneous record (p.1).'* This method was chosen over other methods such as observation, interviews and document analysis, because it allows for data to be collected from multiple members of staff concurrently, frequently and over a considerable period of time, without the need for the author to be present at the moment of data collection (260). This was particularly important not only with regards to logistics, but also to guarantee the confidentiality and anonymity of service users. Moreover, through diaries, events were recorded in their natural setting as and when they happen, minimising

the delay between the activity taking place and being recorded. Another relevant advantage of using diary data was that it allowed for cross-sectional comparisons across different members of staff, in addition to studying the processes between the individuals and their teams.

There are some limitations of the diary method that can create doubts about whether the records are complete, affecting the reliability and validity of the data (260). Although the diary method has the potential to be a rich source of information, it is plagued by a lack of control of the researcher. A researcher is dependent on the diarist for accuracy of recording and in some circumstances, there may be incentives for the participant not to record accurate information (259). It is important that diarists are committed and dedicated to their participation so that the risk of respondents constructing the diary retrospectively, providing partial information or dropping out completely is minimised.

Alaszewski's definition of diaries can be used to characterise the structured, electronic diary that was used in this study (259):

- A record: The entries into the document included all activities that RSWs undertook during the data-collection period. The record took the form of a time-structured written document. RSWs could choose from pre-determined categories of activities to select the activity that they engaged in and were then asked to record the time spent on this activity. Dialogue and co-production of the study materials had taken place continually for six months prior to the study starting with most RSWs already informed and engaged with the study claim. During this time, the template of the diary was designed by the author in collaboration with RSWs, who were asked to provide a list of their main activities. The categories in the diary were selected from this list, including the option 'other' to allow for activities to be recorded that did not fall within any of the categories. In addition, a column for comments was added in which the RSWs could provide more detail into their activities. As such, the diary method allowed for the collection of both quantitative and qualitative data. The diary was piloted by four RSWs before it was used in the data collection phase.
- Regularity: The diary was organised around a sequence of entries of all daily activities over a period of four months during which the RSWs kept the diary.

- Personal: The entries were made by RSWs who were recruited into the study. The RSWs sent the diary to the author every two weeks.
- Contemporaneous: The RSWs were instructed to make entries into the document as close to the time of when the activities occurred as possible.

The diary method is commonly used alongside other methods (261). Diaries are particularly useful to open areas of investigation and to identify patterns of issues that may need to be explored later in greater detail with more intrusive techniques (260). This fits with the principles of critical realism and will be applied in the current study: the outcomes of initial analysis of the diary data will be used to guide the RSW focus group.

5.8.5 Focus groups

Focus groups were selected as the most suitable method to elicit rich data by exploring staff members' experiences in relation to key findings from the questionnaires and diaries. This allowed the initial data to be placed into a robust real-world context and to gain further insight into the roles, processes and relationships that shape renal psychosocial services. The focus groups took place with members of the MDT (Study I) or RSWs (Study II). The MDT focus groups were organised by local Principal Investigators, who were instructed by the author to invite all members of the psychosocial team (where available) and at least one dialysis nurse and a consultant. The principal investigators approached the MDT members, booked a meeting room and sent participant information sheets to those who agreed to participate. Written consent was obtained by the author from all participants prior to the start of the discussion. The focus groups had a maximum of eight participants. All discussions were recorded using an encrypted voice recorder, transcribed verbatim and deleted after transcription. Focus groups were chosen over individual interviews, since it was the element of group interaction – which emerges during the group discussions – that was of specific interest for this study. A limitation of focus groups is the considerable effort it takes to organise the discussion, especially in this study, where bringing together several members of renal staff at the same time requires more logistical work than individual interviews would do. Indeed, in unit E, no nurses were able to attend the focus group, due to time constraints. Another limitation of focus groups is the possibility that group dynamics obscure some of the more controversial perspectives and that not all opinions are heard if there are dominant

characters in the group (262). Particularly during the moderation of the focus groups with MDTs, the author was aware of these limitations and the questions were designed in such a way that they could be directed at specific members of staff. Interestingly, restrictions put in place to stop the spread of COVID-19 meant that some focus groups had to be replaced by individual telephone interviews, which possibly allowed staff to speak more freely about the service provision of colleagues. The original ethical approval already covered the use of group or individual interviews.

5.9 Analytical considerations

To increase readability of this thesis, the specific processes of quantitative and qualitative data analysis will be discussed along with the findings across Chapters Six, Seven and Eight. This section will explain how statistics were employed in this study, since the conventional interpretation of statistics, applying an Humean perspective on causality, does not fit with critical realism.

Demi-regularities were identified in the first, quantitative phase of the study using statistical analysis in Stata, with logistic regression analysis used as the main statistical tool. The third research question requires some measure of comparative prevalence to be able to determine differences between the varying study sites, in addition to a measure discounting that the likelihood that any differences found are due only to chance. This type of question calls for the use of statistical analysis (263). Regression claims to be a causally-oriented technique that aims to explain the variation in a dependent variable in terms of a set of supposedly causally-related independent variables (264). From a critical realist perspective, there are some limitations to this approach, since it remains in the empirical domain without attempting to discover underlying mechanisms. Moreover, the procedure assumes that systems are closed, variables are not dependent on each other and causality is linear. This does not fit with the open, interconnected and non-linear systems under study in critical realism. Regression analysis further assumes that variables that have not been included, possibly because they are unknown or impossible to measure, have only a small and essentially random effect. It might well be, however, that these effects are large (264). In recognition of these limitations, a rethinking was required of the purpose of statistical analysis in this study. As said, it is used to identify patterns, or demi-regularities, within the data. Regression is a very valuable

method to this end; it validates possible explanations by confirming or falsifying them (264). As such, in this study, statistics functioned as a form of evidence for an explanation, rather than as an explanation in itself (263).

To add further evidence for possible explanations for differences in outcomes found, this study also used qualitative explorations. With regards to analysing qualitative data, an issue that is often discussed is the danger of forcing data to fit with preconceived hypotheses (265). The author was aware that at the start of the study, they had very little knowledge about social work and were sceptical about the necessity of RSW, perhaps influenced by comments from others in the renal field or by negative public perceptions discussed in chapter 3. In an attempt to reduce any bias due to this preconception and in awareness of some of the limitations of the diary method discussed earlier, RSWs were actively involved in checking and confirming the results as they emerged through follow-up telephone calls or email contact. This process, called member checking, is seen as an appropriate way to increase validity and reliability of a study (266).

Qualitative methods were used to answer questions focused on discovering the who, what and where of psychosocial service delivery. Therefore, qualitative analysis focused mainly on creating a qualitative description (267), taking patient and staff comments at face value. The data were organised and presented based on information that was manifest, which allowed the author to stay close to the data (268). Descriptions of patient experiences and processes of psychosocial care were compared within themes and across units. Where possible, analytical frameworks were grounded in data collected through quantitative explorations. The author shared the results of the coding process and analysis with their supervisor, who had been involved in administration of questionnaires and was also present at focus groups. Through discussions with this supervisor, the interpretation was confirmed, agreed and verified.

5.10 Ethical considerations

Full ethical approval was obtained from the University of Salford and NHS Research Ethical Service, Health Research Authority (Appendices 7 & 8). In addition, all Research and

Development offices from the participating Trusts confirmed their capability and capacity to host the research.

5.10.1 Anonymity and confidentiality

The research involved patients in HD units, psychosocial service users and psychosocial staff in study sites. One of the main ethical issues was anonymity and confidentiality, as patients may have felt reluctant to provide information about their personal situation and their views on the psychosocial services if they were identifiable. Similarly, staff might not want to share any sensitive information about experiences of working with other staff or higher management if their identities were not protected. The issue of anonymity and confidentiality was managed through routine coding of surveys and interview transcripts. In addition, assurances were given to patients that any information given regarding staff would not be reported back to staff without anonymisation and the removal of any clues that might lead to the identity of the patient being uncovered. However, patients and staff were made aware that if any danger to others or self was highlighted, the author had a duty of care to report it through the appropriate channels.

5.10.2 Informed consent

Before the data collection process started, the psychosocial staff in the study sites and RSWs were given an information pack, explaining the purpose of the study. Staff could decide whether they would like to participate. In addition, staff were given an information sheet and provided with the opportunity to ask questions to the author throughout the duration of the study. Prior to the focus group, written informed consent was obtained. Patients were provided with an information sheet at least 24 hours before they were presented the questionnaire. Informed consent was assumed upon completion and return of the questionnaire. It was made explicit to patients that they could withdraw from the study at any time.

5.10.3 Risk and burden of participation

A further ethical issue that was considered was the risk and burden of participation. There was the potential that patients would find participation in the study through the completion of the questionnaire burdensome or upsetting. A short questionnaire was selected to reduce

the risk of overburdening the patients. Participants were reminded that they would only have to share information if they felt comfortable to do so. Participants that expressed feeling distressed and wanting psychosocial support were advised to discuss their feelings with the nurses, or were given a telephone number of the local KCUK advocate or counselling helpline. Some patients preferred to give the author consent to approach the nurse for a referral on their behalf. In unit A, where no psychosocial support was available, a leaflet of the KCUK telephone counselling and support service was added as a final page to all questionnaires. In unit D, the psychosocial team had left leaflets of their service in the waiting area, which were distributed if patients expressed a need for referral.

For RSWs, the main issue regarding burden of participation was that of time they would invest in the study. The study was designed with a view that RSWs could embed the research activities in their standard daily practice and continue to do so after the study was complete. Some RSWs were included in the design phase to make sure that the research activities were as relevant and efficient as possible.

5.10.4 Recruitment of participants

The process of recruitment of RSW service users had a powerful impact on the extent to which this research study was able to evaluate services. Access to these patients had to be sought through the RSWs to ensure anonymity and confidentiality. This meant that for the pre- and post-intervention questionnaires, the social workers were responsible for recruitment of the patients, including obtaining informed consent and distribution of the questionnaires. For this reason, the level of commitment and motivation of the social workers was of vital importance for this study. Also, this brought with it several risks regarding the reliability of the data. Although instructed to attempt to recruit each new patient referred to the service, the RSW was in a position to exclude patients, without the author knowing. Moreover, good administrative skills were required, to ensure that the research codes on the pre – and post-intervention questionnaires and the participant list all corresponded. These risks were mitigated by the author through close communication with the RSWs throughout the research project to ensure that they were kept well informed with a clear understanding of what was required of them. RSWs were involved from the early stages of the research to

make them aware of the need for this research and to build engagement and a sense of ownership.

5.10.5 Security of data

All electronic data was stored on the University's secure F-drive, only accessible via a password protected computer. All hard paper copies of data, including questionnaires and consent forms, were stored in a locked filing cabinet in a locked room, accessed only by the author. An encrypted voice recorder was used to protect the anonymity of the participants in the case of loss of the device.

5.11 Chapter summary and conclusion

This chapter presented the philosophical, theoretical and conceptual underpinnings of this thesis. Philosophically, the ideas of critical realism will be applied to investigate renal psychosocial services. A much cited summary of critical realism's fundamental traits states that it '*claims to be able to combine and reconcile ontological realism, epistemological relativism and judgmental rationality*' (269). In this thesis, ontological realism implies that there exists a reality of psychosocial service provision which is stratified, differentiated, structured and changing. Epistemological relativism tells us that our knowledge about these services is fallible but, as judgmental rationality suggests, there are some theoretical and methodological tools we can use in order to discriminate among theories regarding their ability to inform us about the external reality (223). A psychosocial service will be treated as an open system that is made up of diverse agents and elements that interact and connect in a complex way. The services have the ability to change and adapt, based on changes either within the system or within the context they operate in. The measurable element on which empirical data will be gathered, is distress. Distress in this study is defined as an unpleasant emotional state, which extends along a continuum of different levels of severity. Distress will be measured by questionnaires, whereas the relationships and processes within the system of psychosocial (and particularly social work) service delivery will be explored using focus groups and interviews.

The data collection process created an overwhelming amount of data, some of which has been presented in the following chapters to answer the study aims and objectives. Data not

presented in these chapters will be explored for future publications and project reports for KCUK. The next chapters present the findings in three main themes. Chapter Six focuses on distress, exploring the concept and prevalence of distress in a context of service delivery in ICHD patients; Chapter Seven is engaged with different models of psychosocial care, comparing and contrasting outcomes and processes of psychosocial care across the seven study sites; Chapter Eight presents an in—depth exploration of the RSW role.

Chapter 6: Distress of in-centre haemodialysis patients

6.1 Introduction

This chapter presents the first of three themes that were examined within this study of UK psychosocial services – distress. First, it provides insight into the prevalence of distress and patient reported need for support, using quantitative data obtained through a psychosocial needs-assessment across the main and satellite units of five study sites. Then, qualitative data from field notes are used to explore the meaning of distress in the ICHD population, contributing to the conceptual debate about distress. Findings highlight the importance of adapting a biopsychosocial approach to distress, through the prevalence and distribution of patients' psychosocial issues and their relationship with distress levels. Various systems through which services are provided that can both cause and relieve distress are explored, illustrating a wide variety of issues that the DT is able to extract from patients. Whilst psychosocial issues of ICHD patients have been discussed by other researchers (Chapter 2), the findings presented here extend understanding and provide novel insight into the usefulness and practical implications of capturing distress for the delivery of renal psychosocial services. They also provide a basis for further exploration and discussion from a unique health systems perspective in the chapters to follow.

6.2 Data analysis methods

With regards to quantitative data, the following data analysis methods were used to obtain the results presented in the sections below:

Simple descriptive techniques, including frequency tables and crosstabulations, identified the prevalence and proportion of distress across separate demographic variables and the number and proportion of psychosocial issues. 95% confidence intervals (CIs) were calculated to define the likely range of values which contains the true proportion found in the whole ICHD population.

As an initial exploration of the data, and to see how separate demographic variables contribute to the prevalence of distress, regardless of psychosocial staffing ratios and other variables, several univariable logistic regression analyses were employed. This method was

also used to explore the association between perceived need for support and patient demographics.

The univariable analyses were then followed by multivariate logistic regression analyses. Firstly, to investigate the relationship between psychosocial staffing ratios, patient demographics and distress and secondly, to explore whether certain problem domains could serve as a predictor of distress.

Finally, Pearson's correlation test and a t-test were utilised to explore whether there is a correlation between patient distress levels and number of psychosocial issues and reported need for support.

The qualitative data in this chapter consisted of field notes of comments that patients gave as they completed the questionnaire and have been treated as rich descriptions and elaborations on what could have been simple yes/no answers. Qualitative data are presented as quotes with corresponding codes to identify sex (F or M), unit (A-F) and participant research number, for example M-B50. It is important to consider that patients were not asked to provide this extra data and that whilst many felt a need to clarify their answers, many others did not. This had implications for the analysis and interpretation of this data. For example, nobody was asked to share their experience regarding Personal Independence Payments (PIP) specifically, yet one patient might have decided to air their frustration about the process of applying for PIP whereas another patient who also experienced this problem might have simply answered 'yes' to the question about whether they experienced issues with finances of benefits in the PC. Because of this, it is not possible to make any statements about exact group sizes or proportion of patients experiencing distress due to a certain cause, outside of those recorded quantitatively with the PC.

A combination of content analysis and thematic analysis techniques (270–272) was used to elicit information that would allow a specific exploration into the concept of distress (section 6.3.2) and experiences of service provision (section 6.3.6). For the analysis of data related to the meaning of distress, data were coded in an analytical framework of theoretical categories (271) based on the conceptual literature of distress discussed in section 2.6.1. This included

the distinctions between physical or psychosocial, transient or permanent, and common or disabling distress. After initial analysis, a final feature of distress was added, namely whether it was disease-related or general. To explore the delivery of services in relation to this distress, a thematic framework, grounded from questionnaire data, was applied to field notes related to service provision. Using content analysis, patient responses to the open question about who was currently supporting them were systematically categorised. The information used for content analysis was only the (professional) title of the person who offered support, for example 'daughter', 'psychologist' or 'social worker'. Three categories were created which reflected systems through which patients were supported: the patient's social circle, (community) social services, and the (mental) healthcare system, which included the renal unit. Using thematic analysis, field notes of wider comments related to psychosocial service provision were coded to any of these systems, to illuminate how patients found support within any of these areas. As the coding process progressed, it became clear that the support (or lack thereof) and the organisation of the services delivered within these systems, could also contribute to patient distress. Therefore, two subthemes were created in the data-driven framework (Appendix 9), so that the final analysis allowed an exploration of how service provision could serve as a causal mechanism to relieve or create distress across three different systems.

6.3 Results

6.3.1 Data and Sample

The findings have been derived from data collected as part of the cross-sectional psychosocial needs-assessment for Study I across five main units and their 18 satellite units. Details of this method have been described in chapter 5 (Methodology). There were 1617 patients on ICHD in the participating units. Of these, 707 returned the questionnaire, resulting in an overall response rate of 43.7%. The response rates were higher in the main units (ranging from 49.0% to 82.0%), where the author was present to administer the questionnaire face-to-face if patients were unable to complete the questionnaire themselves.

From the total sample (n=707), 36 respondents did not complete the DT and 7 patients chose not to complete the PC. In addition, some patients did not report their demographic information, which led to varying numbers of missing data. Instead of using listwise deletion,

which would have resulted in the loss of important information on some analyses, pairwise deletion was used to maximise the available data on an analysis by analysis basis. The majority of respondents were male, belonged to the white ethnic group and were aged over 70 (Table 8). Whilst the distribution of gender in the sample was similar to that in the general ICHD population (61.1% male), the sample underrepresented patients from a non-white background, which made up around 30% in the general ICHD population. The median age of the general ICHD population is 67.4 years (UKRR, 2020). Furthermore, the majority of patients had been on dialysis for six months to three years, lived together with their partner or family and was retired. The number of respondents dialysing in a main unit was equivalent to those receiving treatment at satellite units.

Table 8. Respondent characteristics and proportion per subgroup

Characteristic	N	%
Total	707	100
<i>Unit Type</i>		
Main unit	347	49.08
Satellite unit	360	50.92
<i>Sex</i>		
Male	435	61.53
Female	262	37.06
Missing	10	1.41
<i>Age Category</i>		
18-39	56	7.92
40-49	56	7.92
50-59	140	19.80
60-69	151	21.36
≥70	297	42.01
Missing	7	0.99
<i>Ethnicity</i>		
White	608	86.00
Other	86	12.16
Missing	13	1.84

Characteristic	N	%
<i>Time on Dialysis</i>		
<6 months	106	14.99
6 months to 3 years	267	37.77
3 to 5 years	136	19.24
>5 years	173	24.47
Missing	25	3.54
<i>Living situation</i>		
Living alone	170	24.05
Living together	518	73.27
Missing	19	2.69
<i>Employment situation</i>		
Employed	77	10.89
Unemployed	13	1.84
Unable to work	259	36.63
Retired	340	48.09
Missing	18	2.55

Support with the completion of the questionnaire was provided to 409 (57.9%) patients. Whilst some of these patients completed the questionnaire in under 5 minutes, others elaborated on their answers; the maximum completion time was 45 minutes. Patients' comments during completion of the questionnaire were recorded as field notes. Upon design of the questionnaire, it was not the intention nor the expectation that such a rich data set would emerge through these field notes, yet it provided valuable contextual information. In total, 248 field notes were taken, which have been analysed as qualitative data, to acquire further insight into the concept of distress and the organisation of service provision. The distribution of characteristics of patients who provided comments was similar to that of the general study population, although a higher proportion of field notes came from unit B, where the author also visited the satellite units. The field notes varied from a few words, to half a page worth of text. Box 3 provides examples of field notes taken in unit A.

Box 3. Examples of field notes recorded during the administration of the questionnaire

M-A22: 'There is no support here, only some group therapies. Only a few staff treat you like a human, instead of patient. Doctors all say different things.'

M-A34: 'The main reason for my distress is that I can't work, I am waiting for a transplant so I can get back to work. I am so bored because I'm not working.'

M - A27: 'I'm having issues with my ability to have children. We've been to a fertility clinic. I like to do dialysis at home, but the council says we aren't eligible for a house because we aren't citizens yet. We are willing to pay, we just need a house.'

F- A52: 'I have been on dialysis for 11 years. I was offered some support when I had just started but didn't take it, I just got on with it. I need to know the nurse, I get very anxious if I am touched by a nurse that I don't know. The nurses are good at offering advice, but I think it would good to have some professional support. I had a transplant, but it failed, having no support then was tough mentally.'

M- A12: 'My main reasons for my distress are fears and a lack of information. I have been a kidney patient for 16 years. Last year, I was unwell every month. I kept working, because I thought dialysis would jeopardise my job. Then, I spent 3 weeks on the ICU on a ventilator and had a severe delirium. After it, I couldn't stop thinking about it, I was dreaming about it and I had a lot of fears. I tried to get someone to help me but there was no help. I wrote down 30 pages of experiences, my wife has read it, but I still haven't seen anyone about it.'

6.3.2 Distress is ...

In the context of identifying a need for psychosocial services, this section investigates the concept of distress, as captured by the DT and PC. Distress was often just below the surface; most patients shared their personal experiences and worries without reservation. The question 'how much distress have you experienced in the past week?' was found adequate to prompt patients to think about how they were feeling. Patients only had to respond with 'yes' or 'no' to be able to complete the PC which allowed them to indicate that they had an issue without having to provide any detailed information, yet many did. This section combines quantitative data on the distress (DT), anxiety (AT), depression (DepT) and anger thermometers (AngT), alongside qualitative information, guided by and examining theories surrounding the conceptualisation of distress described in chapter 5. Four themes around opposing characteristics of distress emerged; physical or psychosocial, transient or permanent, 'normal' or disabling, disease-related or general, which illustrated how distress took on many different forms and varied in size:

... physical or psychosocial

The NCCN describes distress as a 'multifactorial unpleasant emotional state, relating to ... discomfort' (NCCN, 2018, p.2). Firstly, it was investigated whether their tool, the DT, captures this 'emotional discomfort' by calculating the Pearson's correlation coefficients for the DT and the other emotional thermometers. The DT and the AT were found to be strongly correlated $r(651) = .72, p < .001$ and so were the DT and the DepT: $r(650) = .69, p < .001$. The DT and the AngT were found to be moderately correlated, $r(643) = .51, p < .001$. This showed that there was an underlying (unobservable) variable reflected in the empirical findings of the thermometers, indicating that the DT indeed captures 'emotional discomfort', encapsulating feelings of depression, anxiety and anger. In line with the principles of critical realism, this demi-regularity was further explored, using qualitative data, to expose a more detailed and complicated story about what distress means to kidney patients.

Of 333 patients with distress, 53 (15.9%) did not report a score of 4 or higher on any of the thermometers for anxiety, depression or anger. The characteristics of this group of patients were similar to that of the overall study population, apart from the age distribution: this type of patient was older (55.8% over 70, as opposed to 43.8% in the general study population)

and less young (5.8% under 50, as opposed to 15.7% in the general study population), with those aged between 50-69 representative of the overall study population. Most of these patients reported moderate as opposed to severe distress scores; of those with moderate distress, 22.4% of patients fell in this group, this was 8.8% of those with severe distress. Especially the difference between those with a DT of 4 and those with a DT 10 is notable, as out of the first group, 36.7% of patients report no issues on the ETs, whereas this is 0% for those in the latter group. This is important to consider when using the DT to determine a cut-off score for a referral for psychosocial services and highlights the importance of exploring the PC for further details about reasons for distress. This exploration revealed that 41.5% of these patients only reported physical issues, all of these patients were over 50. This indicated that for some patients, and particularly some elderly patients, distress was linked to the general experience of bad health and physical discomfort. For example, four women stated how they were distressed, reporting DT scores of 7, 9 and 10, whilst naming either the flu, pneumonia, cellulitis or shortness of breath as reasons for their distress. These women did not report any other psychosocial issues and reported scores between 0 and 2 on the anxiety and depression scales.

Alternatively, the answers of this group of patients could also indicate that distress as a term is more acceptable and carries less stigma than terms such as anxiety and depression, which is why the NCCN chose the term distress (85). This might be particularly relevant for older people, for whom mental illness is often more likely to present with physical rather than emotional symptoms, as they grew up in a time that talking about mental health was much more stigmatised and depression and anxiety were often seen as a sign of weakness (273).

As a proportion of all patients with distress, the number of patients who equated distress with physical wellbeing was small (6.6%). The majority of patients gave responses that indicated they perceived distress as the multifactorial emotional state that the correlation analyses revealed and the DT intended to capture. Patients described how their distress was an amalgamation physical, social and psychological issues. For example, one patient explained how his DT score of 8, due to problems with employment and walking, were linked to his worsening condition of breathlessness. A woman explained how *'everything went down-hill'* (F-A3) after she was no longer able to work:

'I had to retire because of ill health, after they first tried to sack me. I am a single mom and now I have been refused PIP. I feel depressed and I worry about my children and finances. I feel isolated, but I am too tired to go out'. F-A3

Others also explained how their physical issues and need for treatment affected their functioning and psychological wellbeing:

'When I'm poorly, I get very ill. It has destroyed my way of life. I feel useless, frustrated. I can't clean, bake, nothing as fast anymore. Sometimes I think I don't want to do it anymore.' F-A21

'I had a heart attack last year and my transplant failed. Now I can't work, I can't go on holiday, I feel like an alien sometimes. I just get fed up with everything.' M-B7

'I used to do body building and sports, now I'm just a slave to the machine.' M-B17

'Once your kidneys fail, there is no life, it's just the hospital'. F-B60

Many patients shared this frustration or sadness about how their illness and the treatment had negatively impacted their life, talking about how *'one problem is that the dialysis process is so intrusive (F-F46)* or how it had a *'devastating effect' (F-A21)* on their family and daily activities. Whilst some gave insight into psychological issues that were present before treatment, most patients described how the biopsychosocial impact of their disease led them to feel distressed, corresponding to White & Grenyer's conceptual model (described in chapter 5).

... transient or permanent

The second theme identified the distinction between distress as a transient or permanent phenomenon. Many respondents described distress as a transient phenomenon, which would subside as people adjust to their new circumstances (97). They explained how their distress used to be high in the past, but had now reduced:

'I used to be more uptight, but I'm getting over it now. It [dialysis] has changed my whole lifestyle, but it is actually better than expected.' M-A28

'Last year, things were a lot worse. There were so many things in all areas. I was depressed for two months.' M-D80

'A year ago, I was a lot more down, but I've lost a lot of that now.' M-C47

Respondents also reflected on how distress can have a fluctuating nature (97). A man (M-D81) who reported a DT score of 7, identified the passing of his mother as a stressor, stating that the questionnaire captured him at a bad moment and that he was not distressed normally. Other patients explained how generally, their distress levels varied from day to day, or even within the day:

'I feel weak and scared when I am alone. Then, my distress is an 8, but when my wife is with me, I don't feel distressed, maybe a 2.' M-B39

'On most days I feel fine, but on some days, I feel very distressed. I'm just managing financially, but I worry about the future, what if I lose my work. Those financial worries make me feel depressed sometimes.' F-A45

Whilst patients were not asked specifically how they managed to transition from a period of high distress to lower distress, some explained that they *'needed support'* (M-B46) to bring their distress down, explain how the counsellor *'made a hell of a difference'* (M-C4), whereas others stated that they *'just found other things to do'* (M-B95) and *'accepted that dialysis is the thing of the future'* (M-F13).

Other respondents, however, suggested that distress was a more permanent and recurrent theme in their lives. Distress was described as a symptom of an underlying diagnosed psychological disorder, as something that respondents have or have not learnt how to live with. For example, one patient (F-B29), who reported to *'feel ok at the moment'* said that her DT score was high (7), but that she knows how to deal with that level of distress now, explaining how she has been *'diagnosed with anxiety disorder more than 20 years ago'*.

'My main reason for my distress is my depression. I have been on anti-depressants for years.' F-A13

Other patients reported low DT scores, attributing that to using anti-depressants. Similarly, two men talked about how distress appears to be part of them, and that whilst they felt better than usual when completing the questionnaire, high distress periods were always looming:

'My distress is not too bad at the moment. I had a bad year last year and I've had many mental health problems in the past. I get worried and anxious about lots of little things, that is who I am.' M-B8

'I don't feel distressed now. I have just been on holiday for the first time in 19 years, which has lifted my spirit.' M-D5

... *'normal' or disabling*

Qualitative field note data showed that respondents' different views about the normality of their distress warranted caution with the interpretation of the DT scores as a predictor of need for services. Some patients stated that *'they never get distressed'*, yet others saw distress or feelings of sadness as something that is part of life, saying: *'I feel depressed sometimes, but nothing serious'* (M-C4), *'you're not human if you're not distressed'* (M-B95), or *'everybody gets a bit down sometimes'* (M-B43). It was found that a certain distress score could be 'normal' and controllable for one person, but disabling for another, illustrating the highly subjective nature of distress. For example, two women who both had a distress score of 5 stated:

'I'm a bit fed up, but it is nothing drastic.' F -D21

'I'm distressed because there are decisions to make about my treatment and I find it difficult to cope on my own, without any support.' F-E8

This demonstrated that whilst both women reported the same DT score, they displayed a different urgency for support. This links to Horwitz (97), who referred to distress as a normal, or expected response to stressful life events, to argue that these responses do not require an

intervention. The findings further showed that even if distress could be expected, it is not always there, highlighting the deeply personal and construed nature of distress:

[This man used a communication chart] *'My distress is 0. I had a severe stroke, which left me with communication issues, amongst others. But I do not dwell on my problems.'*
M-C16

'My distress is 3. I had a stroke, which has had a bad impact on my health and sight. I am almost blind and live in a nursing home now.' F-A16

'My distress is 3. I am terminally ill, I'm not sure how to best go about it.' M-C39

My distress is 2: I'm waiting to hear from my cardiologist to see if they can do an operation. If not, I will be end-of-life in 6 months. M-B22

... disease-related or general

The last characteristic identified was related to the origin of patients' distress. Some patients clearly stated how their distress was a result of issues directly related to their illness and the treatment. They spoke about their health problems or the intrusiveness of dialysis as the main reason for distress, or expressed anxiety about treatment issues such as problems with vascular access and needling:

'I'm stressed about my fistula. The needling is not going right so each morning it is very stressful to get on [the dialysis machine].' M-B50

'I want to stop dialysis. I just feel ill and tired all the time, I don't feel the benefits anymore.' M-B45

'I am only 46 and I am terminally ill. Dealing with that prognosis is my reason for distress.'
F-D85

As illustrated in previous sections, for others, having ESRD and needing dialysis treatment had impacted on their functioning and wider general social and emotional wellbeing.

'I've had to reduce my working hours to cope with the demands of dialysis. I'm getting a transplant in 6 weeks, but I get anxious when I think about the operation and if I will be able to manage with my reduced income when I have to take sick pay afterwards'. M-B6

'My wife is ill, and I want to be there to support her during her appointments, but I can't because of dialysis, and I don't want to change the schedule. I also can't work. The CAB (Citizens Advice Bureau) 'helped' in the past but filled the forms in wrong so now I am in debt. I worry about this so much at night, that I can't sleep'. M-B25

However, there was also a group of patients that experienced distress as a result of issues that any person could experience regardless of illness, such as the loss of a loved one. In this context, patients particularly reported family-related worries or disputes:

'The issues with my family are causing me distress. My daughter is suicidal and my husband is depressed, but he won't talk to anyone about it. I've been to see the psychologist in the unit about this.' F-D17

'My daughter told me she was abused by my partner. Now she has moved out'. F-C130

'My grandson has mental health issues. I can't stop worrying about him'. F-B53

Some respondents reported that they had received help from renal psychosocial staff in managing this type of issue. For example, a woman reported that she had been to see the renal psychologist to discuss her problems with her son who was suffering from substance abuse issues. A man explained that the social worker had helped him to make funeral arrangements after his wife had passed away.

6.3.3 Prevalence of distress

Overall, a DT score of ≥ 4 was observed in 333 out of 671 respondents, indicating that 49.6% (95% CI: 45.7-53.5) of patients were experiencing some form of distress. Of these, 25.9% (174 cases, 95% CI: 22.7 – 29.4) were identified as having mild-to-moderate distress (DT score 4-6). A DT score of ≥ 7 was observed for 159 cases, indicating that 23.7% of patients (95% CI: 20.5 – 27.1) were experiencing severe distress, possibly indicative of a diagnosable

psychological problem. Findings from univariable logistic regression analyses (Table 9) showed significant associations between distress and gender, age, time on dialysis and employment situation. Specifically, women, those aged under 59, patients on dialysis for less than 3 years and those who were unemployed or considered themselves unable to work, were more likely to be distressed than men, those aged over 70, on dialysis for more than 5 years and retired.

Table 9 Univariable logistic analyses for association between distress and demographic variables

Variable	Distress (DT ≥ 4) % (n)	OR (95% CI)	P-value	Likelihood-Ratio Chi2
Total (n=671)	49.6 (333)			
Unit Type (n= 671)				$\chi^2(1)= 2.28, p = .131$
Main unit	52.48 (180)	1.00	-	
Satellite unit	46.65 (153)	0.79 (0.58-1.07)	.131	
Sex (n=661)				$\chi^2(1)= 5.70, p = .017$
Male	45.93 (192)	1.00	-	
Female	55.56 (135)	1.47 (1.07-2.02)	.017	
Age (n=664)				$\chi^2(4)=31.55, p <.001$
18-39	73.58 (39)	4.23 (2.20-8.14)	<.001	
40-49	66.04 (35)	2.95 (1.59-5.47)	.001	
50-59	55.56 (75)	1.90 (1.25-2.87)	.002	
60-69	48.94 (69)	1.45 (0.97-2.19)	.071	
≥ 70	39.72 (112)	1.00	-	
Ethnicity (n=659)				$\chi^2(1)=1.68, p = .195$
White	48.53 (281)	1.00	-	
Other	56.25 (45)	1.36 (0.85-2.18)	.197	
Time on HD (n=650)				$\chi^2(3)=8.60, p = .035$
<6 months	54.46 (55)	1.77 (1.07-2.91)	.026	
6 months to 3 yrs.	53.97 (136)	1.73 (1.16-2.58)	.007	
3 to 5 yrs.	50.38 (66)	1.50 (0.95-2.38)	.085	
>5 yrs.	40.36 (67)	1.00	-	
Living situation (n=654)				$\chi^2(1)=0.05, p = .822$
Living alone	48.78 (80)	1.00	-	
Living together	49.80 (244)	1.04 (0.73-1.48)	.822	
Employment (n=655)				$\chi^2(3)=29.54, p <.001$
Employed/in Education	47.14 (33)	1.33 (0.79-2.24)	.276	
Unemployed	69.23 (9)	3.37 (1.02-11.16)	.047	
Unable to work	62.00 (155)	2.44 (1.74-3.43)	<.001	
Retired	40.06 (129)	1.00	-	

6.3.4 Psychosocial issues and distress

The problems that patients reported in the week before completion of the questionnaire were captured through the PC (Table 10).

Table 10. Number and proportion of respondents reporting issues on the PC

Issues by domain	N (%)	N (%) ≥1 issue	Issues by domain	N (%)	N (%) ≥1 issue
<i>All problems</i>		632 (90.3%) (7 missing)			
<i>Practical issues</i>		439 (62.7%)	<i>Spiritual issues</i>		83 (11.9%)
Mobility	248 (36.5%)		Facing mortality	45 (6.5%)	
Finance	130 (18.6%)		Loss of purpose	45 (6.5%)	
Bathing/Dressing	120 (17.6%)		Losing faith	11 (1.6%)	
Transport	114 (16.3%)		Relating to God	10 (1.4%)	
Lack of information	85 (12.1 %)				
Treatment decisions	73 (10.4%)		<i>Physical issues</i>		511 (73.0%)
Housing	67 (9.6%)		Fatigue	330 (48.5%)	
Work	58 (8.3%)		Dry/Itchy skin	200 (29.5%)	
Childcare	15 (2.1 %)		Pain	188 (27.8%)	
			Breathing	152 (22.3%)	
<i>Family issues</i>		96 (13.8%)	Eating	138 (20.3%)	
Family health	96 (13.6%)		Tingling	126 (18.6%)	
Dealing w/ child(ren)	48 (6.8%)		Constipation	95 (14.0%)	
Dealing w/ partner	46 (6.5%)		Nausea	95 (14.0%)	
Ability to have child	9 (1.3%)		Nose	95 (14.0%)	
			Diarrhoea	92 (13.5%)	
<i>Emotional issues</i>		469 (70.0%)	Feeling swollen	72 (10.6%)	
Sleep	237 (34.9%)		Urination	66 (9.7%)	
Depression	223 (31.2%)		Indigestion	47 (6.9%)	
Anxiety	176 (25.2%)		Fevers	28 (4.1%)	
Boredom	164 (23.5%)		Mouth sores	27 (4.0%)	
Adjusting to illness	145 (20.8%)				
Feelings of isolation	111 (15.9%)		<i>Cognitive issues</i>		209 (33.3%)
Fears	108 (15.5%)		Forgetfulness	160 (23.4%)	
Appearance	82 (12.0%)		Memory	145 (14.3%)	
Sexual	42 (6.2%)		Poor thinking	73 (10.7%)	
Substance abuse	8 (1.2%)		Confused	47 (6.9%)	

Some physical issues could also be categorised within the practical or emotional domain, falling in the remit of psychosocial care. Those issues, such as ‘mobility’, ‘sleep’ and ‘substance abuse’ have been moved to reflect this. A large majority of patients (90.3%) reported experiencing at least one problem. Whilst the largest number of patients (73.0%) reported issues in the physical domain, a considerable number of patients also reported one or more issues in the emotional and practical domains (70.0% and 62.7% respectively). Fatigue was most commonly reported (48.5%), followed by problems with getting around (36.5%) and sleep (34.9%). Overall, problems in the domain covering spiritual concerns were reported least frequently (11.9%). Specifically, issues regarding relating to God (1.4%), losing faith (1.6%) and childcare (2.1%, in the practical domain) were the least common problems.

A multivariable logistic regression analysis was undertaken to investigate the relationship between type of problem, demographic variables and distress prevalence (Table 11). The regression model found a collective significant effect: LR χ^2 (20) = 226.04, $p < .001$. Specifically, the problem domain was found to significantly predict distress, with patients experiencing practical, familial or emotional problems more likely to experience distress than those who did not. In addition, patients who were on dialysis for less than 3 years were found to be more likely to be distressed than those on dialysis for more than 5 years.

Table 11 Multivariable regression model for predictors of distress including problem domains

	Predictor	B (se)	OR [95% CI]	p
<i>Problem domain</i>	Practical	1.063 (0.218)	2.992 [1.951,4.588]	<.001
	Family	0.644 (0.201)	1.764 [1.190,2.617]	.005
	Emotional	1.456 (0.241)	4.714 [2.937,7.567]	<.001
	Physical	0.219 (0.248)	1.278 [0.787,2.076]	.322
	Spiritual	0.391 (0.332)	1.824 [0.952,3.495]	.070
	Cognitive	0.262 (0.216)	1.314 [0.858,2.012]	.209
<i>Unit Type</i>	Main unit <i>reference</i>			
	Satellite unit	-0.032 (0.202)	0.968 [0.652,1.438]	.873
<i>Sex</i>	Male <i>reference</i>			
	Female	0.229 (0.205)	1.267 [0.848,1.892]	.248
<i>Age Category</i>	18-39	0.383 (0.488)	2.021 [0.777,5.255]	.149
	40-49	0.183 (0.46)	1.390 [0.564,3.427]	.475
	50-59	0.320 (0.372)	1.483 [0.716,3.075]	.289
	60-69	0.005 (0.288)	1.006 [0.572,1.769]	.983
	≥70 <i>reference</i>			
<i>Ethnicity</i>	White <i>reference</i>			
	Other	0.362 (0.362)	1.742 [0.928,3.277]	.096
<i>Time on Dialysis</i>	<6 months	0.560 (0.341)	2.158 [1.167,3.993]	.014
	6 months to 3 years	0.616 (0.251)	1.883 [1.152,3.079]	.012
	3 to 5 years	0.478 (0.297)	1.814 [1.013,3.249]	.049
	>5 years <i>reference</i>			
<i>Living situation</i>	Alone <i>reference</i>			
	Together	-0.064 (0.288)	0.928 [0.594,1.451]	.663
<i>Employment</i>	Employed	-0.289 (0.415)	0.631 [0.280,1.423]	.303
	Unemployed	0.123 (0.759)	1.544 [0.349,6.840]	.528
	Unable to work	0.105 (0.317)	1.113 [0.598,2.073]	.630
	Retired <i>Reference</i>			

6.3.5 Need for support

Overall, 20.5% of respondents stated they would like professional support for their issues, but were not currently receiving any (Table 12). Univariable logistic regression analysis indicated that there were statistically significant associations between perceived unmet need for support and age and employment situation. Patients aged under 69 and those who were employed or unable to work are more likely to report an unmet need for support than those aged over 70 and retired.

Correlation analysis showed that distress levels and number of issues reported were positively correlated $r(642) = .55, p < .001$, with patients who reported more issues also experiencing higher distress levels. An independent samples t-test was run to determine whether there was a difference in distress scores among those who reported a need for services and those who did not. A significant difference in distress levels among the two groups was found ($t(230.887) = -9.739, p < .001$); the average distress score for patients who reported a need for services was 2.6 points higher than those who did not. This indicates that the DT score might be a useful tool to determine a need for psychosocial services. However, in line with the principles of critical realism, it should be remembered that these findings serve as trends, demi-regularities, and that not every person with distress and issues wants psychosocial support.

A deeper exploration, also using qualitative data, highlighted that a linear causality of 'if A, then B' between issues experienced, distress and need for services was not necessarily expected. Around a third (37.5%) of patients with distress stated that they were already receiving support, from professionals or friends and family. Of those, 17.9% of patients wanted additional support. Of those who were distressed, but not yet receiving support, an overwhelming 81.3% of patients wanted help. In total, out of all distressed patients, around half (50.7%) stated that they would like to receive (more) professional support.

Table 12 Univariable logistic regression analyses of perceived unmet need for support

Variable	% unmet need	OR [95% CI]	p	Likelihood-Ratio Chi2
Total	20.50	-		-
Unit type (n=684)				$\chi^2(1)= 1.22, p = .270$
Main unit	22.19		-	
Satellite unit	18.79	0.81 [0.56-1.18]	.271	
Sex (n=681)				$\chi^2(1)= 0.42, p = .518$
Male	21.03			
Female	18.97	0.88 [0.59-1.30]	.519	
Age Category (n=683)				$\chi^2(4) =29.22, p<.001$
18-39	35.85	4.19 [2.15-8.16]	<.001	
40-49	32.73	3.65 [1.87-7.11]	<.001	
50-59	25.90	2.62 [1.56-4.42]	<.001	
60-69	22.45	2.17 [1.28-3.68]	.004	
≥70	11.76		-	
Ethnicity (n=677)				$\chi^2(1)= 1.07, p= .300$
White	19.76		-	
Other	24.71	1.33 [0.78-2.27]	.291	
Time on Dialysis (n=667)				$\chi^2(3)= 6.16 p=.104$
<6 months	26.92	1.98 [1.09-3.62]	.026	
6 months to 3 yrs	22.43	1.56 [0.94-2.59]	.088	
3 to 5 yrs	17.91	1.17 [0.64-2.16]	.604	
>5 yrs	15.66		-	
Living situation (n=674)				$\chi^2(1)= 1.90, p= .168$
Living alone	24.40		-	
Living together	19.37	0.74 [0.49-1.13]	.163	
Employment (n=676)				$\chi^2(3)= 32.06, p<.001$
Employed/in Education	30.26	3.26 [1.80-5.90]	<.001	
Unemployed	30.77	3.34 [0.98-11.36]	.054	
Unable to work	28.63	3.01 [1.96-4.63]	<.001	
Retired	11.75			

Although this was not something that this thesis set out to explore, qualitative comments from patients pointed towards individual differences in people's response to issues and distress and attitudes towards psychosocial services.

'I don't think talking to a psychologist would help, I've just got so many physical issues, I just have to get on with it.' F-B6

'I have seen the counsellor in the past but that made me more depressed. I like to keep things in the past and just move on.' M-C50

'I was told to see a psychologist, but I don't want to. I'll blank everything out.' M- B3

6.3.6 Distress in the context of service provision

One of the advantages of mixed methods is the ability to use the qualitative data to generate an in-depth contextual account of the relation between distress and service provision, further explaining the quantitative findings. Patients (n=251) who answered 'yes' to the question about whether they received support, were asked to clarify who was helping them. Not all patients answered this question; Table 13 shows the results of the content analysis of 233 answers, illustrating the main sources of support for patients. Several patients reported receiving support from multiple professionals (n=13).

Table 13. Reported sources of support

Type of support	Total N = 246 (%)
Family/friends	99 (40.3)
Social worker	26 (10.6)
Carer	23 (9.3)
Counsellor	19 (7.7)
GP/Consultant	18 (7.3)
Psychologist	17 (6.9)
Council	17 (6.9)
Other	27 (11.0)

Other sources for support included: Citizens Advice Bureau (CAB)(3), occupational therapist (2), physiotherapist (2), patient advocate (2), Auriga (2), housing association (1), welfare advisor (2), nursing home (1), psychiatrist (1), support worker (2), complex care nurse (1), red cross(1), stroke team(1), shelter(1), Age UK coffee meetings(1), district psychiatric nurse (1), Doctor at a day centre for Alzheimer's patients (1), discharge team (2).

Field notes highlighted that patients were not always certain what the job title was of the person supporting them or which organisation they were affiliated to. This was particularly the case for social care support:

'I believe it was a SW who spoke to me, she suggested going to bingo clubs, I don't know where she was from'. F-B63

'When I came out of the hospital everybody came, I don't know who I saw then... What does a SW do?' M-B3

'I am waiting on a walking frame but I'm not sure where this will come from'. F-B74

'I am getting help from a social worker. They rang me up; I don't know who they're with'.

M-F32

It also became clear from an answer of a patient (F-B36) who claimed to receive support from a renal counsellor in a unit that did not employ renal counsellors. Moreover, four patients in unit B stated that they were receiving support from a RSW, who had left six months prior to the data collection period.

'I am seeing the RSW about these problems, but have not heard anything since filling in the forms. I am waiting to hear back from her'. F-B5

'The RSW is helping me, his name is Nigel'. [The RSW was not called Nigel]. M-B32

'I can see the RSW whenever I want. She's helped me a lot in the past'. F-B12

This means that this data about sources for support has to be treated with caution, yet when looking at the data per unit it shows patterns of patient access to support that mostly reflect the psychosocial staffing models (Table 14). Interestingly, no patients in unit F (which employs dedicated renal psychologists) stated that they were receiving psychology support.

Table 14. Sources of psychosocial support per unit

	SW (26)	Couns (19)	Psy (17)	Welfare advice (2)		GP (18)	Carer (23)	Council (17)
Unit A (no staff)	3 (11.5%)	1 (5.3%)	1 (5.9%)	0 (0%)		3 (16.7%)	3 (13.0%)	3 (17.7%)
Unit B (Psychology)	4 (14.4%)	0 (0%)	8 (47.1%)	0 (0%)		7 (38.9%)	10 (43.5%)	9 (52.9%)
Unit C (Couns + Welfare)	1 (3.8%)	14 (73.9%)	1 (5.9%)	2 (100%)		4 (22.2%)	3 (13.0%)	5 (29.4%)
Unit D (SW+Psy+Couns)	8 (30.8%)	3 (15.9%)	7 (41.2%)	0 (0%)		4 (22.2%)	6 (26.1%)	0 (0%)
Unit F (SW+Psy)	10 (38.5%)	1 (5.3%)	0 (0%)	0 (0%)		0 (0%)	1 (4.4%)	0 (0%)

In line with critical realisms search for causal mechanisms, field notes were explored to identify sources of alleviation of distress within patients’ environments, adapting a person-in-context perspective often used by social workers. Based on the above data, thematic analysis created three themes, reflecting systems of origin of support (Table 15). Support from family or friends was classed as ‘social support system’, support services related to social care (including benefits and social care support offered by the council, RSWs, welfare advisors, or charities) was classed as ‘community and social services’; support from psychologists, counsellors, GPs and other services delivered in the renal unit or hospital (including transport) were classed as ‘(mental) healthcare system’. During the coding process, it became clear that the support, or a perceived lack or inadequacy of services provided, within these systems could also give rise to distress. In total, 102 patients left comments related to the support, or lack thereof.

Table 15. Distribution of field notes providing information about systems of support per unit

Unit (N, % questionnaires completed with support from author)	System (N)
A (25, 39%)	Social support: 8
	Social care: 17
	(Mental) health: 14
B (37, 22%)	Social support: 13
	Social care: 15
	(Mental) health: 33
C (19, 19%)	Social support: 3
	Social care: 6
	(Mental) health: 14
D (12, 16%)	Social support: 2
	Social care: 1
	(Mental) health: 7
F (4, 6%)	Social support: 2
	Social care: 0
	(Mental) health: 3

6.3.6.1 Social support system

It was found that support from one’s social circle could avert distress for some, whilst being a source of distress for others. Here, people could be divided into four different groups: The first consisted of people who reported to feel supported by their family, neighbours or friends, either emotionally or practically. They described having their partner or child as their

carer, having *'good neighbours and good family (M-A2)'* looking after them, or having friends to talk to when they are feeling down. These people reported either no distress, or if they did, stated that they felt like that this social support was enough and they did not require a professional intervention.

Another group described feeling distressed because they did not have this support. They reported feelings of loneliness and described how it was *'difficult to cope alone, without anybody's help'* (F-B18). People in this group did not necessarily lack friends or relatives. In some cases, people felt unsupported by their partners, like this man, who identified his wife's lack of understanding as one of his main reasons for distress:

'My wife doesn't understand. I don't sleep well, so I can be tired, especially after dialysis. But then she tells me to not just sit around and do nothing.' M-G39

'My husband is depressed. He doesn't accept having to be my carer.' F-D17

Similarly, a woman (F-A51) described her husband as *'not always very good, not very nice'*, as she shared that she wet the bed one night but did not want to wake her husband because he *'would be annoyed'*.

A third group consisted of those (mainly elderly women) for whom having to rely on social support was the cause of their distress. This was related to feelings of guilt, or feelings of frustration and anger towards themselves, or because their partner is refusing any outside help.

'I feel useless. I can't clean, bake, I can't do anything as fast anymore. I wake up thinking it is a bad dream, but it isn't. My husband insists on doing the care, he doesn't want anybody else in the house. I am frustrated that I have to rely on people, I want to be able to get around independently, instead of my husband having to drive me everywhere.' F-A21

'My husband and I had a good life before all of this. He doesn't let me get depressed, but I feel guilty, I feel like I am a burden for him.' F-A55

'I feel guilty towards my husband. I can't do the household tasks anymore; he has to shower me and I have to sleep in a separate bed downstairs.' F-F20

'I had a stroke and can't do things around the house anymore. My wife is complaining and moaning that she has to do everything now, but she doesn't want a carer.' M-B8

'My husband does not accept any help in the house. Even a social worker would not be able to make my husband cooperate.' F-C106

6.3.6.2 Community and social services

Almost three quarters (74.7%) of patients of working-age (aged under 60 years old), reported they were unemployed or unable to work, a part of whom would be dependent on the benefits system for their income. As previously seen, many other patients also experienced issues that could require them to engage with the social care system. Some patients described that they were currently in receipt of support through this system and that *'everything was getting sorted'* (F-B74).

'I saw a social worker from the council who helped me get a wheelchair and a mobility scooter.' M-B57

'My husband had a heart attack so now I have a carer and a care manager through the council.' F-C14

'My husband passed away and left a mess behind. He didn't teach me how to do anything, so I had no idea how to pay the bills. I have a support worker from the council now who's been great at helping me.' F-B60

Some patients reported that they *'just'* went online (F-A55), phoned the council, *'knew where to find the social worker'* (F-E14), or asked the nurse for help:

'I applied for my benefits myself, I just asked and googled. I always ask and tell the nurses and it gets resolved. But other people don't.' M-B57

Others reported more difficulties. Patients reported feelings of anger, worry and frustration as a result of interactions with community and social services and that these were a source of distress. Field notes of comments related to this came almost exclusively from patients in units A and B, where no dedicated social care support was available. The findings indicated three main problem areas as patients reported issues with understanding and navigating the system, getting access to support and the adequacy of the support provided.

Some patients described how unclear and difficult the system was to navigate. Patients reported simply feeling too overwhelmed or distressed to act, or appeared to lack the knowledge about which services were available to them and what these services could do.

'My main issues are financial worries and housing, but I don't know if am entitled to any benefits or council housing, because I am not a UK citizen, I'm from Africa.' M-B47

One patient in unit A described how he heard about the blue badge through a friend and had started to inform his fellow patients about council services:

'I phoned the council to ask about the blue badge application and then they told me about this 'Council Allowance', which I had never heard of before. So, I told the people that I share transport with about it now too.' M-A18

Perhaps this was a fellow patient he told:

'Someone told me about this blue badge, I had never heard of it before. I wouldn't know where to get it from. I feel like I don't receive enough information.' M-A32

This woman explained how her husband was able to get them the help they need, reflecting on how it required resilience and a certain level of intelligence:

'My husband is excellent. He went to Age Concern for advice and after that, he went online and just didn't give up. We've not had a lot of help with filling in the forms, but they are really difficult and not well advertised. Anybody who isn't very bright would be terrified, the process is not made easy. I've heard people say they just gave up.' F-A58

Some patients shared their frustration as they had applied for benefits, particularly mentioning issues with PIP assessments or other support from social services, but had to wait a long time for the results or were refused.

'I am still waiting for my PIP appeal. I waited 3 years to get my disabled badge.' M-A7

'I am worried I may not get a disabled badge, but because I can't walk it would mean I wouldn't be able to go out. I also lost my money because of changes in PIP. I am frustrated, because nobody really understands.' F-A13

'When I call the council for a social worker, I need to make 5 or 6 calls before I get anywhere.' F-B25

'I only get employment support allowance, which is only £500 a month. Everybody else seems to be on PIP, but I got refused, I don't understand why.' F-B55

'I have been assessed 3 times now for social care, but I don't hear anything back. There is no case coordination and I am just constantly busy with all my appointments.' M-C106

One man said that the assessors explained that her PIP request got rejected *'because she could walk the stairs'* (M-A26), whereas a woman (F-B9) got told she was not eligible because she had received an inheritance. A man from unit A described the negative consequences of him being refused benefits, with financial problems impacting on his ability to access healthcare, showing how a problem in one system can spill over to cause issues in another. He also showed the need of support with completion of the forms in order for the application to be accepted:

'I was refused for PIP, it got knocked back twice. Then I couldn't afford travel to the hospital, so I missed many appointments a couple years ago. I had to visit the foodbank. There was someone there who helped me with the PIP forms, so my request was finally successful.' M-A69

The need for help to complete forms that he described was reported by other patients, who explained how they were *'unable to negotiate the welfare system, because they were not computer literate'* (M-B67).

'The forms are really hard to fill in'. F-B9

'I tried to get benefits, but it was getting complicated, so I left it'. M-B2

Some had not been successful in their claims until they received welfare advice, although others also stated they were refused help from professionals such as the CAB or a social worker. Another respondent from unit A had also offered his fellow patients advice. He felt that those patients who needed help the most were not able to access it, because the system was too complex to navigate and discouraged people to apply:

'They [DWP] just refuse people, hoping that people give up and don't go for appeal. It is really down to the individual. The weakest ones, those who are not very intelligent, they need it the most but are unable to get it. There are people in this ward that need help from the state, but are being punished. "There is no money", they say.' M-A59

Other patients were dissatisfied with social services, stating that *'local resources were not useful'* (F-A39), the (LA) social worker *'doesn't do much'* (F-A40), or *'said she would get back to me, but never did'* (M-B6). Some were distressed because the support provided was not adequate or had reduced over time:

'Finances are always a worry when you're on benefits.' M-B79.

'I used to have a carer, but they told me I have to pay for it myself now, so I've stopped them coming.' M-C42.

This woman reflected on how the strict eligibility criteria for social services input affected her:

'Social services were a let-down. You've got to be in a crisis situation before you get help and what you get isn't always good. I've organised my own care package now and I pay

for it myself. I can afford to pay, but if I need any more then I can't. I used to have some aids coming through the council, but now, because of the cuts, they don't provide anything.' F-B40

These men were worried or frustrated about the fairness and appropriateness of the system:

'I'm in the middle of a care assessment, I have got carers now, but I am anxious about what will happen care wise and with my finances. They are assessing my finances and determining if I can afford to pay for things myself. I have been told that some things they don't take into consideration. For example, I have an electric wheelchair that needs charging overnight, but someone told me it won't be included in my expected energy costs.' M-B42

'Because of universal credit I was without money for 6 weeks. They call me in at the jobcentre, but a lot of the time I'm not well enough to come in. If you're not in, they cut your benefits.' M-B45

6.3.6.3 *The (mental) healthcare system*

The (mental) healthcare system, and particularly the renal unit, was another structural configuration that influenced how well people could live with their disease in a distress-free manner. For a group of patients, the renal unit enabled them to cope with their illness. These patients describe how they *'really like'* the unit, that *'staff are brilliant'*, and that they feel well supported. They explained how the unit serves as a social space, thus overlapping with the social support system, with some people saying how going to dialysis helps them to overcome loneliness and build new friendships. One patient in unit B (M-B56) described how he used to see his unit in that way, when trips used to be organised for the patients and when they would have *'cultural days'*, during which people would make and bring food. Now, he said, *'that is all gone, along with many staff. They don't see the patient as a person anymore'*.

He was one of a group of patients for which the way services are provided in the renal unit contributed to feelings of distress. This group of patients provided insight into a variety of reported issues that could be categorised as relating to efficiency or to communication in the

unit or in the wider health care system. Patients across all units, genders and ages described how their distress was caused by staffing issues and frustration around the time that was spent waiting for transport or waiting to be attached to the dialysis machine. This man described his distress as solely caused by these issues:

'I'm only distressed when I come here, because it takes them a long time to put me on dialysis. Then by the time I get off, the transport home is gone, so my main issue is they put me on dialysis late. It takes 8 hours of my day. When I am at home, I'm fine.' M-B89.

'I wanted to do home haemodialysis, but they told me it wasn't possible because of a shortage of staff. HHD would give me more freedom and my husband is a doctor so he can help.' F-A55

Other patients also shared they felt there was not enough staff in the unit and that they regularly have to wait for up to 2 hours before they can start their dialysis or until they are picked up for transport. Patients explained how the consequences of these delays are a cause of distress, showing how an issue with service provision in the health care system can have a knock-on effect in other areas:

'I have a carer, but because of issues with transport I often come home too late and miss her.' F-B10

'My main issue is the time that I have to wait to get on the machine, it is frustrating because my son is mentally ill, and he is at home alone when I am on dialysis.' F-C30

Patients reported feelings of distress caused by issues related to communication and inclusion. Firstly, there were patients who reported that they did not know whether they were on the transplant list or not. There were also patients who were experiencing a wider lack of information or disagreement about certain treatment decisions:

'I am angry at the hospital. I did the whole work-up for a Living Donor Transplant and then all of a sudden, they told me I was too old. The communication was really poor, it made me feel depressed.' M-C16

Other patients stated that they ‘never see the doctor (M-B65)’ or that ‘nobody talks, not the nurses, not the dieticians, nobody takes the time to talk (M-C45)’. One man explained how this had serious consequences for his ability to adhere to his treatment:

‘I had my first dialysis session last week, but they didn’t tell me when to come back so I missed my second session. So, I’d say my main problem is not being told when my appointment is’. M-B49

One patient reported distress since he could not understand non-UK nurses because of a language barrier. This affected his faith in the quality of care he was receiving, with him reporting anxiety due to being worried that the nurses would give him the wrong injection.

Patients did not only experience communication issues within the renal unit, but also within the wider healthcare system. They reported that ‘the doctors all say different things’, or that they feel like ‘nothing gets done, they keep passing me on to someone else, passing things back, there is no coordination (M-D40).

‘The communication between my GP and the hospital is very poor. It is so slow, it takes a long time to get things done’. F-A41

Even in a perfect health care system there may still be people that are dissatisfied, yet these examples of sources of distress illustrate that it is important to consider the impact the way care is delivered can have on the psychosocial wellbeing of patients. The findings indicate that improved efficiency, communication and coordination across services could have a beneficial impact on patient distress.

6.3.7 Psychosocial staffing ratios and distress

To investigate the relationship between psychosocial staffing levels and distress, further regression analysis was undertaken. Three similar multivariable logistic regression models were created, differing only by inclusion of either the total ratio of renal dedicated psychosocial staff, the ratio of RSWs or the ratio of renal psychologists/counsellors¹ (Table

¹ Whilst acknowledging the difference between psychologists and counsellors, it was decided to group these professions together in model 3 so that counselling staff (only present in 2 units) could be taken into account.

16). All models included the demographics unit type, sex, ethnicity, age, living situation, time on dialysis and employment situation as predictors.

The results were as follows:

- Model 1 (including total ratios of psychosocial staff): a collective significant effect was found, Likelihood Ratio (LR) $\chi^2(15)=57.50$, $p < .001$. Specifically, the ratio of total psychosocial staff was found to significantly predict distress, with higher ratios of staff leading to a lower likelihood of distress (β $-.47$, $p = .048$). In addition, those aged under 40, on dialysis for less than 5 years and unable to work were more likely to be distressed than patients who were over 70 years old, retired and on dialysis for more than 5 years, after other variables in the model were controlled for.
- Model 2 (including ratios of social work staff): This model also returned a significant result, predicting distress LR $\chi^2(15)=60.28$, $p < .001$. A significant association was found between social worker ratios and distress, with likelihood of distress reducing as social worker ratios increased (β $-.77$, $p = .011$). Similar to model 1, those aged under 40, on dialysis for less than 5 years and unable to work were again found to be more likely to be distressed than patients who were over 70 years old, retired and on dialysis for more than 5 years.
- Model 3 (including ratios of psychology/counselling staff): Overall, the model significantly predicted distress, LR $\chi^2(15)= 53.56$, $p < .001$, with those under 40 and on dialysis for less than 5 years more likely to be distressed than those aged over 70 and on dialysis for more than 5 years. The ratio of psychology/counselling staff was not found to be a significant predictor (β $-.041$, $p = .937$).

Table 16 Multivariable logistic regression models for predictors of distress including staff ratios and demographic variables

Predictor	Model 1 (all psychosocial staff)			Model 2 (RSW)			Model 3 (Psychology/counselling)		
	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p
Ratio									
Total psycho-social staff	-0.465 (0.24)	0.610 [0.38,0.98]	.048						
Social work				-0.768 (0.30)	0.464 [0.26,0.84]	.011			
Psychology/counselling							-0.041 (0.53)	0.958 [0.34,2.70]	.937
Unit Type <i>ref: Main</i>									
Satellite	-0.246 (0.17)	0.782 [0.56,1.10]	.151	-0.298 (0.17)	0.742 [0.53,1.04]	.087	-0.221 (0.17)	0.802 [0.57,1.12]	.201
Sex <i>ref: Male</i>									
Female	0.330 (0.17)	1.391 [0.99,1.96]	.060	0.340 (0.18)	1.405 [0.99,1.98]	.052	0.322 (0.17)	1.380 [0.98,1.94]	.064
Age Category <i>ref: ≥70</i>									
18-39	1.094 (0.42)	2.986 [1.31,6.80]	.009	1.109 (0.42)	3.032 [1.33,6.92]	.008	1.091 (0.42)	2.977 [1.31,6.77]	.009
40-49	0.575 (0.40)	1.778 [0.81,3.89]	.149	0.591 (0.40)	1.805 [0.82,3.95]	.140	0.614 (0.40)	1.848 [0.85,4.03]	.123
50-59	0.181 (0.31)	1.199 [0.64,2.23]	.556	0.181 (0.32)	1.198 [0.64,2.23]	.570	0.216 (0.32)	1.241 [0.67,2.31]	.494
60-69	0.065 (0.24)	1.067 [0.66,1.72]	.784	0.070 (0.24)	1.073 [0.66,1.72]	.772	0.089 (0.24)	1.093 [0.68,1.76]	.712
Ethnicity <i>ref: White</i>									
Other	0.175 (0.27)	1.191 [0.71,2.01]	.503	0.170 (0.27)	1.185 [0.70,2.00]	.528	0.180 (0.27)	1.198 [0.71,2.03]	.501
Time on HD <i>ref: >5 yrs</i>									
<6 months	0.659 (0.27)	1.932 [1.13,3.29]	.016	0.616 (0.28)	1.852 [1.08,3.17]	.025	0.685 (0.27)	1.984 [1.16,3.38]	.012
6 months to 3 yrs	0.589 (0.22)	1.803 [1.18,2.75]	.007	0.568 (0.22)	1.765 [1.15,2.70]	.009	0.635 (0.22)	1.887 [1.24,2.88]	.003
3 to 5 yrs	0.521 (0.25)	1.684 [1.03,2.75]	.038	0.527 (0.25)	1.693 [1.03,2.77]	.036	0.515 (0.25)	1.673 [1.03,2.73]	.039
Living situation <i>ref: Alone</i>									
Together	0.060 (0.19)	1.062 [0.73,1.55]	.745	0.065 (0.19)	1.067 [0.73,1.56]	.737	0.060 (0.19)	1.062 [0.73,1.55]	.756
Employment <i>ref: Retired</i>									
Employed	-0.269 (0.35)	0.764 [0.38,1.51]	.439	-0.265 (0.35)	0.767 [0.39,1.52]	.448	-0.238 (0.35)	0.788 [0.40,1.55]	.492
Unemployed	0.674 (0.68)	1.962 [0.52,7.41]	.314	0.728 (0.68)	2.070 [0.55,7.86]	.285	0.662 (0.68)	1.939 [0.51,7.32]	.328
Unable to work	0.603 (0.27)	1.827 [1.08,3.10]	.027	0.589 (0.27)	1.802 [1.06,3.06]	.029	0.574 (0.27)	1.775 [1.04,3.02]	.034

6.4 Chapter summary and key findings

This chapter, as the first findings chapter, presented the results of an exploration into ICHD patients' distress. Box 4 summarises the main findings of this chapter: High levels of distress were found. Patients did not unambiguously refer to distress as exactly the same concept, it was found to be physical or psychosocial, transient or permanent, normal or disabling, and disease-related or general. The findings illustrated the wealth of information that a relatively simple screening tool like the DT and PC can extract from patients. Patients listed a wide variety of issues that contributed to their distress, demonstrating the importance of looking at distress as a biopsychosocial concept when determining a need for psychosocial services, instead of just screening for psychological disorders such as depression or anxiety. Adapting a service provision perspective to distress illuminated how for many patients, support systems can give rise to or alleviate distress levels. Qualitative information revealed that patients in units A and B, where no social care support is available, might be experiencing more difficulties with accessing support than in other units. Quantitative data also provided a first indication of an influence of psychosocial staffing levels on the prevalence of distress. Based on this finding, the hypothesis was created that there might be differences in prevalence of distress across the study sites, which have different models of psychosocial service provision. In line with the principles of critical realism described in Chapter 5, this initial finding will be treated as a demi-regularity and the hypothesis as fallible. This has shaped the focus of investigation of the next chapter, which further explores this finding by more in-depth comparative and qualitative inquiries.

Box 4. Summary of findings related to research objective two

Objective two:

To explore distress, psychosocial issues and need for support of ICHD patients

- Distress was found to have different forms and meanings; overall it correlated with feelings of depression and anxiety.
- Around 50% of patients experienced some form of distress; women, those aged under 59, patients on dialysis for less than 3 years and those who were unemployed or considered themselves unable to work, were more likely to be distressed.
- A need for support was reported by 20.5% of patients across all sites.
- Patients who experienced practical, familial or emotional problems were more likely to experience distress.
- Distress was higher amongst those who reported a need for psychosocial services, although not all patients with high distress wanted support.
- Distress could be alleviated or brought about by new or changed interactions within systems of social support, the social care system or the (mental) healthcare.

Chapter 7: Investigating models of psychosocial care

7.1. Introduction

Chapter 7 explores the second theme: models of psychosocial service delivery. It presents a deeper exploration of initial findings from Chapter 6, by examining the following hypothesis: increased ratios of psychosocial staff lead to lower patient distress. Whilst Chapter 6 explored the prevalence of distress and issues in the ICHD population in general, this chapter focuses specifically on the differences in these outcomes between units, using a different, wider sample. The first part of this chapter presents the interrogation of this hypothesis, analysing quantitative survey data of distress, psychosocial issues and reported need for support in ICHD patients across seven study sites. The chapter then progresses with an investigation into the practice and organisation of renal psychosocial care for ICHD patients, using data obtained through staff focus groups and individual interviews. The processes of psychosocial service delivery across the seven units are discussed, illuminating the fluid boundaries of the system and highlighting the important role of clinical staff in psychosocial practice. It will then provide examples of integrated psychosocial support along the renal pathway, before critically examining how the current system of provision of renal psychosocial services – or lack thereof – has formed over time.

7.2 Data analysis methods

The quantitative data analysis methods that were used to analyse the data in this chapter were similar to those used in chapter 6.

Descriptive techniques identified the prevalence of distress and need for services across the seven study sites. Univariable logistic analyses were used to explore associations between distress, reported need for services and study sites. To determine whether the unit where patients received dialysis treatment and their demographics served as predictors of distress, multivariable logistic regression analysis was employed. To repeat the analysis in chapter 6, three similar multivariable logistic regression models were created to investigate the relationship between distress and psychosocial staffing ratios.

The qualitative data in this chapter were analysed to create an understanding of approaches to and processes in renal psychosocial service delivery across the seven study sites. Data from

focus groups and interviews were coded, using organisational categories, or rather topics, to sort the data for further analyses (271). These organisational categories reflected the focus group topics (Appendix 11), which were based on areas of inquiry that were already established prior to data collection, based on investigations described in the first four chapters of this thesis (271). After that, a process of thematic analysis was used to interpret, summarise and reconstruct the data in a way that captured the important concepts within the data set (270). This was done by either further categorising the data, looking for similarities and differences, or by connecting the data, looking for connections between statements and events across and within renal units. The themes, then, represent possible causal mechanisms, or explanations, for the differences in distress and service provision across units.

7.3. Data and Sample

To be able to test the hypothesis posited in chapter 6, two additional renal units were recruited and included as study sites. These sites were purposively selected because of their relatively high psychosocial staff to patient ratios. For this additional phase of data collection, the same psychosocial needs assessment was completed as described in Chapter 6, but now in the main units only. The obtained data were merged with data from main units collected as part of the investigation in chapter 6. In total, 752 patients were on dialysis in the main units across all study sites on the days of data collection. Of these, 509 completed the questionnaire, resulting in an overall response rate of 67.7%. The response rates varied from 49.0% to 82.0% across participating centres.

The characteristics of the participants that contributed to the findings in this chapter were similar to those of participants in Chapter 6. A table detailing the characteristics can be found in Appendix 10. The majority of respondents were male and aged over 70 years old. This distribution of gender is similar to the general ICHD population, which is reported to consist for 61.1% of males, with a median age of 67.4 years (UKRR, 2020). Only units B and D had a black and minority ethnic (BAME) population of a similar size as the overall dialysis population, whilst the other units served predominantly or completely white populations. The majority of patients had been on dialysis for 6 months to three years, lived together with their partner or family and were retired.

Four respondents did not complete the DT, whilst others did not provide information on demographic questions or the PC, leading to varying numbers of missing data. Instead of using listwise deletion, which would have resulted in the loss of important information on some analyses, pairwise deletion was used to maximise the available data on an analysis-by-analysis basis.

Throughout this chapter, the units have been sorted based on their psychosocial staff-to-patient ratios, with unit A having no renal dedicated psychosocial staff available and unit G having the highest ratio of staff available to patients. To remind the reader, Table 17 provides an overview of different psychosocial staff models in each unit.

Table 17. Model of renal dedicated psychosocial service provision per study site

Unit Name	No. of ICHD patients	No. of RRT patients	No. of satellite units	Total psychosocial staff ratio	Psychosocial staffing model
Unit A	0-250	501-750	6-8	-	No dedicated staff
Unit B	251-500	1001-1250	3-5	1: 194	Psychology
Unit C	251-500	1001-1250	3-5	1: 163	Counselling & welfare advice
Unit D	251-500	751-1000	3-5	1: 117	Psychology, counselling & social work
Unit E	251-500	751-1000	3-5	1: 109	Social work & psychiatry
Unit F	0-250	251-500	0-2	1: 65	Psychology & social work
Unit G	0-250	0-250	0-2	1: 45	Psychology & social work

On average, ratios of renal dedicated psychosocial staffing in the study sites were higher than ratios found across the country. The average ratio of psychologists in this study is 1 Full-Time Equivalent (FTE) per 562 patients, compared to an average of 1 FTE per 1392 patients. For RSWs, the average ratio in this study is 1 FTE per 344 patients, compared to 1 FTE per 614 patients across the UK (105). In the units that had RSWs available, ratios (calculated as numerical values) varied from 0.19 to 0.53. The variation in ratios for psychologists/counsellors was less; the ratios varied from 0.14 to 0.32.

The qualitative data used in this chapter to explore processes of psychosocial service delivery were collected through four focus groups with psychosocial and clinical staff in units A, C, D and E, which took place in January 2020. Due to restrictions put in place to limit the spread of Covid-19, the focus groups in unit B, F and G were cancelled and replaced by individual

telephone interviews with one member of clinical staff and one member of psychosocial staff in each unit (Table 18). These interviews took place in April 2020.

Table 18 Characteristics of interview participants

Unit	Type of interview	Staff Interviewed
A	Focus Group	Clinical Director Consultant Lead dialysis nurse Dialysis nurse
B	Individual	Psychologist Welfare advisor
C	Focus Group	Clinical director Consultant Consultant nurse Lead dialysis nurse Counsellor x2 Welfare advisor
D	Focus Group	Manager Consultant Lead dialysis nurse Dialysis nurse Psychologist Counsellor RSW x2 Dietician
E	Focus Group	Clinical director Psychiatrist x2 RSW x2 Chaplain
F	Individual	RSW x2 Dialysis nurse
G	Individual	RSW Dialysis nurse

7.4. Results

7.4.1. Distress prevalence across study sites

A univariable logistic regression analysis was undertaken to explore the prevalence of distress across the main units of the seven study sites. The findings (Table 19) indicated a significant association between distress and study site, with patients in units F and G less likely to be

distressed than patients in unit A, B and C. The overall prevalence (48.9%) was almost the same to that found in chapter 6 (49.6%), it varied from 34.1% to 59.2% across units.

Table 19. Logistic regression analysis for association between distress and unit

Variable	Distress (DT ≥4) % (n)	OR [95% CI]	p	LR Chi2
Total (n=505)	48.9 (247)			
Main unit (n=505)				$\chi^2(6) = 15.05, p = .019$
A	56.3 (36)		-	
B	56.3 (36)	1.00 [0.50-2.01]	1.00	
C	59.2 (58)	1.13 [0.60-2.14]	.712	
D	48.0 (35)	0.72 [0.37-1.41]	.332	
E	43.3 (45)	0.59 [0.32-1.11]	.103	
F	34.1 (15)	0.40 [0.18-0.89]	.025	
G	37.9 (22)	0.48 [0.23-0.98]	.044	

Multivariable logistic regression analysis was used to identify whether the unit in which patients received dialysis still served as a predictor of distress, when accounting for other possible confounding factors. A regression model (Table 20) including renal unit and the variables sex, age, ethnicity, time on dialysis, living situation and employment situation significantly predicted distress (LR $\chi^2(19) = 56.77, p < .001$).

Dialysing in a certain unit was found to be a predictor of distress, with patients in unit E ($\beta = -0.718$) or F ($\beta = -1.083$) having a significantly reduced likelihood of distress compared to patients in unit A. Time on dialysis was also found to be a predictor of distress, with patients being on dialysis for a period of 3 to 5 years significantly more likely to report distress than those on dialysis for more than 5 years.

Table 20. Multivariable logistic regression model for predictors of distress

Predictor	B (se)	OR [95% CI]	p
Constant	0.176 (0.348)		
Renal unit			
A <i>reference</i>			
B	-0.161 (0.387)	0.851 [0.40-1.82]	.676
C	0.176 (0.348)	1.193 [0.60-2.36]	.612
D	-0.411 (0.375)	0.663 [0.32-1.38]	.272
E	-0.718 (0.351)	0.488 [0.25-0.97]	.041
F	-1.083 (0.461)	0.338 [0.14-0.84]	.019
G	-0.678 (0.395)	0.508 [0.23-1.10]	.086
Sex			
Male <i>reference</i>			
Female	0.237 (0.202)	1.268 [0.85-1.89]	.241
Age Category			
18-39	0.782 (0.444)	2.186 [0.92-5.22]	.078
40-49	0.776 (0.439)	2.173 [0.92-5.13]	.077
50-59	0.593 (0.369)	1.809 [0.89-3.73]	.108
60-69	0.164 (0.282)	1.179 [0.68-2.05]	.560
≥70 <i>reference</i>			
Ethnicity			
White <i>reference</i>			
Other	0.0366 (0.388)	1.037 [0.48-2.22]	.925
Time on Dialysis			
<6 months	0.411 (0.309)	1.509 [0.82-2.77]	.183
6 months to 3 years	0.360 (0.249)	1.434 [0.88-2.34]	.149
3 to 5 years	0.606 (0.305)	1.833 [1.01-3.34]	.047
>5 years <i>reference</i>			
Living situation			
Living alone <i>reference</i>			
Living together	-0.321 (0.215)	0.725 [0.48-1.10]	.134
Employment situation			
Employed/in Education	-0.511 (0.394)	0.560 [0.28-1.30]	.194
Unemployed	1.401 (0.769)	4.058 [0.90-18.33]	.069
Unable to work	0.583 (0.311)	1.791 [0.97-3.30]	.061
Retired <i>reference</i>			
N	488		

7.4.2. Distress and psychosocial staffing ratios

To examine whether the differences in distress between units presented in Table 20 were associated with psychosocial staffing ratios, three similar multivariable logistic regression models were created, differing only by inclusion of either the total ratio of renal dedicated psychosocial staff, the ratio of renal social workers or the ratio of renal

psychologists/counsellors (Table 21). All models also included the demographics sex, ethnicity, age, living situation, time on dialysis and employment situation as predictors.

It was found that the results confirmed the hypothesis created in chapter 6:

- Model 1 (including total ratios of psychosocial staff): a collective significant effect was found, $LR \chi^2(14) = 47.68, p < .001$. Specifically, the ratio of total psychosocial staff was found to significantly predict distress, with higher ratios of staff leading to a lower likelihood of distress ($\beta -1.11, p = .01$). In addition, those on dialysis between 3 and 5 years were found to have significantly higher distress than those dialysing for over 5 years.
- Model 2 (including ratios of social work staff): This model also returned a significant result, predicting distress $LR \chi^2(14) = 52.57, p < .001$. A significant association was found between social worker ratios and distress, with likelihood of distress reducing as social worker ratios increased ($\beta -1.86, p = .001$). Again, higher distress was found in those on dialysis for 3 to 5 years, compared to those on dialysis for over 5 years.
- Model 3 (including ratios of psychology/counselling staff): Overall, the model significantly predicted distress, $LR \chi^2(14) = 40.60, p < .001$, but the ratio of psychology/counselling staff was not found to be a significant predictor ($\beta -.30, p = .728$). Time on dialysis (3 to 5 years) was the only significant predictor in the model.

Table 21. Multivariable logistic regression models for predictors of distress

Predictor	Model 1			Model 2			Model 3		
	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p
Constant (N=488)	-0.37 (0.32)			-0.41 (0.29)			-0.76 (0.30)		
Ratios									
Psychosocial (all)	-1.112 (0.43)	0.33 [0.14-0.77]	.01						
Social work				-1.861 (0.55)	0.15 [0.05-0.45]	.001			
Psy/couns							-0.301 (0.35)	0.74 [0.14-4.05]	.728
Sex (Male reference)									
Female	0.176 (0.120)	1.19 [0.81-1.76]	.379	0.199 (0.20)	1.22 [0.83-1.80]	.319	0.192 (0.20)	1.21 [0.82-1.79]	.335
Age Category (≥70 reference)									
18-39	0.759 (0.44)	2.14 [0.91-5.04]	.083	0.787 (0.44)	2.20 [0.93-5.21]	.074	0.700 (0.43)	2.01 [0.86-4.72]	.107
40-49	0.747 (0.43)	2.11 [0.91-4.92]	.084	0.763 (0.43)	2.15 [0.92-5.02]	.078	0.796 (0.43)	2.22 [0.95-5.15]	.064
50-59	0.600 (0.36)	1.83 [0.90-3.72]	.096	0.588 (0.36)	1.80 [0.88-3.67]	.105	0.665 (0.36)	1.95 [0.96-3.95]	.065
60-69	0.186 (0.28)	1.20 [0.70-2.08]	.504	0.191 (0.28)	1.21 [0.70-2.09]	.494	0.202 (0.28)	1.22 [0.71-2.10]	.464
Ethnicity (White reference)									
Other	-0.069 (0.38)	0.94 [0.45-1.96]	.859	-0.051 (0.38)	0.95 [0.45-2.00]	.892	0.004 (0.38)	1.01 [0.48-2.10]	.991
Time on Dialysis (>5 yrs reference)									
<6 mths	0.456 (0.31)	1.58 [0.87-2.87]	.137	0.412 (0.31)	1.51 [0.83-2.75]	.180	0.521 (0.30)	1.68 [0.93-3.05]	.086
6 mths to 3 yrs	0.388 (0.25)	1.47 [0.91-2.39]	.119	0.374 (0.25)	1.45 [0.89-2.36]	.131	0.445 (0.25)	1.56 [0.96-2.52]	.070
>3 to 5 yrs	0.624 (0.30)	1.87 [1.04-3.37]	.037	0.618 (0.30)	1.86 [1.02-3.35]	.041	0.648 (0.30)	1.91 [1.09-3.42]	.029
Living situation (Alone reference)									
Together	-0.267 (0.21)	0.77 [0.51-1.16]	.206	-0.291 (0.21)	0.75 [0.49-1.13]	.167	-0.258 (0.21)	0.77 [0.51-1.16]	.217
Employment (Retired reference)									
Employed	-0.506 (0.39)	0.61 [0.28-1.29]	.190	-0.509 (0.39)	0.61 [0.28-1.29]	.190	-0.450 (0.39)	0.64 [0.30-1.36]	.244
Unemployed	1.248 (0.76)	3.49 [0.79-15.5]	.100	1.323 (0.76)	3.76 [0.84-16.8]	.084	1.227 (0.76)	3.41 [0.77-15.1]	.106
Unable to work	0.520 (0.30)	1.68 [0.93-3.04]	.088	0.534 (0.30)	1.71 [0.94-3.10]	.080	0.492 (0.30)	1.64 [0.90-2.95]	.104

7.4.3. Psychosocial issues across units

The overall percentages of patients experiencing psychosocial issues were reported in the previous chapter (Chapter 6). It was found that similar to the prevalence of distress, large variations existed in the number of reported practical issues and most prevalent emotional issues across units (Table 22). Generally, patients in units A and B reported a higher than average number of psychosocial issues and in unit E, F and G reported a lower than average number. Particularly the prevalence of practical issues varied significantly across units.

Table 22 Percentage of patients reporting psychosocial issues per unit

Unit Name	Mobility	Finances	Bathing/ Dressing	Transport	Lack of information	Treatment decision
Av	37.1	17.1	15.8	15.2	12.7	11.2
Unit A	48.4	21.9	18.8	14.1	28.1	21.9
Unit B	50.8	32.3	32.3	23.8	29.7	23.8
Unit C	34.0	14.4	6.4	15.5	9.3	3.1
Unit D	42.3	20.6	11.3	24.7	8.2	9.6
Unit E	32.0	13.5	11.1	7.7	5.8	3.9
Unit F	23.9	8.7	21.7	15.2	4.4	10.9
Unit G	28.1	8.6	8.8	5.2	3.5	5.2
$\chi^2(6) =$	16.16 $p = .013$	18.41 $p < .01$	26.50 $p < .001$	18.13 $p < .01$	45.91 $p < .001$	34.14 $p < .001$
Unit Name	Housing	Employment	Sleep	Depression	Anxiety	Boredom
Av	9.9	9.1	30.3	24.4	26.0	24.9
Unit A	14.1	21.9	31.3	29.7	34.4	32.8
Unit B	12.7	11.1	43.5	31.8	29.7	38.1
Unit C	11.3	11.3	36.6	32.0	23.7	21.7
Unit D	11.0	9.6	39.4	24.7	24.7	28.8
Unit E	8.7	3.9	27.0	26.0	26.0	15.4
Unit F	6.5	2.2	21.8	13.0	19.6	23.9
Unit G	5.2	3.5	12.7	13.8	24.1	13.8
$\chi^2(6) =$	4.24, $p = .64$	21.9 $p < .001$	25.58 $p = .012$	11.98 $p = .06$	4.20 $p = .64$	18.25 $p < .01$

7.4.4. Need for support across units

Finally, univariable logistic regression was used to investigate the perceived need for support² across the study sites. The analysis indicated that there were differences across units ($\chi^2(6) = 37.80, p < .001$), with patients in units C, D, E, F and G, where support with social care issues

² As detailed in chapter 5, data on perceived need for support was collected through a simple yes/no question.

is available, significantly less likely to report a need for support than patients in unit A and B (Table 23). Of the people that reported a need for support, 75.9% were classed as distressed (DT ≥ 4).

Table 23 Univariable logistic analysis of patients reporting a perceived unmet need for support

Unit	% Unmet need for support (n)	OR [95% CI]	p
Total (n=498)	17.6 (87)		
A Reference	35.5 (22)		
B	35.4 (23)	0.996 [0.48-2.06]	.991
C	12.5 (12)	0.260 [0.12-0.58]	.001
D	15.1 (11)	0.370 [0.17-0.83]	.016
E	8.7 (9)	0.172 [0.073-0.41]	<.001
F	13.9 (6)	0.295 [0.11-0.81]	.017
G	6.9 (4)	0.135 [0.043-0.42]	.001

The results presented above were discussed with renal staff during the focus groups, who were not surprised by these findings. They had learnt from experience that patients are better supported by psychosocial services that are integrated in the renal team, thereby confirming the problems that patients experienced with regards to community services as illuminated by field notes in Chapter 6. The reasons why patients were not appropriately supported by services in the community were found to be threefold: the services were often not (timely) available to renal patients; if they were, many patients would struggle to know they exist or how to navigate them without support; or the services would not understand patients' renal specific needs:

'I think if patients have the information, some might be able to access [generic social care services], probably. But not all. If they are having to start from scratch, they might not even be aware that there are such services. If you don't know, you don't know, then there is no way they will find their way through the system. For example, so few patients are aware of OT support. There are people that are unsteady on their feet or are generally frail, who have huge risks with getting out of the bath or in the shower and just a couple of grab handles could make a massive difference. But people don't know about this and you could make an argument, should this information come from the renal centre?' – Patient advocate, unit B.

'It feels like social services are supporting people less and less and they are asking them to look to the community to see if there is anything more available. But you find that especially in little villages, these services don't exist anyway. We spend a lot of time on the phone arguing that somebody warrants intervention. If you can imagine that left to a family to do for themselves, they are often kind of talked out of it and just left with nothing.' – RSW, unit F.

Welfare advisor, unit C: 'I sometimes struggle to discharge patients from clinic because they don't feel they're going to get the appropriate care in their community.' *'Well, actually, I think it's they know they're not going to get it, not just feeling.'* – Counsellor, unit C.

'They're not there, for a start. A lot of those community services do not provide, because of criteria. Social work in the community, psychological services, community mental health teams, they have very strict criteria. You don't want people to get to that point. Also, I'm not sure that a lot of the patients that we see would navigate those services in the community very well. And there is not the expertise. There's a lack of understanding'.
- Manager, unit D

'Yes, I am just going to reiterate that actually community services don't understand renal. Nobody outside of renal understands renal. The GPs don't even understand what being a renal dialysis patient is. They have no clue.' – Nurse, unit D.

'I think it would be truly dreadful if patients have to go through their GP to access psychological services. I think they would wait for a very long time and then they would get a generic psychological package that doesn't in any way have insight into their health problems. In some ways I would even go as far as to say that it could be potentially quite dangerous. There are very specific things about renal care, that if you are not aware of, you could actually do quite harmful therapy.' – Psychologist, unit B.

The following sections describe the findings of the qualitative focus groups and interviews, focusing on themes within the organisation of renal psychosocial service provision that were

identified as possible causal mechanisms leading to the differences in distress and unmet need for support reported. Key themes that emerged were the role that clinical staff play in providing psychosocial support, the processes of psychosocial service provision along the renal pathway and the rationale for type of support provided.

7.4.5. The role of clinical staff in the process of psychosocial service provision

Clinical staff, and particularly dialysis staff, were found to play a vital role in the process of psychosocial service delivery to ICHD patients, highlighting the importance of recognising the interconnectedness between psychosocial and clinical staff. The nurses and dialysis assistants were described as particularly well positioned to identify patients who are dealing with psychosocial issues and support patients with lower-level issues. The consultants in unit C and E felt that whilst they can also identify issues with patients, the dialysis staff were often the first point of contact and patients would be *'most open'* to them. It was suggested that because patients attend the renal unit three times a week, often for long periods of time, theoretically, the nurses should be able to build relationships with these patients. This then allows them to spot changes in patients, to notice when something is *'not right'* (nurse, unit A), for example when a patient is looking unkept or shows signs of unplanned weight loss. It was said that if this relationship is there, patients would be *'most likely'* (nurse, unit D) to tell the nurses if they were facing issues. It was also recognised that dialysis staff had a role to play in managing patients with low-level psychosocial difficulties.

'While it is not necessarily the nurses' role to take care of all of this [psychosocial care], you know it starts with nurses being given the time to spend time with patients.' - Nurse, unit A.

'The nurses would offer advice or support or just generally listening, because I think a lot of the feedback we've had is there's a very family orientated environment in the unit because a lot of the staff have been around for a very long time. The patients build up a rapport with the staff, so they will have an open conversation with them. They do give support. It's more about the dialysis assistants that are having the chance to have that conversation with them. You know them over years. There are a lot of patients that have

been around for a very long time that you do get to know and notice those changes. People do pick up on it. – Counsellor, unit C.

‘The nurses play a huge role. They will often spend, they will know people really well, because they see them 3 times per week sometimes for years. They will notice if there is a change, if someone is not right. I don’t know if it is the same for my other colleagues but often you will have, if you walk through the dialysis unit, that they say, can I have a quick word about so and so. So often there is a lot of that sort of informal support, but still at a very professional level.’ - Psychiatrist, unit E.

Still, it is important to consider that not every patient shares their issues with the dialysis staff:

‘They spend so much time in the unit, it becomes their life, it is not a surprise that their unit is the first port of call if they have issues. But that isn’t true of all patients, there are many patients who won’t say anything. Even I struggle to connect with them. If they don’t recognise the phone number, they won’t answer the phone, they are scared that it will be people demanding money from them. The longer they ignore it the worse it becomes.’ – Patient advocate, unit B.

The data highlighted the impact that the presence of psychosocial staff had on medical staff’s ability to play their part in the provision of psychosocial services. This was mainly illustrated by differences between unit A, where no psychosocial support was available, and other units where psychosocial staff was part of the renal team.

In unit A, the situation with regards to the role of the medical staff in psychosocial service provision was as follows. The lead nurse explained that she thought that most of her team would not have the confidence to be able to advise appropriately on psychosocial issues, particularly those requiring social work. The lack of confidence in how to advise patients was greatly linked to a lack of knowledge about availability of services in the community.

‘It is, you know, with benefits as well, you would refer to CAB [Citizens Advice Bureau], but I don’t even know if they are still open. They were closing some down. I just don’t know enough about this’. – Nurse, unit A.

'Yeah I think my dialysis team would see that, that they don't have the confidence to be able to advise appropriately on social work issues.' – Nurse, unit A.

'The patients, since we are the people they know, they keep asking us and that is putting pressure on us because we don't know the answers.' – Nurse, unit A.

The author was given a list of organisations to contact that would be given to patients in unit A if they were struggling; however, many phone numbers on this list were no longer in operation.

It was said that nurses in unit A did not have enough time to spend with patients, let alone to research community services. Not only was there a lack of knowledge about availability of services, the nurses described a lack of understanding about what the different psychosocial roles entailed, which would be the most appropriate to refer to, or if and how these services could be accessed in the hospital:

'I think there is really a lack of staff understanding about all these services that are out there. What exactly do social work do, other than what you see on the television of them taking kids away. Do we actually know, deep down, what they do? Do we know what psychologists do? Do we know how to get this accessed? Probably a lack of understanding of staff as well. I'm quite privileged, touch wood, that we don't have to know about that, but maybe we should know something about it. Maybe there is something with staff that we need to do that we need to know what's going on'. – Nurse, unit A.

One of the consultants described that social work services were not available in the hospital, but that they have never referred a patient to a social worker in the community. They described picking up tasks that were not part of their role, such as helping patients to complete forms for benefit applications or grants. With regards to psychology support, another consultant explained how the lack of availability of services led to inappropriate referrals within the hospital, with patients still not being supported in the end:

'As well as social work, I think psychology input would be the other one that we're missing. Because now, our only way in is through the psychiatry liaison service. So usually what happens when you refer someone, saying "I think this person needs psychology support", they get seen by a psychiatrist who says "this person doesn't have a mental health problem". Then I say well, "I didn't think they did, that wasn't what I was wanting. I was wanting health psychology input and behavioural support to be able to follow the myriad of restrictions according to the dialysis and come to dialysis more regularly, that sort of issues which are obviously more the demeanour of a psychologist, not a psychiatrist". I've never then seen anybody been referred on from the service. We just get a letter back saying "they don't have a mental health illness, so they are being discharged from the service", despite the fact that in my letter I would say "I don't think there is a mental illness, I want you to help me get this person psychology support". – Consultant, unit A.

In unit A, clinical staff have no choice but to tell patients to contact their GP or a general welfare advice service in the hospital. It was unclear whether patients then actually contact their GP and what support they then receive, this was often not followed-up.

Consultant, unit A: 'I guess it's more a signposting role isn't it?'

'It is, yeah. Get some information, direct them, advise them how to contact these people and then it is up to them to do it.' – Nurse, Unit A.

The results suggest that this process of referral back to primary care (if it occurs) is not sufficient; patient distress and psychosocial issues are highly prevalent in unit A and 35% of patients report that they were not receiving adequate support. In addition, as discussed in chapter 6, the analysis of field notes indicate that patients in this unit are struggling to access (social) services in the community. Staff from units E and F also explained that they felt that without social work support, nurses would have difficulty bringing patients in contact with community services, impacting on patients access to these services:

'It is hard, trying to make contact with the SWs in the community, we just don't have that relationship with the SWs that we have with the RSWs here. So, it is different kind of access altogether.' – Nurse, unit F.

'If a nurse thinks a patient needs community services, probably, it would come through us the majority of the time. Because they are so involved with the medical stuff. They don't have the opportunity to see, where they can signpost to. So, they would come to us and we then see.' – RSW, Unit E.

In unit A, the perceived lack of knowledge and ability to support patients was also found to impact on nurses' work satisfaction.

'It's frustrating when patients ask you this, that and the other and you can't help them.'
– Nurse, Unit A.

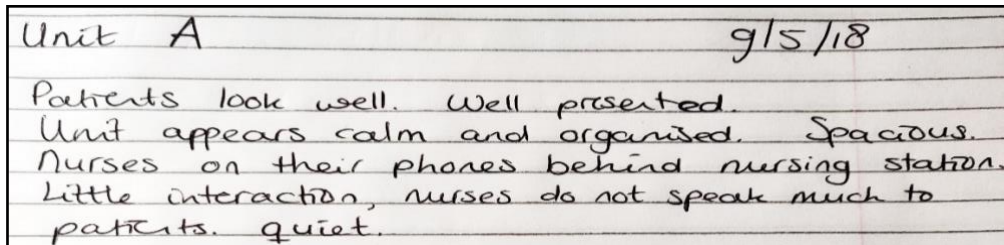
'Staff probably feel a bit under pressure, because you want to be able to help them, but we don't have the resources to do that.' – Nurse, unit A.

Similarly, a nurse in unit G highlighted how nurses and psychosocial staff are connected and interdependent, and how a change in psychosocial staffing would have a knock-on effect on service provision and staff satisfaction of nurses:

'From our point of view, it would increase our workload. We have got a couple of patients that heavily rely on the social work support and the psychological support that they get, if that would be taken away it would have a big effect. We are already under pressure, so I think it would result in loss of staff to be honest. We are at breaking point, there is so much expected of us and our nursing ratios have been changed as well, so if you're having to deal with... I mean we do deal with them on a basic level, basic problems, but if you've got quite complex patients, it is something we wouldn't be able to deal with it I think.' – Nurse, unit G

During data collection, the author observed (and documented in field notes, Box 5) little interaction between the nurses and the patients, with this unit being the only unit where nurses were visibly on their mobile phones behind the nursing station.

Box 5. Field note from observations in Unit A



Unit A 9/5/18
Patients look well. Well presented.
Unit appears calm and organised. Spacious.
Nurses on their phones behind nursing station.
Little interaction, nurses do not speak much to patients. quiet.

Data from interviews and focus groups in other units have been analysed to explore whether these issues are also present in units that have access to renal psychosocial staff.

7.4.5.1 Staff education

In the system of service provision, where psychosocial staff are partially dependent on nursing staff for referrals, it is important that nursing staff understand what kind of support psychosocial staff offer to patients and when they should refer. As discussed, in unit A, this understanding was not always present in nurses. This was also found in unit B, where the RSW had left and it had become clear that this understanding was acquired on the job, through collaboration and education.

'I think at [name unit B] the nurses did understand the difference, they had [name RSW] and us and they saw in terms of what we did was very different. I think for new people who may be coming in, who don't have that experiential insight, they might have more confusion.' – Psychologist, unit B.

Psychological and counselling staff, where present, offered some form of training to clinical staff about how to recognise and manage psychological issues. It was said that this training, together with experience and personal strengths, had an impact on nurse confidence and awareness with regards to identifying and exploring psychological issues:

'What I heard from other colleagues is that it [training] has been very beneficial for them and raised issues that they wouldn't have thought about. I think perhaps also as you get more experienced it is something you become better equipped to deal with. And it is individual as well, we all have our strengths and weaknesses don't we.' – Nurse, unit F

'I think some nurses are [confident], and some aren't. I think those who have worked in renal for a while, who had the ability to come for training, are more confident.' – Psychologist unit B.

The provision of training to nursing staff also highlighted the role that they have in the provision of psychosocial support, with staff explaining that they provided training to:

'Skill up the nursing staff and doctors so that they can do the lower-level, day to day managing of distress'. – Psychologist, unit B.

and

'Highlight what nurses can do and just how far they can go with their listening and just being curious'. – Counsellor, unit C

In unit D, a session of psychosocial issues formed part of nurse introduction training, whereas in the other units the psychological training was available on voluntary basis.

The social workers, only available in units D to G, stated that they also mainly targeted the nurses with education about their role and patients' social issues. In units D and E, this was in the form of a formal training session as part of nurse education or introduction programme, at which also other MDT staff would be present. In unit F and G, the RSW would ask for some time to be allocated in the morning handover or MDT meetings. In these units, staff felt that most patients were adequately supported, with nurses able to recognise issues and knowing where to refer for support. These intuitions appeared to be supported by data, as distress and need for support were relatively low in these units:

'Junior nurses would raise a psychosocial concern with their senior, who is clearly senior and confident about the range of referrals they can make and which they do make. I hope there isn't much of psychosocial distress that is missed by all of us. And I hope that

all of the clinicians see it and feel empowered to address it or make the necessary referrals on'. – Psychiatrist, unit E.

'Yes, the nurses definitely have an understanding. There is always going to be some crossover, that is how it is isn't it, but it is very clear to us who we refer to.' – Nurse, unit G

'If someone gages there is an issue, they will refer. Particularly the specialist nurses are quite keen referrers. You would very rarely see referrals that are inappropriate. - Social worker, unit F.

Education not only led to appropriate referrals, but the relationships that were built and the learning that took place through this training (and teamworking), were also found to increase clinical staff's ability to provide holistic care. One nurse explained how this allowed her to maintain a trusting relationship with patients; another said it left her feeling empowered.

'I think our role is obviously medical, but it is also about providing holistic care, knowing that we have such a great [psychosocial] team that we can call in for expertise.' – Consultant, unit E.

'I think if the nurses wouldn't be able to offer this [support], then there is that loss of trust, if the patients go away and they feel that they're hitting a dead wall isn't it?' - Nurse, unit G.

'I think, over the years, I know I've gained a lot from working with the dieticians, social workers and our supportive care teams and stuff. I know I've gained that knowledge, and I can now... Do you know what I mean? I feel more empowered to do more, but obviously I know my limitations and I know when to pass it on.' – Nurse, unit D.

In unit B, an external welfare advice service was made available specifically to dialysis patients, after the date of the needs-assessment. Patients can be referred to this service by nurses or the local KCUK advocacy officer and a welfare advisor would visit the unit once a month. At the time of the interviews, this service had been offered to patients for around a

year and a half, yet it was felt that patients were not adequately accessing the service, due to a lack of understanding amongst staff and patients, highlighting the importance of education:

'From what I can tell, [name of service] is not part of any process. It is a service that, I think, as people reach a point of desperation and they start talking to nurses and other patients, they might hear about. I get a lot of referrals from people who have spoken to other patients. Nothing to do with any guidance from clinicians or nurses. I still don't think that the majority of staff on dialysis and staff are aware of the service. Navigation of the benefits system suddenly becomes a major issue in patients' lives, but I am not convinced it is at the forefront of anybody's mind in [name unit B]. I've had too many people call me who know nothing at all about the service, that is across staff and patients.' – Patient advocate, unit B.

7.5.4.2 Provision of lower-level psychosocial support

There was a consensus view across the MDTs that nurses and other clinical staff should be able to support patients who had lower-level psychosocial issues, with psychosocial staff as a back-up. Particularly staff from units D-G reflected on how the support of patients with lower-level issues is a team effort, with clinical staff signposting or providing information to patients. This was identified as a possible causal mechanism for reduced distress.

'If it's something that we can sort out with the help of you guys [the psychosocial team] as well then we would try and do that. I think housing, anything like that sort of stuff, goes on. If it's serious or depression, that sort of stuff, then I am not qualified and then I would refer on. If it's someone that's feeling a bit low and needs a bit of support, and actually needs some information on groups, or anything like that, I can do that and I can contact peer support and all that sort of stuff. I can do that.' – Nurse, unit D.

'We're more signposting, we're able to signpost them if they need services. So, if there is someone with financial difficulties or whatever, we can signpost them to different bits and pieces that we know about.' – Nurse, unit F.

‘One part of support that we as a team give, is to help people with loads of different problems, often multimorbid social and psychiatry problems, to actually negotiate their way through health care, what can be quite a complex negotiation between conflicting specialisms, medicines, appointments and investigations. You have to of course ask other specialties to do their specialist bit, but I think we all provide quite a lot of signposting, referral, liaison, it is the same kind of thing. I think that is absolutely a part of our job, that holistic road of “I’m not just about your kidneys, I’m actually about you as a person and all of the complexity that comes with that”’. – Clinical Director, unit E.

Unit D operated a ‘primary nurse system’, which was seen to enhance relationship building and led to referrals into the psychosocial system:

*‘I think for the general dialysis population it is usually our nurses on the unit that pick up any problems. We operate a primary nurse system where we’re looking at all the patients every month, doing their bloods and all the usual stuff, but also talking to the patients, and they, very often, raise issues to nurses, and then we would go on to refer.’
– Nurse, Unit D.*

In unit B, plans were being put in place for each patient to get a named nurse. In unit E, psychosocial staff identified this as an improvement to service delivery that they would like to see transferred to their unit, whereas in unit C, the patients were allocated a different member of staff on each day of dialysis. The idea behind this was that all staff would then get to know the patient.

The RSWs in the geographical area of unit F and G had formed a group and were in the process of implementing another system for nurse involvement. Responding to a lack in clear policies, they had designed a stepped care model (Figure 9), showing the self-organising properties within their system.

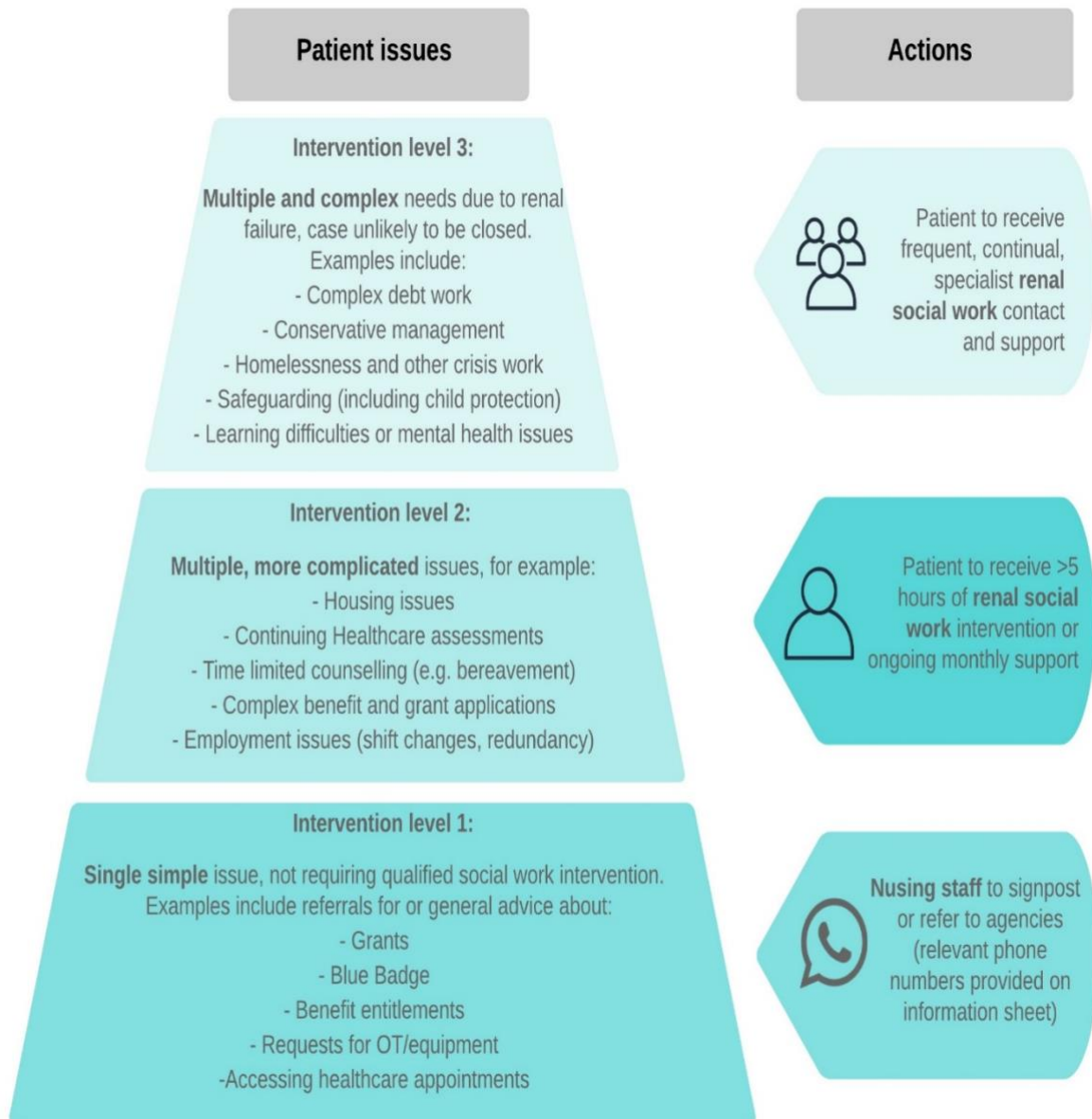


Figure 9. RSW intervention levels (figure created by author based on information provided by RSWs in unit F and G).

The model was first implemented in unit G. The model was meant to formalise the nurses' role in lower-level social care work, to free up RSW time for complex level 3 cases, which the RSWs felt took up about 60% of their caseloads. Nurses were asked to identify what level issue they were dealing with. If it was a level 1 issue, they were then asked to signpost the patient, using information provided by the RSW.

'[Name RSW] has put together a folder for us that we can access so that we can signpost patients towards those services. And we are happy to do that, it is an easy thing for us to do, and we want to support the patients just as much as the SW does. Timewise, it

doesn't take much more time, sometimes it's even quicker just to signpost them than to refer them to the SW. All these little things that we can refer or signpost the patient on to, it's all in the social work folder.' – Nurse, unit G.

A nurse from this unit reflected on how without this 'social work folder' some nurses might not be willing or able to signpost patients, which shows the importance of education for nurses about psychosocial issues and available services:

'I think it would be more difficult if this list wasn't provided and there would be some nurses that maybe wouldn't do it. I mean you get a mix don't you, everywhere. I think when it is accessible and easy, it makes it much quicker for us.' – Nurse, unit G.

The RSW stated that overall, the model was working, but that she had to continuously educate staff about it:

'I just have to recap what the process is. The nurses respond, it is a mixture, some people are really fine with it, some want to know a bit more, some are happy with it, some struggle with it, forget, or don't really want to do it. It is a mixture, but mostly it is well-received.' – RSW, unit G.

She felt that resistance to the model was mainly linked to the nurses feeling that they do not have enough time to take up these tasks, illustrating how attitudes and personal agendas of nurses, as agents, can influence the workings of the system of psychosocial service delivery. This resistance was larger in unit F, where the intervention model had been received with less success:

'The problem we have when we're short staffed on the units...When we talked about intervention levels and we were going to roll them out in [unit F name], she [the sister] was saying, we are way too busy to be taking on those level 1 tasks.' – RSW, unit F.

However, the nurse in this unit contradicted this and said that she and some of her colleagues would take up this role:

'Blue badge, CAB, independent financial support, we know there are all these little things that we can refer or signpost the patient on to. I think we're very much there, picking up all the little bits and pieces. I think you'll always have some nurses that go over and above and go the extra mile anyway.' - Nurse, unit F.

Time constraints were mentioned in all units as a restriction to nurses' ability to provide lower-level psychosocial care and identify patients in need, but in units A, B and C they appeared to have a particularly restrictive effect on nurses' ability to provide support:

'They don't always get the time because there is a very short amount of time to get somebody on and off dialysis and there's always the added pressure of transport into the mix. Sometimes that doesn't always allow for the nurses to have time to really spend because patients are trying either get on very quickly or get off very quickly.' – Counsellor, unit C.

'I think that [nurses involved in lower-level social care] is not likely in the current climate, there is not enough staff, so they are very focused to get patients on the dialysis machine and off. I think their ability to do other things is quite limited'. – Psychologist, unit B.

Similarly, the patient advocate in unit B reflected on how over the years, the approach in many renal units was mainly focused on providing medical care, and that this had increased over the years, hereby seconding comments from patients in unit B about a lack of social activities (Chapter 6). The unit had recognised this and was trying to address this:

'I am being critical here and it doesn't apply to [name unit B] only, it probably applies to most centres and their dialysis units. I think nursing staff on the units just don't have the time. I do think in a lot of units it is increasingly about the process. I think there is awful lot of focus on chemistry and treating dialysis patients; that focus just isn't there on the issues that are peripheral but are key to quality of life. If you talk to patients, they would worry less about being able to take phosphate binders than they would about being able to put food on the table. And I think some patients feel that there isn't a level of interaction. In the past, the units would be an integral part of the patient's social life,

organising special days and trips out. It is indicative of this move towards getting the patient in, treated, and out, without acknowledging that they are a human being. I know [unit B] is trying to address it. They have talked about reintroducing a named nurse, part of what they do is talk to patients.’ – Patient advocate, unit B.

In unit F, the social worker reported similar issues, highlighting the friction that can exist within a system due to staff’s professional or personal internalised goals and values. Yet, unit F and G were also in the process of developing a method to increase a focus on psychosocial support. Although Covid-19 had now temporarily halted these developments, there was the plan to appoint link nurses who would work at the interface of clinical work and lower-level psychosocial service provision:

‘It is about trying to break down a bit of a culture issue that they don’t see the psychosocial aspect as crucial as getting the patients on and off dialysis. That is the reality, I think. So, they were going to release somebody, a nurse, but for us a healthcare assistant would have been fine, to just oversee some of the lower-level 1 stuff. But also, someone who could then debrief colleagues, when they are talking about referrals, saying this is the number you need to ring. That is someone on the ground floor, similar discipline, who could advise a colleague or do it themselves. That person would then be a really good link for us to the dialysis unit.’ – RSW, unit F.

7.4.6. Processes of psychosocial service provision

In this section, the process of psychosocial service provision across the units B to G along the dialysis pathway is explored. Pre-dialysis education sessions, with psychosocial staff present where available, were offered proactively in each unit to transition patients smoothly onto dialysis. During these sessions, psychosocial staff would introduce themselves and explain what services they offer. Patients would then be able to self-refer, or do so later down the line, should they ever feel the need. Whilst input from psychosocial staff in this starting point of the RRT journey appeared similar across all units, differences in staff involvement across unit B to G were identified along the rest of the patient pathway.

Across all units, psychology, counselling and psychiatry staff were found to mainly work on a reactive, referral basis:

'With regard to the role of psychiatry, this is very much reactive and seeing a minority of patients. It is by referral, which might come through social work or through nephrology, or through dialysis nurses.' – Psychiatrist, unit E.

'We're very much reliant on our healthcare professional team actually referring clients to us. Clients can self-refer as well. We get a very occasional GP referral.' – Counsellor, unit C.

It was found that especially with regards to social care support, in unit D, and to a lesser extent unit E, staff had adapted a more proactive, process-oriented way of working than in the other units. For these larger units, this way of working was another possible causal mechanism that led to increased access to psychosocial support for patients and therefore, reduced distress.

In the pre-dialysis phase, in units D and E, patients are routinely visited at home by a nurse and a RSW for an RRT-assessment. This was:

'...about being proactive, helping, suggesting, and hopefully preventing crisis situations happening for people'. – RSW, unit D.

In unit E, it was recognised that whilst most patients received such an assessment, some still slipped through the net if they were not referred by their consultant. To identify and reach these new patients, the RSWs used a list generated by staff at professional pre-dialysis meetings and kept a close eye on the dialysis boards, to cross check referrals. Then, new starters that had not received an assessment were added to a mailing list and received an information pack and the offer to self-refer:

'We certainly try and have contact with everybody pre-dialysis to try and get equality of access to our service.' – RSW, Unit E.

The social workers in unit E recognised that the referral process for these pre-RRT assessments was something that could be improved, as they saw these assessments as:

'The core of their being able to do effective preventative work and build up good relationships'. – RSW, Unit E.

Indeed, in this unit, many patients said that they had seen the RSW in the past and several left comments that alluded short lines of communication between the RSWs and patients:

'I can always find the social workers if I need them, I know where they are'. F-E14

'I've got the social worker's phone number so will ring if I need anything'. M-E81

'I've seen the RSW and the psychiatrist; I can see them whenever I want.' M-E90

'If I need it, the nurses will get the social workers'. F-E74

Most patients have an elective start to dialysis, yet there are also patients whose start is unplanned. To psychosocially support these so-called 'crash-landers', in unit D, emphasis was placed on making all staff aware if a patient is an unplanned starter. Here, a 'transition unit' was created in the dialysis unit, consisting of two or three bays. All psychosocial staff would visit the patients in these bays and introduce themselves and their services and the social worker would complete an assessment. Apart from hopefully preventing crisis situations, this was said to be particularly useful for identifying unplanned starters who might be suitable for home haemodialysis therapy:

'What I've found is a lot of patients who actually are interested in home therapy, and that may not have been picked up if they hadn't come through the transition unit and they'd gone out to the haemodialysis unit and they would have been gone so quickly. It feels like a much more thorough assessment for them.' – RSW, unit D.

In unit E, the RSWs 'made a point' of checking the dialysis boards to identify unplanned starters, who were then approached for an introduction and an information pack.

To identify already established dialysis patients who may need support and to ease the dependence on nurses for referrals, in unit D a screening process was implemented. Once a year for dialysis patients, and every six months for unplanned or new starters, envelopes with the DT questionnaire and an explanatory letter were distributed, for patients to complete and return. The psychosocial staff was surprised by the percentage of patients that reported an unmet need for support, because they felt that this screening would capture patients in distress, yet hypothesised that perhaps patients were missed because they did not return the questionnaire:

'They are given it in an envelope that explains what it is, and it's whether people are then motivated to look at it or to fill it in. So, I suppose that could be where that's happening...' – Manager, unit D.

Such a screening process was not implemented in unit E, where the RSWs explained that they visited the unit regularly to have brief chats with patients.

For those patients who could not receive a transplant, ultimately, long-term dialysis is the only option, until they become too ill to tolerate the treatment. In unit D, the role for psychosocial staff in supporting patients towards the end of their lives was clearly recognised, with the RSW routinely involved in their care and providing a training on supportive care to new nursing staff. Once a month, patients are discussed who are not thriving on dialysis. These patients then have a discussion with a consultant and if they decide to withdraw from dialysis and choose conservative care, they are listed on the End-of Life register. Dialysis staff would work together with the social worker, who would set up services and discuss the different aspects of supportive care with patients and their families at home. In unit E, two conservative care nurses would work together with the chaplain to offer this type of care. The RSWs are available to support this process on a referral basis.

Unit F and G also have access to RSWs, but their involvement was found to be on a more ad hoc basis. With regards to pre-dialysis assessments, the RSWs in both units were no longer involved, but instead supported patients on referral basis:

'Historically, that would have been the case, we would get a referral for each person getting on dialysis, but that doesn't happen anymore. I'm not sure whether that's because... I think the specialised nurses, the pre-dialysis and home therapy nurses and doctors do that themselves. They go in and do the environmental assessment themselves and then if they see any issues, they would refer onto us. They are quite keen referrers.' – RSW, unit F.

The same was the case for unplanned starters or end-of-life care; the RSWs did not report any proactive involvement along the dialysis journey:

'There is no pathway that says, involve social work at this stage. It is more a case of, if somebody gauges there is an issue, they will refer.' – RSW, unit F.

'There isn't a flow chart that says now SW is involved, it might be that I am never involved. It is not as explicitly offered, that might be a useful thing to perhaps explore in the future.' – RSW, unit G.

However, it should be noted that these units were small and staff-to-patient ratios were relatively good: unit F has 1 satellite unit and unit G consists of a main unit only. A nurse, who works across both sites, described the RSWs as *'ever present'* and *'very visible'*. They also described short lines of communication between the clinical staff and the RSWs:

'We have small patient numbers and a small team, so it makes it easy for us. I can imagine if you have a large unit then it would be a different matter altogether. Here, we know each other and they [the RSWs] have always visited the MDTs. We work together very regularly; we are a very good team. It is a proper MDT approach across the two sites. If there is anything, any issue, it comes up within our MDT meeting and discussion. It is dead easy to refer to them. If there are any issues we just pop over to their office.'
– Nurse, unit F and G.

This is different in unit B and C, where psychosocial staff cover a large patient population across multiple sites. The psychologists in unit B and the counsellors in unit C covered all sites by dividing their time and presence across the main unit and satellite units.

In unit B, the psychologists offered their services more proactively to pre-dialysis patients who scored high on a psychological screening tool in the acute kidney care and pre-transplant clinics, but mainly worked on a referral basis with dialysis patients and end-of-life patients. The RSW had left in recent years and was now replaced by welfare advisors, but it was felt that this had left a gap in service provision. A patient advocate, who worked across unit B's region, described that:

'Although the welfare service does work, I think there are some areas that a SW would probably be better able to support a patient. I have no issues with them [the welfare advisors], in an ideal world you would have both. But things like immigration issues, visas, that has got to be done by someone with a qualification. They [the welfare advisors] are never going to plug that gap, and so many on the dialysis unit are not native, and they have got quite a few issues with things like visas, or just with language. It is much easier for a SW to request translation services.' – Patient advocate, unit B.

The psychologist in this unit agreed:

'There is a whole host of... what [RSW name] would do for example, when she was with us, that they [welfare service] wouldn't cover. There is definitely a gap now in service delivery in our unit. If we have complex cases around vulnerable patients with housing issues, financial issues, perhaps carer reviews, all that slightly more difficult, complex stuff, they wouldn't touch it with a with a barge pole.' – Psychologist, unit B.

Just like in unit A, this gap in service provision appears to have led to higher distress and inappropriate referrals, creating pressure on other services:

'When the social worker left, out of desperation, people were like, oh we really need to refer to the renal social worker, but we can't because we don't have one, so let's just refer to the psychologist. Even though the stuff that they were referring were housing issues or work-related stuff or benefits issues and that is stuff that we are just not, that is not our speciality, we are not trained to do that.' – Psychologist, unit B

'I think an awful lot is sent to me. My colleagues and I are becoming social workers by stealth. The level of work we are having to do has increased dramatically both in terms of complexity and volume. There are areas in which we don't have a degree or specialism, we certainly do not have 3 years training as a social worker, but we are increasingly expected to address all sort of issues. Some of it we can do, which is just common sense, but the more complex stuff, immigration issues and things like this we can't help there, I can't risk giving them wrong advice. And that is not what an advocate should be doing. We should be representing the patient, discussing options with them, not saying well this is what you should be doing.' – Patient advocate, unit B

In unit C, psychosocial staff felt that over the years, their service had become largely reactive and that they were now *'completely dependent (Counsellor, unit C)'* on referrals from nurses. The counsellors explained that since patient numbers grew, they were no longer able to actively pick up referrals by visiting patients on the unit or in the clinic waiting areas. Similarly, the welfare advisor explained that since they were employed through the Council and only funded to cover the in-patient ward, they did not have the opportunity to actively engage with people on the dialysis unit:

'It is reactive. It's a very reactive service. A lot of that is down to the fact that I'm social services. The patients are part of the NHS, and so there is this need for being referred into the system. I can't go walking round touting for business, if you like.' – Welfare advisor, unit C.

There was a feeling that because of this, some patients in need of support may not be identified and referred, which could explain the high distress levels found in this unit:

'I think what we've identified, is that we've got to go looking for the patients that aren't coping. We've got to go and identify them, and we've got to be more proactive with those.' – Welfare advisor, unit C

With regards to pre-dialysis care, the counsellor in Unit C explained that nurses provided a lot of the initial support; through the pre-dialysis nurse those in need of support would *'probably*

be picked up'. Crash landers were also not routinely supported, it was felt that those in need of counselling support would often only emerge after the first 6 months on dialysis and those who came through the ward would be seen by the welfare advisor. End-of-life care was provided by a conservative care nurse, who would refer to social services in the community directly as required. A screening process had been discussed for established dialysis patients, but it was felt that the available questionnaires lacked specificity and that the current psychosocial services might not be adequate to support the identified need.

'I think you have to be careful of asking a question and getting an answer, which you then can't do anything about'. – Consultant, unit C.

Although it was not specifically stated, the data indicated that in unit C, especially with regards to social care, there was a possible gap in service provision for dialysis patients, with the welfare advisor spending most of their time on the in-patient ward and not as able to support patients of the dialysis unit due to employment arrangements.

'I've been stuck on the ward all day today and at a computer. There was no way on earth this week I was going to ever get out to a renal unit.' – Welfare advisor, unit C.

This appeared to particularly affect the elderly or those who are generally not able to self-care:

'The issue is that they [dialysis patients] are outpatients. We're an inpatient service, so that sometimes can be quite difficult, to get them the level of support they need. It could be that we ask them to refer themselves, if they're young enough and able enough to do it. Their services would be provided out in the community. A lot of it is signposting, encouraging patients to look at what their options are and to look after themselves, to try and self-care, particularly the younger ones.' – Welfare advisor, unit C.

The issues with the role being focused on the ward was recognised and the unit was making preparations to take this role off the in-patient ward, away from social services, and change it to a care navigation/coordination role for the dialysis unit. Again, a lack of adequate provision was found to result in a spill-over of social care tasks on other staff, with both the

counsellors and a consultant nurse reporting that they would sometimes complete benefit forms with patients.

7.4.7. Rationale for psychosocial service delivery model

The following section explores how the units have come to their current models of psychosocial service delivery. It was found that the availability of services is more dependent on a combination of historical and financial arrangements, staff attitudes and resilience of those championing services, than on recommended staffing ratios.

This can be firstly illustrated by an exploration of how unit B, C and D, all in the same country, came to provide their current psychosocial services.

Unit B was the only unit that had psychosocial staff available, without funding any. The welfare advisors were funded through temporary charity funds and the psychologists fell under the hospital's clinical health psychology department, funded and employed through the acute Trust. Psychology sessions created revenue, paid straight from the CCG to the Trust. Although the psychologists are dedicated to renal patients and their posts were said to be based on renal needs, the renal unit has very limited control over them.

In unit C, there used to be three RSWs and two counsellors. Over time, these social workers were '*offered up for cost savings*' (Consultant, unit C). The counsellors are still present today, albeit in the same numbers, serving a much larger renal population. The data showed that this was simply due to the fact that the counsellors '*were generating a massive income through some backdoor route*' (Consultant, unit C), whereas it was said that the social workers '*did it for love*' (Welfare advisor, unit C). It became clear that a social worker (employed through the council) in this unit would cost money, whereas a counsellor brings in money for each 'clinical client' visit. If counsellors are employed by the NHS or the renal department and they are then doing outpatient clinics (as is the case with dialysis patients), an income is generated through the CCG or GP paying an outpatient tariff. It was said that a payment for social workers used to be included in the dialysis tariffs, but that this changed after an investigation found that not all units used the tariff to provide social worker input.

In unit D there has been a history of RSW provision, since a consultant raised the idea for a specialist social worker, 2 years after the renal unit was opened. After that, a counsellor was added to the team and over the years, coupled with the growth in the department, the renal psychosocial team expanded to include a variation of professions to support the wide array of needs of the patients. Just like in unit C, the team has faced the threat of being sacrificed in times of cost-savings, but unlike unit C, the team persisted and championed the provision of varied psychosocial roles:

'Yes, I've had to evidence why there is a team such as this. Our lead clinician has had to take that to the Trust board and explain why there's a need for a team such as our team, and why can't these things be provided in the community? But we have got through those times and in fact, we've increased our team since those times as well.' –Manager, unit D.

In addition to having support from clinical colleagues, the data showed that the existence of the psychosocial team in this unit was heavily dependent on the creativity and persistence of those championing it. Similar to the counsellors in unit C, the manager said that they are often told that they *'got their team through the backdoor'*, as they explained how they were able to creatively use different budgets to supplement posts. All staff were required to record data on activities, caseloads and referrals, which was used to successfully build business cases to have funding taken over by the Trust. The importance of record keeping and being able to provide the evidence needed to build a psychosocial team, was invaluable. The activity records of psychologists, counsellors and social workers (who were NHS funded, in unit D) were further used to generate income, with different levels of funds for direct contacts of *all* these professions reclaimed through primary care and/or CCG funding.

For as far as staff were aware, in the other units (unit A, E, F and G), psychosocial staff were not able to generate revenue by charging for their client contacts.

In unit A, funding for posts had to come out of the renal budget and it was felt that this budget was barely enough to provide a team of *'core staff'* (consultant, unit A):

'[Name of hospital] is on the tightest, tightest ship, and you can't even get an extra... You know, sometimes you're talking about just an extra £7500 to up nursing hours and they won't even give us that. So, all you're doing is pushing money around and around within the department, within the same roles, whereas often actually you don't even have enough roles of anything. There is just no free-floating cash anywhere.' – Consultant, unit A.

Unit A used to have access to renal social workers. Clinical staff said that *'it was great'* to work with them and they were *'very happy'* (nurse, unit A) with the RSWs. It was explained that the renal unit *'had no control over employing the social workers, it was all done by the council.'* (Clinical director, unit A). So, when the council decided to withdraw the service in 2006, that was the end of the RSW. Initially, the Clinical Director had tried to get a RSW in post by using charitable funds, but this was refused by both the council and NHS management due to the temporary nature of this funding. In addition, the hospital Human Resources department would not allow for a council employee to take up an NHS salary.

'There was no potential to employ anyone directly... but this was a long time ago now, so it might be worth trying again'. - Clinical Director, unit A.

They were not aware when it had last been discussed to provide *'additional services'* like renal psychosocial staff.

This unfavourable environment for psychosocial services in unit A appears to be in contrast with the situation in unit E, which was in the same country. According to a psychiatrist in unit E, the reason why there was psychiatry support as opposed to psychology or psychotherapy, was:

'...purely historical. It is whatever those units were able to get at the time they were developing services.' – Psychiatrist, unit E.

They explained that the psychiatry service had been built *'through efforts of going and seeking finance and getting it'*.

The presence of a social work service in unit E was also found to be historical, developed by a senior social worker, funded and employed through the council, who was *'very involved'* (RSW, unit E) in the renal unit. This social worker managed to get funding allocated from the council to support renal patients. Over the years, with additional funding from the renal budget, they were able to build up the RSW service, which is still there today. Similar to unit A, the council decided to withdraw social work services out of the hospital a couple of years ago, but unlike unit A, the RSWs managed to stand their ground.

With regards to renal funds, the staff in unit A argued that unit E would receive a disproportionately higher amount of funding, because it is a transplant centre:

'They [unit E] get funding for transplant directly that the non-transplant units like us don't get. Which is a sore point, because it is our patients that go to [unit E] to get their transplant and then they get more money to provide the surrounding care and then they come back here 5 days after transplant and then we don't have the money to give them that psychosocial support. So it has been raised before, but they haven't given the cash yet. – Consultant, unit A.

Yet, the staff in unit E explained that only the psychiatrist was (partly) funded through allocations for to transplant services, not the RSWs:

'We are not, we do not have any specific funding through renal transplant services. So we offer a service to anyone who is in the geographical areas that we cover, because they may be pre-RRT anyway, and if they are in hospital we would see them, but we don't offer a service to those who come to [unit E] for their transplant outside of the areas that we cover'. – RSW, unit E.

Whilst this shows a gap in service provision, since it means that patients from unit A would still not be able to access social work through transplant services in unit E, it also suggests that unit E has managed to fund its RSW service without the additional money going into transplant services. Table 24 presents an overview of differences in funding and employment sources.

Table 24. Funding sources for psychosocial staff per unit

Unit	B	C	D	E	F	G
Welfare advisor		Renal (LA employed)				
Social work			Trust	LA & renal (LA employed)	Renal	Renal
Counselling		Renal	Trust			
Psychology	Trust (Health psychology)		Trust		Renal	Renal
Psychiatry				Trust, renal and liver transplant budget (Psychiatry liaison)		

7.4.7.1 Staff attitudes and resilience

Many staff across the units made comments about how they were ‘lucky’ to have the services that they have. This in itself signifies that the availability of psychosocial services was seen to be a postcode lottery. Yet, it was found that the reason why some psychosocial services had developed over time where others had disappeared, was not only related to differences in funding arrangements and luck. It also greatly depended on attitudes and support from other staff towards the service and the resilience and persuasiveness of those championing it.

In unit B, the psychologist explained how they felt that the psychology service had mainly developed over the years thanks to her tirelessly making the case, emphasising again the need for evidence:

[What has been the rationale behind this model of service delivery?] This is going to sound really arrogant, but, me. I came in as a part-time role many years ago and I just battled. And I don't know if they gave it to me in the end to just shut me up. I think, if you get a foot in the door, once you have psychologist in post and services see what you can offer, but also what they can't have, because you've only got so many hours in a day. I collected lots of data around patient distress, data around what we could be offering if we had increased funding. Then it gets slightly easier to keep making the case for more.’ – Psychologist, unit B.

They also explain how the clinical staff in the unit have helped them make the case with higher-level hospital management, and how it requires a certain type of person to fight the corner of psychosocial care:

'You have to be really assertive at [Hospital B] with management, almost to the slightly painful uncomfortable level. Because they are like rottweilers, the businesspeople. That is not everybody's cup of tea, to battle in that way I don't think. Also, the renal team have been fantastic over the years at backing our case over the last few years, so quite a lot of emotive comments from consultants and nursing teams saying we need more of this etc.' – Psychologist, unit B.

This need to 'battle' for posts and the importance of support from clinical staff in the renal unit was also mentioned in units D, E, F and G:

'There is a lot of goodwill and a lot of support from my managers, the Director of Medicine and the Clinical Director to support psychosocial posts, because they can see that there is a huge benefit.' – Manager, unit D.

RSW, unit E: 'We've had to really fight for our post.' 'Yes, I think that we have worked very hard to point out how much we value all of our team members and fought to retain them within the renal unit.' – Clinical Director, unit E.

'Thanks to our senior manager, we are on the agenda in the clinical governance meetings now. We're quite vocal in those meetings. We've had to constantly promote ourselves, raise our hands up and say this is what we're doing. That's not easy and we have to keep doing it. We're all a few steps away from not having a job, so we need to keep battling for it and keep being creative about it. I'm quite cheeky, but I would say, you need to be resilient.' – RSW, unit G.

Finally, beliefs about what a psychosocial service should entail appeared to impact the provision of services. RSWs were said to be an essential part of psychosocial service delivery, apart from in unit C. In this unit, the welfare advisor argued that it *'has been proven'* that the

renal unit does not suffer without the presence of RSWs and that patients could access SWs in the community:

'With all due respect, our dialysis patients are outpatients. They live in different communities and they have social workers in the community if they need that level of support. We're going to signpost them to community services anyway. I will set it up, but eventually their case will be taken up and they'll have a social worker in the community. In my opinion, it's not critical that you have a social worker working in a hospital because there are 200 or 300 outside there.'- Welfare advisor, unit C.

The welfare advisor suggested that if patients were not receiving support, this was not necessarily because of a lack of input from social services, but because of a lack of care navigation and knowledge about availability of services. They stated that patients need someone visible in the unit who could advise or refer them to community services and then follow-up on whether patients were able to access the appropriate support. Whilst the welfare advisor was currently not checking whether patients accessed support, they argued that this could be performed by unqualified staff:

'You don't need a renal social worker, as long as you've got someone that knows a little bit about the council, who has a knowledge of renal and knows what's going on. To be a qualified member of staff, is that any different to being a case officer who can advise someone, who knows the system?'- Welfare advisor, unit C

The data showed that there might be some truth in this comment, with patients (and nurses in unit A) describing a lack of knowledge about services (Chapter 6). Yet, it contradicts claims made by psychosocial staff across other units, who said that a SW qualification is needed to deal with the complexity of some cases, to help patients access community services and, increasingly, to support those who do not meet the criteria for social services support. This will be further discussed in the next chapter (chapter 8).

7.4.8. Fluid boundaries of renal psychosocial services

Findings identified that patients can face a large array of issues that are not necessarily renal related (Chapter 6). MDT members across all units reported that because of the close relationships they have with patients, they are often seen as the patient's first point of contact if there is an issue. This sometimes means that patients with non-renal issues take up medical and psychosocial renal resources, as was also reported in Chapter 6. In unit C, an extra counselling post was only funded on the basis that this post would be renal-specific. However, the counsellors felt that if patients were not able to access community services, they should and would step in to help, not only patients, but also relatives:

'Actually, over Christmas or prior to Christmas I had - it was a relative that was coming with anxiety and depression and suicidal thoughts. They had been to their GP and the GP had directed them to a community counselling service that wasn't able to respond to them. Actually, yes, we have taken that person on.' - Renal counsellor, unit C.

This was also reported in unit E, where especially the elderly, less mobile patients were often still being seen by the RSWs, because it was felt that these patients would not be able to attend appointments in the community. The psychiatrist and social workers in this unit felt that as other services were largely unavailable, drawing strict boundaries around the service was not always possible nor useful. Renal care was seen as entailing someone's whole life, especially since there often is a spill-over of non-renal issues negatively affecting renal treatment. The psychiatrist in unit E explained, for example:

'It does not matter whether someone has been depressed long before they were a kidney patient; their depression might still affect their ability to come to dialysis and tolerate everything that goes with it'. - Psychiatrist, unit E

The social worker in unit F agreed:

'If we can help and resolve, then we should do, because we're not there just looking at dialysis or kidneys, there is a person at the end of the dialysis line and if we can help in any way then we should.' - RSW, Unit F.

The data suggested that renal psychosocial services serve an important role by filling up gaps left by community-based services. For dialysis patients, attending their treatment sessions is a matter of life or death; it was argued that often the rationale for involvement of renal psychosocial staff comes from the sheer practicality of making sure that patients are able to do so:

'I was thinking of an example where there was a situation of domestic violence, the liaison between the unit, the social workers, psychiatrist, consultants, was absolutely crucial because this person had to go to a place of safety, see women's aid in the dialysis unit so the dialysis unit had to make sure that they had privacy. And of course, the unit needs to know where someone is living so they can pick them up and this person had moved from place to place and of course had to be transferred to another hospital in another part of the hospital. So that part of that person's life hadn't particularly to do with renal problems, but the dialysis unit were absolutely pivotal in the support and liaison.' – RSW, unit E.

7.5 Chapter summary and key findings

This chapter integrated quantitative and qualitative findings to explore and compare outcomes and processes of psychosocial care across seven UK renal units. Box 6 and 7 summarise these findings, related to objectives three and four of this study.

Differences in the prevalence of distress, psychosocial issues and need for support were found across the case study sites, with lower prevalence reported in units that employed higher levels of dedicated renal psychosocial staff. This confirms the hypothesis posed in Chapter 6 and suggests that publicly available, community-based services are not adequate to give patients the support they need, as was also reiterated by renal staff. This study showed that RSW ratios appeared to be the most important predictor of distress, and patients in units with practical support (including welfare advice) reported the lowest level of need, highlighting the importance of the presence of this support to patients. The findings do not support any statements about whether psychology or counselling, or RSW or support work, would be the most efficient use of resources. Further investigations into the complexity and severity of patient issues are needed to answer this type of questions.

The data showed that the delivery of psychosocial services is mostly driven by psychosocial staff themselves and that attention to psychosocial wellbeing is not automatically provided. Yet, the investigation into the organisation of renal psychosocial care highlighted the reliance of psychosocial staff on clinical staff for successful service delivery. Clinical staff play an important role in identifying, informing and referring patients to ensure they can access psychosocial services. Moreover, there was the expectation that nurses would take on the responsibility for lower-level psychosocial support. It was felt that dialysis nurses were particularly well-suited for this role since they were in very regular contact with patients. This makes the dialysis nurse role different than that from other nurses. Yet, barriers, most notably time restrictions and personal attitudes towards psychosocial care, meant that not all clinical staff would take up this role. Whilst some did not want to, others felt they were not able to, or lacked the confidence to do so. Training on psychosocial issues was identified as a factor that influenced nurse ability to take up this part of their role. The support of adequate leadership and management, championing a holistic model of renal care that includes psychosocial support was found to be another important factor needed to establish a multidisciplinary approach to renal care.

Further, the data showed that not only is there no model in terms of psychosocial staffing types and levels, there is also no standardisation of processes of service delivery: each unit involved different types of psychosocial staff, in different ways, at different times along the renal pathway. The four units with the lowest distress levels appeared to have the most organised approaches to the delivery of psychosocial care. Two of these, to differing extents, had designed clear processes to offer psychosocial support pro-actively as patients moved along the renal care pathway. For example, some units offered patients a psychosocial RRT assessment, or had specific processes in place for those with an unplanned start to dialysis or those who were withdrawing from dialysis, with psychosocial support offered at set points in the process. Other units operated stepped-care models for RSW and psychology support, with psychosocial staff closely working with clinical staff to manage lower-level issues and patients only being referred to staff in case of more complicated issues. The current findings suggested that both methods could lead to reduced distress, and that the unit size could play a part in how process-oriented the service provision should be. The question of how different

processes of provision of psychosocial support influence outcomes requires further investigation.

Psychosocial support is still often seen as an add-on, instead of being part of comprehensive renal care. In all units, psychosocial staff explained how they had to 'battle' for their posts, signifying the precarious nature of psychosocial services. Psychosocial staff who had been successful in securing resources explained that they had the support of leading figures in the unit and were able to provide evidence of the need for their service – highlighting the importance of this and future research to inform a future psychosocial workforce. Staff were funded through different mechanisms, with money coming from different 'pots' (such as LA, NHS, or charities), with some units able to reclaim funds from the CCG. With different funding, come different remits, which lead to further variation within roles, as will also be described in the next chapter. Still, it has become clear that many renal patients deal with mental health challenges, which are not necessarily related to their renal illness. With generic psychosocial service provision increasingly unavailable, the number of patients coming to renal psychosocial staff in need of support has increased in recent years. Some staff are required to distinguish between renal needs and general mental health needs, yet it can be wondered if offering all patients access to psychosocial support through the renal unit, regardless of the source of their distress, would bring us a step closer to integration of services.

Box 6: Key findings related to objective three

Objective three: To investigate differences in distress, psychosocial issues and need for support across renal units with different models of psychosocial service provision.

- The prevalence of distress varied from 34.1% in unit F to 59.2% in unit C; patients in units F and G were significantly less likely to be distressed than patients in units A, B and C.
- Higher levels of psychosocial staff, and particularly RSW, predicted lower levels of distress; when taking staffing levels into account, demographic variables (apart from time on dialysis) were not found to be predictors of distress.
- Generally, patients in unit A and B (without practical support) reported psychosocial issues in numbers that were higher than average; patients in these units were significantly more likely to report a need for psychosocial services than those in the other units.

Box 7 Key findings related to objective four

Objective four: To generate an understanding of processes of service delivery within different models of renal psychosocial care.

- Clinical staff, and particularly dialysis nurses and assistants, played an important role in identifying and referring patients with distress, as well as managing those with lower-level issues.
- Training and support from psychosocial staff increased nurse ability to identify, refer and/or manage patients with psychosocial issues.
- In unit F & G, psychosocial staff developed stepped-care models to formalise the nursing role in providing psychosocial services.
- Time restrictions, personal interest and appreciation of importance of psychosocial care influenced medical staff's involvement in psychosocial care.
- Examples of proactive, process-oriented psychosocial care were found, to different extents: pre-dialysis psychosocial education (all units apart from unit A), psychological (unit B) and psychosocial (unit D) screening, routine pre-dialysis RSW assessments (unit D and E), explicit offer of support to unplanned starters on dialysis (unit D and E), and routine RSW involvement in conservative care process (unit D).
- Gaps in service provision led to inappropriate referrals across the system.
- The availability of psychosocial services was dependent on historical and financial arrangements, staff attitudes and resilience of those championing them.

Chapter 8: The renal social worker

8.1 Introduction

The third and final theme identified within this investigation into renal psychosocial service delivery, was the role of the RSW to explore in depth the finding that a better RSW-to-patient ratio led to significantly reduced patient distress. Chapter 4 described that in the US, RSWs are in a valued position, since ESRD is the only disease for which Medicare's care requirements stipulate a Masters-level trained clinical RSW working within every interdisciplinary team. Similarly, in Australia the RSW appears to be the first point of contact for renal psychosocial care. In contrast, in the UK, the staffing levels of (mostly bachelor-level trained) RSWs have reduced dramatically over the past 15 years, by 19%, from 55.0 to 44.6 FTE (106). The results described in Chapter 6 and 7 highlighted that for some patients and staff, there was a lack of understanding about the RSW role, its impact and/or its necessity. Building on these findings, this chapter presents the results of Study II, an investigation that aimed to provide greater clarity on the RSW role. The scope of RSW role is captured, by mapping the issues for which patients are referred, followed by an exploration of the activities that the RSWs undertake to offer support for these problems. The relationship between the prevalence of distress, anxiety and depression before and after RSW involvement is investigated. Qualitative data are examined to understand and explore the influences, challenges and opportunities for the future of the RSW profession.

8.2 Data and Sample and data analysis methods

The data collection methods for this study have been described in detail in Chapter 5 (Methodology). Fifteen RSWs from nine different renal units were involved in the embedded study, who provided the author with data from the following sources:

- Diaries: In order to provide insight into their daily activities, the RSWs completed an electronic diary, for a period of four months. RSWs started completing their diaries at different times, as soon as the local Research and Development offices confirmed capacity and capability to participate in the study. Overall, the diary data were collected between March and October 2018.
- Pre- and post-intervention questionnaires: In total, the RSWs recruited 161 of their service users into the study. These 161 patients completed a pre-intervention

questionnaire, reporting on their emotional status (captured by the DT, PC and other emotional thermometers), issues and expectations of the service. As can be seen in Table 25, there was no difference between men or women participating in the study. The majority of participating service users was between 51-60 years old, with over 70% below 60 years of age. The sample was predominantly white, mainly dialysis (HD and PD) patients, of whom the majority had been on dialysis for less than 3 years. The majority lived together with a partner or family and considered themselves unable to work, whilst 18% of respondents was still in employment. After intervention, all patients were asked to complete a post-intervention questionnaire, which again asked them to rate their emotional status and issues, in addition to reflecting on their experience and satisfaction with the service. Those who did not complete the post-intervention questionnaire were sent a letter from the RSW, together with another copy of the questionnaire once. In total, 88 out of 161 patients returned the post-intervention questionnaire, a response rate of 55%. Of those, eight patients did not provide a DT score on either the pre-intervention questionnaire or the post-intervention questionnaire, or both. Five patients did not complete the questions about their levels of anxiety and depression in the pre- or post-intervention questionnaires. Missing data has been excluded on an analysis-by-analysis basis.

- Focus group: Eight RSWs participated in a focus group about their role and activities at the University of Salford in July 2018.
- Secondary data: Where available, the RSWs provided the author with data on their referral numbers, active caseloads and any audit documents that they had prepared. There were however differences in the practice and quality of record keeping, which meant that not all RSWs were able to provide this data.

Table 25. Characteristics of respondents to the pre-intervention questionnaire

Characteristic	N	%	Characteristic	N	%
Total	161	100	Total	161	100
Sex			<i>Time on Dialysis</i>		
Male	79	49.1	<6 months	20	12.4
Female	80	49.7	6 months to 3 years	35	21.7
Missing	2	1.2	3 to 5 years	17	10.6
<i>Age Category</i>			>5 years	20	12.4
18-40	36	22.4	Not applicable	63	39.1
41-50	33	20.5	Missing	6	3.7
51-60	46	28.6	<i>Living situation</i>		
61-70	26	16.1	Living alone	51	31.7
>70	18	11.2	Living together	106	65.8
Missing	2	1.2	Missing	4	2.5
<i>Treatment Modality</i>			<i>Employment situation</i>		
Pre-dialysis	32	19.9	Employed, in education	29	18.0
HD	78	48.4	Unemployed	7	4.3
PD	12	7.5	Unable to work	94	58.4
Transplant	25	15.5	Retired	28	17.4
Conservative care	1	0.6	Missing	3	1.9
Carer	8	5.0	<i>Ethnicity</i>		
Missing	5	3.1	White	123	76.3
			Other	37	23.1
			Missing	1	0.6

8.3 Data analysis methods

8.3.1 RSW activities and scope

To gain insight in the scope of the RSW role, data were concurrently collected and analysed, to form an iterative interaction between what is known and what knowledge is further required. Throughout this process, verification of findings, through checking, confirming and making sure, ensured reliability and validity (274).

Based on initial, informal discussions with RSWs, a diary was created, which formed the basis for this exploration. The aim of the analysis of the diaries was to identify and make sense of patterns in the data, which can be done most easily if the data are presented in numbers and codes (259). All separate diary files were cleaned and merged into one STATA file, with variables reflecting categorical variables for the type of activity and a continuous variable for time spent per activity. Descriptive analyses, including the calculation of totals, means, and interquartile ranges of time, were performed for each activity category. For this first exploration into RSW activities, the diary had been designed in such a way to ensure

that the RSWs would record their activities as accurately and unambiguously as possible. To explore the wider scope of RSW, other sources of information, involving qualitative data, were used. Some RSWs provided comments in the diaries, describing what issue their activity was meant to resolve and who they had been in contact with to resolve this. For illustration, Figure 10 shows an excerpt from a diary.

Discharge activities	10	T/C care provider for hospital patient's dependent daughter re: discharge plans, check notes
Initial assessment	45	Finish assessment write up, liaise with admin and send to responsible medical staff
Benefits advice/forms/review	10	Left message re: cancel appt, left message re: liaising with hospital CAB re: benefits, write up case note
Research	10	describe research, leave with patient info sheet, not able to go through with me today--ward visit
Holiday	5	Discussed holiday plannign support available in the future

Figure 10. Excerpt from RSW diary

A request for secondary data on current caseloads led to descriptions of caseloads, to varying details (see table 26 for an excerpt of a detailed description). Other sources of information included participant master lists, in which RSW were asked to list the main patient issues of those patients who were recruited in the study, and the pre-intervention questionnaires, in which the patients were asked to list what issues they would like help with. All qualitative data on patient issues were analysed thematically and brought together under categories that illustrate the wide variety of issues that RSWs concern themselves with. Themes represented categories of patient issues, which were developed through a process of comparison of different issues. Each new issue was considered in terms of whether it fitted under an earlier category and if this was not the case, a new category was developed (259). The final coding framework is presented in the results section (section 8.4.1 – A visualisation of RSW, Figure 12).

Table 26. Excerpt from description of current RSW caseload

Pt. nr	Current issues	Past issues	Current Practical tasks	Current Psychosocial support
1.	<ul style="list-style-type: none"> • Post-transplant psy adjustment • Depression • Financial stress • Employment issues • Alcohol excess 	<p>Previous involvement over 3 years.</p> <ul style="list-style-type: none"> • Support on dialysis for mental health • Adjustment to treatment • Assistance to equip and clean home • Employment • Finance /grants/benefits 	<ul style="list-style-type: none"> • KCUK grant for mortgage • Advice on employment rights 	<p>Depression and alcohol excess. Liaison with alcohol nurse and meeting in outpatients to talk through feelings post-transplant</p>
2	<ul style="list-style-type: none"> • Depression/fear • Loss of hope • Treatment burden • Mobility /pain • Childcare /single parent • Concordance 	<p>Known for 3 years post-transplant and return to dialysis. Current contact arose from 'checking in' while on dialysis and building relationship.</p> <ul style="list-style-type: none"> • Benefits and general support. • Job • Managing on dialysis. 	<ul style="list-style-type: none"> • Key safe • Referral to OT • Liaison with consultant and psych • Advocacy with complaints about dialysis 	<p>Support with mental health/concordance and specific use of symptom targeted intervention.</p> <p>Plan peer-support meeting with another patient.</p>
3.	<ul style="list-style-type: none"> • Release from prison • Homelessness • Benefits • Mental health • Mobility 	<p>Known for 4 years. MDT communication to manage alerts for violent behaviour associated with personality disorder.</p> <ul style="list-style-type: none"> • Grant for mobility scooter. • Housing advocacy. • Mental health support. • Ongoing support in dialysis while serving sentence. 	<ul style="list-style-type: none"> • Follow up any practical tasks post release e.g. emergency access to grant, clothing etc • Reinstate grant for mobility scooter. • Current Extensive /crisis communications and planning with criminal justice and homeless services. 	<p>Regular contact by phone/ face to face to support with complex feelings and behaviour and alerts to MDT if building up.</p>

The results of the workforce mapping, initial analysis of distress and diary data, and questions that arose from the literature review, were used to inform the design of focus group topics. These topics shaped the analytical framework (Appendix 12) used to theme data.

Quantitative analysis of pre-and post-intervention questionnaires explored any differences in patient outcomes after RSW involvement. Descriptive techniques, including frequency tables and crosstabulations identified the prevalence of distress and psychosocial issues across the

pre-intervention patient population. Three separate, exact McNemar tests were run to determine whether there was a difference between prevalence of distress, anxiety and depression before and after RSW involvement.

8.4 Results

The results are organised within three themes. The first theme focuses on activities and scope of RSW, using quantitative and qualitative data to present an overview of what the role entails. The second theme uses quantitative data to explore the outcomes of RSW involvement, and the final theme uses focus group data to investigate the position of the RSW within the LA and health care systems.

8.4.1 The scope of Renal Social Work

8.4.1.1 Patient issues

The results from the pre-intervention questionnaires show that generally, RSWs support patients who are experiencing distress. Of the 155 patients that provided a distress score before RSW involvement, almost all patients (91.6%) were classed as distressed and a large proportion (67.8%) reported a severe distress score of 7 or higher. 13 patients did not experience distress; six of those were seen as part of a routine pre-RRT assessment. These patients stated that they '*didn't know*' what they wanted out of the service, or wanted advice about the financial support available to them. The other seven non-distressed patients were HD patients. Of these, four requested the RSW's help to apply for a holiday grant, which is a relatively simple issue; the other three patients required help with their finances. Based on data from the PC, Table 27 **Error! Reference source not found.** provides an overview of the proportion of patients that reported a certain psychosocial issue before RSW intervention.

Table 27. Patient issues reported on the PC prior to RSW intervention

Issue	N (%)	Issue	N (%)
Finance	105 (64.0%)	Transport	43 (26.2%)
Anxiety	104 (63.4%)	Family health issues	41 (25.0%)
Sleep	104 (63.4%)	Lack of information	33 (20.1%)
Mobility	90 (54.9%)	Loss of purpose	27 (16.5%)
Depression	87 (53.0%)	Dealing with child	19 (11.6%)
Adjusting	71 (43.3%)	Dealing with partner	19 (11.6%)
Boredom	69 (42.1%)	Facing mortality	18 (11.0%)
Fears	63 (38.4%)	Sexual issues	13 (7.9%)
Housing	62 (37.8%)	Ability to have child	9 (5.5%)
Feeling isolated	58 (35.4%)	Childcare	7 (4.3%)
Bathing/Dressing	52 (31.7%)	Relating to God	6 (3.7%)
Decisions	50 (30.5%)	Losing faith	5 (3.0%)
Employment	48 (29.3%)	Substance abuse	4 (2.4%)
Appearance	47 (28.7%)		

Some patients required support for a single issue, but the data indicated that often, patients experienced multiple problems simultaneously. To illustrate, of the patients that reported housing issues, 80.1% also reported financial issues. Of those experiencing anxiety, 47.1% reported feeling isolated. The RSWs explained that frequently, as they start to work with a patient, a complex web of issues becomes apparent and the final outcomes of their involvement can be completely unrelated to the initial reason for referral. These complexities can mean that an initial practical problem can spiral to have a negative effect on a patient's medical treatment, in line with the biopsychosocial model of care:

'So someone comes in and says: "I've got dialysis, but I can't afford to come in, can I get free transport?" "Why can't you afford to come in?" You find out that they might not be on the benefits they are entitled to, they have used up all their savings, they are on a tiny, tiny income. They are not eligible for benefits because they have got no entitlement to public funds or they are using the money for some other issue and they can't live within the situation that they've got. That then leads to depression, anxiety, their house is going to be taken away from them, the gas bill can't be paid, the electric bill can't be paid and it's a spiral of all these practical issues that can be unpicked and solved one by one that leads them to poor adherence and poor dialysis treatment for example.' – Debra, RSW.

During the focus group, when asked for reasons for their involvement, a RSW pointed out that:

'[RSW] does not necessarily have to do with the patients' illness, or with decisions about their illness, but is about everything that goes on in their lives.' – Jennifer, RSW.

The RSWs would not only get involved to support patients, some were found to extend their services to carers, for example for emotional support or a carer assessment.

8.4.1.2 RSW activities

The next section explores the activities that RSWs undertake. It was stated that:

'We do whatever we need to do to help patients cope with their renal disease. It sounds so simple, doesn't it? But everyone is so different, and everyone's experience of renal failure is so different'. – Jennifer, RSW.

As such, RSWs do not have one type of intervention that can be applied to all patients. Analysis from the diary data indicated that the role consists of a wide variety of activities and responsibilities linked to a large number of patients issues that manifest. The key activities that emerged are shown in Figure 11. RSW involvement would entail either solving an issue directly, or through advocating, referring or liaising with other members of renal staff, or outside agencies and/or organisations. Importantly, one intervention would often include multiple activities. With regards to emotional support, two RSWs explained that they also have a counselling qualification. Unlike in the US, counselling therapy, such as CBT, was not something that RSWs would routinely be involved in.

Figure 11 shows that large variations existed between how much time each RSW spent on the different activities and whether the RSW even did certain activities, such as supportive care or hospital discharge work. For example, time spent on financial issues varied from 3.8% to 36.2% and whilst one RSW hardly spent any time (0.4%) on discharge activities, another spent 28.6% of their time on them.

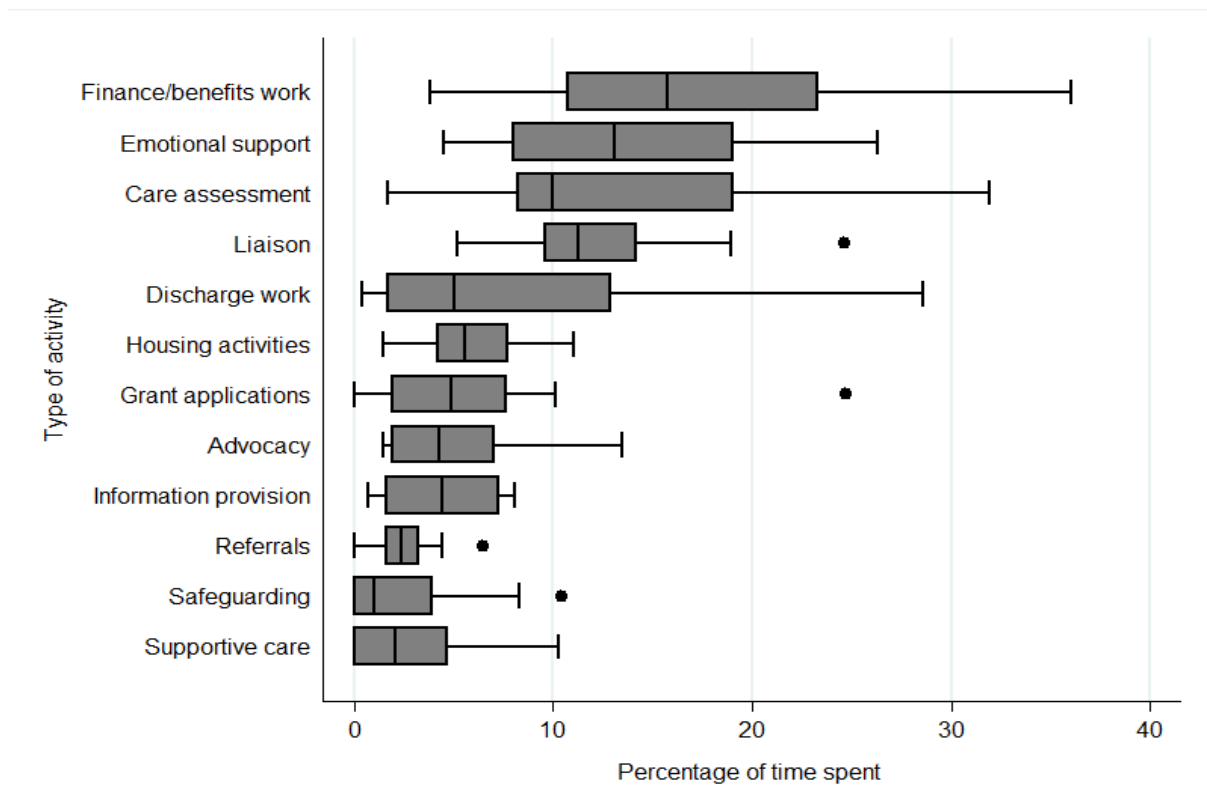


Figure 11. RSW main activities, based on time spent per activity

Activities that were not directly patient-related, such as attending meetings, travel time and administrative tasks, are not reflected in Figure 11, although large variations exist in time spent on those activities also.

Qualitative data analysis provided further insight into the main reasons for these variations. Firstly, differences in funding and employment arrangements were found to impact on RSW activities. As described in chapter 2, the psychosocial workforce survey showed that around 50% of RSWs were employed by the LA and the other 50% were employed by the NHS Trust or Mental Health Trust. Funding for the majority of posts came from the renal department or the hospital budget (69.4%), whereas some posts were (joint or completely) funded by the LA (19.4%) or through other arrangements such as charity funds (11.2%). Only RSWs employed through the LA have the authority to put care packages in place or undertake statutory assessments for other services that are provided through the LA, as long as these patients live within the area that their jurisdiction covers. Occasionally, these RSWs would submit a request to trigger their own assessments, thereby circumventing the long waitlists of the LA. This was not the case for non-LA funded RSWs, who explained that an important part of their role was to advocate for patients to ensure that they receive appropriate and timely support:

'Advocacy is a big part of our specialist role. We have to phone, push the case, argue the case. If there is a need, often they'll prioritise ringing us back. Or for an OT assessment, if you don't say the right thing, they can sit on the waiting list for ages and ages.' – Carmen, RSW.

'I think that is the point, they do wait for ages. We can't do those assessments. We can't bump people on the list. So, the only way for a renal social worker without that LA jurisdiction to help is to phone up and say this person is high needs, they look healthy, but they are not because of this, this and this. That is really where a lot of our role comes in, advocating for these patients.' – Maria, RSW.

The composition of the MDT and the processes of care delivery were identified as other reasons for variation in roles, in addition to differences in the availability and quality of community services. This highlighted how the activities of RSW were dependent on the presence or absence of other professionals or organisations and how the RSW role is shaped as a result of it. For example, some RSWs stated they worked together with a hospital benefits worker or were able refer patients to a good local disability advice organisation. This meant they would spend less time on benefits work than others who did not have that opportunity. In a similar way, and linked to findings described in the previous chapter, it was found that if the renal unit had access to a wider renal MDT and nurses as opposed to RSWs were routinely part of the process of service delivery in areas such as supportive care or pre-dialysis care, the RSW would be less involved in those activities than other RSWs who were part of that process. To illustrate, the RSW from unit D, where psychosocial staff are part of the supportive care process, reported the highest percentage of time spent on supportive care. Instead, Becky, in whose unit this support was provided by dedicated nurses, reported one of the lowest percentages:

'I am very rarely involved in discharge. I have deliberately stayed away from that. We have a discharge coordinator so there is no point in doing double the work. I also do less with supportive care. We have supportive care nurses. Same with pre-dialysis nurses, they would be doing the home visits for example.' – Becky, RSW.

Maria, who covers a very large patient group on her own, emphasised the need for social work input in these processes. However, she felt that her patient population was too large for her to be involved in all areas and that it would be best if dedicated RSWs were assigned different areas of focus along the patient pathway:

'We don't have a supportive care structure at the moment, to manage exactly that, people in the last year of their life, to coordinate between social services the last care that they need and make sure that they get continuing care to make sure they don't have to pay for the care at the end of their life as is their right. We don't have anything apart from me. I'd really like a supportive care social worker in my team to take that on. And also pre-dialysis social worker, I'd like... I'd like my team to be very big! Because we are too big for one person to do everything' – Maria, RSW.

Other RSWs, who covered smaller patient groups, stated that they would 'move across' (Karen, RSW) the different areas and felt that this was one of the important qualities of RSW, to be able to provide continuity of care. It was recognised that staff levels and unit sizes played an important role in how well staff would be able to do this:

'It is down to number of workers for how much you can actually focus in different areas. At the moment, we have a finger in different pots and it moves as the demand shifts.' – Karen, RSW.

'Yes I think it depends on the area and the size of the unit, because I think we would find it quite useful to have a dedicated person in that team. So they can really build up the contacts with the individuals in that team.' - Maria, RSW.

The RSWs also explained they were not all funded to cover the same treatment modalities. Some, for example, were only funded to cover the dialysis population and not to get involved in transplant care. In theory, this could lead to further variation in the role. In practice, however, the RSWs would often still see patients of all modalities, which means that the population they cover is larger than the population they are funded to cover.

'A while ago, when they were talking about funding, the consultant said that the majority for funding was to look after the HD population and conservative care. However, we support across the board.' – Karen, RSW.

'So do we, but we do not have funding for that at all.' – Martina, RSW.

For some other activities, it was something as practical as the RSW's working schedule that influenced whether or not they would be involved in them:

'I used to be involved in discharge activities, but now that I have gone part-time I am not doing that anymore. I am also not involved in pre-dialysis education as much anymore, because they always run the pre-dialysis clinics on a Friday and I don't work that day'. – Jennifer, RSW.

Lastly, an important factor to consider when exploring the differences in roles is the large variation in RSW-to-patient ratios, identified within the renal psychosocial workforce mapping (Chapter 2). The RSWs were asked to present data on their yearly caseloads, which 12 RSWs provided. An exploration of this data indicated that there were differences in access to and in the breadth and depth of the RSW role across units. Table 288 offers some interesting insights as the referrals could be a sign of need for the service, or for awareness and knowledge of psychosocial issues and the service in those who refer. Firstly, it shows that there was a large difference between the number of patients that had been referred to the RSWs in one year, from 72 to 520 patients per 1 FTE. The RSWs explained that they would typically have some form of contact with all referrals, but that their caseloads can vary. Logically, this large discrepancy means that some RSWs have much more time to spend on an intervention than others. In addition, Table 27 shows the referrals as a proportion of the RRT population in the unit. RSWs also often covered the pre-dialysis population, which are not included in these numbers, yet these proportions offer interesting insights into the reach of the RSWs across the units, which vary largely from 7.2% to 61.6% of RRT patients. Generally, referrals appeared to be higher if ratios were higher, except for number 2 (whose pseudonym is not named to increase anonymity). Her response, however, indicates that perhaps this reflects an issue with record keeping, with referrals only recorded if the case is taken on:

'I get referrals all the time and I have to be really, really careful that I don't take too much on, because once you're involved with somebody and you're working when them, they have expectations so I have to try not to take too much on. So I might say to the person who is referring, look, I will see this patient but it might be three weeks, if they are not happy with that, this is what you can do and I try to find them help elsewhere.'

– No.6

Table 28 RSW referrals for the year 2017-2018

RSW number	1 FTE per RRT	Referrals per 1 FTE	RRT population
1	1:118	72	72/118 (61.1)
2.	1:1090	78	47/654 (7.2)
3.	1:395	93	130/554 (23.5)
4.	1:277	106	106/194 (54.6)
5.	1:265	116	139/319 (43.6)
6.	1:380	172	378/837 (45.2)
7.	1:500	265	476/901 (52.8)
8.	1:4372	520	416/3498 (11.9)

Qualitative findings indicate that where referral numbers were lower, RSWs appeared to have wider roles and could work more preventatively. There was time for holistic assessments, home visits and service development, such as representation at MDT meetings, research and organising group-level activities. In addition, the RSW was more visible across the units, could actively promote their service, identify patients in need and work with patients across the whole renal spectrum, including those who are not immediately engaging. Quantitative findings presented in Chapter 7 suggest that these could all be potential mechanisms for reduced patient distress on a unit level. Particularly home visits were seen as a valuable activity:

'If the patient dialyses here, I would also go and introduce myself on the unit. If not, I will probably go and see them in the community, unless something is identified that someone says like this person would like to see you in centre. Or the opposite, that people say this person is very private and doesn't want to speak in centre. You get a completely different impression from someone when you see them at home. So many times I've proved it to myself because I've seen people on the unit and they seem well, they appear appropriate, but then you see them at home and they are crumbling and it

is all a façade, and people say you know “that is kind of my game face when I go to dialysis and I try to be cheerful for other people, but actually inside it is not working for me”, or “I’m struggling with this this and this”. So yes, I think you get to know people better, most people, in their own environment.’ – Jennifer, RSW.

The reach and scope of the role reduces as patient ratios worsen:

‘Last year, I got over 150 referrals on top of my ongoing caseload. It just got too much, so I decided not to see CKD patients anymore. I also don’t travel to the satellite units anymore, although I know it might be difficult for those people to come and see me here. I help patients more over the phone than in real time. I don’t just go into the unit to chat to patients and introduce myself or advertise the service. There’s just much more demand for the service than I can handle on my own.’ – Layla, RSW.

‘I don’t go onto the renal wards anymore. I used to do a lot more on the renal unit. Within the team we used to split up all the new patients that came between us and introduce ourselves and say hello, but as the team we don’t have the time to do that anymore.’ – Maria, RSW.

The RSWs who cover large patient groups with minimal staff time stated that their resources would be mostly taken up by crisis patients, facing urgent situations such as imminent homelessness or visits from the bailiff. As such, the waiting times for less urgent cases would start to rise and the RSW involvement for these patients would involve more signposting or offering advice over the phone or email, as opposed to home visits.

‘I essentially have contact with everyone that is self-referred or referred. I don’t necessarily see them all, I would phone them up. I tell them who to contact and tell them to call me back if they need any help if they get the form. So, I won’t see them, just to say that. Depending on how busy I am on a particular time when I see someone, I might not go in as much depth with the support that I am offering to them as I might with someone else where I know I have a space next week. And where I can, I refer people on. I very rarely do any home visits. I think in all the years I’ve maybe done three. It takes

up so much time. If there is someone complaining about a housing problem, then they can send me photos or videos. I use a lot of that nowadays instead of coming over to see how bad it is.’ – Maria, RSW.

‘Like say if Mr X needs a new mattress, because his old one is uncomfortable, that wouldn’t be a priority. I would ring the person and say are you able to fill in a grant form. I try to send it via email, it saves me a bit. If someone can do that, I try to do it and not make it face-to-face. It’s one of the things that is difficult about the job, because it can be that you think it is about a new mattress and then it turns out there is actually also something completely different going on.’ –Jennifer, RSW.

Whilst some of these ways of working could be further explored as they might be examples of how to use modern approaches to be more time-efficient, it could be argued that due to this way of working issues could go unnoticed. Moreover, these RSWs were less visible to patients and staff, as they have less time to visit the units and attend meetings. The previous chapter identified the importance of education and relationship-building between staff and patients to ensure referrals and thus increased access to psychosocial services. These findings suggest that there is not only inequitable access to services between, but also within renal units.

8.4.1.3 A visualisation of RSW

The RSWs stated that they were often asked to explain what their role entailed. As previously described, data from pre-intervention questionnaires, diaries and caseloads were collated to visualise the scope of RSW (Figure 12). Figure 12 illustrates the large variety of issues that the RSWs were found to be involved with. Apart from providing further insight into problems that some patients might face, it also demonstrated that the RSW role, and the system it is part of, is broad and seems to entail:

‘...anything that improves the patients’ quality of life’ – Jennifer, RSW.

RSW involvement was categorised relating to issues within eight prominent domains:

- activities of daily living, including issues around personal care and equipment.
- finances and benefits, mainly relating to welfare advice and employment issues.
- housing, including issues with people's living situations and appropriateness of housing for home haemodialysis.
- treatment, mainly relating to supporting patients along their journey across the whole renal pathway.
- caregiver, supporting the needs of carers, sometimes also after the patient has passed.
- mental health, including ongoing support for patients with low mood and liaison for patients with more considerable mental health issues.
- social life, supporting relationships and social activities.
- legal issues, safeguarding and other issues that requires RSWs specific knowledge of the law.

Examples of issues within these themes are listed in the coloured boxes in Figure 12. An overview (although non-exclusive) of the large variety of possible agents and organisations that the RSW could interact with as part of their involvement is also mapped onto Figure 12 in the white boxes.

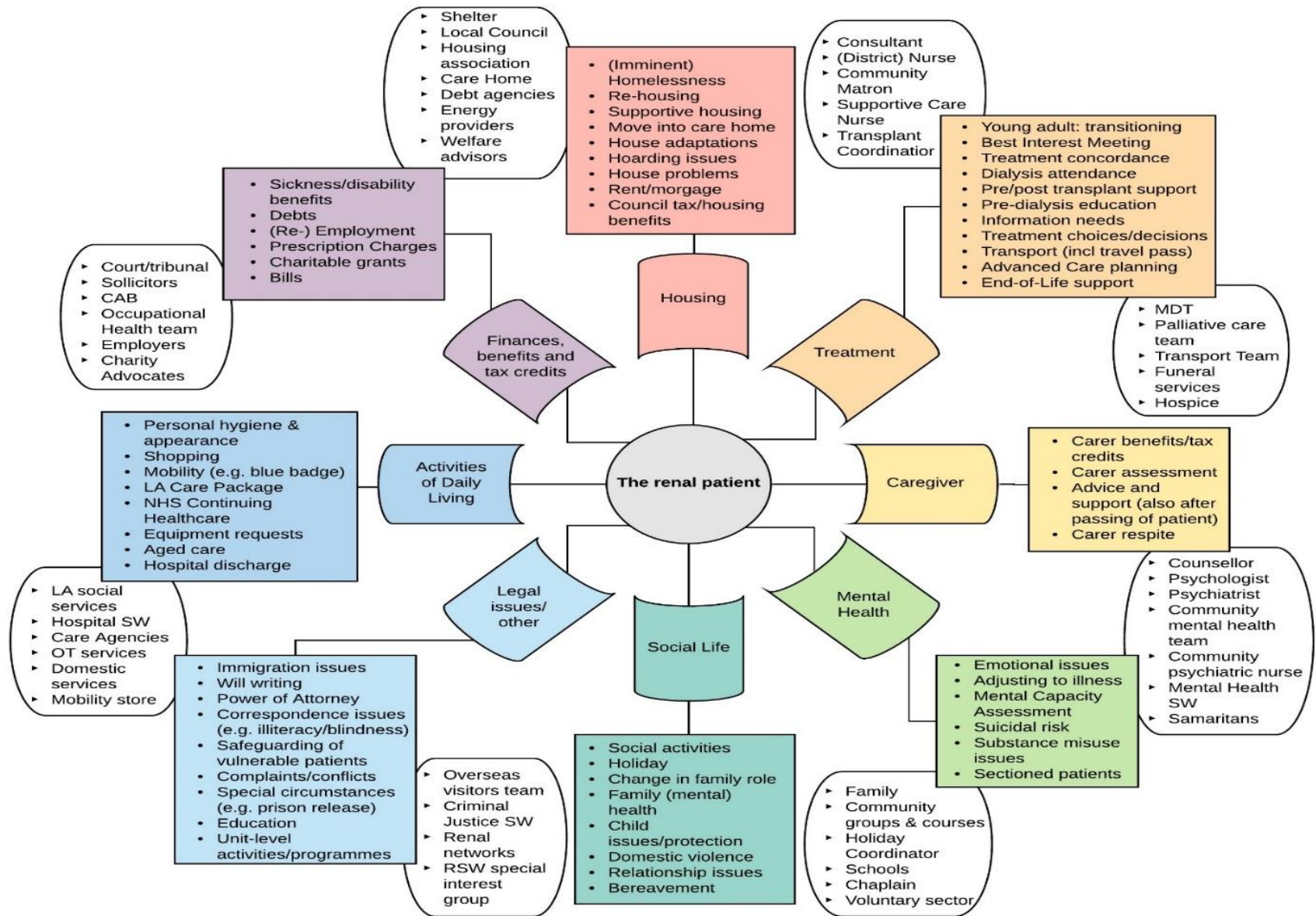


Figure 12. The scope of RSW: patient issues and interacting agents

8.4.2 Evaluating RSW involvement

Data from the pre-and post-intervention questionnaires were used to investigate the relationship between RSW involvement and patient distress. As previously mentioned, 55% of patients who completed a pre-intervention questionnaire returned their questionnaire post intervention. There was no significant difference between respondents and non-respondents on the basis of their demographics, indicating that all patient types might be as likely to return the questionnaire (Table 29). However, patients’ capacities and personalities were perceived to have an influence on the response rates:

‘The main difficulty is that most of these [non-respondents] are precisely the people who need our help to complete paperwork because of either capacity, fatigue and/or poor motivation. Some of them are young and notoriously bad at communicating. Of the older ones, two are now blind and one of them is suffering from memory loss so she probably won’t remember what the intervention was for. So that is why they are unlikely to be able to return the form without any assistance.’ – Martina, RSW.

Table 29. Comparison post-intervention questionnaire respondents versus non-respondents

Characteristic	Non-respondents (%)	Respondents (%)	Total (n=161)	Comparison of proportions
<i>Emotional issues</i>				
Distress	90.0	94.1		$\chi^2= 0.911$; p=.340
Anxiety	87.1	84.1		$\chi^2= 0.292$; p=.589
Depression	72.5	66.7		$\chi^2= 0.607$; p=.436
<i>Sex</i>				$\chi^2= 0.952$; p=.329
Male	32 (41.0)	46 (59.0)	78	
Female	39 (48.8)	41 (51.2)	80	
<i>Age Category</i>				$\chi^2= 7.95$; p=.093
18-40	19 (52.8)	17 (47.2)	36	
41-50	15 (45.5)	18 (54.5)	33	
51-60	19 (42.2)	26 (57.8)	45	
61-70	6 (23.1)	20 (76.9)	26	
>70	11 (61.1)	7 (38.9)	18	
<i>Ethnicity</i>				$\chi^2= 0.717$; p=.397
White	53 (43.4)	69 (56.6)	122	
Other	19 (51.4)	18 (48.6)	37	
<i>Treatment Modality</i>				$\chi^2= 9.545$; p=.089
Pre-dialysis	21 (65.6)	11 (34.4)	32	
HD	31 (39.7)	47 (60.3)	78	
PD	4 (33.3)	8 (66.7)	12	

Transplant	11 (45.8)	13 (54.2)	24	
Conservative care	1 (100.0)	0 (0.0)	1	
Carer	2 (25.0)	6 (75.0)	8	
<i>Time on Dialysis</i>				$\chi^2= 4.221; p=.377$
<6 months	6 (30.0)	14 (70.0)	20	
6 months to 3 years	15 (42.9)	20 (57.1)	35	
3 to 5 years	9 (52.9)	8 (47.1)	17	
>5 years	7 (35.0)	13 (65.0)	20	
Not applicable	32 (51.6)	30 (48.4)	62	
<i>Living situation</i>				$\chi^2= 0.984; p=.321$
Living alone	26 (51.0)	25 (49.0)	51	
Living together	46 (42.6)	62 (57.4)	108	
<i>Employment situation</i>				$\chi^2= 4.142; p=.247$
Employed/in education	18 (62.1)	11 (37.9)	29	
Unemployed	3 (42.9)	4 (57.1)	7	
Unable to work	39 (41.9)	54 (58.1)	93	
Retired	11 (39.3)	17 (60.7)	28	

Three separate, exact McNemar Chi-Square tests were run to determine whether there was a difference between prevalence of distress, anxiety and depression before and after RSW involvement (Table 30). The tests determined that there were significant differences in the prevalence of distress ($p= .007$) and anxiety ($p= .008$) before and after RSW intervention, but not in the prevalence of depression ($p = .252$).

Table 30. Prevalence of emotional issues before and after RSW involvement

Prevalence measure	Before RSW involvement	After RSW involvement	Overall percentage change	P-value
Distress (n=80)	75 (93.8)	64 (80.0)	-14.7%	< .01
Anxiety (n=83)	70 (84.3)	57 (68.7)	-18.6%	< .01
Depression (n=83)	56 (67.5)	52 (62.7)	-7.1%	.252

8.4.3 Factors influencing RSW practice

The previous chapters have identified a positive influence of RSW involvement on patient wellbeing, although the dramatic reduction in RSW numbers that has taken place over the last 15 years signals the profession is under threat. It has become clear that the RSW role is very much a fluid role, evolving in response to many external factors within different areas. The LA, the UK's social care system, and the renal unit have been identified as the main areas influencing RSW practice.

8.4.3.1. The position of RSW within the Local Authority

The RSWs described a disconnect between current practice within statutory social work in the LA or the hospital, versus how they perform their role. In chapter 3, it was described that statutory social work had gone through many changes over the years, focusing increasingly on safeguarding and care commissioning. RSWs appear to fulfil a broader role, similar to social work practice before the 1990 Community Care Act:

‘Renal social work is about being creative, getting into old-school, old fashioned social work. It is about getting to know people well and getting the best for them, because you know them well.’ – Jennifer, RSW.

The findings highlighted that the detachment of RSW from statutory social work has created a challenge, particularly for RSWs employed or managed through the LA. Since RSW does not fit within the management structure of statutory social work, the LA managers often do not appreciate the value of the RSW role:

‘I don’t feel valued by the LA that employs me. I feel resented. The LA are constantly seeing us as a hinderance, even though it is funded by the renal unit. But you’re providing a different level of care and support to people that the regular LA don’t, so you don’t fit into their tight package.’ – Karen, RSW.

This ‘resentment’ appeared to be mainly due to a lack of understanding about the RSW role, in combination with increasing pressures on community social work. One RSW identified her team was facing the same issues, illustrating how tensions in one system (in this case the LA) due to agents having their own agenda, can create issues for RSWs in another system they are part of (the renal unit):

‘We’ve had to fight to maintain posts...particularly the seniors were saying, why do you not pick up all your statutory assessments, not doing all the adult support protection work in the community for your clients? I think the image was that we try and avoid work. I think when a service is beleaguered, when you’re feeling a bit overworked,

anyone who looks like they're not pulling their weight, you are going to be a bit annoyed.' – Megan, RSW.

It was argued that RSWs support patients across the large catchment area that the main and satellite units cover, instead of just across the area covered by the council that employs them. If pulled into undertaking adult protection work or care package assessments for all their patients, they would not have time to carry out their specialist renal role:

'...of doing pre-RRT assessments, or things like giving advice on housing and benefits and doing counselling approaches for people who are anxious about treatment, or transplant'. – Megan, RSW.

It was said that because SW colleagues or seniors from other areas often do not understand this, there is a need to *'get the image right'* (Carmen, RSW). This starts with educating the direct line managers, who also often have

'...no idea what [the RSWs] day-to-day work is.' – Martina, RSW.

'It's about explaining that this is a preventative, nurturing service, that is around the patient, that the patient is a priority and that it is not like thinking in a LA statutory way.'
– Jennifer, RSW.

A lack of understanding about the RSW role within their own management and the wider social work community was not the only issue. Levels of supervision through the LA had reduced over a number of years, with managers based in the community rarely visiting the hospital. As a result, and linked to findings in the previous chapter, most RSWs did not have a dedicated senior to provide a manager presence within the *'upper-levels'* (Carmen, RSW) of the NHS, leaving the RSWs without someone to liaise or challenge issues with other managers in the hospital.

The feelings towards RSWs within the council, meant that the LA was perceived to be *'not a nice environment to work in'* (Karen, RSW). Yet, it was said that in theory, being NHS funded

but LA employed was a *'good balance'* (Jennifer, RSW) and enabled the RSW to offer support in the most effective way. However, because of the current lack of recognition, some LA funded RSWs were considering requesting to be placed under the NHS auspices completely. Being part of the NHS structure solely offered different challenges, discussed later.

Whilst the disconnect between the two types of social work was a challenge to the role, the findings demonstrated that RSWs practising in a holistic and comprehensive, *'old school'* (Carmen, RSW) way of working, could be better positioned to support renal patients than statutory social workers, for several reasons:

Accessibility

The RSWs who were funded through the renal budget explained that they were accessible to all patients for as long as they were under the care of a nephrologist. By not applying the strict eligibility criteria, the RSWs can offer support to many patients who would not get *'through the front door'* of social services. The RSWs explained that if these patients would contact social services, they would be addressed by so-called *'customer contact workers'* (Martina, RSW), who are not *'proper social workers.'* There was a consensus that assessments by these contact workers were not always fair and that patients were not asked the right questions to enable them to fully explain their situation and need for services:

'The patients are being, may I say it, deliberately stopped from accessing a proper social work assessment.' – Maria, RSW.

Instead, RSWs could support patients with lower needs for whom the LA would have no duty to assist and as such, worked in a more preventative instead of reactive way, to try to ensure that these lower needs did not escalate into a crisis. Carmen described that this meant that RSW were perhaps more *'therapeutic'* or a *'deluxe version'* as opposed to LA social work which:

'... only provides to those that have a need for safeguarding and care packaging. Anything beyond that is farmed out to the third sector and independent teams.' - Carmen, RSW.

RSWs explained that their expertise and advocacy support was needed by many patients to access community services and that the outsourcing of support to other organisations created problems. These organisations were not always able to support patients appropriately, as Maria found upon returning from maternity leave after her post had not been covered, leaving patients to try and access services on their own:

'My answering machine basically said for this year I'm not here: go to CAB with this problem, go to the law centre for this, or go to the council. That's it. Then I came back to find out a lot of people with high level disabilities had their ESA stopped and were about to be evicted, they had their PIPs dropped to lower levels. So, I came back to a lot of problems because my patients couldn't access the community services.' – Maria, RSW.

Data from pre-intervention questionnaires showed that in addition to practical problems, many patients accessing RSW services also suffer from emotional problems such as anxiety and depression. The RSWs explained that patients were not only struggling to access community social services, but community mental health services were also increasingly under pressure. This has led the RSWs, particularly those without renal psychology colleagues, to feel like they are *'also holding that patient group [with psychological issues] afloat'*, by providing lower-level emotional support.

RSWs were not only more accessible to patients because of their inclusive eligibility criteria, but also due to being based in the hospital. This allowed the RSWs to build relationships with medical staff, which have been identified in the previous chapter as an important part of renal psychosocial service delivery. Furthermore, most RSWs stated that they visited the units and patients knew who they were and how to self-refer to the service.

Holistic and continuous care

Renal patients often faced a variety of simultaneous problems. The RSWs argued that because services were now so fragmented, without their support, some patients would be left to interact with many different agencies and professionals across the health and social care systems on their own. Patients that required their support often felt too ill, overwhelmed or distressed to actively access these fragmented services. As was also indicated by findings in

Chapter 6, the RSWs argued that some patients did not know which services were available, or they lacked the capacity to keep an overview of their care.

'The agencies in the community are increasingly difficult to get hold of. People are living with so much distress, ill health and as a result lack motivation, strength and power, that they just give up.' - Carmen, RSW.

The RSWs acknowledged the importance of the nursing role in supporting patients with psychosocial issues, yet argued that the complexity of the social services system makes it difficult to navigate. Patients in the units come from different areas, covered by different LAs and other local organisations, making it difficult for nurses to be aware of services offered in the community and how to refer to them and following-up whether patients access the services. The RSWs argued that this is *'where they come in'*, because they are able to assess all patient issues and take on a case management role, a holistic service that other providers cannot offer:

'The nurses on the ward are not going to unpick all of the patient's problems, they are not going to have the knowledge to unpick this. No one else is, if you send someone out to the homeless team they will look at the homelessness, then they have to go to CAB, then referred to law centre for the next thing, then dietician, so many different places and they won't go because they've got 20 other appointments to get to. And no one, the outside agencies, they don't care enough about the whole issue to stop and unpick everything. And that is where we, renal social workers, come in, because we have the knowledge and experience to do that.' – Debra, RSW.

Not only do the RSWs provide holistic care, they also provide continuity of care, supporting patients as their needs change throughout their whole renal journey, from pre-dialysis to end-of-life care. This was considered beneficial for the patients, because unlike statutory SWs, the RSWs are able to build relationships, learn about patients' supportive networks and understand what works and what does not work for them. RSWs were able to:

'...cut through some of that bureaucracy that you would have in the wider social work setting'. - Jennifer, RSW.

'They get to know us, and that's what people don't get in Local Authority social work. They get an intervention and then it's closed and then somebody else comes along. And people value that continuity, because patients become fed up with having to tell the same thing to people time and time again.' - Maria, RSW.

This relationship was an essential requirement of a good intervention, because some patients would not share their personal problems before a certain level of trust was gained. The RSWs further stated that both hospital and LA social work would close cases much earlier than the RSWs would do, especially if patients were not engaging. Since non-concordance or non-attendance were often a reason for the RSW to get involved in the first place, they argued that immediately giving up on a patient that does not engage would go against their objectives.

Knowledge of the condition and the renal team

Moreover, the RSWs have knowledge of renal disease and awareness of the impact of the illness on a patient's physical and emotional wellbeing, daily schedule and wider social situation. RSWs argued that their renal expertise, together with being based in (proximity of) the renal unit and having a relationship with the renal team, provides further advantages of RSW as opposed to LA social work:

'...knowing the condition and the team is what makes the difference.' - Layla, RSW.

By acting as the mediator between medical staff and patients it allowed them to support those who experience distress due to questions or disagreements about their treatment:

'I find a lot time that I might be mediating between medical staff and patients and I think what they hear from medical staff, how they hear it, is different to when they talk to us. We've got the link with it, but we are not clinical.' – Karen, RSW.

It also meant that the RSWs were able to benefit renal patients on a group-level, by challenging issues that affect multiple patients, or by organising peer-support activities or initiatives for several patients at the same time. Furthermore, RSWs were usually able to offer more flexibility in scheduling appointments around or during treatment times, offering ease of access by seeing patients in the units, although some would also do home visits if preferred. They also reported having greater understanding and continued engagement when patients miss their appointments.

RSWs work more easily, in an integrated way, with other (renal) allied health professionals, such as psychology or occupational therapy services. This integration in the team, knowledge of the patient, and understanding the importance of treatment, is vital to be able to respond swiftly when situations arise that could stop patients from attending their treatment. Carmen stated that since these problems were *'normally a crisis'* and *'normally chaotic'*, being at the *'front-line allows RSWs to be responsive and immediate'*, unlike LA social services as became clear from this dialogue:

'When I was on annual leave last year there was a carer in crisis, and they [social services] said 'we'll give you a list of care agencies', because she was self-funding'. – Becky, RSW.

'...Which is against the care act'. – Debra, RSW.

'Yes, two days later her husband was in hospital because he was so poorly, the list of care agencies hadn't even gotten to them by that time'. – Becky, RSW.

Finally, the findings showed that RSWs specialist knowledge of renal disease was of vital importance to help patients articulate the impact that the illness had on their lives in such a way that would grant them access to (benefit) support they were entitled to. Especially for dialysis patients, this can be complex, since their health and ability to look after themselves can fluctuate greatly throughout the day. It was said that if RSWs did not help to complete requests for support and followed up with advocacy efforts, patients were often refused.

'As a renal social worker, you know the condition and the symptoms, so you know how to ask the right questions when filling in forms, when to explore, or get more into details. For example, someone might say 'yes' to the question if they can get dressed or can

walk up the stairs, but then don't say that they will be so tired after that they have to rest for 3 hours. Non-renal staff won't know this and then patients won't get the support they should be getting.' – Layla, RSW.

The criteria [from social services] are strict, but we can frame it in such a way, only through having the knowledge, that specialism. It is not saying that we are winging people through because we are throwing our weight about, they genuinely should meet the need. Alternatively, if they don't then we become creative and look at third sector agencies, grants, or different ways of working, different ways of supporting people. If we didn't, I don't think things would move on for that patient or that family. They would remain static.' – Carmen, RSW.

Renal knowledge was also required to advocate for patients during assessments for PIP or social care packages

'... otherwise they [the assessors] will miss things out. People often have to wait a long time for an assessment to then hear they do not get the equipment; they'd have to buy that themselves. Then I say: "But have you told them you can't get down the stairs and about difficulties with meals etc?", then their response will be: "Well, they didn't ask".'
– Maria, RSW.

8.4.3.2 Inadequacy of the UK's social care system

The UK's social care system has placed increasing pressures on RSWs and their ability to support patients. All RSWs - regardless of funding or employment arrangements - have to work within the confines of what is provided by the LA. This means that although all patients are entitled to a RSW assessment, this does not automatically entitle them to LA support. As eligibility criteria tightened, RSWs saw the referrals to their services increase, as did the time they spent advocating for patients with the LA. In line with what was described in the previous chapter, the RSWs felt that services within the social care system were increasingly inadequate.

'Increasingly, so often, and this is my bugbear at the moment, I am referring and people are just not acting on referrals. In fact, I feel like they are tearing it up, people are just not getting responses. You leave a referral with people and you think 'job done', but then you find that it has not been followed through. And for me, I want to know that something is done, it is completed. So increasingly we're finding that things are not done, especially with children services at the moment, you can refer, leave a message, and agencies are just not following things through. Because they are flat out, no doubt, but that leaves us leaving someone we've assessed needing A, B, C kind of left in limbo.'

– Carmen, RSW.

This quote also illustrates the importance of the RSW in a coordinating role, following up and keeping overview of different aspects of patient care.

Changes in the social care system, and particularly the benefits system, in combination with increased pressures on community and hospital social services, have led to increased referrals to the RSW service and changes to the role. Since the introduction of PIP and universal credit, benefits work has increasingly drained RSW resources. Megan and her team had explored their referral data between 2010 and 2018 and found that their referrals in the same two-month period had increased from 17 in 2010 to 71 in 2018. In 2010, their role seemed to almost exclusively consist of conducting pre-RRT assessments and this number stayed relatively stable over the years, increasingly referrals related to benefits issues, grant applications, discharge planning, housing issues, carer support and other issues such as immigration and homecare were received. Specifically, referrals for benefits increased from 1 in 2010 to 15 in 2018 over the same two-month period.

Yet, benefits work is not part of the social work qualification and the RSWs emphasised that they were not benefits experts and that they would *'gladly refer that on'* (Layla, RSW). However, if there were no other adequate services available to refer onto, such as hospital benefits advice or CAB, the RSWs felt compelled to support patients with their benefits questions. The reason being they *'get good results'* and were aware of how imperative finances are for someone's wellbeing, and what the far-reaching consequences of patients not receiving the benefits they are entitled to would be:

'This is what people live on, their income. I never do them [pip applications] lightly, so if it takes two visits to make sure it is all correct, then that time is really important to patients. Because the tribunal side of things, there is one patient now who waited more than a year for the tribunal date. So yes, it has to be right from the start.' – Jennifer, RSW.

Even though a new PIP application could easily take up four hours of their time, the RSWs were reluctant to have the benefits work completely taken away from them. It was seen as valuable, because it offered a 'way in' to build a relationship with the patient and often illuminated more complex issues that fell within the remit of RSW.

'You never know what might come up during a PIP assessment. Last week, I went to a patient to complete the form, but we ended up discussing his feelings and options for withdrawal from dialysis instead.' – Megan, RSW.

Therefore, RSWs would like to keep the link to benefits work by joint working with a renal dedicated benefits worker or a renal social work assistant. This member of staff could then take up the lower-level (benefits) work, but still escalate the case within the same team if required. This would then leave the RSWs more time to

'...focus on more complex cases, research, service development and group work'. – Debby, RSW.

8.4.3.3. The position of RSW within the renal unit

Several challenges for the RSW role were identified within the renal unit as an organisation. Firstly, the RSW service need was increasing, not only because the patient group had grown over the years, but also because mainly those on dialysis were said to be increasingly frail and vulnerable. Aside from these individuals often requiring social care, it was stated that they also often have a higher need for advocacy input:

'Often people don't follow up on services themselves. I guess you could say "well they should be more proactive in doing so", but again, if you are feeling so rubbish and when

you look at the dialysis population in centre, at least now, so many are frail, so many are unwell, older, then it becomes very difficult to stand up and fight people after waiting to be answered for half an hour, an hour.’ – Carmen, RSW.

Despite growing patient numbers, RSWs felt hospitals were reluctant to extend their hours. In addition, in many renal units, RSW posts were often not covered during maternity or long-term sick leave, or filled once a RSW retired or moved to another job. This has reduced RSW-to-patient ratios, leaving the RSWs feeling like they are *‘only scratching the surface’*.

‘I think it is a real struggle. I know that there are patients that I miss, with the best intention in the world I know that I can come back from a weekend and have 30 referrals. 10 people saying: ‘Can you see me?’ And then 10 self-referrals from people that I have seen before.’ – Maria, RSW.

Whilst a lack of funds is often the simple explanation that is offered in these contexts, the findings indicated that this might be linked to questions about the purpose and necessity of the RSW role within the hospital setting.

‘We all agree that renal social workers have special knowledge, but we are up against convincing the powers that be, because in our hospital they are saying ‘We don’t have a special social worker in oncology and all the other specialities. If we don’t need one in the other specialities, why do we in renal?’ and I think that is what we are up against, you know?’ – Rebecca, RSW.

In addition to RSWs having to defend why their role was a necessity, the findings from the previous chapter highlighted that in unit C, a sentiment prevailed that the social work profession was not necessarily what patients need. Staff in these units argued that instead, an unqualified professional, such as a benefits advisor or social support worker, could provide all the social care related support patients need. The RSWs argued that specialist knowledge of the illness, the law and available services is required to help patients get the support they are entitled to. Moreover, RSW consensus opinion was that staff who did not have a social work qualification may not have this extended knowledge of the law and are not

appropriately trained to manage complex cases in which patients require several levels of input.

During the focus group, all RSWs shared that they felt valued by the renal department and that they saw themselves as an integrated part of their team. However, a closer look at the data indicated a slightly different picture.

'I don't think it is a positive experience for everybody with the MDT. The medical model still prevails. Our lead nurse, she doesn't see the social wellbeing and the mental health of our patients as critical as their physical care and I think this is an issue that we've had with more nurses.' – Carmen, RSW.

Carmen implied that the impact of psychosocial issues and the importance of solving these issues, was not necessarily recognised or seen as a priority by all the established (medical, consultants and nurses) staff in the unit. She referred to working with the MDT to change these attitudes as *'a battle'*, with other RSWs also explaining that they often have *'trusted colleagues'* that they work with. This indicated that RSWs and their work were not necessarily seen as an essential part of the MDT by every member of staff in the unit. Instead, Carmen felt that RSW will *'always be considered a commodity'*. Jennifer had been in her post for more than 15 years and said that *'at the most part'* she had a *'great'* relationship with nurses and consultants. However, she also stated that she:

'...worked hard to do that, it is not an easy job to do that, it is not an easy job to do... You have to go in there and sometimes you just have to come 'this is how I feel today' and you've got to give it to staff and say this is our patient and this is why we are here, it's not just about mitigation and just about turning up for dialysis, we need to look at it a bit more in depth.' – Jennifer, RSW.

An area in which the recognition and integration of the RSW in the team was most visible, was that of referrals into their service. The RSWs explained that they received varying levels of referrals from across and within units. This was dependent on the nurses' awareness and

attitudes towards psychosocial problems, but the data suggested that this was also linked to medical staff's knowledge about the availability and scope of the service:

'We find that when we've done a particular bit of work with the consultant about somebody, then for a little while all the emails will be with referrals. But then they will forget about us and the referrals will reduce again. So, I think sometimes you know, when all our colleagues are busy, they do know what we do, but what is the referral... what is the first thing. So, we have to keep reminding them of the breadth of what we do.' - Megan, RSW.

Similarly, it was indicated that RSWs value is not always recognised, for example when they are not asked to provide support to one of their clients if they decide to withdraw from treatment:

'And that is one of the things which can be really difficult, when talking about withdrawing about dialysis and they bring in someone they don't know at all and you think "but we have known this person for 5 years!"'. – Martina, RSW.

In line with this, and with findings presented in chapter 7, RSWs also stated that it was essential for them to keep educating the MDT about their role, and the difference between their role and that of statutory social work. This is particularly important for RSWs who are relatively new in their post, with those who are more established saying that:

'they've known everybody for a long time, so people tend to know what you do, and when you do it'. – Jennifer, RSW.

Whilst Karen said she felt that patients accessed her service *'through luck, more than anything'*, the data suggested that this 'luck' appeared to be linked to the relationship that the RSW had with a patient's consultant or nurse, and the awareness that this member of staff had of psychosocial issues and the RSW service.

Educating the MDT about the RSW role was found to be important not only to ensure that patients were referred to the service in the first place, but also to generate appropriate referrals. Most RSWs reported a lack of a clear referral pathway, with inappropriate referrals taking up their time and making their role more chaotic at times, in addition to complicating record keeping efforts:

'We get all sort of referrals - we get stopped in the corridor, or asked during an MDT meeting, often emails, or clinic letters in our pigeon hole.' – Debby, RSW.

Some said that they had tried to implement a referral process, with varying success.

'We don't want to make it bureaucratic and prevent a referral, but it helped us to allocate it, so we can record all the referrals.' – Karen, RSW.

Becky also reflected on the *'really poor referrals'* that she sometimes received:

'Just a name and when they dialyse and that they want to see a social worker. Once a nurse even told me that the reason for referral was that the patient just looked really sad, she hadn't even discussed with him if he wanted to be referred to me. I've tried to get people to do it via a different way, I said "you wouldn't accept a referral just by speaking to you".' – Becky, RSW.

There were additional issues within the renal unit that caused concern for the RSW role. Firstly, the hospital structure was often not set up to provide the RSW with adequate management, supervision and training. This mainly affected those employed and funded through the NHS, supervised by other psychosocial staff or nursing staff, instead of by an experienced social work manager. NHS-employed RSWs did not have access to the LA training. Instead, they stated that they could access NHS training, but this was of lower quality. Furthermore, NHS RSWs were not able to access the LA recording systems, which meant that they could not review a patient's historical social care record to examine if community social work was or had been already involved. This was something that the LA RSWs described as one of their valuable additions to the MDT. Conversely, many RSWs reported that they could

not record on the hospital system, which meant that there was often no record of their involvement in patient care. Those that could record stated that they would often only put a note on the record to say they were involved, but did not see it as appropriate to write down the details of their involvement for all the staff to see. Especially if the patient had self-referred to the RSW, and many did, this meant that sometimes staff would not be aware that the RSW was working with their patients.

Lastly, the RSWs role was affected by the physical structure of the renal units. RSWs reported issues with the availability of rooms as a restriction to their service, especially in the satellite units. For example, Maria's decision to run a social care clinic in one unit and not the other, purely came down to the practicalities of available space:

'I used to do it at another hospital, but the room they had available to me was a tiny and very hot room, uncomfortable, I was often told to move.' – Maria, RSW.

8.4.4 The autonomous RSW

The previous sections painted an image of the RSW profession being under threat, appearing to exist at the mercy of higher powers within the LA or the hospitals, heavily influenced by economic and political trends in the UK. Yet, the findings showed that on a day-to-day basis, the RSWs felt their course of action was often of their own choosing, with the RSWs describing high levels of autonomy in their daily practice. Jennifer, who was LA-employed but NHS funded, illustrated that these levels of independence appeared to be linked to the previously described lack of understanding about the role and the funding and management arrangements:

'I have been able to kind of design the service, because I don't think anybody really knew. It runs as I wish it to run, nobody else really knows that much about it as I do probably. The managers don't set me any targets about how many patients I see or anything. As far as they are concerned, they think: 'you are running the renal service here, that's what you do, numbers aren't really important as such, as long as you're seeing the people that they want you to see within a decent timescale, that's what the renal unit are paying for'. – Jennifer, RSW.

Jennifer was not the only RSW who explained that she had designed the service herself or had been able to allocate her caseload to best fit her situation. However, it can be questioned whether this freedom was ultimately in the RSW's best interest, personally and professionally. Whilst some see this autonomy as *'the nice thing about renal'* (Jennifer, RSW), others feel that it also makes the post *'very isolated'* (Karen, RSW), describing a feeling of *'having to carry the whole service on your shoulders.'* (Carmen, RSW). The lack of monitoring of her work had left Karen feeling vulnerable:

'The problems that I have encountered by being funded by LA but employed by the hospital with having to go to coroners is that the legal team of both sides... you don't get that support. You are in the literally in middle and on your Jack Jones and that can be really isolating.' – Karen, RSW.

Whilst the RSWs stated that they decide when to open and close a case, previously described findings suggested that their activities were heavily influenced by the referrals and composition of MDT and the RSWs relationship with their renal team. Although the RSWs describe themselves as autonomous, their activities appear to be heavily influenced by arrangements within the systems they are part of, and vice versa.

8.5 Chapter summary and key findings

This chapter presented the findings of a first-ever exploration of the UK RSW role. It was found that instead of forming a routine, integrated part of renal care, RSW assessment and support is often offered at the discretion of medical staff or through self-referrals. As such, RSWs often support patients and carers with high levels of distress. The RSWs, with their broad and creative role, serve an important purpose in advocating for patients and filling the growing gaps left by community social services. They are able to offer continuous rather than episodic care and support patients that would not meet the strict LA eligibility criteria. The findings showed that this support leads to significantly reduced distress and anxiety. However, findings indicated that the RSW role was poorly understood and not always recognised by renal staff. As staffing ratios worsened, RSWs increasingly moved into the periphery, further

enhancing invisibility, and perpetuating a lack of clarity about the role. Box 8 provides an overview of the key findings in relation to the RSW role.

Box 8. Key findings relating to objective five

Objective five: To gain a deeper understanding of the renal social worker role

- The renal social worker role is broad, fluid and ill-defined, with variations in roles found linked to differencing in employment and funding arrangements, MDT configurations, standardised processes of care, availability of community services and staff-to-patient ratios.
- The reach and scope of RSW reduces as patient ratios reduce
- RSW is different than statutory social work (hospital social work or LA social work). In theory, RSWs are better positioned to support renal patients than LA social workers, because they are accessible, flexible, able to offer continuous and holistic care, and importantly, they have knowledge of the condition and the renal team.
- RSW face several challenges: increasing patient numbers in combination with higher complexity of patient need and reduced staffing hours; lack of understanding about the role in the hospital and in the LA, leading to resentment in the LA and clinical staff questioning the necessity of the role.
- A lack of adequate management, leadership, supervision and training has left RSWs to work autonomously, often alone, and without a voice.

Chapter 9: Discussion

9.1 Introduction

The overall aim of this study was to investigate the organisation, processes and outcomes of renal psychosocial service delivery in the UK, which had been largely unexplored. This ultimate chapter brings together and discusses the main study findings alongside existing evidence, exploring the implications and recommendations for practice and future research. It particularly focuses on new knowledge created in this thesis that is of relevance for policy makers and practitioners in allocating resources to the management of psychosocial services. In summary, this thesis:

- Established the current state of the renal psychosocial workforce for the first time in almost 20 years, highlighting large inequalities in service provision and exceedings of recommended staffing benchmarks across the UK.
- Showed how these inequalities could lead to differences in patient outcomes, by exploring the prevalence of distress and need for support across renal units, purposively selected based on their models of psychosocial service provision. Evidence was provided of the impact that renal psychosocial staff, and particularly RSWs, had on patient distress, which was confirmed by another investigation that found reduced distress and anxiety levels after RSW intervention.
- Drew attention to the importance of involvement of clinical staff in the process of psychosocial care delivery and highlighted barriers to this involvement.
- Used the DT and PC to determine the need for renal psychosocial services, giving new insights into the high burden of practical, social care related issues experienced by patients and their difficulties with accessing community social services, in addition to confirming research on the prevalence of psychological problems.
- Presented findings of the first-ever in-depth exploration of the RSW role, which identified threats to this unique, specialised profession that stand in the way of efficient, integrated working.

The chapter concludes with a discussion of strengths and limitations of the study.

9.2 Inequality in psychosocial service provision

The mapping of renal psychosocial services undertaken as part of objective one of this study (Chapter 2) provided new insights into the state of the renal psychosocial workforce. It highlighted a variety of models and availability of psychosocial services across units within the UK. An exploration of relevant policy documents (Chapter 3) showed that one of the reasons for this variation could be found in renal policy. Policy documents that state patients must *'have access to'* psychosocial services (170) hardly seem strict or specific enough. This suggests that renal units do not have to employ staff to provide these services, nor does it clarify the type and number of staff that should be accessible. It appears that due to this 'no-rules policy' on psychosocial support for renal patients, some renal units have created their own, local approaches to psychosocial service provision, with other units not providing any renal psychosocial support at all. Instead of being seen as a standard part of renal care across the country, findings showed that the availability of dedicated psychosocial services is very much dependent on the resilience, persistence and creativity of those championing it in their unit.

The high prevalence of distress and reported need for services in the current study suggest that there is an argument to be made for increased patient access to psychosocial services. It was found that almost half (48.9%, 95% CI: 44.5 – 53.4) of ICHD patients participating in this study experienced some form of distress ($DT \geq 4$), with 23.7% of patients experiencing severe distress ($DT \geq 7$). In addition, 20.5% of patients reported an unmet need for support. The use of the DT is a relatively new phenomenon in renal research; to the author's knowledge, only two studies explored distress as measured by the DT in UK renal patients. The first study is from Alston (86) who validated the DT in the renal population and whose classification is used in this study. Studying one renal unit, Alston found distress in 54.7% and severe distress in 23.4% of HD patients. Another study, by Damery et al. (15) studied distress in participants along the whole ESRD pathway, including pre-RRT, dialysis and transplant patients. They used a different classification of distress, also incorporating scores on the ETs. Patients were defined as having mild-to-moderate distress if they scored between 4 and 7 on the DT (regardless of scores in the other ET domains), or scored 0 – 3 on the DT and 4 – 7 on one or more of the anxiety, depression and anger thermometers, with no thermometer exceeding 7. Damery et al. (15) found mild-to-moderate distress (DT score 4-6) in around 35% of HD

patients, and found severe distress in 12.3% of their overall study population. The ETs have not been validated in the renal population, yet had this classification been used in the current study, the prevalence of mild-to-moderate distress would have been similar at 35.6%. The level of severe distress would be higher than what Damery and colleagues found, namely 23.5%. However, this last comparison is less appropriate since the results from Damery et al. (15) represent scores across the RRT population. Moreover, the focus of their investigation was on mild-to-moderate distress; patients in receipt of psychiatric services were excluded and they distributed questionnaires via post. The current investigation brought issues to light with patients receiving RSW intervention not returning questionnaires without support. It was found that this type of patient often scored high on the DT, which might indicate that Damery et al. (15) underestimated the prevalence of severe distress.

The identified variance in models of service delivery was further explored in objective three, which asked whether there were differences in distress, psychosocial issues and need for support across units with different models of service provision. By doing this, the current study specifically and uniquely added a health systems research perspective to investigations of distress, which highlighted important findings: after accounting for levels of psychosocial service provision, demographic factors (apart from time on dialysis) did not emerge as significant predictors of distress. Instead, higher ratios of psychosocial staff, and particularly social work, were found to decrease the prevalence of distress. Moreover, it was found that patient-reported need for these services was higher in renal units where psychosocial staffing numbers are low or non-existent. Damery et al. (15) also found higher levels of need in units without renal psychologists available, yet reported no influence of service delivery models on moderate distress. Again, since the current study also took severe distress into account, a comparison between their and current findings is not entirely appropriate. However, Damery and colleagues made no mention of the presence of a RSW, whose availability plays an important role in reducing distress, according to the current findings.

These findings have an important implication for the delivery of renal psychosocial services, as they suggest that specialist, renal-dedicated services are better able to support patients than those provided through generalist pathways. Current policies on LTCs advocate for a shifting of burden of care, including psychosocial care, into the community. However, the data

showed that this is not appropriate for ICHD patients, who receive much of their care in hospitals and for whom community services were found to be often unavailable, inaccessible, or inadequate. New guidance is required that offers clear standards of practice and staffing recommendations on which to base future funding allocations for dedicated renal psychosocial support. Although further investigations are necessary, this study provided insights that could be used to develop such guidance.

9.3 Psychosocial = psychological + social

The psychosocial workforce mapping further found that the configuration of the workforce had changed over the last 15 years. Overall, the adult psychosocial workforce had increased by 12.8%, which was mainly due to psychology staff increasing more than tenfold. RSW services however, had reduced by 19%. The results showed an interesting trend: the combined psychology and counselling/psychotherapy workforce had become almost the same size as that of the social workers. This recent development appears to be unique to the UK and has led to the creation of new service provision models, that vary of those reported in other countries such as the USA, Canada and The Netherlands, where the RSW still seems to be the main person for support (175,177,181). The current investigations identified several factors that might have contributed to this reduction. The profession is under threat from within LAs and the role is often poorly understood within the renal unit. Perhaps since the Care Act (2014) placed the responsibility of providing social care with the LAs, renal units have increasingly stepped away from providing this aspect of care. It might not have helped that RSWs are not able to create revenue, unlike psychologists and counsellors. Whatever the exact reason for this change, the current results do not support such an alteration in the composition of psychosocial services. Instead, they provide a compelling case for the continuing existence of RSW, especially at a time when LA services are increasingly difficult to access.

Distress was related to feelings of anxiety, depression and anger, yet encompassed more than distress narrowly defined as a diagnosable mood disorder, which is often the subject of psychological interventions. Distress represented the impact of biopsychosocial factors on emotional wellbeing, resulting in a '*negative emotional state*' relating to feelings of worry, sadness or frustration. Answers on the PC brought to light a wide range of issues that patients

can encounter on their renal journey. Issues in the practical, as well as the emotional domain were significantly found to predict distress and many patients experienced issues that fell within the remit of the RSW. Distress was not significantly lower in those units that only offered psychology or counselling support, highlighting the importance of including social work perspectives as well as psychological perspectives in approaches to psychosocial service delivery. Psychological theories of health and illness that are used to explain patients' variable responses to ESRD diagnosis and treatment often emphasise that the experience of distress is likely to be determined by an individual's personal degree of resilience and individual coping resources. Whilst the role that personality plays in distress is important to consider, the data clearly highlighted that the experience of distress could also be linked to social issues and patient's interactions with three systems: the patients' social circle; the UK's social care system; and the renal unit as part of the wider health care system. This indicates that for some patients, a focus on the person in their environment, as advocated by social work's ecological theory might be more appropriate to alleviate issues. Rooted in this perspective is the understanding that a person's issues are intertwined with the social environment in which they operate (275). For example, if a patient is highly distressed because they cannot get up the stairs, this perspective suggests that it is far more valuable to investigate what in the individual's environment causes him to be distressed. It does not simply label the patient as distressed because of a personality flaw.

This study highlighted the role of RSWs in alleviating patient distress, yet both Alston (86) and Damery et al. (15) focused more on the importance of psychological input to help renal patients manage distress. The findings showed that as the name implies, psychosocial services should include psychological, as well as social (care) services. Yet, the increase of the psychology workforce has appeared to come at a cost of the social work workforce; only 18 units (24.7%) had access to both psychology and social work services. This might reflect a failure of commissioners to recognise the complementary nature of the different roles and responsibilities that these two professions have, and that only together, they can form a psychosocial service. A recent commissioning guidance for cancer 'psychosocial' support (212), suggests that this issue might not be limited to renal services. The report presents the so-called Pan-London psychosocial support pathway for adults, which seems to largely focus on psychological issues. The psycho-oncology team is described, but the place for social work

in the pathway is not clear. Social work representation was notably missing from the steering groups that designed the pathway and oversaw the programme. This further reiterates the need for research on social work in chronic care pathways to inform policy.

Now more than ever, the RSWs are required to demonstrate their unique worth. The RSWs explained that their core practice represented a whole systems approach to solving patient issues, more so than generalist LA and hospital social work services. RSWs would not often get involved in signing off care packages or other services that are available through the council. Instead, the value of their role to patients is in providing a *'one-stop-shop'*; holistic care with a focus on advocacy, without adhering to eligibility criteria. Importantly, this study has shown that in this sense, RSWs differ from hospital or community social workers, whose ability to advocate and look at the 'whole person' is debilitated by pressures to ration services since the introduction of care management and personalisation in combination with austerity (128). The findings indicate that if a renal unit does not have access to a RSW, patients are deprived of a member of staff who serves an important purpose, filling a gap left by inadequate community social services. Specifically, the findings showed that issues described by patients with LTCs accessing the benefit system (72) are also experienced by renal patients. The RSWs respond to some of these key issues in social care through informing patients (and clinical staff) about available social care services; using their renal knowledge to help patients access the services they are entitled to; finding creative solutions to support patients for whom public services will not provide; and offering continuous care to help patients to keep an overview of the complex and fragmented aspects of their care. Whilst these issues have been described in general literature (Chapter 2) and were reiterated by psychosocial staff in this study, further research is required to explore the extent to which they affect renal patients.

9.4 Recommended staffing ratios

Staffing recommendations and clear standards of practice are needed to guide renal units in their future funding allocations, yet such standards are not available and the evidence base for the benchmarks provided in the 2002 report is unclear. Moreover, the recommendations are based on RRT patients, which include haemodialysis, peritoneal dialysis or transplant

patients. This does not clearly reflect the work psychosocial staff were found to do with the wider ESRD population, including pre-RRT patients and those choosing conservative care.

With regards to psychology services, the existing recommendations of 1 FTE per 500 RRT patients appear to be similar to recommendations in cancer care. The NICE stepped-care model of psycho-oncology intervention levels (Chapter 4), that was also used by psychologists in unit F and G, estimated that 15% of patients will need level 3 support, delivered by a counsellor/psychologist, and 10% of patients will need a level 4 intervention, delivered by a psychologist and/or psychiatrist (211). The previously mentioned initiative focused on developing a cancer care model for psychological provision across London estimates a yearly caseload of 120 new patients per full-time level 3/4 worker (212). Applying this to renal care, and using an acuity model, the recommendation for level 3/4 counselling/psychology staff would be 1 FTE per 480 RRT patients, similar to the current recommendations.

For social work, the UK recommendations are similar to those in other countries such as the US, Canada and the Netherlands. As discussed in chapter 4, practice standards in these countries stipulate a proactive way of working, offering all patients a psychosocial assessment at home as they move along the patient pathway, initially in the pre-RRT phase, for example. Having contact with every patient would reduce the dependency on clinical staff for referrals and the RSWs could argue that it would mean that renal care is in line with NICE guidelines (171) stipulating pre-RRT psychosocial evaluations and that it would allow them to work in the preventative way envisaged in the Care Act. The study highlighted that RSWs in the US appear to articulate their role in identifying and treating psychological issues such as depression more clearly than the UK RSWs. Some UK RSWs have a counselling qualification from an accredited University, which in cancer care means that they could also perform psychological screening and level 3 psychological interventions in addition to their social work interventions (212). The possibilities for up-skilling the RSWs that do not have this qualification could perhaps be explored to expand the scope of the profession in such a way that the RSW becomes the first point of contact for renal psychosocial support in the UK, with complex mental health issues treated by psychologists and/or psychiatrists.

To address the elephant in the room: proactive working, offering assessments to every patient, is only possible if staffing levels are adequate. Most RSWs operated a reactive model of care. For some, their service was reactive in a sense that inappropriate staffing levels, in combination with high volumes of often crisis-driven referrals, meant that they got caught in the immediacy of those demands and got stuck in a 'hamster wheel' of generic lower-level tasks. These RSWs were found to be increasingly invisible, both to patients and to staff, as they were too busy to attend MDT meetings or visit the unit. This poses the risk of RSWs losing recognition for their skills and unique contribution to renal patients with complex psychosocial situations. Or worse, in times of financial constraints, invisibility almost inevitably leads to questions about the necessity of a post. Others, who have higher staffing levels were able to support patients in an earlier stage of their problems, yet most were still reactive in the sense that they responded to referrals instead of offering their services proactively to patients.

Based on the existing staffing recommendations, the staffing requirement for RSW would be 437.8 FTE. This is a large increase from the current establishment of 44.6 FTE, and it could be questioned how realistic this requirement is in times of financial difficulties and a general shortage of staff in the nephrology workforce. Not every patient will need or want psychosocial support. Studies with oncology patients found that many patients who reported distress and were offered a referral did not intend to use psychosocial services (276). However, it is possible that this depends on the type of service available for patients, with a US study showing that while only 36% of dialysis patients were willing to see an outside psychosocial support provider and even fewer followed up on that referral, 86% of patients preferred to receive services from their facility RSW (277). Still, the benefits, and particularly cost-effectiveness, of offering every patient a pre-RRT psychosocial assessment remain unclear and require further investigation. However, findings showed that patients who have been on dialysis for 3-5 years experienced significantly higher distress, indicating that only assessing patients as they start dialysis might fail to recognise those in need of support already established on dialysis.

In light of these considerations, an acuity model for psychological and RSW involvement based on regular screening with the DT could form the basis of a more cost-effective alternative for

RSW staffing recommendations. The following section provides a first insight into what such a model could look like, inspired by the psychological intervention levels recommended by NICE (211) in oncology and the RSW intervention model developed in unit F and G (Chapter 7). Questionnaire responses of patients in unit A (without any dedicated psychosocial support) were used to populate this psychosocial stepped-care model, consisting of three levels of need (Table 31). Patients were classed as level 1, 2 or 3, using scores on the DT as a baseline. Depending on the number and type of emotional and practical problems, this score was adapted for around one fifth of patients (Appendix 13). As can be seen in Table 30, 28.1% of patients were classed as level 2, and 18.8% of patients were classed as level 3 requiring support. The later percentage is similar to estimates of prevalence of interview-defined depression in ICHD patients, at 22.8% (82).

Table 31. Populated renal psychosocial stepped care model for unit A

Unit A	Categorisation criteria	N (%)
Level 3 Psychiatrist/psychologist and/or social worker	Severe distress (DT \geq 7) and multiple practical and emotional issues	12 (18.8%)
Level 2 Social worker and/or counsellor	a: Moderate distress (DT 4-6) and more than one practical or emotional issue, or b: Severe distress (DT \geq 7) but no emotional issues	18 (28.1%)
Level 1 Nurse/support worker	a: Low distress (DT 0-3), or b: Moderate distress (DT 4-6) but one or less practical or emotional issues	34 (53.1%)

It is envisaged that if RSW are upskilled with a counselling qualification, they could take on level 2 cases, under supervision of a psychologist. Patients classed as level 3 would also receive an initial assessment and support from an RSW. This means that, if RSW could take on counselling tasks, around 47% of patients in unit A are estimated to need RSW involvement. This model needs further developing; further research is needed across multiple sites, to determine how many patients would need psychology/psychiatry input, and to check the accuracy of this initial classification, perhaps by professionally assessing patients and tracking the length and type of involvement. To transfer this model into a workforce calculation, adequate yearly caseloads for RSWs need to be established, as there is currently no guidance about what constitutes a safe and manageable RSW caseload. Applying the Dutch

recommended caseload of 85 patients per RSW - based on increased RSW involvement for 30% of patients - would mean that the RSW recommendation for HD patients 1:180. This would mean that across the UK, 143 FTE of RSWs is required to support ICHD patients. If all patients with level 3 issues required psychology input, the workforce recommendation for psychology involvement in unit A is estimated at 1:640 patients. Importantly, the above workforce calculation is only based on prevalence of cases in ICHD patients and therefore presents a limited picture. It does not cover the wider RRT population, nor does it include any other work of RSW and psychology/psychiatry at other points along the renal pathway and work with families and carers. It also does not include 'indirect' work delivered by these members of staff, such as attendance at MDT meetings, or education and training of level 1 staff.

9.5 Using the DT to determine a need for psychosocial issues

As discussed, the proposed stepped care model is based on a screening process to determine need for services. The DT was found appropriate to get patients to think about their psychosocial wellbeing, and particularly the PC was able to elicit a wide range issues, making it a useful screening tool in the context of providing holistic, multidisciplinary care. This is in line with Alston (86) who explored the acceptability of the DT in renal patients and found that only one out of 285 patients found it objectionable. According to the NCCN guidelines (85) a score of 4 or more on the DT could warrant a referral to psychosocial services. Although the DT was found useful to get patients to open up about their feelings and this cut-off score could help to determine urgency, findings indicated that the PC and a question about perceived need for support should be the main aid to decide whether someone might benefit from a referral. Some respondents who reported a low DT score still reported a need for support for issues that fell within the remit of psychosocial services. This is also why, in the context of an initial screening for need for psychosocial services, the DT and PC might be more appropriate than screening tools that aim to identify patients who meet the diagnostic criteria for psychological disorders. Those tools might fail to recognise those with other issues, such as social care needs or lower-level, yet still debilitating, psychological problems. For example, practical problems (such as issues with social care or transport) would not necessarily make a patient report distress that would meet the criteria for a formal diagnosis of anxiety or depression. Yet, in order to solve these problems and prevent them from contributing to

negative health outcomes, a patient might still require support from a social worker. This is particularly relevant for the elderly, who were found to report the lowest levels of distress, yet are known to be the biggest users of social care.

There are however some practicalities that need to be considered. Firstly, the findings indicated that doing the screening face-to-face, verbally, instead of through self-administered questionnaires might be most appropriate. This to ensure that those, for whatever reason, unable to read or write, or those who have trouble understanding forms, are offered the opportunity to complete the screening. It also allows the administrator to ensure that patients interpret the DT correctly. This is important as some patients were found to flip the scales, thinking that 10 was the no distress score, whereas actually this reflects highest distress. Whilst this is resource intensive, if RSWs (or support workers if available) complete the screening, it could serve as an initial assessment and increase relationship building and visibility of the RSW in the renal unit, which could speed up the screening process over time. The exploration of the RSW role highlighted patient issues, such as blue-badge applications, bereavement, immigration problems, treatment adherence, preparing the house for home-haemodialysis, needle phobia and the wish to withdraw from dialysis, that could be added to the PC to make it more UK and renal-specific. The long list of physical symptoms was found to increase the time spent on completion of the questionnaire, as some patients felt the need to discuss every issue they had. Whilst some physical issues could be a sign of psychological problems, some of the problems in the list, such as urination, fevers and mouth sores could be removed as they might be less relevant in the context of ICHD patients than oncology patients.

9.6 Nurses as pivotal agents in the system of psychosocial service delivery

Quantitative findings showed a general pattern of reduced distress as psychosocial staffing ratios increased, yet qualitative findings indicated that just the presence of psychosocial staff did not automatically make a functioning psychosocial service. The concepts of systems theory were found useful to guide an investigation into the processes of service delivery, which identified the role of clinical staff as another possible causal mechanism for reduced distress.

A systems approach allowed us to view a renal psychosocial service as an open system, made up of a set of interacting and interdependent agents. The exploration of the RSW alone, which identified the many different types of people and organisations that a RSW could come into contact with, provided some insight into the complexity and lack of clear boundaries of the system of renal psychosocial service delivery. The agents that were part of the system included people such as psychologists, social workers, doctors, nurses, patients, commissioners, or organisations such as care homes, charities, LAs and many more. The findings highlighted that the presence, attitudes and values of any of these agents influenced whether renal psychosocial services were available and how these services were delivered. Particularly RSWs were found to be co-evolving and adjusting to their environment, with the boundaries of their role shaped and renegotiated depending on the presence and quality of other services.

The following section draws artificial boundaries around the system of psychosocial service delivery to illustrate how it functions as a result of interconnectedness and emergent properties of three main agents within the renal unit: patients, dialysis staff and psychosocial staff. The findings showed how each of these agents can form barriers or bridges on the patient's road to adequate psychosocial support. Emergence happens if all agents are enablers; linking services and making the whole greater than the sum of its parts (264). Theoretically, in units with renal dedicated psychosocial staff available, the process of psychosocial service delivery starts with the patient experiencing an issue. The patient then either solves the issue themselves, self-refers to the renal psychosocial service, or notifies dialysis staff of their problems. Dialysis staff either signpost the patient to community services or refer them to renal psychosocial services. This places importance on the role of dialysis staff in informing patients on available services and identifying patient distress and issues. During the focus groups, clinical staff recognised that this aspect of care was part of their role and some also felt that they should support patients with lower-level psychosocial problems. Importantly, training from and the experience of joint working with psychosocial staff appeared to increase dialysis staff's confidence, awareness and ability to fulfil their role within the process of psychosocial care.

Figure 13 illustrates a simplified theoretical explanation of emergent properties in the system of renal psychosocial service delivery, to show how staff training and joint working could lead to better psychosocial support from psychosocial staff, dialysis staff, and patients themselves. On the right side of Figure 13 is a unit in which there is no psychosocial staff available. Patients might express their issues, but nurses cannot refer to psychosocial services and may lack the ability, knowledge and confidence to signpost patients to general services, or identify and manage lower-level psychosocial issues, highlighted recently by Combes et al. (14). Adding psychosocial staff to this system (as illustrated on the left side of Figure 13) firstly means access for those patients who express a clear desire to be referred. Over time, through training from psychosocial staff, nurses become more aware of psychosocial issues and available services, which allow them to detect issues and inform and refer or signpost patients. Informed patients might then be better able to arrange support themselves (particularly with regards to social care issues). Finally, through continued interaction and joint working with psychosocial staff, nurses become more confident in managing lower-level psychosocial issues. The value of such spontaneous psychosocial support by nurses has been demonstrated in cancer care (278). As such, a multiplier effect is visualised: adding psychosocial staff to a renal unit does not only give patients access to psychosocial interventions, it also has a knock-on effect on dialysis staff's and patients' abilities to solve (lower-level) psychosocial issues, creating the system of psychosocial service delivery that is functioning as something larger than any of its parts.

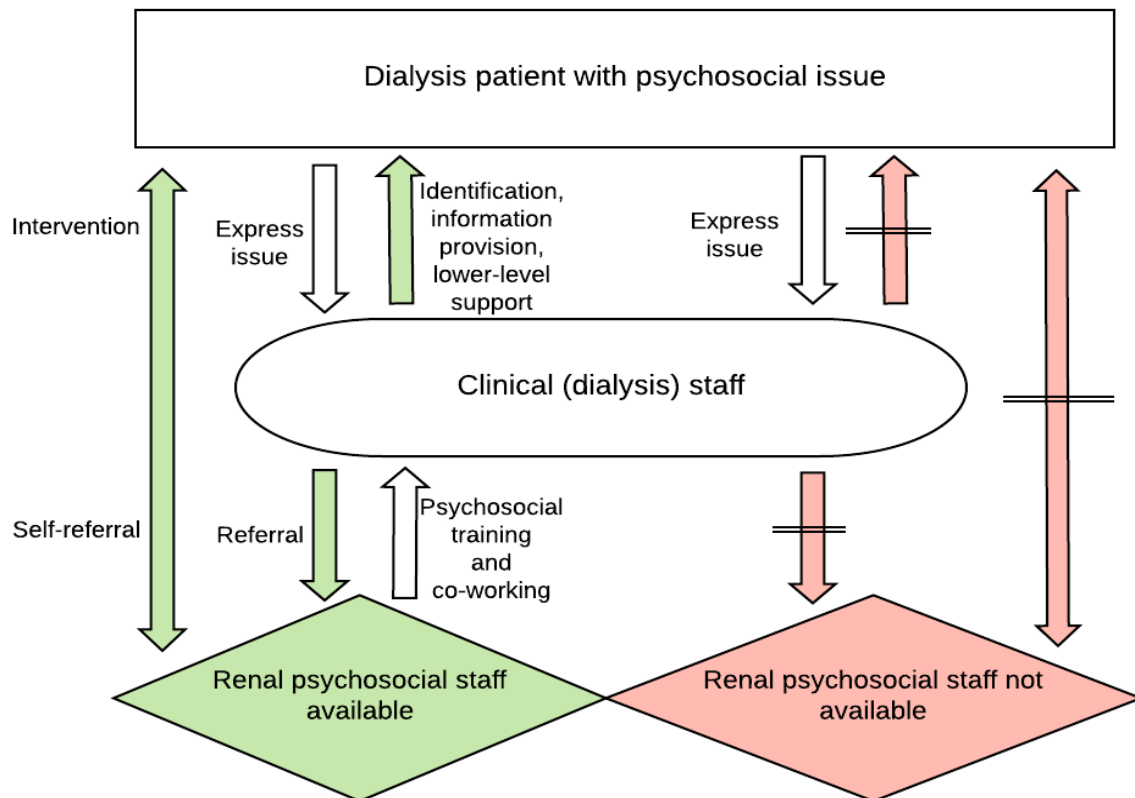


Figure 13. Emergence in the system of renal psychosocial service

In reality, the current study identified several factors that challenge the working of this system. Firstly, as one of the participants put it, *'the medical model still prevails'* (Carmen, RSW): a focus on patient distress is often not automatically reinforced as the norm, as was also found by Combes et al. (14). Furthermore, the system is heavily influenced by changes in its context and environment. Due to increasing patient numbers and reduced availability of community services, the pressure on renal psychosocial services has grown over the years. Psychosocial staff explained that this meant that they had become increasingly dependent on referrals from dialysis staff to ensure that patients were accessing their service. The findings suggested that this increased dependency might prove not to be conducive to service delivery. Dialysis staff have their own barriers that prevent them from fulfilling their role in identifying and managing patient distress – and might even result in dialysis staff becoming barriers to psychosocial care themselves. It was found that time restrictions, experience, personal interest and attitudes towards the importance of psychosocial care determined whether dialysis staff played their part in the process of psychosocial service delivery, or whether they even saw it as their role in the first place. These findings again compliment those from Combes and colleagues, who specifically explored renal consultants' and nurses'

views about distress. They found that staff felt that detecting distress was everyone's role, yet each staff group were quick to identify another staff group as better placed than themselves to deal with distress. Staff working with ICHD patients were least likely to see emotional support as part of their role, as they focused more on the technical aspects of dialysis (14). It is important to consider that none of the interviewees in the study from Combes and colleagues had received psychosocial training. Like the current study, they identified the importance of staff education and support from managers to create a culture in the unit in which a focus on psychosocial issues is part of the care process. Findings from research on the delivery of psychosocial cancer care suggest similar challenges and educational needs among health professionals (278–280)

This then has consequences with regards to inequality in patient access to the service, with a risk that only those who shout the loudest or who have built relationships with clinical staff that recognise the importance of psychosocial aspects, receiving support. Whilst some patients stated that they would request help if required, the findings showed that many patients were unaware of the availability of services and/or unclear about what these services could do for them. In addition, some patients felt that they should not 'bother' the dialysis staff with their issues because they appeared busy. Damery and colleagues (16) found that the jovial and upbeat atmosphere created by staff in the units inhibited some patients from expressing their issues. It is therefore recommended that training on psychosocial issues form part of clinical staff's inductions and that formalised, continuous efforts of staff education are included in the psychosocial staff's role description. The delivery of this training locally by members of the renal psychosocial team might foster relationship building and joint working. However, a nation-wide program, such as a recent e-learning resource developed by the Psychology of Dementia team at NHS Education for Scotland to enhance understanding of the causes of stress and distress in dementia (281), could also be explored. Moreover, these findings further implicate the importance of screening to alleviate a dependence on clinical staff to identify those in need of support.

[9.7 Repositioning the RSW at the heart of renal psychosocial service delivery](#)

The stepped-care model designed in this research places the focus on RSWs as the first point of contact for renal psychosocial care. Yet, findings showed that for RSWs to form an integral

part of the renal pathway, much higher levels of joint working are required, instead of the RSWs coming in from the periphery, as is currently often the case. Research published by the Social Care Institute for Excellence identified broad organisational, cultural/professional and contextual factors that can help or hinder joint working in MDTs (282). Linking the study findings to these factors highlights several issues in current practice that stand in the way of an effective partnership between RSWs and the rest of the renal team, which need to be considered in future models of joint working.

Cameron et al. (282) explain that an understanding of the shared aims and underpinning philosophy of any joint initiative is central to its success. The findings show that both medical staff and RSWs could do more to establish a focus on shared medical and psychosocial outcomes. As discussed, relationship building, education and leadership championing such an approach are required to create it. However, many RSWs lack appropriate management and feel like their values are often not represented at higher-level meetings in the hospital.

Inadequate staffing levels across the unit mean that RSWs are often unable to attend MDT meetings or visibly position themselves in the unit and that clinical staff lack the time to attend psychosocial training. This negatively affects staff's ability to engage in negotiations to create a culture of psychosocial support in the unit and it further exacerbates the lack of understanding about roles and responsibilities, which was found to be another factor for successful joint working (282). Current practice of RSWs often entails responding to gaps in service provision in the unit and the wider social service system whenever and wherever they arise. Whilst some flexibility is regarded positive (282) and this means that the RSWs are responsive and support patients with a wide array of needs, it can lead to issues around role boundaries and further unclarity about the role. This is most visible in the area of benefits advice, where RSWs have been increasingly pulled into without this being part of their qualification. Furthermore, disagreements about the nurses' role in provision of lower-level psychosocial support can lead to friction without adequate leadership.

Co-location of RSW and clinical staff was seen as invaluable for the provision of renal psychosocial services. It encouraged informal contact and quicker and easier communication between the two groups of staff, enabling relationship building efforts. Cameron and

colleagues also highlighted this as a factor that enhanced joint working. However, the findings suggested that in some cases, co-location had possibly led to too much informality, which could negatively impact the RSWs ability to manage their service. As opposed to psychology or psychiatry services, RSWs often do not have a formal referral process, with RSWs reportedly receiving referrals as they are being stopped in the corridors by staff and patients alike. The lack of an adequate referral process was found to be detrimental for record keeping efforts. Record keeping is supposed to facilitate communication and information sharing, another essential element of joint working (282). Yet, the findings showed that many RSWs are not able to record their involvement on the hospital systems due to system restrictions. In addition, they often do not formally report the outcome of their assessments and interventions in the patient record through letters to the referrer, like the psychologist and psychiatrist in this study and RSWs in the Netherlands (283) would do. This affects the visibility of the RSW role and undermines efforts at fostering an understanding of the professional role and value of RSWs. The RSW argued that often, after an initial referral for a seemingly small issue, a complex web of psychosocial issues becomes apparent that warrants an intervention from a qualified RSW. Due to the identified lack of communication and information sharing, this might not always be evident to clinical staff. Moreover, if RSWs are not adequately recording all the patients that are referred and their subsequent level of involvement, the exact demand for their service remains unclear, which hinders attempts at recommended workforce calculations.

These findings have several implications for practice. With their knowledge of both the illness and the social care system, RSWs have the potential to be an essential part of the road to integration of health and social care for kidney patients as is so often advocated in policy documents. On a higher, national level, UK studies on integrating health and social care identified similar cultural, operational and territorial barriers, such as issues with interprofessional relationships and infrastructure, including a lack of interoperability between information systems and issues with or a lack of pooled budgets and misaligned incentives between managerial staff (284,285). Yet, it is important to consider that these studies focused on larger, inter-organisational forms of integration. Many RSWs are already fully funded, employed and managed by the NHS, which means that some of the challenges to integration identified in these papers are already mitigated, which perhaps offers opportunities for the

future. Still, RSWs appear to be stuck in a vicious circle: their role is fluid, ill-defined and poorly understood and evidence on the impact of their role is lacking; funding for their role is reducing while patient numbers are increasing; due to increasing pressures they become more invisible, leading to further unclarity about the role. For the profession to survive, this circle needs to be broken. As discussed, renal managers and other renal staff need to be made aware of the importance of psychosocial support, through training and education. Then, together, it should be explored how social workers can be integrated within the system of renal care, instead of being left to their own devices as is often the case. The findings indicate that this could mean that different units make different agreements, based on other services that are available and agree on referral processes that are appropriate for the unit. The previous sections have illustrated aspects that need to be considered. The literature review (chapter 4) provided ideas about how the RSW role could be shaped in such a way that specialised RSW interventions, in addition to 'normal' RSW practice, achieve renal-specific outcomes. For example, US RSWs developed group interventions to target non-adherence, reporting increased diet, treatment and medication adherence (192,194,198). In the Netherlands, Hofman & van Wijk (283) provided a step-by-step guide, including assessment forms, to detail RSW involvement or interventions along the dialysis pathway. Similar toolkits have been developed by the US' Council of Nephrology Social Workers (CNSW) (177). Detailing RSW involvement in this way could help RSWs better define and articulate their role. In addition, evaluating interventions that target renal outcomes could enable RSWs to make clear the value of their role to the bottom line of the renal unit, as well as to the patient. This could then provide the data that is needed to create a business case for further expansion of the service to secure RSW's future. However, whilst this comprehensive study formed a good first step in building RSW capacity for research and service evaluation, they require further support to continue. Furthermore, the level of organisation and formalisation of the RSW role apparent in the US and The Netherlands (both insurance-based) was not found in the UK. Success in or attempts at framing RSW involvement were found to be individual, unit-specific initiatives, instead of based on profession-wide guidance published by the RSW professional network. To facilitate and set off the change that is needed to formalise the RSW role, perhaps KCUK could add requirements and conditions related to joint working, supervision, training, management and service development if they agree to fund RSW posts in the future.

9.8 Strengths and limitations

Since the delivery of renal psychosocial services was such an unexplored area, this study purposively took a wide, explorative approach. The overwhelming amount and breadth of data collected as a result of combining quantitative and qualitative methods, is a considerable strength of this study. Questionnaires highlighted patterns in patient outcomes that could not be found with a smaller sample of individual interviews alone, yet focus groups added a more representative dimension to factors at play within renal psychosocial service provision that no questionnaire could capture. As in every study, several methodological choices were made that influenced the type of data obtained, and therefore the conclusions that can be drawn from this study. This section discusses the strengths and weaknesses for some of these main decisions: the choice of study sites, the decision to explore the RSW role through a process of service evaluation, and the selection of distress measured by the DT as outcome of service delivery.

9.8.1 The selection of study sites

This study took place in a real-world environment, studying processes and outcomes of care as they occurred in renal units. Therefore, the data that could be obtained was influenced by the models of care within participating renal units. The average psychosocial staffing ratios in this study were higher than the overall UK renal psychosocial staffing ratios. Based on current findings, this suggests that the overall distress prevalence that was identified may have been underestimated. Furthermore, by coincidence, the proportion of BAME patients in the study sites was lower than the average, which suggests that the prevalence of distress might have been further underestimated (15).

This study was the first to show an impact of RSW staffing levels on patient distress in the UK. As a strength, an attempt was made to increase validity of this finding by adding two additional study sites to confirm or reject the hypothesis that was made based on initial findings. Only RSW ratios were found to significantly predict distress, yet this is not to say that renal psychologists and counsellors do not impact patient distress levels. The ratios of psychological staff were much more equal across units than RSW ratios, which could have contributed to the current findings. There was however no unit available that had higher ratios of psychology staff than the ones already participating in this study (105).

Unfortunately, quantitative findings were also not able to provide any further clarification related to the lack of consensus about whether RSWs or unqualified staff would be best able to support patients with their social care issues. A unit that employed a welfare advice service could not be recruited in the study, and there were no other units with high ratios of unqualified support staff.

A further limitation was that due to a lack of available data, it was not possible to examine the findings in the wider, unit-specific context. Particularly a link between socio-economic status or deprivation and service delivery and distress was not explored, mainly because the selected study sites were in different UK countries. Data on deprivation are only available for the general population and is not comparable across the different countries in the UK, because different metrics are used. In addition, this type of data is often provided per LA, yet patients from many different LAs might be dialysing in the same unit. Future studies should consider adding questions related to socio-economic status to the demographics section of a questionnaire, since a higher demand for psychosocial services, and particularly social work, might be expected in units with higher levels of deprivation.

9.8.2 Distress as a unit-level outcome in ICHD patients

This was the first study to explore outcomes of psychosocial service delivery across different renal units with varying models of service provision. It was decided to measure an outcome at unit-level, involving all ICHD patients in the unit, instead of at psychosocial service user-level. This meant that, in order to be able to make valid comparisons, many patients had to be recruited into the study. With regards to measuring the prevalence of distress in ICHD patients, the strengths of this study include its high response rate and the large number of main and satellite units that served as study sites. Even the lowest response rate (in unit F) was still relatively high (49%), although variability between the units was found. However, there was no indication that response rate variability affected the results, with the highest (unit G) and lowest (unit F) response rates showing the lowest distress prevalence. Of relevance for the aim of exploring distress across different models of service provision, this increases the probability that the scores are representative of the patients in the participating units. As a limitation, though, it should be recognised that this investigation did not include members of the wider RRT population, who are also often in need of support of psychosocial

services. As the qualitative explorations have shown, the type and level of support to these patients also often differ across units; the impact on patient distress in these patient groups requires further investigation.

The intent to reach a large number of patients led to the choice of questionnaires as a method of data collection, which came at a cost of more in-depth explorations that would have been more resources intensive. For example, it was not possible to explore patients' access and use of general psychosocial services in the hospital or community. This type of data is often not recorded by renal units and would thus require the tracking of individual patients. By offering patients support with completion of the questionnaire, a valuable glimpse into patient experiences with psychosocial services was obtained. The high number of patients requesting support with the questionnaire was unexpected and it meant that data collection was more labour intensive, yet this was also one of the strengths of the study. The wealth of information about patients' experiences and causes of distress that was obtained through administering the questionnaire was overwhelming. It meant that distress could be explored in a way that would not have been possible with a self-completed questionnaire alone, highlighting the advantage of mixed-method approaches.

9.8.3 Exploration of RSW through service evaluation

Finally, funding requirements of the research project from which this PhD emerged left their mark on the study design. A focus on the RSW role was stipulated in the project plan, in addition to an emphasis on RSW capacity-building with regards to service evaluation. For this reason, RSW were actively involved in the data collection and recruitment process. For many RSWs, this was their first experience with research and their participation was a strength of the study. The success is visible, with one of the RSWs now starting their own PhD and some RSWs planning to take the DT and the activity diaries forward in their practice. The involvement of RSWs in the data collection process also brought with it some challenges, which highlight the need for increased social work staffing levels and dedicated time in the RSW role description for research and training to enable RSWs to further develop their service evaluation skills. Firstly, due to time restrictions and the unpredictable nature of the job, RSWs felt that they did not always have the time to introduce the study to patients, provide them with an information sheet and complete the pre-intervention questionnaire. In

addition, sometimes, RSWs felt that it was inappropriate to ask a patient to participate if they were highly distressed or were dealing with sensitive concerns, such as safeguarding issues. This highlights an issue with RSWs as 'gatekeepers' to the research and could mean that due to a potential selection bias the sample is not entirely representative of the RSW population, with people dealing with more acute and complex issues not recruited. It is important to consider how this challenge might affect future attempts at service evaluations as part of RSW practice. Perhaps it can be explored whether standard practice can involve a formal intake, which includes the completion of an assessment/outcome tool before any services are offered, as is often the case in psychology services. A further limitation was that this was a prospective service evaluation, not a controlled study of RSW intervention versus standard care. Whilst the innovative use of the DT to re-evaluate distress over time was a strength of the study, it cannot be said with certainty that the observed improvements in distress and anxiety were directly attributed to the RSW intervention.

9.9 Recommendations

Recommendations emerge from this discussion of findings, which are presented here in bullet points as suggestions to improve and build on existing clinical practice, national policy and the scope for future research.

9.9.1 Recommendations for policy and practice

- Access to integrated, renal-dedicated psychosocial support across all stages of the renal pathway should be unambiguously included as a requirement in renal policy documents. This guidance should offer clear standards of practice and workforce recommendations for psychosocial staff. Specifically, NICE guidance should reinstate a quality statement about patient access to psychosocial support as a national priority for improvement to reduce inequality in availability of services across the country.
- An increase in the renal psychosocial workforce is recommended and renal units should explore processes that can be put in place to bolster effective joint working and to ensure that a focus on psychosocial wellbeing is a standard part of renal care. Importantly, attention needs to be brought to social care issues, as well as psychological issues. For example, particularly in units with low psychosocial staffing levels, units could consider using link nurses, health care assistants or social care coordinators, who

are highly visible on the unit, to serve as a bridge between patients and psychosocial staff.

- Clinical staff require training about how to recognise and respond to psychosocial issues and how to manage patients with lower-level distress. In addition, they require education and support from psychosocial staff, so that they are aware of the appropriate channels for referral or signposting.
- To further the identification of those in need of psychosocial support, a screening process is recommended. This is particularly relevant to ensure that those already established on dialysis are not overlooked. The DT (including the PC) was found to be a useful tool; renal specific problems should be added to the checklist to make it more appropriate for the renal context.
- The opportunities for up-skilling RSWs with a counselling qualification and psychological assessment skills should be explored, so that the RSW can serve as the first point of call for patients with psychosocial issues. It should also be explored how the RSW role can be framed so that it makes clearer contributions to the renal unit, by offering group-interventions to target non-adherence, for example.
- On a unit-level, changes need to be made to ensure effective partnership working between RSWs and the rest of the renal team. Unit managers should lead the development of arrangements that foster relationships and greater understanding of roles and referral processes, as well as providing RSWs with access to adequate supervision, training and reporting systems.
- On a national level, the RSW's professional body (the BASW-RSIG) requires support and pragmatic directions to grow and develop its voice and agency to challenge the status quo. This is necessary to bring it into a good position for collective action, including political advocacy, that could overturn RSW's existential crisis.

9.9.2 Recommendations for research

For policies to stipulate processes of renal psychosocial care and staffing recommendations that are based on scientific evidence and to create a universal model of psychosocial service delivery, further research is needed. Building on the current findings, future research should:

- Further test and develop the proposed acuity based stepped-care model. Formal psychosocial assessments could confirm or reject the adequacy of the DT and problem checklist in identifying patients in need for psychosocial support. Linked to this, practice-based research, involving service evaluations, could then determine the proportion of patients that were referred and the type of support they required. Importantly, this research needs to take place across the whole RRT pathway to identify whether there are differences in the type of support that is required as people move along the pathway.
- Investigate the time requirements that are needed to provide support within established intervention levels, to determine appropriate caseloads for psychosocial staff.
- Explore how distressed patients from minority groups, who perhaps have limited literacy/knowledge of English can be identified and included within the process of psychosocial service delivery.
- Develop research to explore how unit-specific and contextual factors might impact the need for provision of psychosocial services across different areas of the UK.
- Investigate the extent to which identified issues with navigating and accessing social care services impact the lives and health outcomes of kidney patients.
- Further build the evidence-base of RSW, by evaluating the impact of their interventions. Importantly, these evaluations should target renal outcomes and patient outcomes, to enable RSWs to make clear the value of their role to the bottom line of the renal unit, as well as to the patient.

9.10 Chapter summary and conclusion

This final chapter focused on drawing together and discussing the key findings of this study and presenting implications for practice. Since the area of renal psychosocial service delivery was mostly unexplored, the wealth of new information that this thesis has brought to light was overwhelming. The level of variation that was found in staffing models, funding arrangements and organisation of service provision could not be predicted at the start of this study. Whilst this made the study more complex, it also highlighted the need for a national renal psychosocial pathway and psychosocial service specification to ensure equal access to renal psychosocial support across the country. The study findings provide practitioners and researchers with a platform from which to create such a pathway. From a patient perspective, it has identified a need: ICHD patients experienced a high prevalence of distress, psychosocial issues and need for support. From a service perspective, it has provided evidence that dedicated psychosocial staff play a role in reducing these issues. The findings support the incorporation of renal psychosocial support in the renal care pathway, especially since community services are currently unable to deliver. Renal psychological services have become more available over the years, yet the findings provide evidence that, as the name implies, psychosocial support should include assistance with psychological as well as practical and social care related issues. The study described the challenging environment in which RSWs operate, but also offered ideas for possible opportunities to guard the future of this important profession. From a systems perspective, the findings showed that simply adding psychosocial staff to a renal unit is not enough to achieve true multidisciplinary working and integration of renal psychosocial services in models of care. These models are often too medically driven; training and education for clinical staff is necessary to achieve a focus on holistic patient care that includes an awareness for psychosocial issues. The provision of integrated, holistic care for LTCs has been a national policy priority for years now. Progress has been slow, but descriptions of the development of processes and new ideas for delivering renal psychosocial care in the current study sites offer hope for the future. Whilst this study has achieved its aim of gaining a deeper understanding of UK renal psychosocial service provision, it has by no means created a full understanding of the subject. If anything, it has highlighted the scope and need for future research on the topic; recommendations have been provided for ideas that need to be developed further and shared across renal units to ensure equal access to renal psychosocial support across the UK.

The peer-reviewed publications that have been published as part of this study so far have added value to the limited knowledge base within this subject area. Further publications are planned, including a policy paper and a paper about the value of the RSW role, which will hopefully drive a change in policy and practice and contribute towards greater psychosocial wellbeing of renal patients in the future. Throughout this PhD, the findings of this study have been disseminated to KCUK, which is now exploring options for further development and implementation of the proposed stepped-care approach.

As for me, moving forwards, I plan to continue my work in the field of health systems research, but combine it with my interest and experience in international development. I am looking forward to building an academic career in global health research and applying the knowledge and skills I have obtained throughout this PhD journey to benefit some of the most vulnerable people in the world.

Mapping the UK renal psychosocial workforce: the first comprehensive workforce survey

Maaïke L. Seekles^{1*}, Paula Ormandy² and Emma Coyne³

Abstract

Background: Emerging evidence of psychosocial problems in CKD patients has led to an acceptance that a focus on the emotional wellbeing of the patient should be included in the provision of comprehensive CKD care. It is unclear if an increased attention for psychosocial needs in guidelines and policy documents has led to a rise in psychosocial staffing levels or change in composition of staff since the last workforce mapping in 2002. This paper offers a critical analysis and in-depth discussion of findings and their implications, in addition to providing an international perspective and exposing gaps in current knowledge.

Methods: Data on psychosocial staffing levels was taken from a survey based on the Scottish Renal Association's (SRA) staffing survey that was sent to all units in England, Wales and Northern-Ireland in 2016. In addition, data from a psychosocial staffing survey designed by and distributed via psychosocial professional groups was used. This data was then completed with Freedom of Information (FOI) requests and collated to describe the current renal psychosocial workforce in all 84 UK renal units. This was compared to results from the last renal workforce mapping in 2002.

Results: The results from this mapping show great variability in models of service provision, significant exceeding of benchmarks for staffing levels, and a change in staffing patterns over the past 15 years. Adult psychology services have increased in number, but provision remains low due to increased patient numbers, whereas adult social work and paediatric services have decreased.

Conclusion: A lack in the provision of renal psychosocial services has been identified, together with the absence of a general service provision model. These findings provide a valuable benchmark for units, a context from which to review and monitor provision alongside patient need. Along with recommendations, this paper forms a foundation for future research and workforce planning. Research into best practice models of service provision and the psychosocial needs of CKD patients lies at the heart of the answers to many identified questions.

Keywords: Psychosocial, MDT, Workforce, Nephrology

Background

Chronic Kidney Disease (CKD) is a worldwide public health problem, with increasing incidence and prevalence, high costs, and poor outcomes [1]. Forecasted growth in the prevalence of the disease together with predicted further reductions in the nephrology workforce requires forward planning to ensure appropriate

management and access to services [2, 3]. Indeed, in the UK too, the population is ageing and with it, the prevalence of CKD and its impact on the health systems grows. It is expected that 2.6 million people (6.1%) aged 16 and older in England have CKD stage 3–5 [4]. According to the 2017 UK Renal Registry report, 61,256 adults received Renal Replacement Therapy (RRT), of which 28,632 dialysis, on the 31st of December 2015 [5]. In addition, 941 children (< 18 years) with established renal failure (ERF) were receiving treatment at paediatric nephrology centres in 2015 [6]. The number of people

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receiving RRT has grown with 3.9% between 2014 and 2015 [5] and with around 50% over the past decade [7]. CKD, and particularly RRT, poses a high burden on the NHS health care budget. Estimates suggest more than half of the total expenditure on CKD is for RRT, although the RRT population only comprises 2% of the total diagnosed CKD population [7]. For that reason, an important aim of CKD care is to effectively delay or prevent progression of the decrease in renal function and, as a result, the need for dialysis as RRT [8].

Living with CKD provides many ongoing physical, emotional, financial and/or social challenges throughout an individual's renal journey. Rapidly developing research has shown that these could result in psychosocial problems, not only for patients, but also for families and carers. The most frequently reported psychological disorders in CKD patients are depression, anxiety, and adjustment disorders [9–11]. Recent studies suggest a prevalence of interview-defined depression of approximately 20% in CKD patients [12], with 40% of dialysis patients showing depressive symptoms [13]. In CKD patients, depressive symptoms were found to be independent predictors of adverse clinical outcomes, including faster progression to end-stage-renal disease and thus RRT, increased hospitalization, and mortality [14, 15].

As a result of the physical and psychosocial consequences of the disease and associated comorbidities, the care for CKD patients is complex, multifaceted and often fragmented among different specialties [16]. It is suggested that this type of care is best provided according to a multidisciplinary care model. CKD patients who participate in renal multidisciplinary care which includes psychosocial support show slower renal function decline in advanced stage CKD and improved clinical outcomes, timing initiation of dialysis with functional vascular access and reduced mortality [8, 17, 18].

Even though evidence on psychosocial problems in CKD is still emerging, there is an acceptance that a focus on the emotional and psychosocial needs of the patient should be included in the provision of comprehensive medical care to the CKD patient [11]. It is unclear if this increased attention for psychosocial needs has led to an increase in psychosocial staffing levels or change in composition of staff. Over the past 10 years, several national guidelines and policy documents have highlighted the psychological and social aspects of CKD. These include The National Service Framework for Renal Disease [19, 20]; the current NHS England service specifications [21, 22] and the previous 2014 National Institute for Health and Clinical Excellence (NICE) Chronic Kidney Disease quality standard [23]. However, the revised 2017 NICE quality standards [24] no longer prioritise access to psychosocial support for people with renal disease, why this changed is unclear.

In 2002, the British Renal Society (BRS) executed the last audit of the entire nephrology workforce to date. A workforce plan published the findings from this survey, together with recommendations for establishments and staffing levels across each professional group involved in renal healthcare [25]. For psychosocial care, recommendations were only given for social work and psychology. For RRT patients, a benchmark ratio of 1 Whole Time Equivalent (WTE) social work per 140 RRT patients was advised. The desired psychology ratio was said to be depending on the social work ratio. Namely, if the social work benchmark was met, then the recommended psychology ratio was 1 WTE per 1000 RRT patients. If the social work benchmark was exceeded, a psychology provision of 1 WTE per 500 RRT patients was recommended. In addition, the report offered a recommendation for the dialysis patient-to-social worker ratio, namely 1 WTE per 70 dialysis patients [25]. There is limited evidence available to support these recommendations [2]. The report further showed variability in the availability of the recommended types of professionals between units, with few having a full staff complement. Notably lacking were social workers, psychologists and counsellors [26]. Even though the data on psychosocial staff was limited, in adult services, the majority of psychosocial staff was social workers (76%), then counsellors/psychotherapists (16.6%) and then psychologists (7.3%) [25].

This paper presents the key findings of the most comprehensive investigation into the UK psychosocial workforce in 15 years. The aim was to assess the levels of psychosocial staff and map it against the 2002 recommendations and to explore whether there has been a change in size and composition of the current renal psychosocial workforce in the last 15 years. Renal psychosocial services were defined as psychological and/or social care provided by psychosocial staff to meet patients' informational and emotional needs. Whilst, to a certain extent, nurses might provide this type of care also, the focus of this investigation was only on staff specifically recruited to provide psychosocial support to renal patients. The crude results of this investigation can also be found in a lay report published in 2018 [27]. This paper provides a different presentation and more critical analysis of a selection of the data, offering a more in-depth discussion of findings and their implications. It offers an international perspective, serving as a platform to stimulate other countries to compare and contrast psychosocial service provision. Moreover, it exposes gaps in our current knowledge and, along with recommendations, it forms a foundation for future research and workforce planning.

Methods

The data that was used to complete this workforce mapping was collected through separate initiatives by a

number of collaborating organisations. First, in 2016, the BRS asked Clinical Directors (CDs) of all parent units in England, Wales and Northern-Ireland to complete an excel file, based on the Scottish Renal Association's (SRA) staffing survey [28]. This workforce survey has been used by the SRA for several years and asks for details on all renal staffing and facilities in the unit, including psychosocial staff. Despite numerous reminders, the response rate to the questions about psychosocial staff was only 64.8%. Coinciding with the BRS survey, an online questionnaire was designed jointly by the British Psychological Society Renal Network, the Renal Psychological Services Group and the British Association of Social Workers Renal Special Interest Group. The link to this questionnaire was distributed through the above networks late 2016 and was envisaged to be completed by all individual members of renal psychosocial staff in the UK (including Scotland). Psychosocial staff were asked to provide information on a wide range of questions about qualifications, WTE, type of interventions provided, time in post, funding of post and concerns about the service, among others. Since the overall number of psychosocial staff members was not known, response rates were hard to define. However, 104 professionals returned the questionnaire, which, based on current findings, would mean a response rate of 55.3%. In 2017, Kidney Care UK (KCUK), in collaboration with the University of Salford, supported a researcher to combine, clean and validate the results of both surveys to provide an overview of the psychosocial staffing levels per unit. Conflicting information was found, with renal psychosocial staff contradicting information provided in the BRS workforce survey. Therefore, Freedom of Information (FOI) requests were sent to all 84 hospitals, asking for details only about the type, number and WTE of renal staff. The response rate was high, with 96.4% of units replying to this request within the end date of the data collection period. In addition, email contact between the researcher and renal staff took place to ask for clarification of data. Finally, 100% of the units provided information through at least one of the data collection methods. Whilst data triangulation increased the reliability of the data, all CDs were then asked to confirm accuracy of the findings with 82% of CDs adhering to this request.

The data was managed in Excel and a selection of data - number and WTE of staff - were analysed using Stata 14 software for summary and descriptive statistics to investigate the research questions of this publication. To calculate staff-to-patient ratios, the adult CKD, RRT and paediatric ERF patient number data was obtained from the 19th UK Renal Registry Report [5, 6]. Every attempt was made to collect complete data in the current investigation, however, there was some missing data, with not all WTEs provided for all staff. This had consequences

for the calculations of totals and ratios. Namely, the total WTE per profession with more than 10 staff identified was calculated based on assigning the average WTE to the missing data. This was done for three out of 68 social workers and three out of 64 psychologists. Staff-to-patient ratios were only calculated for the units that employ psychosocial staff and provided information on WTEs of staff. Information on the number of young adult patients (aged 16 to 24) per unit was not available and therefore individual youth worker ratios could not be calculated.

Data as presented in the 2002 workforce report was used to compare the current findings to those 15 years ago and assess current ratios against the set benchmarks. The 2002 report only provided information of WTE of social workers and psychologists and did not provide information on variation in ratios or whether benchmarks had been met, which limited the possibilities for comparisons. In addition, it only provided benchmarks for social work and psychology, and not for other psychosocial staff.

Results

2017 Establishment of renal psychosocial workforce

Table 1 shows the identified staffing levels in adult and paediatric services as per July 2017 across 84 renal units in the UK, a complete list of identified psychosocial staffing per parent unit can be found in Additional file 1. It was observed that some of the units employed non-traditional members of psychosocial staff, such as a cultural and health liaison officer. Three units contracted external companies, namely Auriga and Citizens Advice Bureau (CAB), to provide patients with welfare and benefits advice. The four main providers of psychosocial services in the nephrology setting were identified as social workers (35.6, 95% confidence interval [CI] = 28.8, 42.8), psychologists (34%, CI = 27.3, 41.2), counsellors/psychotherapists (15.7%, CI = 10.5, 20.7) and youth workers (5.2%, CI = 2.1, 8.4). Of these four types of professionals, 12.4% worked in paediatric services, whereas only 1.5% of the entire RRT population is under 18 years of age. The numbers of psychosocial staff available to renal patients in a unit varied from zero to seven ($Mdn = 2.37$, $IQR = 1-3.75$). Twelve units (14.3%, CI = 7.6, 23.6) had no renal dedicated psychosocial service and sixteen units (19.1%, CI = 11.3, 29.1) had one member of psychosocial staff available to patients. In the other units, different members of staff worked together in varying combinations.

Patient-to-staff ratios

Table 2 shows the median and dispersion of adult patients per 1 WTE staff per unit, for psychologists, social workers and counsellors/psychotherapists. Dialysis

Table 1 Number, WTE and proportion of psychosocial staff with 95% confidence intervals

Adult services				Paediatric Services			
Profession	N	WTE	% of total N	Profession	N	WTE	% of total N.
Social work	58	44.6	36.3 [28.8, 44.2]	Social work	10	7.4	32.3 [16.7, 51.4]
Psychology	51	27.2	31.9 [24.7, 39.7]	Psychology	14	5.7	45.2 [27.3, 63.9]
Counselling/ Psychotherapy	28	15.0	17.5 [11.9, 24.3]	Play therapy	2	2.0	6.5 [0.8, 21.4]
Youth work	9	6.5	5.6 [2.6, 10.4]	Play worker (unqualified)	2	2.0	6.5 [0.8, 21.4]
Welfare advisor	3	2.2	1.8 [0.4, 5.4]	Counselling/ psychotherapy	1	0.5	3.2 [0.08, 16.7]
Social care practitioner	1	1.0	0.6 [0.02, 3.4]	Youth work	1	0.25	3.2 [0.08, 16.7]
Assessment & support coordinator	1	0.85	0.6 [0.02, 3.4]	Music therapy	1	0.2	3.2 [0.08, 16.7]
Cultural & health liaison officer	1	0.8	0.6 [0.02, 3.4]	Total	31	17.05	
Trainee CB ^a therapist	1	0.4	0.6 [0.02, 3.4]				
Psychiatrist	2	Not known	1.3 [0.2, 4.4]				
Psychology assistant	2	Not known	1.3 [0.2, 4.4]				
External companies (Auriga and CAB)	3	Not known	1.8 [0.4, 5.4]				
Total	160	Not known					

^aCB therapist stands for Cognitive Behavioural Therapist

patients include all dialysis modalities and RRT also includes transplant patients. In addition, the table shows the proportion of units that meet the benchmark ratios as recommended in the 2002 workforce report [25]. There are no units that meet the social work requirements, which means that the psychology requirement for all units is 1 WTE per 500 RRT patients. Only four units meet this requirement, three of which are in Wales. Some units that employ psychologists also offer a counselling service. Taking the counselling and psychology provision together would mean that one additional unit has a provision of 1 WTE psychologist and counsellor for less than 500 RRT patients. It is however not specified in the 2002 recommendations how the presence of counselling services in a unit affect the psychology requirements.

Notable variations exist between the staff to dialysis patient ratios across different units. For social work, the unit with the best staff ratio per dialysis patient had a

ratio of 104, exceeding the benchmark with 48%. This was 165 for psychology and 171 for counselling. The worst ratio for social work was 1895. This was 4430 for psychology and 7390 for counselling. Figure 1 shows the variation in dialysis patient-to-staff ratios per profession. Ratios for RRT patients showed similar variations. Figure 2 provides an overview of the different ratios across all units that have psychology and/or social work provision.

Differences in median ratios for adult psychology and social work services across the four UK countries have been observed (Table 3). No renal counsellors/psychotherapists were identified in Wales and Scotland, in Northern-Ireland one unit was found to employ a counsellor. Most renal units in Scotland (5 out of 9) do not have any renal dedicated psychosocial staff, but instead operate a general model of psychosocial service provision. Ratios for psychology and social work services were the lowest in Wales.

Table 2 Ratio of adult patients per 1 WTE staff per renal unit

	No. of units	Mdn	Q1	Q3	IQR	Proportion of units meeting benchmarks 95% CIs
Psychology	33					
Dialysis		675	368	1290	922	No benchmark available
RRT		1392	838	2665	1827	4.7% [1.3, 11.7]
Social Work	32					
Dialysis		311	195	385	190	0
RRT		614	396	929	533	0
Counselling/ Psychotherapy	15					
Dialysis		591	298	905	607	No benchmark available
RRT		1358	905	2035	1130	No benchmark available

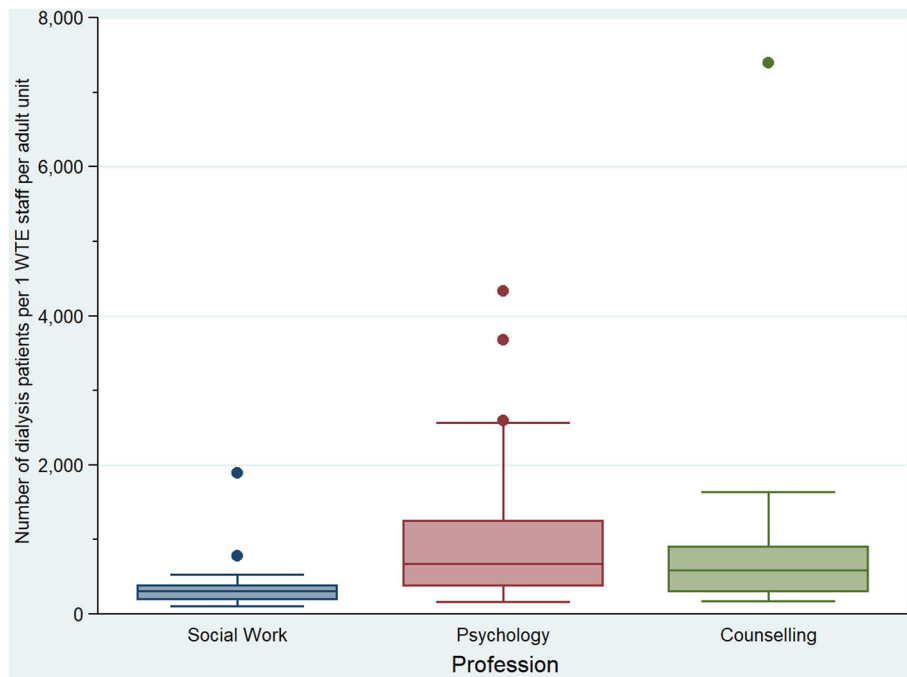


Fig. 1 Variation in dialysis patient-to-staff ratio per profession

The ratios for number of ERF patients per 1 WTE staff in paediatric services are summarized in Table 4. The ratios in paediatric services were substantially lower than in adult services, which means that even though there are far fewer children with ERF than adults on RRT,

relatively more staff is employed in paediatric units. The 2002 recommendations for paediatric services were based on WTE staff per million population of the entire region that a hospital served [25] and not on the number of renal patients in paediatric services. For that reason, it

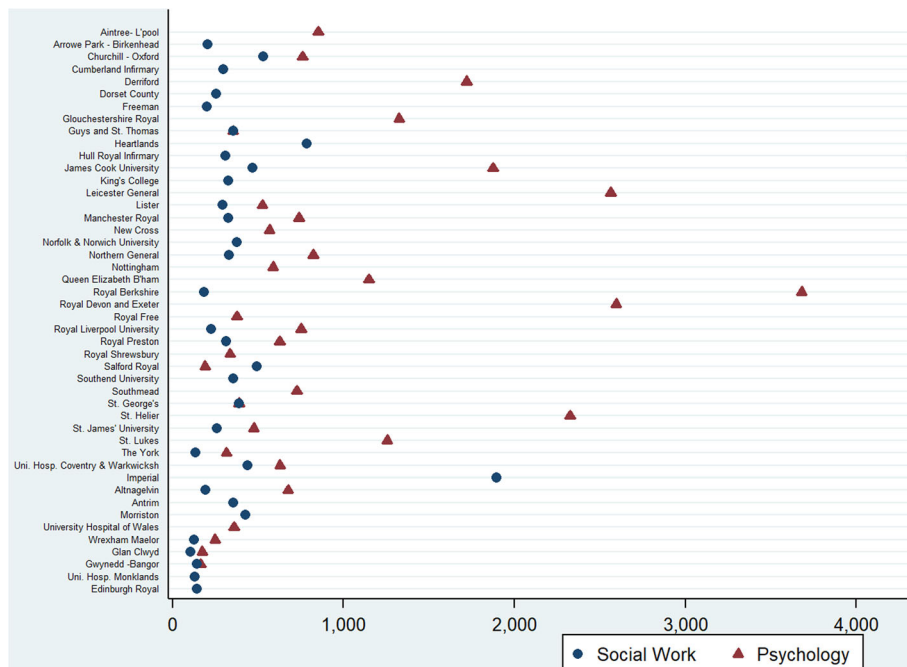


Fig. 2 Social work and psychology staff- to- dialysis patient per unit

Table 3 Ratios of adult dialysis patients per 1 WTE staff per country

	No. of units with provision	Mdn	Q1	Q3	IQR	% of adult units offering psychosocial services
England						
Social work	24	328	257	414	157	90.3
Psychology	28	745	500	1522	1022	
Wales						
Social work	4	132	114	284	170	80.0
Psychology	4	211	169	304	135	
Northern-Ireland						
Social work	3	274	193	355	162	80.0
Psychology	1	675	–	–	–	
Scotland						
Social work	2	137	132	141	9	33.3
Psychology	0	–	–	–	–	

could not be usefully determined whether the found ratios met the set requirements.

Comparisons to 2002 workforce

As previously stated, the 2002 workforce report only provided complete information on workforce data for renal social workers and psychologists. Therefore, changes in the workforce since 2002 can be reported for renal psychologists and social workers only. The total WTE of renal psychologists has increased with 1088%, from 2.5 to 27.2 WTE. Instead, the adult social worker WTE has decreased with 19%, from 55 to 44.6 WTE. The percentage of adult units without social worker input has increased with 252.1%, from 14 to 49.3%. In addition, the results show that in 2017, 29.6% of units had no psychology or social work support available. Only four units (4.7%, CI = 1.3, 11.7) provided adequate psychology provision and for all units the social work provision was inadequate. The 2002 workforce report did not offer any data on adequacy of provision to compare against.

Taken together, the adult workforce of these psychosocial professions has increased with almost 25% over the past 15 years. However, over the same time, the RRT population has increased with over 50%. Table 5 shows a comparison of overall adult staff to patient ratios, including units without psychosocial services.

Paediatric renal psychology and social work services have decreased with 20.6% over the last 15 years.

Table 4 Median and quartiles numbers of ERF paediatric patients per 1 WTE staff

	No. of units	Mdn	Q1	Q3	IQR
Social work	8	71	41	105	64
Psychology	11	93	71	220	149
Play therapy	2	60	32	87	55

Psychology provision decreased with 6.6%, from 6.1 to 5.7 WTE and social work services decreased with 28.9% from 10.4 to 7.4 WTE. In 2002, it was reported that three paediatric units (21.4%) did not have social work input and six units (43%) had no psychology input. Now, the number of paediatric units without social work input has increased with 66.7%, to five units (35.7%). Instead, the number of units without psychology input has decreased with 66.7%, to two units (14.2%). All paediatric units have at least one social worker or psychologist present, even though in one of the units the psychosocial service is made up of a psychologist who works less than 0.1 WTE on renal services.

Discussion

This investigation set out to assess the current renal psychosocial workforce, to map it against 2002 recommendations and compare it with staffing levels found in 2001. Limitations to this audit included incomplete and conflicting provision of data by the renal units, because of which the total WTE of staff for psychologists and social workers had to be calculated based on average numbers, and the ratios could not be calculated for all units. Uncertainties about the accuracy of the 2002 workforce report complicated the comparison of 2001 data to 2017 data. However, every attempt has been made to extrapolate an accurate and reliable workforce data set, overcoming inconsistencies and non-responses for data items. The researchers achieved a 100% response rate from listed renal units and 82% of units confirmed that their data was correct. Given this, the reported data can be considered highly accurate.

Variation in renal psychosocial staffing

The results show a great variety in models and availability of psychosocial services within the 84 renal units and UK countries, with Wales reporting the best

Table 5 Average 1 WTE adult staff- to- patient ratios for all units

	2001		2017		2002 Recommendations	
	Dialysis	RRT	Dialysis	RRT	Dialysis	RRT
Renal Psychologists ^a	Unavailable	1: 15233	1: 1053	1: 2252	Not known	1: 1000/500
Renal Social Workers	Unavailable	1: 693	1: 642	1: 1373	1: 70	1: 140

^aWhen taking psychology and counselling/psychotherapy services together, the 2017 establishment is 1:668 for dialysis patients and 1:1429 for RRT patients

staff-to-patient ratios. These findings suggest that a general service provision model for renal psychosocial care in the UK is lacking. Guidelines that state patients must 'have access to' psychosocial services [21–23] hardly seem strict or specific enough. This suggests renal units do not have to employ staff to provide these services, nor do they clarify the type and number of staff that should be accessible. At a very pragmatic level, adequacy of staffing ultimately determines whether guidelines issued to improve care and safety are implemented [29]. However, sufficient consideration of staffing levels and how they may be a factor in suboptimal care seems to have been overlooked when drafting these documents.

Psychosocial staffing models

The recommendations as set out in the 2002 report provided guidance for the provision of social work and psychology. An update of these recommendations should be considered, since it is currently unclear how the presence of counselling and youth services in a unit affects the social work and psychology requirements. Moreover, a recommendation for paediatric services based on the number of children with ERF is lacking. Even though the recommendations for social work are similar to those in Australia and the USA, the evidence base for these benchmarks has been questioned [2, 29]. To inform the development of future recommendations, it is useful to explore and compare recommended levels of provision in other physical health specialities in which psychosocial workforce planning has evolved. In paediatric and adult cystic fibrosis (CF), the care standards require 1 WTE psychologist and 1 WTE social worker per 150 patients [30]. This model involves providing all patients with routine psychosocial care and not stratifying on the basis of psychosocial need. The recommended levels for social work provision are broadly similar in both CF and RRT, but the recommendations for psychology services differ quite considerably. These seem to be more in line with those in cancer care, where NICE estimates that 15% of patients will need level 3 (counsellor/psychologist) support and 10% will need level 4 (psychologist/psychiatrist) intervention [31]. This has led to the development and application of a cancer care model for psychological provision across London [32], which suggests a maximum yearly caseload of 150 patients per full-time level 3/4 worker. It should be

noted that this oncology model is for psychological intervention only and not social work services. In 2014, these services appeared to be mostly provided by charity funded oncology social workers and social services [33]. Regardless of whether it is desirable that the help of charities is needed to provide access to social work, this suggests that the variety in psychosocial service provision is not limited to kidney care, but exists within care pathways across other long-term conditions. Applying the cancer care model to renal care would allow for the inclusion of counsellors/psychotherapists in the recommendations and the use of an acuity model; of every 600 RRT patients, 150 patients would require level 3/4 intervention. Sharing of psychosocial provision across other long-term conditions such as diabetes and oncology, may be a way this could be operationalised for smaller units, indeed in some areas this is already established practice. However, even though patients with chronic conditions seem to experience an impact of their disease in similar psychosocial areas, it cannot be assumed that the need for psychosocial services is the same in both CKD and oncology patients.

Exceeding benchmarks

The above comparisons suggest that the renal recommended staffing levels from 2002 are in line with a social work provision model of providing support to all RRT patients and a psychological provision model of providing support to approximately 25% of the RRT population. However, these recommendations should also include pre-dialysis and palliative care work [25], which is now not clearly reflected in the recommendations based on RRT patients. The survey findings show that not one of the 84 renal units meet the requirements for psychology and social work services together, with average staff-to-patient ratios far exceeding the benchmarks. Based on the recommendations, the current staffing requirement for adequate adult renal social work would be 437.8 WTE and for psychology services this would then be 61.3 WTE. Given that the social work establishment currently is 44.6 WTE, it should be questioned how realistic these benchmarks are.

Although health systems and training of professionals vary across countries, studies from the USA [29] and Australia [2] show that the exceeding of social work benchmarks appears to be a consistent theme that fits

within a wider, global shortage of the whole nephrology workforce [3]. In 2011, American renal social work benchmarks were exceeded in 10 out of 50 states. Apart from one state reporting a ratio of 1:425, the median ratio for other states exceeding the recommendations for dialysis patients was 1:150 [29]. In Australia, a recent study in Queensland showed a ratio of 1:191 dialysis patients, whereas one in Western Australia in 2007 calculated ratios of 1:322 [2]. Even though it should be noted that these countries seem to have less renal psychological provision than the UK, the overall UK renal social worker-to-dialysis patient ratio of 1:624 is considerably higher. Indeed, a lack of UK psychosocial service provision appears to be identified by this investigation. Yet, this cannot be concluded based on the current evidence, or lack thereof. Further research into psychosocial problems and need for services is required, to provide an evidence base to support and update 2002 staffing recommendations.

A changing workforce

The comparison of the current workforce with the 2001 workforce shows that overall, the WTEs of psychologists and social workers have increased with 12.8%, thanks to the large (1088%) increase of adult psychology staff. Instead, paediatric psychosocial services and adult social work saw their workforce decreasing. The results show an interesting trend, namely that the combined psychology and counselling/psychotherapy workforce has become almost the same size as that of the social workers. Indeed, the increase of psychology services seems to have come at the cost of social work services. The 2002 report shows that traditionally, renal social workers provided psychosocial support for CKD patients, as still seems to be the case in the USA and Australia [2, 29]. The employment of renal psychologists and counsellors/psychotherapists is a relatively new and unique phenomenon in the UK, leading to the creation of new service provision models. Even though this shift could be a result of the increasing evidence on psychological problems and interventions with CKD patients – or possibly the lack of high-quality studies that could form an evidence base for renal social work – the reasons for units deciding to employ certain members of staff requires clearer understanding. However, with benchmarks for social work far exceeded, one can wonder if there is enough time for social workers to provide the complex case work activities that they are trained to do. Indeed, renal social workers in the USA have reported that high caseloads prevent them from providing adequate support and that, in their view, patients are being denied access to good quality services [34]. There is a need to investigate whether this is also the case in the UK, manifesting in an unmet need for support, or that patients

access services through other routes if adequate dedicated provision of psychosocial care in their unit is lacking. It is unclear whether in these units the role of the nurses is expanded to include a certain level of psychosocial support, or whether patients access psychosocial services through the general hospital team or their GP. Moreover, the effectiveness of other models of service provision needs to be evaluated, to determine whether there is a difference in patient outcomes of services provided by renal dedicated staff or general staff.

Recommendations for future workforce audits

As described above, the data collection process for this paper was complicated and time-consuming and it requires improvement to make it appropriate for regular, future psychosocial workforce audits. Namely, the BRS workforce survey (based on the SRA survey) was a large document that would take time to complete, which might explain the low response rates. In addition, if the psychosocial section of this larger survey contained no data, it was unclear whether this was because there was no staff available, or whether the section was not completed. Moreover, the contradictory information found between data from CDs and psychosocial staff could suggest that staff roles are not always clear. Also, the survey asked to list renal dedicated psychosocial staff and thus did not include general psychosocial services that patients might have access to. This might explain the differences in findings from a national survey into renal young adult transition services in 2016, which found a higher number of units having access to psychology or youth work services [35], than found in the current investigation. Intuitively, a renal dedicated psychosocial service is provided by any member of psychosocial staff, with time specifically allocated for renal patients, who is funded through the renal budget or a renal charity. Future workforce audits could include a question around funding streams of services, to increase understanding around different funding models of psychosocial care.

Instead, the questionnaire distributed through the psychosocial professional groups provided detailed information that was likely to be accurate, as it came directly from psychosocial staff. However, since the questionnaire was distributed through the professional networks there was a high possibility that it did not reach all members of psychosocial staff, especially those that are not members of the professional groups. Moreover, this questionnaire would not reach the units that do not have any psychosocial provision, therefore not allowing them to confirm their lack of services. The FOI requests proved useful for collecting data from units that did not initially respond, since hospitals have a legal obligation to reply to FOI requests within 20 working days [36].

The confirmation of final results by CDs was believed to increase the reliability of findings and did not show any indications of response bias. Namely, the CDs that did not confirm results were thought to have varying numbers of psychosocial staff available to their patients.

Through combining the learning from all different data collection methods used in this paper the following recommendation can be made: Future psychosocial workforce audits should use a simple electronic survey, asking about type, number, WTE and funding of psychosocial staff. This survey should be completed by psychosocial staff where available, but should be sent to CDs of all units, either directly via email or via FOIs, to warrant a return if there is no psychosocial staff available.

Conclusion

While there are clear limits to our understanding, this investigation can be seen as a robust baseline from which to explore further research and more regular future workforce audits. The results from this mapping show great variability in models of service provision. It appears that the lack of clear policies and guidelines about the provision of psychosocial services has given units the freedom to design their own models, with some units seemingly prioritising psychosocial care more than others. Moreover, significant exceeding of benchmarks for staffing levels and a change in staffing patterns over the past 15 years have been observed. It is unclear whether the apparent lack of psychosocial services influences the ability of staff to adequately fulfil their tasks and whether it has consequences for the psychosocial wellbeing of patients. Research into the psychosocial needs of CKD patients lies at the heart of the answer to many identified questions. Moreover, there is a need to investigate current models of psychosocial service provision and to identify and share good practice of how best to address the needs of patients. Ultimately, the outcomes of these investigations could guide the development of an evidence-based psychosocial care pathway. Similar to findings 15 years ago, our investigation today shows that renal dedicated psychosocial staff is lacking, suggesting that formal emotional and psychological support is often seen as a relatively low priority, especially in a financially constrained, medically driven environment [26].

Additional file

Additional file 1: Psychosocial Provision per Renal Unit in July 2017. An overview of data on the availability of renal dedicated psychosocial staff per renal unit as per July 2017. The unit name is shown in bold if the data is confirmed by the clinical director. (DOCX 24 kb)

Abbreviations

BRS: British Renal Society; CAB: Citizens Advice Bureau; CD: Clinical Director; CF: Cystic Fibrosis; CI: Confidence Interval; CKD: Chronic Kidney Disease;

ERF: Established Renal Failure; FOI: Freedom of Information; KCUK: Kidney Care UK; NICE: National Institute of Clinical Excellence; RRT: Renal Replacement Therapy; SRA: Scottish Renal Association; WTE: Whole Time Equivalent

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Authors' contributions

MS has been involved in the design, analysis and interpretation of data, drafting the article and providing intellectual content. PO and EC have both been involved in the conception of the research, revision of the article and provision of intellectual content of critical importance to the work described. All authors have read and approved the final manuscript.

Ethics approval and consent to participate

Not applicable. Since this paper presents results of a workforce audit, comparing current staff levels against set standards, according to the Health Research Authority 'defining research table' [37] and 'decision tool' [38] this study is not classed as research requiring further Research Ethical Commission (REC) approval. Consent to participate was assumed upon completion of the survey.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Examining patient distress and unmet need for support across UK renal units with varying models of psychosocial care delivery: a cross-sectional survey study

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ABSTRACT

Objective To examine in-centre haemodialysis patients' emotional distress and need for support across UK renal units with varying models of psychosocial service provision.

Design The study used a cross-sectional survey design. Logistic regression analysis was used to examine patient distress, as captured by the Distress Thermometer, and need for support, across different renal units.

Setting Seven renal units across England, Wales and Scotland. The units were purposively selected so that varying workforce models of renal psychosocial services were represented.

Participants In total, 752 patients were on dialysis in the participating centres on the days of data collection. All adult patients, who could understand English, and with capacity (as determined by the nurse in charge), were eligible to participate in the study. The questionnaire was completed by 509 patients, resulting in an overall response rate of 67.7%.

Outcome measures The prevalence of distress and patient-reported need for support.

Results The results showed that 48.9% (95% CI 44.5 to 53.4) of respondents experienced distress. A significant association between distress and models of renal psychosocial service provision was found ($\chi^2(6)=15.05$, $p=0.019$). Multivariable logistic regression showed that patients in units with higher total psychosocial staffing ratios (OR 0.65 (95% CI 0.47 to 0.89); $p=0.008$) and specifically higher social work ratios (OR 0.49 (95% CI 0.33 to 0.74); $p=0.001$) were less likely to experience distress, even after controlling for demographic variables. In addition, a higher patient-reported unmet need for support was found in units where psychosocial staffing numbers are low or non-existent ($\chi^2(6)=37.80$, $p<0.001$).

Conclusions The novel findings emphasise a need for increased incorporation of dedicated renal psychosocial staff into the renal care pathway. Importantly, these members of staff should be able to offer support for psychological as well as practical and social care-related issues.

Strengths and limitations of this study

- This is the first study to investigate distress in renal patients across varying models of psychosocial service delivery, providing a unique health systems research perspective.
- The sample size of the study was large, with participants from seven renal units across the UK.
- The overall response rate was high, increasing the probability that the findings are representative of the patients in participating units.
- Those from black and minority ethnic groups were under-represented in the responses.
- The cross-sectional study design provided a snapshot of distress in renal patients, but future studies should consider a longitudinal panel study to capture changes in distress over time, for individuals and groups of patients along the renal pathway.

INTRODUCTION

Chronic kidney disease (CKD) is a worldwide public health problem, with increasing incidence and prevalence, high costs and poor outcomes.¹ The disease is typically progressive and can be divided into five stages of increasing severity, with treatments based on these stages. For a small, but significant percentage of people, CKD progresses to end-stage renal disease (ESRD). At this stage, which is irreversible, the kidneys are no longer able to function and renal replacement therapy (RRT)—dialysis or transplantation—becomes necessary to maintain life.^{2,3} According to the latest Renal Registry data, there were 64 887 patients receiving RRT in the UK at the end of 2017. Of these, 37.3% received in-centre haemodialysis (ICHHD), 5.4% received peritoneal dialysis, 2.0% dialysed at home and 55.2% had received a transplant.⁴ People with CKD often have a range of comorbid disorders. Some of these,



such as hypertension and diabetes, are risk factors of the disease. Others, such as heart failure or chronic pulmonary disease, are often coprevalent as a result of CKD or because of shared risk factors.^{5 6} Living with CKD, and especially ESRD, provides many ongoing physical, emotional, financial and/or social challenges throughout a patient's renal journey. These consequences of the disease and its comorbidities make patient access to expertise in medical, nursing, dietetic, pharmacological, psychological and social care areas essential.⁷

In recent years, against a global backdrop of shortages in the nephrology workforce, there have been increasing calls for a change in the existing models of renal care to manage the demands of an increasing CKD burden. A collaborative care model, in which a greater share of the work is performed by allied health professionals (including psychosocial staff), is one of the proposed solutions.⁸ Acceptance that a focus on the psychosocial needs of the patients should be included in comprehensive psychosocial care has grown in recent years,⁹ yet this has not always translated into practice. Internationally, limited evidence suggests differences in the level and type of renal psychosocial care accessible to patients. A recent Europe-wide study found that multidisciplinary teams (defined as teams consisting of allied health professionals, eg, expert nurses, dietitians and social workers) were routinely available to patients with CKD in only eight out of 17 studied countries.¹⁰ In the USA and Australia, renal dedicated social workers appear to be the point person responsible for providing psychosocial care, although in both countries high case loads and exceeded benchmarks were reported.¹¹⁻¹³ US renal social workers are in a special position, since ESRD is the only disease for which Medicare's Conditions for Coverage Mandate requires a masters-level trained social worker on every interdisciplinary team.¹⁴ Generally, in the UK, while all members of staff within the renal unit have a role in providing general psychosocial support, the core specialist psychosocial professionals include a psychologist (clinical, counselling or health), a counsellor or a psychotherapist, and/or a social worker. There are differences in the training and expertise of these professionals. A psychologist will have undertaken a minimum of 6 years of training to doctorate level and will mainly support patients with diagnosed, complex mental health issues; a counsellor or psychotherapist will have a minimum of an undergraduate diploma, but may have a bachelor's degree or postgraduate qualifications and will support patients with emotional or behavioural issues; a renal social worker will have a bachelor's degree in social work and/or a postgraduate social work qualification and, broadly speaking, focuses on improving patients' quality of life and functioning in society by connecting them to community and social care services. While the lines between these professions often seem blurred, it is important to recognise that these roles are not interchangeable and each professional uses different, and sometimes complementary, approaches to support patients. A recent workforce report by Seekles

*et al*¹⁵ showed that in the UK, over the past 15 years, a change in renal psychosocial staffing levels had taken place. The number of renal social workers had reduced dramatically, while renal psychologists and counsellors had grown in numbers. In the UK too, recommended staff-to-patient ratios were far from being met. A general UK renal psychosocial service provision model was lacking: most renal units incorporated different psychosocial teams, made up of varying types and numbers of staff, while some units completely lacked any form of dedicated psychosocial support.¹⁶

Currently, UK guidelines from the National Health Service England¹⁷ and the National Institute for Health and Care Excellence³ vaguely state that haemodialysis (HD) patients 'must have access to' psychosocial services, without clarifying the type and number of staff that should be accessible. This, and the large variety in models of service provision found, reflects a lack of empirical studies on the delivery of psychosocial services that can inform evidence-based staffing standards and regulations. This paper presents the findings of an investigation that used the concept of distress—broadly defined as 'a multifactorial unpleasant experience of a psychological (ie, cognitive, behavioural, emotional), social, spiritual, and/or physical nature'¹⁸—to explore the association between ICHD patient's distress, their perceived need for support and UK models of renal psychosocial service delivery. Studies have found that distress can have a negative effect on quality of life, health outcomes and costs, emphasising the importance of addressing psychosocial issues in renal patients.¹⁹⁻²¹ The research question asked whether there is a relationship between different UK models of renal psychosocial service delivery, self-reported distress and need for support of ICHD patients. This investigation forms part of a larger, nationwide mixed methods study that aims to understand how renal psychosocial services are delivered in the UK.

METHODS

Participating renal units

The study used a cross-sectional survey design and included ICHD patients from seven main renal units across England (n=3), Wales (n=2) and Scotland (n=2). The sites were purposively selected out of a total of 89 renal units, informed by the outcomes of a recent renal psychosocial workforce mapping,¹⁵ to ensure an inclusion of different staffing ratios and models of psychosocial service provision. Ratios were determined based on the number of RRT patients (as opposed to ICHD patients) from the latest UK Renal Registry,⁴ since the members of psychosocial staff cover the whole range of RRT patients, including transplant patients. To obtain a numerical value for ratios suitable for comparisons and analysis, the full-time equivalent (FTE) of psychosocial staff was divided by the number of RRT patients in that unit, multiplied by 100. For example, one FTE social work per 100 patients would equate to a ratio of 1. Throughout this paper, the

Table 1 Characteristics of participating renal units

Unit name	ICHD patients (n)	RRT patients (n)	Satellite units (n)	Psychosocial staffing model
Unit A	0–250	501–750	6–8	No dedicated staff
Unit B	251–500	1001–1250	3–5	Psychology
Unit C	251–500	1001–1250	3–5	Counselling and welfare advice
Unit D	251–500	751–1000	3–5	Psychology, counselling and social work
Unit E	251–500	751–1000	3–5	Social work and psychiatry
Unit F	0–250	251–500	0–2	Psychology and social work
Unit G	0–250	0–250	0–2	Psychology and social work

ICHD, in-centre haemodialysis; RRT, renal replacement therapy.

units have been sorted based on their patient ratios, with unit A having no renal dedicated psychosocial staff available and unit G having the highest ratio of total psychosocial staff available to its patients. To protect the anonymity of the participating renal units, exact characteristics that could lead to identification cannot be provided. Instead, [table 1](#) provides an overview of indicators of unit size, in addition to the psychosocial provision model. As can be seen, all units have different models of psychosocial service provision, apart from units F and G, who differ in their staff-to-patient ratios.

On average, ratios of renal dedicated psychosocial staffing in the study sites are better than ratios found across the UK. The average ratio of psychologists in this study is 1 FTE per 562 patients, compared with an average of 1 FTE per 1392 patients. For social workers, the average ratio in this study is 1 FTE per 344 patients, compared with 1 FTE per 614 patients across the UK.¹⁵ Comparison of overall staffing ratios was not possible due to a lack of comparable data. Furthermore, only units B and D had a black and minority ethnic population of a similar size as the overall UK dialysis population, while the other units served predominantly or completely white populations.

Patient and public involvement

The study design was developed with input from patient representatives, who were asked to comment on the appropriateness of the outcome measures and provide insight into the expected burden and time required for participation. Patients were not involved in the recruitment or further conduct of the study. The results will be disseminated to participants and the wider renal units through Kidney Care UK's marketing channels (website, posters) at the end of the project.

Participants and recruitment

All adult ICHD patients who could understand English, and with capacity (as determined by the nurse in charge), were eligible to participate in the study. Data collection took place between March 2018 and July 2019. Renal unit staff at each Trust provided all eligible patients with a letter of invitation and an information sheet. The University research team would visit the unit 1 week later to

distribute the questionnaires (with information sheets), which were to be completed by patients while on dialysis. Consent was assumed on return of the completed questionnaire. To prevent selection bias, patients were allowed help with completion of the questionnaire.

Sample

The sample size was restricted by the number of patients dialysing in the renal units. In total, 752 patients were on dialysis in the participating centres on the days of data collection. Of these, 509 completed the questionnaire, resulting in an overall response rate of 67.7%. Non-participants either refused to participate, were asleep, did not feel well enough to participate, did not speak English or lacked capacity. The response rates in participating units varied from 49.0% in unit F to around 82.0% in units D and G.

As can be seen in [table 2](#) the majority of respondents were male and aged over 70 years old. This distribution of gender is similar to the general UK ICHD population, which is reported to consist of 61.9% of males. The median age of the general ICHD population is 67.5 years.⁴ The study sample was almost entirely made up of people from the white ethnic group, which is different from the total ICHD population, in which this group makes up around 70% of patients.⁴ Furthermore, the majority of patients had been on dialysis for 6 months to 3 years, lived together with their partner or family and were retired.

Four respondents did not complete the Distress Thermometer (DT), while others did not provide information on other questions, leading to varying numbers of missing data. Instead of using listwise deletion, which would have resulted in the loss of important information on some analyses, pairwise deletion was used to maximise the available data on an analysis by analysis basis.

Measurements

The questionnaire used the US National Comprehensive Cancer Network's¹ DT and Problems Checklist¹⁸ as the

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Table 2 Respondent characteristics and proportion per subgroup

Characteristic	n	%
Total	509	100
Main unit (psychosocial model)		
Unit A (no staff)	64	12.6
Unit B (psychology)	65	12.8
Unit C (counselling+welfare advice)	98	19.3
Unit D (social work+psychology+counselling)	73	14.3
Unit E (social work+psychiatry)	104	20.4
Unit F (social work+psychology)	47	9.3
Unit G (social work+psychology)	58	11.4
Sex		
Male	311	61.1
Female	192	37.7
Missing	6	1.2
Age category		
18–39	50	9.8
40–49	51	10.0
50–59	97	19.1
60–69	104	20.4
≥70	201	39.5
Missing	6	1.2
Ethnicity		
White	460	90.4
Other	42	8.3
Missing	7	1.4
Time on dialysis		
<6 months	87	17.1
6 months to 3 years	193	37.9
3–5 years	91	17.9
>5 years	130	25.5
Missing	8	1.6
Living situation		
Living alone	147	29.7
Living together	349	70.3
Missing	13	2.6
Employment situation		
Employed	67	13.2
Unemployed	14	2.8
Unable to work	183	36.0
Retired	237	46.6
Missing	8	1.6

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instrument to measure distress. Although initially developed to screen for distress in oncology patients, the DT has been validated for use in the UK renal population.²² It is a simple one-item screening tool, designed to be part of health professionals' daily practice, which asks patients to rate their distress on a 11-point Likert scale from 0 (nothing) to 10 (extreme). For analysis, distress was examined through a binary variable of distress 'caseness', with DT scores of ≥ 4 denoting distress.¹⁸ Studies using the DT in renal care are limited, but a meta-analysis of studies in oncology patients found a good balance between pooled sensitivity (0.81, 95% CI 0.79 to 0.82) and pooled specificity (0.72, 95% CI 0.71 to 0.72) at the cut-off score of 4 when comparing the DT to other diagnostic tools, such as the Hospital Anxiety and Depression Scale and Beck's Depression Inventory.²³ However, for the current study, this is less relevant since the DT was not used to identify patients with diagnosable mood disorders, but to determine the prevalence of distress defined as 'an unpleasant emotional state' and allow for comparisons across units. Distress, here, does not unambiguously refer to the same concept.²⁴

Patients indicated which issues were causing them distress by ticking a box on the Problem Checklist. The questionnaire included further tick-box questions, with the options yes or no, to determine whether patients were currently in receipt of psychosocial support; and if not, whether they would like to receive this support. Information on sociodemographic characteristics (sex, age, ethnicity, living situation and employment situation) was captured using closed questions.

Data analysis methods

The prevalence of distress and 95% CIs were calculated using the cut-off score described in the Measurements section. Univariate logistic regression was then applied to examine the associations between distress, study sites and demographic characteristics. Subsequently, multivariable logistic regression was used to identify whether study site, staffing ratios and further demographic variables served as predictors of distress. All variables were entered simultaneously. Finally, univariate logistic regression was used to investigate the perceived need for support and prevalence of problem types across the study sites. All analyses were conducted using Stata V.14.2 statistical software.²⁵

RESULTS

Overall, a distress score of ≥ 4 was observed in 247 out of 505 respondents, indicating that 48.9% (95% CI 44.5 to 53.4) of ICHD patients were experiencing some form of distress. Mild to moderate distress (DT score 4–6) was identified in 25.7% of patients (130 cases, 95% CI 22.0 to 29.8). A DT score of ≥ 7 was observed for 117 cases, indicating that 23.2% of patients (95% CI 19.6 to 27.1) across all study sites were experiencing severe distress.

Findings from univariate analyses (table 3) showed an association between distress and study site, with patients

Table 3 Summary of univariate logistic analyses for association between distress and demographic variables

Variable	Distress (DT ≥4) % (n)	OR (95% CI)	P value	LR χ^2
Total (n=505)	48.9 (247)			
Main unit (n=505)				$\chi^2(6)=15.05, p=0.019$
A	56.3 (36)		–	
B	56.3 (36)	1.00 (0.50 to 2.01)	1.00	
C	59.2 (58)	1.13 (0.60 to 2.14)	0.712	
D	48.0 (35)	0.72 (0.37 to 1.41)	0.332	
E	43.3 (45)	0.59 (0.32 to 1.11)	0.103	
F	34.1 (15)	0.40 (0.18 to 0.89)	0.025	
G	37.9 (22)	0.48 (0.23 to 0.98)	0.044	
Sex (n=499)				$\chi^2(1)=2.23, p=0.135$
Male	46.3 (143)			
Female	53.2 (101)	1.32 (0.92 to 1.89)	0.136	
Age category (n=499)				$\chi^2(4)=22.36, p<0.001$
18–39	60.0 (30)	2.46 (1.30 to 4.64)	0.005	
40–49	62.0 (31)	2.68 (1.41 to 5.07)	0.003	
50–59	61.9 (60)	2.66 (1.61 to 4.39)	<0.001	
60–69	47.1 (49)	1.46 (0.90 to 2.36)	0.122	
≥70	37.9 (75)		–	
Ethnicity (n=498)				$\chi^2(1)=1.22, p=0.269$
White	48.3 (220)		–	
Other	57.1 (24)	1.43 (0.76 to 2.71)	0.272	
Time on dialysis (n=497)				$\chi^2(3)=2.99, p=0.393$
<6 months	48.8 (42)	1.28 (0.74 to 2.22)	0.371	
6 months to 3 years	52.1 (100)	1.46 (0.93 to 2.30)	0.097	
3–5 years	51.1 (46)	1.40 (0.82 to 2.42)	0.216	
>5 years	42.6 (55)		–	
Living situation (n=492)				$\chi^2(1)=1.00, p=0.316$
Living alone	52.1 (76)		–	
Living together	47.1 (163)	0.82 (0.56 to 1.21)	0.316	
Employment situation (n=497)				$\chi^2(3)=26.17, p<0.001$
Employed	42.4 (28)	1.14 (0.65 to 1.98)	0.649	
Unemployed	78.6 (11)	5.65 (1.54 to 20.83)	0.009	
Unable to work	61.2 (112)	2.43 (1.64 to 3.62)	<0.001	
Retired	39.3 (92)		–	

DT, Distress Thermometer; LR, likelihood ratio.

in units F and G less likely to be cases than in units A, B and C. Further associations were found with age group and employment situation. Specifically, those aged 18–39, 40–49 and 50–59 and those patients who were unemployed or considered themselves unable to work were significantly more likely to be distressed than those aged 70 or above and retired.

A multivariable logistic regression model (table 4) including renal unit and other demographic variables sex, age, ethnicity, time on dialysis, living situation and

employment situation was found to be a significant predictor of distress (Likelihood Ratio (LR) $\chi^2(19)=56.77, p<0.001$). The renal unit that patients belonged to significantly predicted distress, with being a patient in unit E ($\beta -0.718$) or F ($\beta -1.083$) significantly reducing the likelihood of distress compared with being a patient in unit A. Time on dialysis was also found to be a predictor of distress, with being on dialysis for a period of 3–5 years significantly increasing the likelihood of distress. Age group and employment situation were not found to be predictors.

**Table 4** Multivariable regression model for predictors of distress including renal unit and demographic variables

Predictor	B (SE)	OR (95% CI)	P value
Constant	0.176 (0.348)		
Renal unit			
A (reference)			
B	-0.161 (0.387)	0.851 (0.40 to 1.82)	0.676
C	0.176 (0.348)	1.193 (0.60 to 2.36)	0.612
D	-0.411 (0.375)	0.663 (0.32 to 1.38)	0.272
E	-0.718 (0.351)	0.488 (0.25 to 0.97)	0.041
F	-1.083 (0.461)	0.338 (0.14 to 0.84)	0.019
G	-0.678 (0.395)	0.508 (0.23 to 1.10)	0.086
Sex			
Male (reference)			
Female	0.237 (0.202)	1.268 (0.85 to 1.89)	0.241
Age category			
18–39			
	0.782 (0.444)	2.186 (0.92 to 5.22)	0.078
40–49			
	0.776 (0.439)	2.173 (0.92 to 5.13)	0.077
50–59			
	0.593 (0.369)	1.809 (0.89 to 3.73)	0.108
60–69			
	0.164 (0.282)	1.179 (0.68 to 2.05)	0.560
≥70 (reference)			
Ethnicity			
White (reference)			
Other	0.0366 (0.388)	1.037 (0.48 to 2.22)	0.925
Time on dialysis			
<6 months			
	0.411 (0.309)	1.509 (0.82 to 2.77)	0.183
6 months to 3 years			
	0.360 (0.249)	1.434 (0.88 to 2.34)	0.149
3–5 years			
	0.606 (0.305)	1.833 (1.01 to 3.34)	0.047
>5 years (reference)			
Living situation			
Living alone (reference)			
Living together	-0.321 (0.215)	0.725 (0.48 to 1.10)	0.134
Employment situation			
Employed/in education			
	-0.511 (0.394)	0.560 (0.28 to 1.30)	0.194
Unemployed			
	1.401 (0.769)	4.058 (0.90 to 18.33)	0.069
Unable to work			
	0.583 (0.311)	1.791 (0.97 to 3.30)	0.061
Retired (reference)			
n	488		

Further regression analysis was undertaken to provide more insight into the relationship between distress and psychosocial staffing ratios. Three similar multivariable logistic regression models were created, differing only by inclusion of either the total ratio of renal dedicated psychosocial staff, the ratio of renal social workers or the ratio of renal psychologists/counsellors (table 5). The difference between psychologists and counsellors should be acknowledged and emphasised, yet it was decided to group these professions together in model 3 so that counselling staff (only present in two units) could be taken

into account. In the units that had renal social work available, ratios varied from 0.19 to 0.53. The variation in ratios for psychologists/counsellors was less; the ratios varied from 0.314 to 0.32. All models included the demographics sex, ethnicity, age, living situation, time on dialysis and employment situation as predictors.

The results were as follows:

- Model 1 (including total ratios of psychosocial staff): a collective significant effect was found, LR $\chi^2(14)=47.68$, $p<0.001$. Specifically, the ratio of total psychosocial staff was found to significantly predict

Table 5 Multivariable logistic regression models for predictors of distress including staff ratios and demographic variables

Predictor	Model 1			Model 2			Model 3		
	B (SE)	OR (95% CI)	P value	B (SE)	OR (95% CI)	P value	B (SE)	OR (95% CI)	P value
Constant	-0.37 (0.32)			-0.41 (0.29)			-0.76 (0.30)		
Ratios									
Total psychosocial staff	-1.11 (0.43)	0.33 (0.14 to 0.77)	0.010						
Social work				-1.860 (0.55)	0.15 (0.05 to 0.45)	0.001			
Psychology/counselling							-0.30 (0.86)	0.741 (0.14 to 4.02)	0.728
Sex									
Male (reference)									
Female	0.176 (0.120)	1.19 (0.81 to 1.76)	0.379	0.199 (0.20)	1.22 (0.83 to 1.80)	0.319	0.192 (0.20)	1.211 (0.82 to 1.79)	0.335
Age category									
18–39	0.759 (0.44)	2.14 (0.91 to 5.04)	0.083	0.787 (0.44)	2.20 (0.93 to 5.21)	0.074	0.700 (0.43)	2.01 (0.86 to 4.72)	0.107
40–49	0.747 (0.43)	2.11 (0.91 to 4.92)	0.084	0.763 (0.43)	2.15 (0.92 to 5.02)	0.078	0.796 (0.43)	2.22 (0.95 to 5.15)	0.064
50–59	0.600 (0.36)	1.83 (0.90 to 3.72)	0.096	0.588 (0.36)	1.801 (0.88 to 3.67)	0.105	0.665 (0.36)	1.946 (0.96 to 3.95)	0.065
60–69	0.186 (0.28)	1.20 (0.70 to 2.08)	0.504	0.191 (0.28)	1.210 (0.70 to 2.09)	0.494	0.202 (0.28)	1.224 (0.71 to 2.10)	0.464
≥70 (reference)									
Ethnicity									
White (reference)									
Other	-0.069 (0.38)	0.94 (0.45 to 1.96)	0.859	-0.051 (0.38)	0.95 (0.45 to 2.00)	0.892	0.004 (0.38)	1.01 (0.48 to 2.10)	0.991
Time on dialysis									
<6 months	0.456 (0.31)	1.58 (0.87 to 2.87)	0.137	0.412 (0.31)	1.51 (0.83 to 2.75)	0.180	0.521 (0.30)	1.68 (0.93 to 3.05)	0.086
6 months to 3 years	0.388 (0.25)	1.47 (0.91 to 2.39)	0.119	0.374 (0.25)	1.45 (0.89 to 2.36)	0.131	0.445 (0.25)	1.56 (0.96 to 2.52)	0.070
3–5 years	0.624 (0.30)	1.87 (1.04 to 3.37)	0.037	0.618 (0.30)	1.86 (1.02 to 3.35)	0.041	0.648 (0.30)	1.91 (1.09 to 3.42)	0.029
>5 years (reference)									
Living situation									
Alone (reference)									
Together	-0.267 (0.21)	0.77 (0.51 to 1.16)	0.206	-0.291 (0.21)	0.75 (0.49 to 1.13)	0.167	-0.258 (0.21)	0.77 (0.51 to 1.16)	0.217
Employment									
Employed	-0.506 (0.39)	0.61 (0.28 to 1.29)	0.190	-0.509 (0.39)	0.61 (0.28 to 1.29)	0.190	-0.450 (0.39)	0.64 (0.30 to 1.36)	0.244
Unemployed	1.248 (0.76)	3.49 (0.79 to 15.5)	0.100	1.323 (0.76)	3.76 (0.84 to 16.8)	0.084	1.227 (0.76)	3.41 (0.77 to 15.1)	0.106
Unable to work	0.520 (0.30)	1.68 (0.93 to 3.04)	0.088	0.534 (0.30)	1.71 (0.94 to 3.10)	0.080	0.492 (0.30)	1.64 (0.90 to 2.95)	0.104
Retired (reference)									
n	488		488			488			

distress, with higher ratios of staff leading to a lower likelihood of distress (β -1.11, $p=0.010$). Being on dialysis for a period of 3–5 years was also found to significantly increase the likelihood of distress.

► Model 2 (including ratios of social work staff): this model also returned a significant result, predicting distress, LR $\chi^2(14)=52.57$, $p<0.001$. A significant association was found between social worker ratios and

Table 6 Univariate logistic analysis of patients reporting a perceived unmet need for support per study site

Unit	% unmet need for support (n)	OR (95% CI)	P value
Total (n=499)	17.6 (88)		
A	35.5 (22)		
B	35.4 (23)	0.996 (0.48 to 2.06)	0.991
C	12.5 (12)	0.260 (0.12 to 0.58)	0.001
D	16.9 (12)	0.370 (0.17 to 0.83)	0.016
E	8.7 (9)	0.172 (0.073 to 0.41)	<0.001
F	13.9 (6)	0.295 (0.11 to 0.81)	0.017
G	6.9 (4)	0.135 (0.043 to 0.42)	0.001

distress, with likelihood of distress reducing as social worker ratios increased ($\beta -1.86$, $p=0.001$). Again, time on dialysis (3-5 years) was found to significantly predict distress.

- Model 3 (including ratios of psychology/counselling staff): overall, the model significantly predicted distress, LR $\chi^2(14)=40.60$, $p<0.001$, but the ratio of psychology/counselling staff was not found to be a significant predictor ($\beta -0.30$, $p=0.728$). In this model, only time on dialysis (3-5 years) was found to significantly predict distress. To note, a model including psychology ratios only showed similar, non-significant results.

One or more practical issues (such as problems related to finances or housing) were reported by 43.4% of patients; 60.9% reported one or more emotional issues (such as depression or fears). It was found that 17.6% of respondents wanted to receive psychosocial support for their problems, but were not currently receiving any. Univariate analysis indicated that there were differences across units ($\chi^2(6)=37.80$, $p<0.001$), with patients in units C, D, E, F and G significantly less likely to report an unmet need for support than patients in units A and B (table 6). Of the people who reported a need for support, 75.9% were classed as distressed.

DISCUSSION

Main findings

It was found that almost half (48.9%, 95% CI 44.5% to 53.4%) of all ICHD patients participating in this study experienced some form of distress, indicating the need for psychosocial support and services. In general, our results suggest that there is a significant relationship between the different UK models of renal psychosocial service delivery and ICHD patient distress. An association between distress and models of psychosocial service provision was found and the results indicated that psychosocial staff-to-patient ratios significantly predict distress in patients. Specifically, patients in units with higher total psychosocial

staff ratios and higher social work ratios were less likely to experience distress, even after controlling for their sex, age, ethnicity, time on dialysis, living situation and employment status. Furthermore, differences across units were found in patients reported unmet need for support, with patients in units with both practical (as provided by a social worker/welfare advisor) and emotional support (from a psychologist/counsellor) available significantly less likely to want (additional) support.

Strengths and limitations

The key limitation of this study is its cross-sectional nature. A longitudinal panel study that would measure patient's distress levels before and after receiving certain psychosocial services (or no such services) would have had a higher internal validity; however, such study was not possible for practical reasons. Due to the selection of study sites based on psychosocial service provision models, the average psychosocial staffing ratios in this study were higher than the overall UK renal psychosocial staffing ratios. Based on our findings, this suggests that generalising these results to the whole ICHD population could underestimate overall distress prevalence. Importantly, one of the strengths of this study is the high response rate. Even the lowest response rate (in unit F) was still relatively high (49%), although variability between the units was found. There is however no indication that response rate variability affected the results, with the highest (unit G) and lowest (unit F) response rates showing the lowest distress prevalence. Of relevance for the aim of exploring distress across different models of service provision, this increases the probability that the scores are representative of the patients in the participating units. To our knowledge, this is the first UK study to show an impact of renal social worker staffing levels on patient distress. This is not to say that renal psychologists and counsellors do not impact patient distress levels. The ratios of psychological staff were much more equal across units than the social work ratios, which could have contributed to the current findings. Further research could explore distress across units that have notable differences in psychology staffing levels. Due to a lack of available data, it was not possible to examine the current findings in the wider, unit-specific context, including factors such as patients' access and use of general psychosocial services in the hospital or community. However, in-depth qualitative research was completed with renal staff to explore the wider process of psychosocial service delivery in each study site in a linked component of this study (findings to be reported elsewhere).

Implications

This is the first study to explore distress in ICHD patients across different models of renal psychosocial service provision. While the overall prevalence of distress was in line with estimates from other studies that used self-reported measures for depression and anxiety,^{9 20} it is the difference in prevalence across units that is of importance.

Associations between distress and demographic variables have been widely reported in other studies,^{26 27} however our results show that after accounting for models of service provision, other demographic factors (apart from time on dialysis) do not emerge as significant predictors of distress. This finding contradicts recently published findings by Damery *et al* who reported no influence of service delivery models on distress in their study.²⁶ There are a couple of possible explanations for this discrepancy. First, Damery *et al* only compared the prevalence of mild to moderate distress, leaving the prevalence of severe distress out of their analysis and excluding patients using psychiatric services since CKD stage 5 from participation. In the context of psychosocial service delivery, the current study took all levels of distress into account and did not exclude those who were already receiving support. Second, while Damery *et al* did not report staff-to-patient ratios, only renal psychologists are mentioned, which appears to reflect little variation in models of service provision across the participating units. Any differences in staffing levels might have been too small to result in differences in patient distress. Finally, there was no mention of the presence of renal social workers, whose availability plays an important role in reducing patient distress, according to the current findings.

The findings of this study are relevant for policymakers and practitioners in allocating resources to the management of distress in renal patients and in the wider context of psychosocial service delivery for those with long-term conditions. Not only does the evidence presented here show that renal psychosocial staff play a role in reducing patient distress, the results also highlight a higher patient-reported need for these services in hospitals where psychosocial staffing numbers are low or non-existent. This is in line with Damery *et al* who found higher levels of need in units without renal psychologists available, compared with those with renal psychologists available.²⁶ Yet, psychosocial services have steadily reduced over the last years,¹⁶ leaving patients having to look for support from services provided in the community. The results could indicate that these services are inaccessible or unable to provide the support patients need, leading to higher distress. Further research is needed to explore whether this is the case for the whole dialysis population, including patients on home HD and peritoneal dialysis.

Symptoms of distress can have a negative effect on patient quality of life, medical outcomes and costs, through reduced treatment adherence and increased rates of mortality, hospitalisation and length of hospital stay.^{19–21} Therefore, the findings emphasise a need for increased numbers of integrated psychosocial staff and a renal psychosocial care pathway, which, importantly, should include practical as well as emotional support. However, the main challenge to implementing psychosocial support is the lack of robust evidence to indicate adequate psychosocial staffing levels. While further investigation into appropriate staffing levels is necessary and the wider number of patients on all treatment modalities

should be taken into account to determine these, the findings provide a first indication of the minimum ratios of psychosocial staff required. The first participating unit with a dedicated social worker to have significantly lower distress levels than a unit without any support had a staffing ratio of 1 social worker per 392 RRT patients; the staffing ratio in the first unit with a dedicated psychologist to have significantly lower distress levels was 1 psychologist per 525 RRT patients. For social work, this is still much higher than recommended staffing ratios of 1 full-time worker per 140 RRT patients, to allow access to both routine and complex social work support for each patient as they move along the renal pathway. A further challenge to the implementation of renal psychosocial services is ensuring that access to these services is equitable across the country, not just based on a postcode lottery. This study highlighted geographical differences in distress prevalence, related to access to renal dedicated psychosocial services. In addition, it is important to consider the role that dialysis staff play in the process of delivering psychosocial services. There is the expectation that dialysis staff support patients who experience lower level distress²⁸ and psychosocial staff are often dependent on dialysis staff to inform, identify and refer patients in need for support to their service. Yet, a recent study by Combes *et al*²⁹ found that dialysis staff experience significant barriers in identifying and responding to distress, related to skills and knowledge, but also role perceptions.

To relieve some of the dependence on dialysis staff, screening patients for distress could be another way to identify patients in need. It is essential that the focus of this screening is not only on detecting clinically significant distress that could warrant a psychological intervention. Instead, for it to identify patients that could benefit from any type of psychosocial service, screening processes should bring patients to light who are experiencing distress, in the wider sense of the word, and/or psychosocial issues. For example, practical problems (such as issues with social care or transport) would not necessarily make a patient report distress that would meet the criteria for a formal diagnosis of anxiety or depression. Yet, in order to solve these problems and prevent them from contributing to negative health outcomes, a patient might still require support from a social worker. The use of the DT and Problem Checklist, already recommended in US oncology care guidelines,¹⁸ would allow for such a wide approach to screening and has been found to be an acceptable tool in the renal population.²² Still, even with this wide approach to capturing distress, our results show that it cannot be assumed that distress equals need for support. As such, any screening tool should always include a question that captures a patient-reported need and want for psychosocial services.

In conclusion, our findings support the incorporation of dedicated psychosocial support in the renal care pathway. At a time of calls for the evaluation and restructuring of CKD care models to improve outcomes and reduce the costs of care, the need for true integration of renal psychosocial services in new models of care can no longer be ignored.

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Patient consent for publication Not required.

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Appendix 3: The scoping review process

Table 31. Overview of articles explored during scoping review

Author and Title	Study type & subject	Wider information on psychosocial staffing models and follow-on search (if applicable)
1. Da Silva-Gane, M., Goovaerts, T., Elseviers, M. M., Lindley, E. J., (2002). Information and counselling for patients approaching end-stage renal failure in selected centres across Europe. <i>EDTNA/ERCA journal</i> , 28(1), 49–55.	A survey exploring pre-ESRD programmes across 35 renal units in 10 European countries.	The study gives minimum insight into psychosocial staffing at renal units in Europe: in 61% of units a social worker is involved in pre-ESRD education; 29% involved a counsellor. Details on specific situation in each country are not provided and number of participating centres was not equal per country: 10 out of 35 participating units were from the UK, and 9 were from Italy.
2. Aswanden, C. (2003). Discovering the culture of haemodialysis units: an ethnography. <i>EDTNA-ERCA Journal</i> , 29(4), 192–194.	An ethnographic study, using observation and interviews (N: unknown) in two UK dialysis units. It examined the culture and social life of dialysis units from a staff and patient perspective.	Not applicable.
3. Bath, J., Tonks, S., & Edwards, P. (2003). Psychological care of the haemodialysis patient. <i>EDTNA-ERCA Journal</i> , 29(2), 85–88.	A qualitative study, using interviews (N=10) to describe patient psychosocial issues in one UK dialysis unit. Based on one quote, the author concludes that ‘the psychological care system in place at the unit appeared to work well, dealing actively with problems as they arose.’	The author suggests that there is a renal psychologist available in the study site. There is no mention of social work or other psychosocial services. This is confirmed by data from the workforce mapping (chapter 2). No further searches were done.
4. Cheng, Y. Y., Wong, Y. F., Chu, B. Y., Lam, W. O., & Ho, Y. W. (2003). Rehabilitating a dialysis patient. <i>Journal of the International Society for Peritoneal Dialysis</i> , 23 Suppl 2, S81–S83.	This article presents a renal rehabilitation program – including pre-dialysis education, in-centre training and community rehabilitation- in a Chinese regional dialysis unit.	As part of the program, patients had access to medical social workers. A further Google search based on this into nephrology social work in China revealed no relevant documents.

<p>5. King K. (2003). Multidisciplinary contributions to rehabilitation: a National Kidney Foundation survey of the dialysis health care team. <i>Advances in renal replacement therapy, 10(1), 78–83.</i></p>	<p>A quantitative survey study that explores the performance of rehabilitation efforts to maximise vocation potential, functional status, and quality of life, by varying renal team members.</p>	<p>The staff responses indicate that in the US the renal team consists of nephrologists, nurses, social workers and dieticians. The author states that ‘one of the primary, federally mandated roles of the dialysis social worker is to provide clinical counselling’. A google search was done to find further information into this mandate.</p>
<p>6. Frank, A., Auslander, G. K., & Weissgarten, J. (2004). Quality of Life of Patients with End-Stage Renal Disease at Various Stages of the Illness. <i>Social Work in Health Care, 38(2), 1–27.</i></p>	<p>Quantitative study (N=71) exploring quality of life across pre-dialysis, haemodialysis and peritoneal dialysis patients in a renal unit in Israel. Discusses the importance of a social worker and describes some social work interventions.</p>	<p>The authors suggest that social workers are part of the dialysis team in Israel. Investigation of the referenced article (Furr, L.A. (1998), Psycho-social aspects of serious renal disease and dialysis: A review of the literature. <i>Social Work in Health Care, 27 (3), 97-118</i>) did not reveal any further details about this. However, another referenced article</p> <ul style="list-style-type: none"> - Auslander, G., Dobrof, J., & Epstein, I. (2001). <i>Comparing Social Work’s Role in Renal Dialysis in Israel and the United States. Social Work in Health Care, 33(3-4), 129–151</i> <p>explained that most renal units in Israel and the US have dialysis social workers, although in the US the social workers are more accountable to government agencies. Google searches related to ‘psychosocial staff’, ‘renal social work recommendations and quality standards’ in Israel found one recent article</p> <ul style="list-style-type: none"> - Haviv, Y.S & Golan, E. (2020) Global Dialysis Perspective: Israel, <i>Kidney360, 1 (2), 119-122,</i> <p>that stated that: ‘Each dialysis unit must employ a social worker with a mandatory visit every 3 months’. A reference to quality standards, further regulations or evidence base is not provided and could not be found by additional searches.</p>
<p>7. Giles.S., (2004). Establishing Evidence-Based Renal Social Work Practice Guidelines, <i>Journal of Nephrology Social Work, 23, 48-52</i></p>	<p>An audit study to explore whether a system implemented and practiced by a renal social worker in a Canadian pre-ESRD clinic to ensure that all new patients received an assessment before starting treatment, was working.</p>	<p>A benchmarking workload study at the Toronto General Hospital showed that renal social work at the hospital was understaffed. These finding are further supported by the NKF guidelines for patient to social workers ratio, which is 75 patients to every 1 master’s-level social worker. A search for recent Canadian guidance on psychosocial staffing levels identified the following document:</p>

		<ul style="list-style-type: none"> - Allen et al., (2019). <i>Nephrology social workers standards, scope of practice, and staffing guidelines</i>. CANSW document.
8. Bogatz S, Colasanto R, & Sweeney L. (2005). Defining the impact of high patient/staff ratios on dialysis social workers. <i>Nephrology News Issues</i> , 19(2):55-60.		<p>A Google search to identify this article led to two recent article that provide information on US nephrology social worker staffing ratios:</p> <ul style="list-style-type: none"> - Merighi, J. R., Zheng, M., & Browne, T. (2018). Nephrology social workers' caseloads and hourly wages in 2014 and 2017: Findings from the National Kidney Foundation Council of Nephrology Social Workers Professional Practice Survey. <i>Journal of Nephrology Social Work</i>, 42(1), 31–59. - Wolfe, A.W. (2014). The Festering Crisis of Inadequate Nephrology Social Work Staffing: What are the Options for Improvement? <i>National Kidney Foundation Journal of Nephrology Social Work</i>, 38(1), 10-19.
9. Tallis, K (2005). How to improve the quality of life in patients living with end stage renal failure. <i>Renal Society of Australasia Journal</i> , 1(1) 18–24	An overview, defining the concept of quality of life, the impact of ESRD on patient’s quality of life and the role that nurses play in enhancing patient quality of life.	Not applicable.
10. Baines, L. S., Zawada, E.T., & Jindal, R. M. (2005). Psychosocial profiling: a holistic management tool for non-compliance. <i>Clinical Transplantation</i> , 19(1), 38–44.	A review article, discussing the concept of psychosocial profiling and protocol for supportive services for transplant patients in a UK unit, which involves a multi-faceted approach using psychotherapeutic principles as a means to detect, understand and treat non-compliance in patients on dialysis and in recipients of kidney transplants.	Not applicable
11. Browne, T. (2006). Nephrology Social Work: History in the Making. <i>Journal of Nephrology Social Work</i> , 25, 11-29.	A review, summarising research about psychosocial issues in CKD and ESRD. In addition, it provides evidence of the efficacy of nephrology social work interventions.	<p>The author explains that federal guidelines dictate that in the US, ‘every dialysis and kidney transplant centre must have a master's-level social worker on its interdisciplinary medical team’.</p> <p>A google search on this identified a more recent article by the same author:</p>

		<ul style="list-style-type: none"> - Browne, T. (2019). The Role for Nephrology Social Work in the New Kidney Disease Paradigm—Moving Ahead by Remembering How We Got Here, <i>National Kidney Foundation Journal of Nephrology Social Work</i>, 41(1), 9-22, in which the author repeats the same evidence.
<p>12. Beder, J. (2007). Evaluation Research on Social Work Interventions: A Study on the Impact of Social Worker Staffing. <i>Social Work in Health Care</i>, 47(1), 1–13.</p>	<p>A quantitative study (N=62), which compared differences in depression and quality of life outcomes between US dialysis patients who had access to a social worker on three days compared to those who has access to a social worker on two days.</p>	<p>The author references several studies that showed that social work interventions have positive outcomes that were explored further:</p> <ul style="list-style-type: none"> - Beder, J. (1999). Evaluation research on the effectiveness of social work intervention on dialysis patients: The first three months. <i>Social Work in Health Care</i>, 50(1), 15-30. - Dobroff, J., Dolink, A., Lichtiger, E., Uribarri, J., & Epstein, L (2001). Dialysis patient characteristics and outcomes: The complexity of social work practice with the end stage renal disease population. <i>Social Work in Health Care</i>, 33(314), 105-128 - Johnstone, S. (2005). Wellness programming: Nephrology social work expands its role in renal disease management. <i>Nephrology News & Issues</i>, 19(12), 59-71. <p>None of these specifically compared outcomes across varying staffing arrangements.</p> <p>A further referenced article:</p> <ul style="list-style-type: none"> - Roberts, J., & Johnstone, S. (2006). Screening and treating depression: Patient preferences and implications for social workers. <i>Nephrology News & Issues</i>, 20, 43-49 <p>found that dialysis patients prefer to receive treatment for their depression from their dialysis clinical social workers as opposed to being referred to outside agencies.</p>
<p>13. Callahan, M.B. (2007) Designing Nephrology Social Work interventions to Improve Self-Management and Adherence based on the Dialysis Outcomes and Practice Patterns</p>	<p>This article describes several nephrology social work interventions to improve patient self-management and adherence or teaching staff to understand change.</p>	<p>The article contained several references to other articles and reports about social work interventions that were further explored:</p> <ul style="list-style-type: none"> - Johnstone, S. (2003). Making peace with fluid: Nephrology social workers lead cognitive behavioral intervention to reduce health risk behavior. <i>Nephrology News and Issues</i>, 17(13), 20–31.

<p>Study. <i>The Journal of Nephrology Social Work</i>, 26(5), 11-17.</p>		<ul style="list-style-type: none"> - Johnstone, S. & Callahan, M.B. (2007). Living longer, living better. National Kidney Foundation, Kidney Learning System. - National Kidney Foundation/Council of Nephrology Social Workers' Outcome Training Program. (2006). <i>Nephrology Social Work Practice: An Outcomes-Driven Model</i>. Chicago. <p>These articles provided information and guided the identification of further articles on outcomes in nephrology social work and evidence of effectiveness of social worker interventions.</p>
<p>14. Callahan M. B. (2007). Begin with the end in mind: the value of outcome-driven nephrology social work. <i>Advances in chronic kidney disease</i>, 14(4), 409–414.</p>	<p>This descriptive article makes the case for a strategic 'outcomes-driven' social work model of practice, working towards improving patient outcomes with set interventions along the CKD pathway.</p>	<p>The author describes how outcomes-driven social work programs, such as the Living Longer, Living Better program (described by already identified article from Johnstone and Callahan above) can contribute towards support patients, whilst also meeting industry related targets related to treatment adherence and self-management.</p>
<p>15. Murphy F, Jenkins K, McCann M, Sedgewick J. (2008) CE: Continuing Education article. Patient management in chronic kidney disease stages 4 to 5. <i>Journal of Renal Care</i>, 34(4), 191-198.</p>	<p>An overview of physical symptoms and psychological issues in patients with CKD stages 4 and 5, emphasising the importance of patient education and choice of renal replacement therapy.</p>	<p>In this UK article, it states that 'CKD patients should have access to a counselling service'. There is no mention of social work.</p>
<p>16. Spry L. (2008). Building the chronic kidney disease management team. <i>Advances in chronic kidney disease</i>, 15(1), 29–36.</p>	<p>An article that describes three models of CKD care, of which one includes social work support, related to changes in US health care reimbursement.</p>	<p>Not applicable.</p>
<p>17. Bissonette, J.M. (2011). <i>Evaluation of an advanced practice nurse led inter-professional collaborative chronic care approach for kidney transplant patients: the TARGET study</i>. PhD thesis, University of Ottawa.</p>	<p>A non-randomised, controlled quantitative PhD study (N=180) showing improved processes and outcomes of care for kidney transplant CKD patients in an advanced practice nurse led approach to care.</p>	<p>The author states that: 'The Ministry of Health, Ontario Joint Policy and Planning Committee (JPPC, 1997), funding formula for the ambulatory CKD clinic care of patients with stage 4 or greater CKD (eGFR < 30 ml/min/1.73m²) is at a higher rate when the healthcare team includes two or more healthcare professionals, in addition to the physician (e.g., APN, dietitian, social worker or pharmacist). The funding rate for each clinic appointment, for kidney transplant patients with stage 4 CKD or greater and seen by an inter-professional</p>

		<p>healthcare team, is \$240.00 as compared to \$90.00 for those patients with CKD stages 1 to 3, and not seen by an inter-professional healthcare team’.</p> <p>Further google searches to find more recent information about these funding arrangements identified the following article:</p> <ul style="list-style-type: none"> - Blake, P.G. (2020). Global Dialysis Perspective: Canada. <i>Kidney 360, 1(2)</i>, 115-118. <p>It states: ‘Social workers and dietitians are required and available to all patients on dialysis, and reimbursement takes this requirement into account. However, most provinces do not mandate specific provider-to-patient ratios, and fiscal pressures have led to a perceived shortage of sufficient allied health support in many centers.’ No further references were provided.</p>
<p>18. Idier, L., Untas, A., Koleck, M., Chauveau, P., & Rascle, N. (2011). Assessment and effects of Therapeutic Patient Education for patients in hemodialysis: a systematic review. <i>International journal of nursing studies</i>, 48(12), 1570–1586.</p>	<p>A review of 35 articles about the impact of therapeutic patient education programs for haemodialysis patients.</p>	<p>The authors discuss the following article that was explored further:</p> <ul style="list-style-type: none"> - Cabness, J., Miller, C., Martina, K., 2007. Mastering hemodialysis to reverse patterns of missed and shortened treatments. <i>Journal of Nephrology Social Workers</i> 27, 45–51. <p>It found a higher decrease for missed and shortened HD sessions in a social worker led intervention group compared to a nurse-led intervention group.</p>
<p>19. Karkar A. (2011). Caring for Patients with CRF: Rewards and Benefits. <i>International Journal of Nephrology</i>, 2011.</p>	<p>A background article that describes the medical, social and psychological care that is needed to support patients in the pre-ESRD phase and following RRT.</p>	<p>The author mentions that in this Saudi Arabian unit, the renal team includes a social worker. Further Google searches into this found an article from 2001 that suggests that social workers are the main provider of psychosocial care, present in 55% of units, yet no recent relevant documents were found.</p>
<p>20. O’Donoghue, D. (2011). Achieving quality: the need for a multi-professional approach. <i>Journal of Renal Nursing</i>, 3(3), 110-114.</p>	<p>In this commentary article, the author argues that the complexities of advanced renal disease result in the need for cohesive multidisciplinary team working in the UK.</p>	<p>The author states that: ‘To support kidney care multiprofessional team-working, new arrangements were put in place in England for adult services from April 2011. Payment to trusts for first outpatient visits that are multiprofessional will receive a 50% uplift (price for doctors-only visits £198 vs £328 for first MDT visits) with ongoing</p>

		<p>multiprofessional care attracting more than double physician-only outpatient attendances (£257 vs £128).’</p> <p>A further google search into these arrangements revealed the NHS payment by result guidance. It states that multi-professional attendances are defined as multiple care professionals seeing a patient together, at the same time. The document makes no reference to psychosocial input.</p>
21. Murdoch, A. (2012). Renal social workers: Vital members of the renal multidisciplinary team. <i>Journal of Renal Nursing</i> , 4(1), 34-36.	An overview of what UK renal social workers do, followed by two patient case studies and an illustration of exceeded benchmarks.	Describes issues around social work staffing and funding.
22. Strand, H., & Parker, D. (2012). Effects of multidisciplinary models of care for adult pre-dialysis patients with chronic kidney disease: a systematic review. <i>International journal of evidence-based healthcare</i> , 10(1), 53–59.	A systematic review aimed at comparing the effectiveness of multidisciplinary care with traditional medical care on the progression of CKD in pre-dialysis phases. The authors identified only four articles.	The authors state that: ‘the findings indicate that Multidisciplinary care with distinct educational parts and ongoing support had a positive effect on delaying the progression of CKD for patients in stages 3–5 of this condition. As a secondary effect, this care delayed the time interval to need RRT.’
23. Campbell, K. L., & Murray, E. M. (2013). Allied health services to nephrology: an audit of current workforce and meeting future challenges. <i>Journal of renal care</i> , 39(1), 52–61.	An audit of the allied health workforce providing renal services (excluding transplant) in Queensland, Australia.	<p>The author explained that the found ratios exceed local benchmarks stipulating a ratio of 1 RSW on 70 dialysis patients and a ratio of 1 psychologist on 200 patients.</p> <p>A Google search to find local guidelines on renal psychosocial staffing led to the Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) guidelines, however these made no reference to psychosocial support. No national guidelines were found. The search further led to a low-quality, not peer-reviewed, article:</p> <ul style="list-style-type: none"> - Fortnum et al., (2016). Scope of Renal social work role in Australia, <i>Social Work Focus</i>, 1(1), 34-37.
24. Boulware, L.E., Hill-Briggs, F., Powe, N.R., (2014).	A randomised-controlled trial, showing improved discussion and active pursuit of	The authors referenced an article that used a similar intervention to achieve increased live donor kidney transplantation, that was

<p>Effectiveness of Educational and Social Worker Interventions to Activate Patients' Discussion and Pursuit of Preemptive Living Donor Kidney Transplantation: A Randomized Controlled Trial. <i>American Journal of Kidney Diseases</i>, 61(3), 476-486.</p>	<p>living kidney transplant after a 'Talking about Live Kidney Donation' intervention, delivered by a social worker, compared to standard care.</p>	<p>explored further. This intervention was delivered by health educators instead of social workers:</p> <ul style="list-style-type: none"> - Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. <i>American Journal of Transplantation</i>, 7(2):394-401.
<p>25. Schell, J.O., Bova-Collis, R., & Eneanya, N.D. (2014). An interdisciplinary approach to dialysis decision-making in the CKD patient with depression. <i>Advances in chronic kidney disease</i>, 21(4), 385-391.</p>	<p>A case-based discussion of depressive symptoms in CKD patients and the role of the interdisciplinary care team in the US.</p>	<p>The authors state that: 'In particular, the masters-prepared social worker has demonstrated competencies in counseling as well as behavioral and social systems knowledge that can be applied to offer support, assistance in care decisions, and evaluation of symptoms.' The authors reference the following articles, that were further explored:</p> <ul style="list-style-type: none"> - Cukor, D., Ver Halen, N., Asher, D. R., Coplan, J. D., Weedon, J., Wyka, K. E., Saggi, S. J., & Kimmel, P. L. (2014). Psychosocial intervention improves depression, quality of life, and fluid adherence in hemodialysis. <i>Journal of the American Society of Nephrology : JASN</i>, 25(1), 196-206. - Hedayati, S. S., Yalamanchili, V., & Finkelstein, F. O. (2012). A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. <i>Kidney international</i>, 81(3), 247-255. <p>The latter article led to the following article:</p> <ul style="list-style-type: none"> - Weiner, S., Kutner, N. G., Bowles, T., & Johnstone, S. (2010). Improving psychosocial health in hemodialysis patients after a disaster. <i>Social work in health care</i>, 49(6), 513-525.
<p>26. Yee J. (2014). Resolved: the case for CKD clinics. <i>Advances in chronic kidney disease</i>, 21(4), 327-330.</p>	<p>Article presenting a proposed model for an idealised interdisciplinary CKD clinic.</p>	<p>The authors state that: 'The components of the CKD clinic could include a social worker, pharmacist, an advanced practitioner (AP), renal nutritionist, and nephrologist, with the patient at the nexus of care. A psychologist, physiotherapist, and chiropodist could also fill valuable roles but likely on an as-needed basis'</p>

<p>27. Bennett, P. N., Schatell, D., & Shah, K. D. (2015). Psychosocial aspects in home hemodialysis: A review. <i>Hemodialysis International</i>, 19, 128–134.</p>	<p>A review, which aimed to provide a psychosocial guide for new start-up home HD programs. The authors are from Australia, the US and India and state that it is important that a psychologist or counsellor is proactively involved in the program to support patients with mental health issues.</p>	<p>The authors state that: ‘in the United States, the Kidney Disease Quality of Life-36 survey is required for adult dialysis patients annually for use in care planning.’ A Google search to find more information on this requirement identified a document detailing the ‘Standards of practice for nephrology social work – 6th edition’ by Browne et al. (2014).</p>
<p>28. Best, J.M., & Bonner, A. (2015). PREPARE Study: Patient satisfaction survey with care provided in the low clearance clinic. <i>Renal Society of Australasia Journal</i>, 11(2), 62-67</p>	<p>A quantitative research article (N=47), exploring patient satisfaction in pre-dialysis patients who attend a multidisciplinary low clearance clinic that manages and prepares patients for RRT.</p>	<p>The authors provide some insight into psychosocial staff available at the LCCs in Australia: ‘multidisciplinary support was offered to 88% of patients at the low clearance clinic, consisting of a dietician, social worker, pharmacist and clinical psychologist.’</p>
<p>29. Bale et al., (2016) Psychosocial factors in End-Stage Kidney Disease Patients at a Tertiary Hospital in Australia. <i>International Journal of Nephrology</i>, 2016, 1-6.</p>	<p>A quantitative study, using audit data (N=244). It explored demographics and issues of patients who were referred to an Australian renal social worker.</p>	<p>The authors reference Australian guidance that suggest involvement of a social worker in early stages of CKD: - D. W. Johnson, E. Atai, M. Chan et al. (2013) KHA-CARI guideline: early chronic kidney disease: detection, prevention and management. <i>Nephrology</i>, 18(5), 340–350.</p>
<p>30. Cooper, B., Dang, K., Jones, A., & Thomas, A. (2017). The psychiatry-integrated nurse practitioner role in hemodialysis: An opportunity to provide nurse practitioner care between the interface of psychiatry and hemodialysis. <i>CANNT Journal</i>, 27(1), 13-18.</p>	<p>This article presents a model of psychiatry-integrated nurse practitioner care at a Canadian renal unit. A medical psychiatry nurse became the psychiatry point-of-care consultant for the unit to bridge a gap in access to outpatient psychiatry services.</p>	<p>Not applicable.</p>

Res code: A/UnitName/ 001

QUESTIONNAIRE A –Psychosocial Needs Assessment

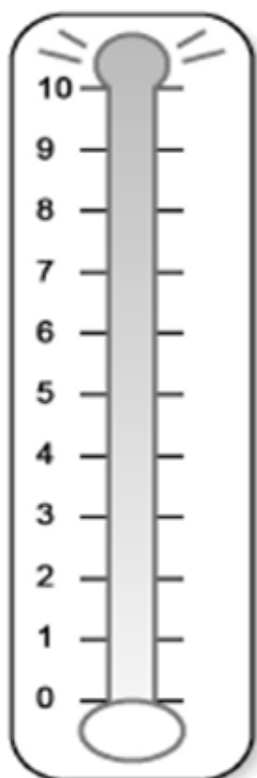
This questionnaire is a simple measure designed to capture your needs. It asks you to rate on a scale of 0-10 (10 being the highest) the level of distress you are experiencing, and which problems are causing you concern (if any). The questionnaire is anonymous and has a research code, the second section asks a few details about you but does not require your name.

Section 1: Your Psychosocial Problems and Need

1. Do you have any problems that are causing you concern and distress?

First, please circle the number (0-10) that best describes **how much distress you have been experiencing** in the last week including today.

10 = Extreme Distress



0= No Distress

Second, please indicate if any of the following have **been a problem for you** in the past week including today. Just tick the boxes that apply and leave blank those that do not affect you.

Practical Problems

- Housing
- Financial/Insurance
- Work/employment/school
- Transportation
- Child care
- Treatment decisions
- Lack of information

Family Problems

- Dealing with children
- Dealing with a partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness/anxiety
- Adjusting to my illness
- Isolation/feeling alone
- Boredom

Spiritual/Religious Concerns

- Relating to God
- Loss of faith
- Facing my mortality
- Loss of my sense of purpose

Physical problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhoea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling hands and feet

Cognitive Problems

- Forgetfulness
- Seeing/hearing things
- Feeling confused
- Poor thinking

Other problems: _____

2. If you have ticked **YES** to one or more of the problems in Q1, **please list the problems below that cause you the most distress** to a maximum of three:

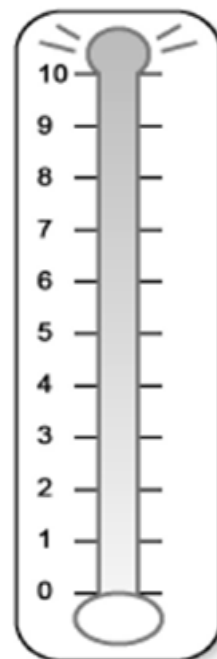
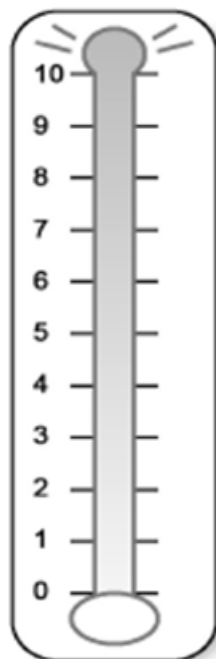
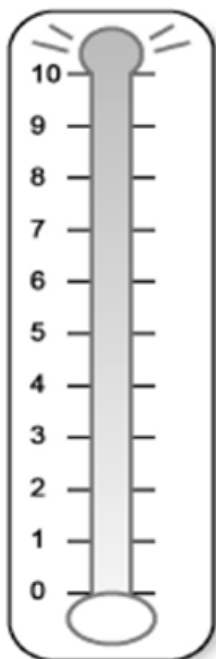
<p><i>First problem: (please state)</i></p> <p style="text-align: center;">↓</p>	<p><i>Second problem: (please state)</i></p> <p style="text-align: center;">↓</p>	<p><i>Third problem: (please state)</i></p> <p style="text-align: center;">↓</p>
--	---	--

3. Then identify for each problem below **how much help** you think you need?

I Need Help
10 = Desperately

I Need Help
10 = Desperately

I Need Help
10 = Desperately



0 = Can manage myself

0 = Can manage myself

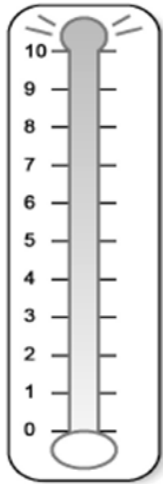
0 = Can manage myself

4. In these three columns, please **mark the number (0-10)** that best describes how you been feeling in the past two weeks, including today.

Anxiety

Please mark how severe is your anxiety? Anxiety means feeling worried, tense, agitated

10 = Extreme

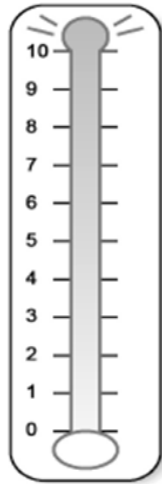


0 = None

Depression

Please mark how severe is your depression? Depression means feeling down, low, withdrawn

10 = Extreme

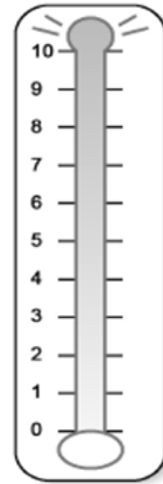


0 = None

Anger

Please mark how severe is your anger? Anger means feeling annoyed, irritated

10 = Extreme



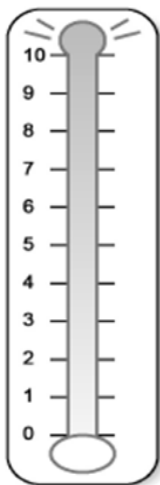
0 = None

5. In the first two columns below, please indicate how much impact your problems have on you; if you had any pain and the burden you've experienced, and an overall health score.

Pain

Please indicate how much pain you are suffering

10 = Extreme



0 = None

Burden

How much has all this affected you? To what extent can you still do normal activities?

10 = Cannot function at all

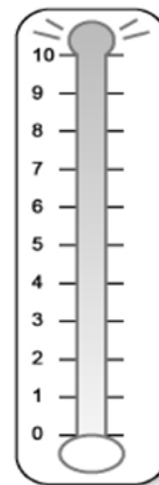


0 = No effect on me

Overall Health

Please indicate how good or bad your own health is today. 10 is the best health you can imagine and 0 the worst

10 = Best Health



0 = Worst Health

6. Are you already receiving help for these problems? *(circle answer)*

Yes No Not applicable

7. If Yes, who is helping you? (e.g. psychologist, social worker, welfare advisor, CAB, counsellor, family/friend or other) *please list:*

.....

8. If No, are you on a waiting list to receive help for these problems? *(tick answer)*

Yes No

9. If No, would you like help for these problems? *(tick answer)*

Yes Maybe No

If you have answered 'Yes' to this question please discuss with your dialysis nurse as you may need to be referred to an appropriate support service.

10. Have you had help with filling in this questionnaire? If yes, by whom?

.....

Section 2: About You *(circle the response that best describes you for each question)*

11. Age? *(tick only one)*

18-30 31-40 41-50 51-60 61-70 Over 70

12. Gender? *(tick only one)*

Male Female Prefer not to say

13. Employment or Education status? (tick only one)

- Full-time work Part-time work Full-time education Retired
 Unemployed Choose not to work Unable to work due to illness

14. Who do you live with? (tick only one)

- Live alone Live with a partner Live with family
 Live in sheltered accommodation/Care facility Prefer not to say

15. How long have you been on dialysis? (tick only one)

- Less than a month 1 - 6 months 7 months - 1 year
 1 - 3 years 3 - 5 years More than 5 years

16. Which of these ethnic groups would you say you belong to?

WHITE

- British
 Irish
 Any other White background,
please state.....

BLACK OR BLACK BRITISH

- Caribbean
 African
 Any other Black background,
please state.....

ASIAN OR ASIAN BRITISH

- Indian
 Pakistani
 Bangladeshi
 Any other Asian background,
please state.....

MIXED

- White and Black Caribbean
 White and Black African
 White and Asian
 Any other Mixed background,
please state.....

CHINESE OR OTHER ETHNIC GROUP

- Chinese Any other ethnic group,
please state.....

THANK YOU FOR TAKING THE TIME TO COMPLETE THE QUESTIONNAIRE

Res code: B/Unit Name/SW Initials/ 0

QUESTIONNAIRE 1 –Psychosocial Needs Assessment (pre-intervention)

This questionnaire is a simple measure designed to capture your psychosocial needs. It asks you to rate on a scale of 0-10 (10 being the highest) the level of distress you are experiencing, and which problems are causing you concern (if any). The questionnaire is anonymous and has a research code, the second section asks a few details about you but does not require your name.

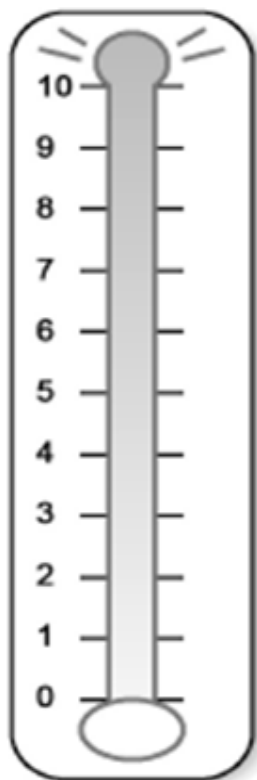
Section 1: Your Psychosocial Problems and Need

1. Do you have any problems that are causing you concern and distress?

First, please circle the number (0-10) that best describes **how much distress you have been experiencing** in the last week including today.

Second, please indicate if any of the following have **been a problem for you** in the past week including today. Just tick the boxes that apply and leave blank those that do not affect you.

10 = Extreme Distress



0= No Distress

- | | |
|---|--|
| <p><u>Practical Problems</u></p> <p><input type="checkbox"/> Housing</p> <p><input type="checkbox"/> Financial/Insurance</p> <p><input type="checkbox"/> Work/employment/school</p> <p><input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> Child care</p> <p><input type="checkbox"/> Treatment decisions</p> <p><input type="checkbox"/> Lack of information</p> <p><u>Family Problems</u></p> <p><input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> Dealing with a partner</p> <p><input type="checkbox"/> Ability to have children</p> <p><input type="checkbox"/> Family health issues</p> <p><u>Emotional Problems</u></p> <p><input type="checkbox"/> Depression</p> <p><input type="checkbox"/> Fears</p> <p><input type="checkbox"/> Nervousness/anxiety</p> <p><input type="checkbox"/> Adjusting to my illness</p> <p><input type="checkbox"/> Isolation/feeling alone</p> <p><input type="checkbox"/> Boredom</p> <p><u>Spiritual/Religious Concerns</u></p> <p><input type="checkbox"/> Relating to God</p> <p><input type="checkbox"/> Loss of faith</p> <p><input type="checkbox"/> Facing my mortality</p> <p><input type="checkbox"/> Loss of my sense of Purpose</p> | <p><u>Physical problems</u></p> <p><input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> Diarrhoea</p> <p><input type="checkbox"/> Eating</p> <p><input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> Feeling swollen</p> <p><input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> indigestion</p> <p><input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> Pain</p> <p><input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> Substance abuse</p> <p><input type="checkbox"/> Tingling hands and feet</p> <p><u>Cognitive Problems</u></p> <p><input type="checkbox"/> Forgetfulness</p> <p><input type="checkbox"/> Seeing/hearing things</p> <p><input type="checkbox"/> Feeling confused</p> <p><input type="checkbox"/> Poor thinking</p> |
|---|--|

Other problems: _____

2. If you have ticked **YES** to one or more of the problems in Q1, **please list the problems below that cause you the most distress, to a maximum of three:**

<i>First problem: (please state)</i>	<i>Second problem: (please state)</i>	<i>Third problem: (please state)</i>
↓	↓	↓

3. Then identify for each problem below **how much help** you think you need?

I Need Help

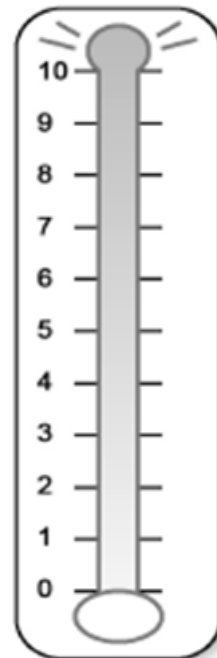
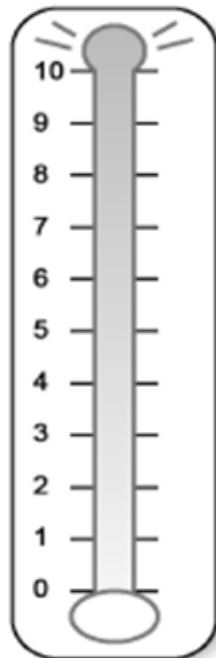
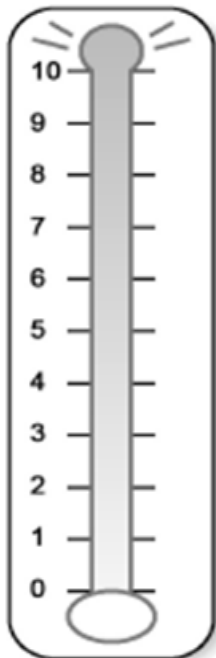
I Need Help

I Need Help

10 = Desperately

10 = Desperately

10 = Desperately



0 = Can manage myself

0 = Can manage myself

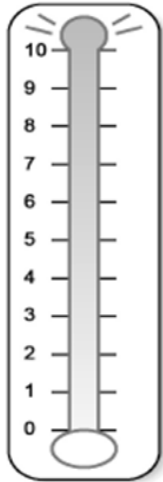
0 = Can manage myself

4. In these three columns, please **mark the number (0-10)** that best describes how you been feeling in the past two weeks, including today.

Anxiety

Please mark how severe is your anxiety? Anxiety means feeling worried, tense, agitated

10 = Extreme

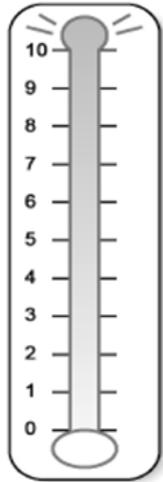


0 = None

Depression

Please mark how severe is your depression? Depression means feeling down, low, withdrawn

10 = Extreme

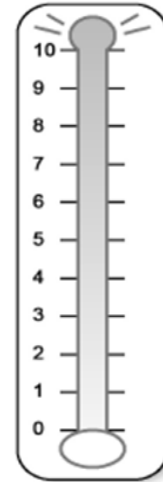


0 = None

Anger

Please mark how severe is your anger? Anger means feeling annoyed, irritated

10 = Extreme



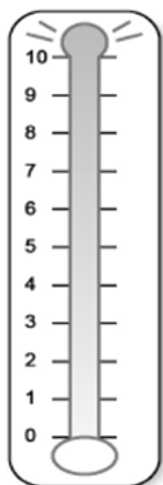
0 = None

5. In the first two columns below, please indicate how much impact your problems have on you; if you had any pain and the burden you've experienced, and an overall health score.

Pain

Please indicate how much pain you are suffering

10 = Extreme

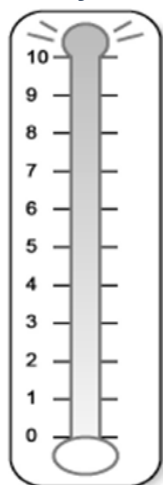


0 = None

Burden

How much has all this affected you? To what extent can you still do normal activities?

10 = Cannot function at all

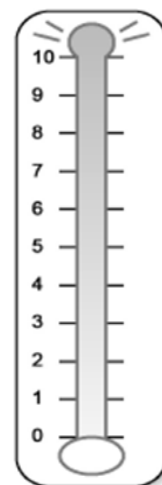


0 = No effect on me

Overall Health

Please indicate how good or bad your own health is today. 10 is the best health you can imagine and 0 the worst

10 = Best Health



0 = Worst Health

6. You have been asked to fill in this questionnaire, because you will be seeing a social worker.

What problem(s) would you like the social worker to help you with?

.....
.....
.....
.....

7. **What result would you be satisfied with or expect after seeing the social worker, even if this takes some time to achieve?**

.....
.....
.....
.....

8. **Have you had help with any of your problems before?**

- a. Yes
- b. No
- c. Not applicable

9. **If Yes, who was helping you?** (e.g. family, friend, volunteer, psychologist, social worker, welfare advisor, counsellor, etc).

.....

Section 2: About You (circle the response that best describes you for each question)

10. **Age?** (tick only one)

- 18-30 31-40 41-50 51-60 61-70 Over 70

11. **Gender?** (tick only one)

- Male Female Prefer not to say

12. **Employment or Education status?** (tick only one)

- Full-time work Part-time work Full-time education Retired
 Unemployed Choose not to work Unable to work due to illness

13. Who do you live with? (tick only one)

- Live alone Live with a partner Live with family
 Live in sheltered accommodation/Care facility Prefer not to say

14. What is your current treatment modality? (tick only one)

- Haemodialysis Peritoneal Dialysis Transplant
 Not yet on dialysis

15. How long have you been on dialysis? (tick only one, if applicable)

- Less than a month 1 - 6 months 7 months - 1 year
 1 - 3 years 3 - 5 years More than 5 years

16. Which of these ethnic groups would you say you belong? (tick only one)

WHITE

- British
 Irish
 Any other White background,
please state.....

BLACK OR BLACK BRITISH

- Caribbean
 African
 Any other Black background,
please state.....

ASIAN OR ASIAN BRITISH

- Indian
 Pakistani
 Bangladeshi
 Any other Asian background,
please state.....

MIXED

- White and Black Caribbean
 White and Black African
 White and Asian
 Any other Mixed background,
please state.....

CHINESE OR OTHER ETHNIC GROUP

- Chinese Any other ethnic group,
please state.....

THANK YOU FOR TAKING THE TIME TO COMPLETE THE QUESTIONNAIRE

Res code: C/Unit Name/SW initials/ 00

QUESTIONNAIRE 2 –Psychosocial Needs Assessment (post intervention)

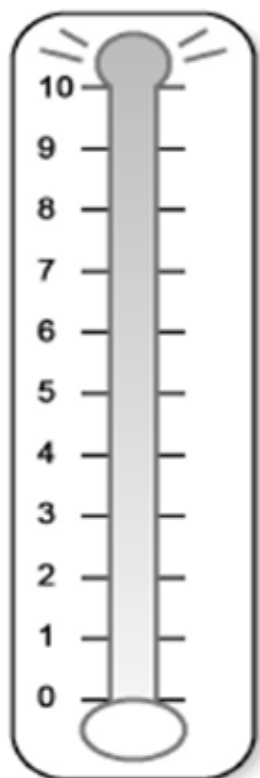
This questionnaire is a simple measure designed to capture your psychosocial needs. It is the same as you have filled in before; it asks you to rate on a scale of 0-10 (10 being the highest) the level of distress you are experiencing, and which problems are causing you concern (if any). The second section will ask you about your experience and satisfaction of you seeing a social worker. The questionnaire is anonymous and has a research code, although the third section asks a few details about you it does not require your name.

Section 1: Your Psychosocial Problems and Need

1. Do you have any problems that are causing you concern and distress?

First, please circle the number (0-10) that best describes **how much distress you have been experiencing** in the last week including today.

10 = Extreme Distress



0= No Distress

Second, please indicate if any of the following have **been a problem for you** in the past week including today. Just tick the boxes that apply and leave blank those that do not affect you.

Practical Problems

- Housing
- Financial/Insurance
- Work/employment/school
- Transportation
- Child care
- Treatment decisions
- Lack of information

Family Problems

- Dealing with children
- Dealing with a partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness/anxiety
- Adjusting to my illness
- Isolation/feeling alone
- Boredom

Spiritual/Religious

Concerns

- Relating to God
- Loss of faith
- Facing my mortality
- Loss of my sense of purpose

Physical problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- constipation
- Diarrhoea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling hands and feet

Cognitive Problems

- Forgetfulness
- Seeing/hearing things
- Feeling confused
- Poor thinking

Other problems: _____

2. If you have ticked **YES** to one or more of the problems in Q1, **please list the problems below that cause you the most distress**, to a maximum of three:

<i>First problem: (please state)</i>	<i>Second problem: (please state)</i>	<i>Third problem: (please state)</i>
↓	↓	↓

3. Then identify for each problem below **how much help** you think you need?

I Need Help

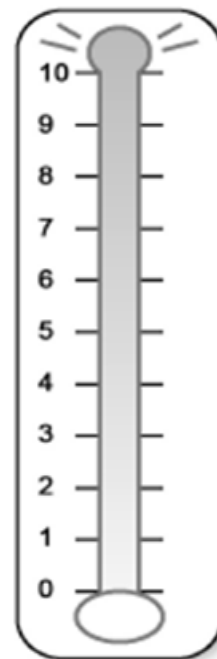
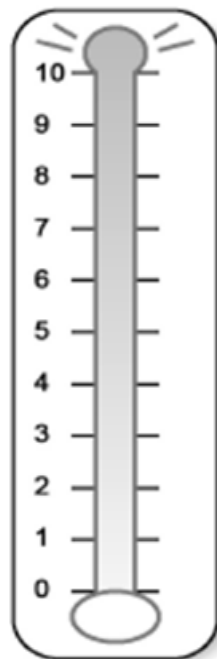
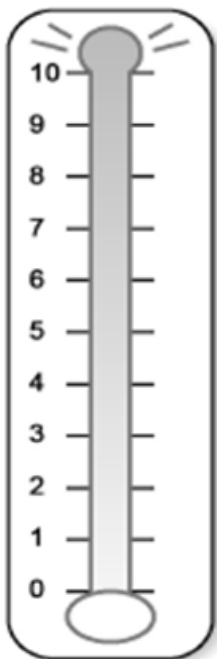
I Need Help

I Need Help

10 = Desperately

10 = Desperately

10 = Desperately



0 = Can manage myself

0 = Can manage myself

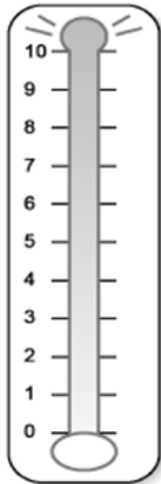
0 = Can manage myself

4. In these three columns, please **mark the number (0-10)** that best describes how you been feeling in the past two weeks, including today.

Anxiety

Please mark how severe is your anxiety? Anxiety means feeling worried, tense, agitated

10 = Extreme

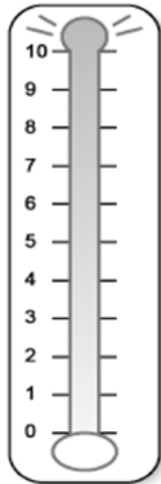


0 = None

Depression

Please mark how severe is your depression? Depression means feeling down, low, withdrawn

10 = Extreme

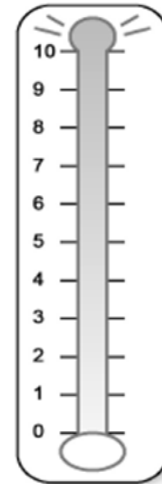


0 = None

Anger

Please mark how severe is your anger? Anger means feeling annoyed, irritated

10 = Extreme



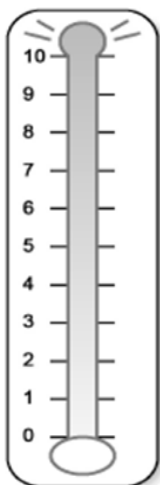
0 = None

5. In the first two columns below, please indicate how much impact your problems have on you; if you had any pain and the burden you've experienced, and an overall health score.

Pain

Please indicate how much pain you are suffering

10 = Extreme

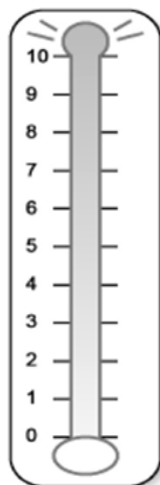


0 = None

Burden

How much has all this affected you? To what extent can you still do normal activities?

10 = Cannot function at all

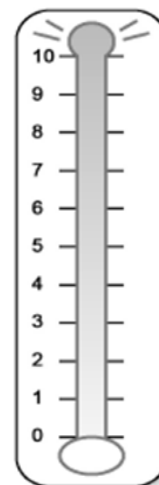


0 = No effect on me

Overall Health

Please indicate how good or bad your own health is today. 10 is the best health you can imagine and 0 the worst

10 = Best Health



0 = Worst Health

6. You have been asked to fill in this questionnaire, because you have been seeing a social worker.

What initial problem(s) did the social worker help you with?

.....
.....

7. On a scale of 1-5 can you rate whether **the social worker has been able to help you?** (where 1 is not helpful and 5 is extremely helpful)

1 2 3 4 5

Not at all helpful

Extremely helpful

If Not helpful, can you explain why?

.....
.....
.....

8. What was the result of you seeing the social worker?

.....
.....
.....
.....

9. On a scale of 0-5 rate the result of you seeing the social worker as to **whether it was what you expected?** Please tick the appropriate box (with 1 being not what expected and 5 being more than expected):

1 2 3 4 5

Not what I expected

More than I expected

10. How satisfied are you with this result? *Please tick the appropriate box (with 1 being not at all satisfied and 5 being very satisfied):*

1 2 3 4 5

Not at all satisfied

Very satisfied

11. From the following statements can you indicate whether you agree or disagree: *(tick appropriate response)*

I felt heard, understood and respected

Strongly Agree Agree Disagree Strongly Disagree Not applicable

We worked on and talked about what I wanted to work on and talk about

Strongly Agree Agree Disagree Strongly Disagree Not applicable

The approach was a good fit for me

Strongly Agree Agree Disagree Strongly Disagree Not applicable

The service provided was right for me:

Strongly Agree Agree Disagree Strongly Disagree Not applicable

12. How would you say the support has helped you? *(tick appropriate response)*

My ability to cope with my condition has improved:

Strongly Agree Agree Disagree Strongly Disagree Not applicable

My self-esteem has improved:

Strongly Agree Agree Disagree Strongly Disagree Not applicable

My understanding of my condition has improved:

Strongly Agree Agree Disagree Strongly Disagree Not applicable

13. Have you had help with any of your problems before? *(tick one box)*

Yes No Not applicable

14. If Yes, who was helping you? (e.g. family, friend, volunteer, psychologist, social worker, welfare advisor, counsellor, etc).

.....
.....

15. Would you recommend the support service to others? *(tick one box)*

Yes No

If No, please explain why:

.....
.....
.....
.....

Section 3: About You *(circle the response that best describes you for each question)*

16. Age? *(tick only one)*

18-30 31-40 41-50 51-60 61-70 Over 70

17. Gender? *(tick only one)*

Male Female Prefer not to say

18. Employment or Education status? *(tick only one)*

Full-time work Part-time work Full-time education Retired
 Unemployed Choose not to work Unable to work due to illness

19. Who do you live with? (tick only one)

- Live alone Live with a partner Live with family
 Live in sheltered accommodation/Care facility Prefer not to say

20. What is your current treatment modality? (tick only one)

- Haemodialysis Peritoneal Dialysis Transplant
 Not yet on dialysis

21. How long have you been on dialysis? (tick only one, if applicable)

- Less than a month 1 - 6 months 7 months - 1 year
 1 - 3 years 3 - 5 years More than 5 years

22. Which of these ethnic groups would you say you belong to? (tick only one)

WHITE

- British
 Irish
 Any other White background,
please state.....

ASIAN OR ASIAN BRITISH

- Indian
 Pakistani
 Bangladeshi
 Any other Asian background,
please state.....

CHINESE OR OTHER ETHNIC GROUP

- Chinese

BLACK OR BLACK BRITISH

- Caribbean
 African
 Any other Black background,
please state.....

MIXED

- White and Black Caribbean
 White and Black African
 White and Asian
 Any other Mixed background,
please state.....

- Any other ethnic group,
please state.....

THANK YOU FOR TAKING THE TIME TO COMPLETE THE QUESTIONNAIRE



WoSRES

West of Scotland Research Ethics Service

Prof Paula Ormandy
Professor Long Term Conditions Research
University of Salford
School of Nursing, Midwifery, Social Work & Social
Sciences
Mary Seacole Building 1.25, University of Salford
Frederick Road,
M66PU

West of Scotland REC 5

West of Scotland Research Ethics Service
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ

Date 10 October 2017
Re-issued 15 Nov 2017

Direct line 0141 232 1809
E-mail WoSREC5@ggc.scot.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Dear Prof Ormandy

Study title: Examining renal psychosocial provision in the United Kingdom
REC reference: 17/WS/0185
IRAS project ID: 227568

Thank you for your letter of 20 October, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

The Sub-Committee noted your response to the issue of recruitment and the possibility of bias but agreed that you had answered it comprehensively. Your explanation was therefore accepted.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public Liability UoS]		15 July 2017
Interview schedules or topic guides for participants [Appendix 14 draft focus group interview topics]	v1	13 June 2017
IRAS Application Form [IRAS_Form_02082017]		02 August 2017
Letter from funder [Kidney Care UK Funding Letter]		
Letter from funder [University of Salford Grant Confirmation Letter]		
Letters of invitation to participant [Appendix 1 participant letter staff]	v1	13 June 2017
Letters of invitation to participant [Appendix 6 participant invitation patient]	v1	13 June 2017
Non-validated questionnaire [Appendix 11 questionnaire B]	V2	29 June 2017
Non-validated questionnaire [Appendix 12 questionnaire C]	V3	29 June 2017
Non-validated questionnaire [appendix 5 questionnaire A]	v3	20 September 2017
Other [Appendix 10 Social Work activity codes]	v1	10 May 2017
Other [Appendix 13 Draft data collection protocol]	v1	13 June 2017
Other [UoS Insurance]		15 July 2017
Other [Response Letter to amendment]		20 September 2017
Participant consent form [Appendix 3 consent form staff]	v2	20 September 2017
Participant consent form [Appendix 9 FG Consent form]	v3	20 September 2017
Participant consent form [Appendix 8 consent form patients]	v2	20 September 2017
Participant information sheet (PIS) [Appendix 2 PIS staff]	v2	01 August 2017
Participant information sheet (PIS) [Appendix 4 PIS patient]	v3	20 September 2017
Participant information sheet (PIS) [Appendix 7 PIS patient referral]	v3	20 September 2017
Research protocol or project proposal [Research protocol]	v2	20 September 2017
Summary CV for Chief Investigator (CI) [P Ormandy CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports

- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/WS/0185	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Canon Matt McManus
Vice-Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers”

Copy to: Mr Nick Hardiker , University of Salford
Mrs Rishma Bhatti, East and North Hertfordshire NHS Trust

West of Scotland REC 5

Attendance at Sub-Committee of the REC meeting

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Canon Matt McManus	Parish Priest (Vice-Chair)	Yes	
Ms Janis Munro	Key Account Manager	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Sharon Macgregor	REC Manager

Prof Paula Ormandy
Professor Long Term Conditions Research
University of Salford
School of Nursing, Midwifery, Social Work & Social Sciences
Mary Seacole Building 1.25, University of Salford
Frederick Road,
M6 6PU

Email: hra.approval@nhs.net

14 November 2017 (*Reissued 15 November 2017 with correction to document list*)

Dear Prof Ormandy

Letter of HRA Approval

Study title:	Examining renal psychosocial provision in the United Kingdom
IRAS project ID:	227568
REC reference:	17/WS/0185
Sponsor	University of Salford

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **227568**. Please quote this on all correspondence.

Yours sincerely

Simon Connolly
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Nick Hardiker , University of Salford*
Mrs Rishma Bhatti, East and North Hertfordshire NHS Trust

Appendix 8: Ethical approval University of Salford



**Research, Innovation and Academic
Engagement Ethical Approval Panel**

Research Centres Support Team
G0.3 Joule House
University of Salford
M5 4WT

T +44(0)161 295 2280

9 August 2017

www.salford.ac.uk/

Maaïke Seekles

Dear Maaïke,

RE: ETHICS APPLICATION HSR1617-155 – Examining renal psychosocial provision in the UK

Based on the information you provided I am pleased to inform you that your application HSR1617-155 has been approved to go forward to NRES.

Once you have received it, please submit a copy of the NRES approval letter to Health-ResearchEthics@salford.ac.uk so that it can be placed on your application file.

If there are any changes to the project and/or its methodology, please inform the Health Research Ethics Support team as soon as possible.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Sue McAndrew'.

Sue McAndrew
Chair of the Research Ethics Panel

Appendix 9: Analytical framework for fieldnote data on sources of support

Table 32. Fieldnote data

System	Unit	Support	Support or lack thereof as a mechanism for distress
<p>Personal social circle</p>	<p>A</p>	<p>17 - DT2. My husband looks after me, I have no problems.</p> <p>61 – DT 0: My husband does a lot for me.</p> <p>15- DT 5: I have a good neighbour and good family, they look after me</p>	<p>21- DT10: I feel useless, frustrated. I wake up thinking it is a bad dream, but it isn't. I let my children think I'm better than I am, that's normal for being a mom. I don't tell them how I feel because it would upset them. It's had a devastating effect on my family. My husband has had to seek information, he insists on doing all the care and won't let anybody in the house. I worry about my husband, he gets anxious and depressed when I'm poorly, I get very ill. I am not able to get around independently, I want to be able to get transport or taxi's instead of my husband having to drive. I am frustrated I have to rely on people. I want someone who could come in the house and speak to me and my husband. To do housework, cupboards are big task, to take me to the shops, or a buddy. He is excellent but gets very angry, he went to the GP and was sent to counselling. I'm frustrated, can't clean, bake, nothing as fast anymore. Sometimes I think I don't want to do it anymore.</p> <p>18- DT 8: My wife doesn't understand. I can be tired because I don't sleep well, but then she tells me not to sit about.</p> <p>51 - DT 10: My main reason is that I am scared that something will happen to me when I am home alone. I have my husband but he has his own problems and is not always very good, not very nice. He has got a sleep apnoea so sleeps in the other room. I've got diabetes and one night I had a hypo and wet the bed. My husband would be annoyed if I'd wake him up so I had to get the bedding of all by myself. Another time, I went to have a bath whilst my husband was asleep in the living room. Then I couldn't get out, so I was in the bath for three hours until my husband woke up and called the fire department. I have a cleaner who comes around 4 times a week, I chat to her. I pay her extra so she can stay longer and talk to me. Maybe I'd like some extra support. I know it all sounds depressed, [starts crying], but I just</p>

		<p>have to get on with it. I once started crying when I was speaking to my daughter about it, my husband would be furious if he found out.</p> <p>55 – DT6: I had a good life before all of this. But my husband doesn't let me get depressed. I just see this as going on forever. I feel like I am a burden for my husband, I feel guilty.</p> <p>53- DT3, I have made a decision: this is part of my life now, I have accepted it. My only issue is that my wife does all the driving, I think she does too much and I feel guilty about that.</p>
B	<p>35-DT0: I don't get distressed. I have a good family network.</p> <p>3-DT10: I had a carer but now my wife does everything.</p> <p>36-DT4: My daughter helped me to fill in the forms for employment support allowance. It was a lot to fill in.</p> <p>43-DTX: My family supports me, and my son is a psychologist, without that I wouldn't survive.</p> <p>37-DT8: I have help at home and my wife is my main carer.</p> <p>105-DT0: I used to have carers, but I stopped them coming because of the expense. Now my daughter and wife look after me.</p> <p>77-DT5: No point talking to professionals, I</p>	<p>9- DT10. I worry about what happens to my daughter if I die. I think she might need to see a psychologist.</p> <p>12 – DT8: On antidepressants. Main reason for distress is husband who has got dementia but refuses help. I would like someone to talk to him.</p> <p>8-DT7: I had a stroke and can't do things around the house anymore and my wife is complaining and moaning that she has to do everything now, but she doesn't want a carer.</p>

		<p>just talk to my friends when I am down.</p> <p>1-DT2: I've got a good wife and am looking on the bright side of life.</p>	
	C	17-DT5: I am on antidepressants and my wife helps me with accepting my illness.	<p>106-DT10: My husband does not accept any help. Even a social worker would not be able to make my husband cooperate.</p> <p>13-DT0: I feel a bit guilty that my wife has to do everything.</p>
	D	46-DT8: I have my wife and don't need any other support.	17- DT 5: Main reason for distress is family issues. I have spoken to psychologist but there is no point. Daughter is suicidal and husband is depressed. He won't accept being my carer and won't talk to anyone.
	F		<p>20- DT2: I feel guilty towards my husband. I can't do the household tasks anymore, he has to shower me and I have to sleep in a separate bed downstairs. I really need help from a cleaner, especially for the windows.</p> <p>DT2: My two daughters help me a lot, they spoil me to death. I just don't want to be a liability for them.</p>
Social care system and community services	A	<p>71-DT8: I received benefits advice through cancer services.</p> <p>59 – DT0: I am part of a working benefits group, which advises people about benefits. It is a £90 subscription. I have given advice on DWP assessment to a few people here in the unit.</p> <p>55- DT6: When I had cancer, I would get help from Macmillan and Maggie's and the nurses. They were very good. Sorted my blue-badge and I could just drop in and have</p>	<p>7-DT 9: My main reasons for distress are depression, my mobility and my finances. I am not receiving any support. I am still waiting for my PIP appeal. I waited 3 years to get my disabled badge.</p> <p>13 – DT6: I am in a lot of pain if I try to move around, I am having difficulty walking and will need a wheelchair in the near future. I am worried I may not get a disabled badge, but because I can't walk it would mean I wouldn't be able to go out. I also lost my money because of changes in PIP. I am frustrated, because nobody really understands.</p> <p>39 – DT7: local resources not useful.</p> <p>40- DT8: I have a social worker through the council, but she doesn't do much.</p>

	<p>a tea. Here, there is never enough staff, but the nurses are good.</p> <p>58 – DT 0: Just accept what’s to be is to be. We’ve had a stairlift put in and the bathroom converted with help from the council. My wife was speaking to a friend about it, they suggested going to the council.</p>	<p>67 – DT9: I feel tortured by DWP work capacity assessment. I was refused for pip, it got knocked back twice. The seafarer’s advice group supported with mortgage payments. Couldn’t afford travel to the hospital so missed many appointments couple years ago. I had to visit the foodbank who helped me and supported with pip forms, finally it was successful. I am now on minimum payments but am worried that the money will go again. The CAB was not helpful, the CIYP were rubbish and no help at all. We should have a social worker here, I am not computer literate, and there is no one to help me negotiate the welfare system.</p> <p>21- DT10: Husband is excellent, age concern gave him some advice, he went online and didn’t give up. We’ve not had any help filling in forms. Forms are really difficult and not well advertised. Anybody who isn’t very bright would be terrified. The process is not made easy. People said they gave up.</p> <p>59- DT0: They refuse people, hoping that people give up and don’t go for appeal. It is really down to the individual. The weakest ones, those who are not very intelligent, they need it the most but are unable to get it. There are people in this ward that need help from the state, but they are being punished. There is no money they say.</p> <p>70 – DT2: Main issue for distress is mobility, I have trouble walking. Someone told me about this blue badge, I had never heard of it before and I wouldn’t know where to get it from. I feel like I don’t receive enough information.</p> <p>18 – DT8: I’m waiting to hear about my blue badge application, my friend told me about that, so I phoned the council myself to do it. Then they told me about this ‘council allowance’ which I had never heard of before, I told the people that I share transport with about it now too.</p> <p>40 – DT0: I had a stroke and was given a social worker through the council. I tried to get in touch after, but we never heard back from her.</p>
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		<p>26- DT 0. I got refused for PIP. They told me: you can climb the stairs. So I didn't get it. CAB helped me to reduce my council tax.</p> <p>3-DT8. I retired because of ill health, after they tried to sack me. I'm a single mom and now I have been refused PIP, I had help from a welfare advisor but lost my appeal.</p>
B	<p>28-DT6: My main issue is facing my mortality. I speak to my social worker about dying. Someone referred me to her, I believe she's from the council. I have to phone her, she isn't of much help, she doesn't do anything.</p> <p>8 – DT4: I received support from social work from the council, they organise respite care when my partner goes on holiday.</p> <p>96-DT10: I seem to forget to pay my bills sometimes. I have some issues at home, I'm kind of a hoarder. The RSW has helped me with grants and pip. I also have another SW for housing issues, to get it cleaned up.</p> <p>9 – DT4: I had a stroke so they sent a social worker to help me. It seems like if you have a stroke, you get a social worker automatically.</p> <p>27 – DT6: Can't get out of the bath and I am stuck in the house because I have no car and have trouble walking, but I have OT coming to the house to assess next month.</p>	<p>25 – DT8: When I first became blind after my tumour, I received support. The CAB helped me with my benefits, but they filled the forms in wrong and now I owe £15000. I have never seen the renal psychosocial staff, but would like help from a social worker. When I call the council for a social worker, I need to make 5 or 6 calls before I get anywhere.</p> <p>9- DT10. Finances are my main issue, I'm currently on sick leave and I'm not receiving pip. They told me that because I received an inheritance from my parents, I would not get any money. The forms are really hard to fill in.</p> <p>42 – DT4: Main reason for distress is I'm in the middle of a care assessment, have got carers now but I am anxious about what will happen care wise and with my finances. They are assessing my finance and determining if I can afford to pay for things myself. Have been told that some things they don't take into consideration, for example I have an electric wheelchair that needs charging overnight, but that it won't be included in my expected energy costs.</p> <p>39 – DT2: I have a problem with bathing and showering, I talked to the council and they gave me a chair for in the shower, but it is no good.</p> <p>45-DT7: Because of universal credit I was without money for 6 weeks. They call me in at the jobcentre, but a lot of the time I'm not well enough to come in. If you're not in, they cut your benefits.</p>

		<p>74 – DT5: I don't think I need any more support, I think it is all being sorted. The social worker is sorting my money out. The OT is looking into getting a chair. I am waiting on a walking frame but I'm not sure where this will come from.</p>	<p>66-DT4: I only get employment support allowance, which is only £500 a month. Everybody else seems to be on PiP, but I got refused, I don't understand why. I'd like to see a SW.</p> <p>32 - DT 8. I just resigned from my full-time job due to stress and fatigue. Now I am in debt and I can't pay my bills, but I'm not on any benefits. I'd like some support.</p> <p>47 – DT7: Main issue is financial worries and housing, but I don't know if am entitled to any benefits or council housing, because I am not a UK citizen, I'm from Africa.</p> <p>2- DT4: I tried to get benefits, but it was getting complicated, so I left it.</p>
	C	<p>98-DT8: I received help from the council.</p> <p>39-DT3: A friend of my stepdaughter works for Age UK. She helped me fill in the benefit forms, otherwise I wouldn't have known. I didn't know I was entitled to anything and the form was extremely complex.</p> <p>56-DT6: I have trouble getting up the stairs, I am waiting for the council to help me relocate.</p> <p>4 DT5: Social services are involved to find me a house with no steps.</p>	<p>106-DT10: I have been assessed 3 times now for social care, but I don't hear anything back. There is no case coordination and I am just constantly busy with all my appointments.</p> <p>6-DT8: I am not sure if I am on the right benefits.</p>
	D		<p>78-DT 1: My main problem is housing, because I want do dialysis at home, but I can't because I have a one bed flat. I saw the social worker when they were assessing my flat, she wrote letters to the council, but it wasn't successful.</p>
	F		

<p>Renal unit and wider (mental) healthcare system</p>	<p>A</p>	<p>13-DT 6. My main issues for distress are my depression, I have been on antidepressant for years, I have been offered psychology help through the diabetes team.</p> <p>21- DT10: I've got excellent backup from my GP. I am on the waitlist to see a psychiatrist.</p> <p>9 – DT 0: If I need help I will just ask the nurses.</p> <p>4-DT8: My husband has Alzheimer's and goes to the day centre, when I'm there I speak to the doctor about my depression once a week.</p>	<p>22- DT 8: There is no support here, only some group therapies. Only a few staff treat you as a human, instead of patient. Doctors all say different things.</p> <p>52- DT6: I have been on dialysis for 11 years. I was offered some support when I just started but didn't take it, I just got on with it. The nurses are good at offering advice, but I think it would be good to have some support. I had a transplant, but it failed, having no support then was tough mentally.</p> <p>DT 10: Treatment decisions is one problem. The communication between the GP and hospital is very poor. Slow, it takes a very long time to get things done.</p> <p>12 - DT 3. My main reasons for my distress are fears and a lack of information. I have been a kidney patient for 16 years. Last year, I was unwell every month. I kept working, because I thought dialysis would jeopardise my job. I spent 3 weeks on the ICU on a ventilator and had a severe delirium. After it, I couldn't stop thinking about it, I was dreaming about it and I had a lot of fears. I tried to get someone to help me but there was no help. I wrote down 30 pages of experiences, my wife has read it, but I still haven't seen anyone about it</p> <p>25 – DT 4: I have been taken off the transplant list, but I don't understand why. It has affected me all, sometimes I see no light at the end of the tunnel.</p> <p>39- DT 7: Main problem is treatment decisions. The doctors should consult the patient more and explain more.</p> <p>40- DT 8: Ticked many issues, but main reason for distress is the waiting around to start treatment. The HD unit does not have enough staff, so it always is a slow start.</p>
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			<p>21-DT10: Nurses here haven't got time to sit and help people, don't think it should be in their education or role either.</p> <p>35- DT 6: Currently involved in a lengthy legal battle for medical negligence, stroke in lower back due to medical inaccuracy. In wheelchair can't walk.</p> <p>55 – DT6: My main reason for distress is treatment decisions. I wanted to do home haemodialysis, but they told me it wasn't possible because of a shortage of staff. HDD would give me more freedom and my husband is a doctor so he can help.</p>
	B	<p>79 – DT5: I have no emotional problems, I've learnt to live with it, but sometimes I get anxiety and depression, I just have my ups and downs, you are no more a moving part of society, no achiever. I saw the renal psychologist in the past. If I need help now, I'd go to my GP.</p> <p>8 – DT4: I had a bad year last year and have had mental health issues in the past. I worry/get anxious about lots of little things, but that's who I am. I can always see my doctor, I used to have a community psychiatric nurse, we decided I was well enough. But I have her number. I've seen a psychiatrist and renal psychologist in the past too.</p> <p>9- DT10. I am seeing a counsellor through the team that is dealing with my sight issues.</p>	<p>10 – DT6: I have carers 4 times a day, but because of issues with transport, I often come back from dialysis too late so I miss my carer at 6pm.</p> <p>65 - DT7: There is no support here, you rarely see a doctor, you're just stuck on the machine and that's it. I've never seen a SW around here or something like that. All staff has reduced. Nurses, doctors, support staff (don't speak English), psychosocial staff. KPA wants money but never see anything of it. We used to have trips, 'cultural days', celebrating a holiday from other cultures, or Christmas trips. That's all gone now, they don't see the patient as a person anymore.</p> <p>25 – DT8: I had a brain tumor 15 years ago, which made me blind. My wife is my carer but she is ill, that is my main problem, because her appointments are at the same time as my dialysis. I would like to hear the doctors myself and be there to support my wife, but I don't want to change my whole dialysis schedule. I was on the twilight shift at first, but I came home too late. I saw the psychiatrist in the past but I feel that he only made me depressed more.</p> <p>96-DT 10: They used to do trips here, but they don't do them anymore, so I just keep to myself now.</p>

	<p>96 – DT10: The RSW has helped me with grants and pip.</p> <p>12- DT4: The PD nurses helped with various things</p> <p>30- DT6: I've seen the renal psychologist before but would like to go back to her.</p> <p>28 – DT6: seeing the renal counsellor for help with PTSD.</p> <p>12- DT8: I have seen the renal psychologist in the past and can see the RSW whenever I want, she helped me with my wheelchair and walking aids. [not aware SW left 6 months ago].</p> <p>43 – DT0: I like it to bits here, everyone is so nice, I'm perfect.</p> <p>2- DT6: The nurses help. The nurse practitioner gives me time, she suffers from kidney disease herself, I still see her.</p> <p>45-DT7: My main problem is that I want to stop dialysis, I'm not feeling the benefits of it anymore, I just feel ill all the time. I have seen the renal psychologist, but I don't think there is any point anymore. I'm just exhausted all the time.</p> <p>64-DT2: The transport is smashing.</p>	<p>17-DT10. I'm very frustrated and angry. My main problem is that there is no holistic care, I have so many serious conditions, but everybody specialises in their own bit and they don't know any of the other specialities. I have to go everywhere. I'm fed up because nobody listens. I've got a lot of mental health issues, I thought I couldn't get any lower but I did. The SW and mental health team were all dragging me down. I didn't even know what a SW was, but the doctor wanted me to see one. The SW was stupid. I don't want to see a psychiatrist. I would like to see the renal psychologist. It's all doom and gloom.</p> <p>48 – DT0: I feel like I could have done with more practical help when I first got diagnosed.</p> <p>31- DT 6: Main reason for distress is having to wait up to two hours to be put on dialysis.</p> <p>30- DT6: There is not enough staff on the unit.</p> <p>42 - DT4: I feel like I haven't received enough information about why certain treatment decisions have been made. I also have a pain, but I can't seem to get an appointment and the GP won't visit. I used to get advice from the renal social worker, about holiday grants and problems that I had with social services. But now that she has left, I don't know what I should do now. I need a renal social worker, someone who can help me practically.</p> <p>15 – DT8: I was supposed to have an operation, but it got cancelled. My stress levels are off the walls.</p> <p>5 – DT7: Main issue is with housing. Second issues is finances, I have issues with council tax, court letters that I want help with. I was seeing the RSW about these problems, but have not heard anything since filling in the forms. I am waiting to hear back from the SW [who left].</p>
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	<p>26-DT8: The transport is brilliant.</p>	<p>39 – DT2: I have seen the renal psychologist in the past, but it didn't help because she didn't want to give me any medication.</p> <p>9 – DT4. I had a stroke so they sent a social worker to help me. It seems like if you have a stroke, you get a social worker automatically. Dialysis is a ball ache. Main reason for distress is transport, I get home very late. Anger is 7 when the ambulance is late again.</p> <p>27 – DT6: Main issue is adjusting to illness. Fears/depression, then libido problems. Lack of information, noncommunication about whether I am on or off transplant list. I think the psychologist should be more approachable.</p> <p>78 – DT3: Main reason for distress is that I was a patient in a satellite unit close to home. Then attracted a disease so had to go to the main centre for treatment which resulted in me losing my space in the satellite unit. Have now been waiting to go back, the journey to the main unit is too long, I spend 3 hours more waiting around.</p> <p>89 – DTX: I couldn't put a number on his distress: I'm more distressed when I come here, because it takes them a long time to put me on dialysis. Then by the time I get off the transport home is gone, so my main issue is they put me on dialysis late. It takes 8 hours of my day. When I am at home, I'm fine. Also lack of information, I've not seen a doctor since I've come here and I don't know whether I'm on the transplant list or not. I try not to get depressed. I don't suppose there is anyone that can help me.</p> <p>76 – DT4: I feel like there is a lack of communication in the unit.</p> <p>13 – DT8: I've seen the psychologist last year, but she is away until July, so then I will see her again. The other psychologist doesn't travel to the satellite unit, but I don't want to travel to the main unit to see her.</p>
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			<p>2- DT6: I don't think a psychologist would help, I've just got so many physical issues, I just have to get on with it. I have spoken to the renal psychologist when I was just diagnosed (10 sessions). It didn't make me feel any better, she didn't know the answers to my questions.</p> <p>11- DT5: My sister wants to donate her kidney to me, be a life donor, but it is taking a long time to get things sorted and I'm not sure where it is up to now. Second problem: I really enjoyed the paddle scheme, but it is finished. I asked if I could still get it, but the nurses won't do it, they don't have the time.</p>
	C	<p>98-DT8: I got support from the sight team.</p> <p>5-DT3: I saw the renal welfare advisor in the past for decluttering my house. And saw the renal counsellor who helped me attend a dentist appointment.</p> <p>12-DT4: My eldest son spoke to the renal counsellor to get some answers.</p> <p>11 – DT6: I am receiving help from the renal counsellor and another counsellor from the hospital.</p> <p>40-DT4: I am aware that there is support in the unit, but my GP is supporting me enough.</p> <p>DT4: I saw the renal counsellor in the past, that made a hell of a difference.</p> <p>120-DT9: I had two failed trips for transplant, both times it got cancelled last minute. My wife is depressed and I feel like</p>	<p>98-DT8: I have never seen or heard about support in the unit.</p> <p>32-DT9: My issue is the time it takes to travel to the unit, I would like to dialyse in a unit that is closer by. I would also like to speak to a psychologist, but I've never seen any psychosocial support in the unit and wouldn't know how to contact them.</p> <p>45-DT7: Nobody talks, not the nurses, dieticians, nobody takes the time to talk.</p> <p>23-DT9: I had all the work-up done for a living donor transplant, but then they told me I was too old. I am angry at the hospital, it has made me feel depressed. There was very poor communication.</p> <p>25-DT7: I've been told I only have 2 years left to live. I am not aware that there is a psychosocial team here.</p> <p>34- DT7: I want to see the counsellor but my employer won't allow the time off and the counsellor doesn't work during the twilight shift when I dialyse.</p> <p>30-DT4: My main issue is the time that I have to wait to get on the machine, it is frustrating because my son is mentally ill and he is at home alone when I am on dialysis.</p>

		I have no life. The renal counsellor is involved, I could not cope without her.	
	D	35- DT2: It is like coming to a social club here in the waiting area. Staff are so good, I just ask them if I need anything, the social worker helped me with a bed and a stairlift.	<p>18-DT6: Some of the nurses are not nice. If you are not nice, why would you be a nurse?</p> <p>80- DT3. Nobody emphasised that there was a support team here. Last year, things were a lot worse, there were so many things in all areas. I was depressed for two months but wasn't offered any support, I wasn't aware it was there. Maybe I'd like to speak to a social worker or psychologist, I might be fooling myself, thinking that I don't need someone.</p> <p>59-DT 7: Have seen the renal support team in the past, but don't feel like I got out of it what I wanted.</p> <p>40-DT 5: I am very angry, my anger is 20 out of 10. The main reason for my distress is that I feel like nothing gets done, they keep passing me on to someone else, passing things back, there is no coordination. My second issue is with transport. My third issue is that I can't understand the nurses. My anxiety is 10 because I don't have a clue what the foreign nurses are saying. I am worried that they give me the wrong injection.</p> <p>46-DT8: I have my wife and don't need any other support. But people who need help, don't get it.</p> <p>86- DT 10: I just moved back to the UK and have only been on dialysis for little over a month. I need to buy a house. I want to buy one close to a unit that has availability, but they won't tell me where I can go.</p> <p>14- DT 1: My son had a stroke. He lives at home with me and needs help. I'd like to do dialysis at home but feel like I am not receiving enough information about how to do that.</p>
	F	<p>DT0: The social workers are always around.</p> <p>DT0: The social worker has been down to the unit.</p>	31 -DT0: My anger is a 4, it is mainly irritation because I am getting conflicting advice from doctors.

<p>Not sure about source or eligibility of support</p>	<p>F32- DT 3: I am getting help from my family and a social worker. They rang me up; I don't know who they're with.</p> <p>B28-DT6: My main issue is facing my mortality. I speak to my social worker about dying. Someone referred me to her, I believe she's from the council.</p> <p>B3 – DT10: I had delirium after my last surgery. When I came out of the hospital everybody came, I don't know who I saw then, but the district nurse still comes. What does a SW do? I have no clue who to ask if I wanted to see a psychologist</p> <p>B17 – DT10: I didn't even know what a SW was, but the doctor wanted me to see one.</p> <p>B89- DTX: I try not to get depressed. I don't suppose there is anyone that can help me.</p> <p>B74 – DT5: I am waiting on a walking frame but I'm not sure where this will come from.</p> <p>39-DT3: I am terminally ill and don't know how to best go about it. I guess I should see a psychologist so they can help me with a plan for how to arrange my will and funeral and those kind of things.</p> <p>B63-DT5: The SW came to me in the hospital, don't know where she was from, but she suggested going to bingo clubs etc.</p> <p>B47 – DT7: Main issue is financial worries and housing, but I don't know if am entitled to any benefits or council housing, because I am not a UK citizen, I'm from Africa.</p>
<p>Arranging support yourself</p>	<p>A9-DT0: If I need help I will just ask the nurses</p> <p>A24- DT5: Google is a great source of information. I use it to find what I need.</p> <p>A55 – DT6: If I need more information I just go online or ask my husband.</p> <p>B64-DT2: I got some money to cover my taxi fares, I just did it myself online.</p> <p>B79-DT5. Finances are always a problem when you're on benefits. I applied for them myself, I just asked and googled. I always ask and tell the nurses and it gets resolved. But other people don't.</p>

	<p>B3 – DT10: I was told to see a psychologist but I don't want to. I tried to blank everything out.</p> <p>B48-DT0: I don't feel depressed at the moment. I'd go to the GP if I do.</p> <p>B77 - DT5: I have a fear of dying. No point in talking to professionals about it, I just talk to my friends when I'm down.</p> <p>B39 – DT2: I have a problem with bathing and showering, I talked to the council and they gave me a chair for in the shower</p> <p>B8 – DT5: Main issue is lack of information. But I will search for it myself on the internet.</p> <p>B10- DT0: I don't have any anxiety or all the things you want me to have. I feel like I receive the support that I need, and otherwise I just ask</p> <p>B2- DT6: I don't think a psychologist would help, I've just got so many physical issues, I just have to get on with it.</p> <p>B25 – DT8: I've seen the renal psychologist in the past, but I feel that there is just too much going on right now so I don't want any more support.</p> <p>C50 – DT7: I have seen the counsellor in the past but that made me more depressed. I like to keep things in the past and just move on. They are there if I need them and they have done alright.</p> <p>D80-DT3: Maybe I'd like to speak to a social worker or psychologist, I might be fooling myself, thinking that I don't need someone.</p> <p>D35- DT2: Staff are so good, I just ask them if I need anything.</p>
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Appendix 10: Respondent characteristics

Table 33. Respondent characteristics and proportion per sub-group

Characteristic	N	%		Characteristic	N	%
Total	509	100		Total	509	100
<i>Main unit</i>				<i>Time on Dialysis</i>		
A	64	12.6		<6 months	87	17.1
B	65	12.8		6 months to 3 years	193	37.9
C	98	19.3		3 to 5 years	91	17.9
D	73	14.3		>5 years	130	25.5
E	104	20.4		Missing	8	1.6
F	47	9.3		<i>Living situation</i>		
G	58	11.4		Living alone	147	29.7
<i>Sex</i>				Living together	349	70.3
Male	311	61.1		Missing	13	2.6
Female	192	37.7		<i>Employment situation</i>		
Missing	6	1.2		Employed	67	13.2
<i>Age Category</i>				Unemployed	14	2.8
18-39	50	9.8		Unable to work	183	36.0
40-49	51	10.0		Retired	237	46.6
50-59	97	19.1		Missing	8	1.6
60-69	104	20.4		<i>Ethnicity</i>		
≥70	201	39.5		White	460	90.4
Missing	6	1.2		Other	42	8.3
				Missing	7	1.4

Appendix 11: Analytical framework case study site focus groups

The unit

- Briefly, could you tell us something about the renal population you are serving? Is there anything that makes this population unique or different from the general UK HD population?
- Do you think psychosocial services should be provided in the unit, or by general/community services? Why? What are your experiences with community services?

Responsibilities and boundaries within the psychosocial service delivery process

- Could you explain the process of psychosocial service delivery in the unit? How are patients in need identified? What type of staff is involved? Referrals? Waitlists?
- What is the role of clinical staff in delivering psychosocial support?
- Do you distinguish between patients that have renal related issues and non-renal psychosocial issues (for example family issues)?

Rationale for delivery model

- What was the reasoning behind having this model of psychosocial staff (or lack thereof)? How is staff funded/employed?
- Do you feel that you do tasks that are outside of your remit?

Adequacy of service delivery

- Do you feel that you are meeting the patients' needs?
- What enables you in providing the services you would like to provide, and what restricts you?
- What do you do well? Is there anything in your practice that you think would be good to share with other units?

Appendix 12: Analytical framework RSW focus group

- Why is RSW needed? Why renal (as opposed to general)? Why social work (as opposed to unqualified support work or benefits advice)?
- How is RSW different from social work in LAs or hospital?
- *RSW numbers have reduced drastically*: why has this happened?
- *Initial findings show a large variety in RSW activities*: Why do you think this is?
- What is your 'professional space'? What is your place within the MDT; do you feel valued?
- How do you deliver your services (identification of patients, referrals, standardised processes)?
- What is needed for RSW to thrive?

Appendix 13: Populating a stepped care model for unit A

Survey nr	DT	AnxT	DepT	AngT	Alston	Stepped care level	Reason for change (if applicable)
6	3	0	0	0	1	1	
9	0	0	0	0	1	1	
15	2	3	2	0	1	1	
16	3	1	2	0	1	1	
17	2	1	0	0	1	1	
19	2	1	1	0	1	1	
20	1	2	0	0	1	1	
23	0	0	0	0	1	1	
26	0	0	0	0	1	1	
27	1	1	1	3	1	1	
28	2	0	0	0	1	1	
30	1	1	1	0	1	1	
33	2	1	2	1	1	1	
37	1	0	0	0	1	1	
54	0	0	6	6	1	1	
47	0	0	0	0	1	1	
60	0	6	0	2	1	1	
53	3	1	1	1	1	1	
58	0	0	0	0	1	1	
59	0	2	0	0	1	1	
61	0	0	3	0	1	1	
66	1	0	0	1	1	1	
68	2	0	2	3	1	1	
70	2	1	2	3	1	1	
72	0	0	0	2	1	1	

2	5	0	0	0	2	1	Main reason for distress is mouth sores and thrush. No psychosocial issues. Low depression, anxiety and anger.
5	5	3	0	0	2	1	Distress was mainly caused by the wait for a gall bladder surgery. No social care or psychological issues.
52	5	7	2	3	2	1	Only reports anxiety related to nursing staff, gets anxious if she is touched by a nurse she doesn't know. No further psychosocial issues.
65	4	2	0	4	2	1	Reports no psychosocial issues, mainly physical problems. Low anxiety and depression score.
24	5	6	6	7	2	1	No practical issues, only ticked 'adjusting to illness' as emotional problem, yet commented saying that he has accepted that dialysis is a thing of the future. Said 'I have no anxiety' yet ticked 6 on thermometer.
34	5	0	0	0	2	1	Main issue is boredom because patient is waiting for transplant to get back to work. No anxiety, depression, anger or other psychosocial issues.
57	6	6	3		2	1	Reported distress and anxiety because of a problem with medication. No psychosocial issues.
63	4	8	0	0	2	1	Reports no psychosocial issues, no depression, and moderate distress. Anxiety is high, caused by fear of falling when patient is alone. --> Nurse/support worker for fall prevention.
18	8	8	2	2	3	1	The reason for distress is that patient's buttonholes are sore. Only one other psychosocial problem listed; namely dealing with partner; wife doesn't understand.
12	3	0	0	0	1	2	Ticked multiple psychosocial issues, particularly bad dreams and fears after experiencing delirium.
11	5	1	6	0	2	2	
8	5	3	0	10	2	2	
25	4	4	3	5	2	2	
35	6	6	4	0	2	2	

42	6	4	3	4	2	2	
43	5	5	5	5	2	2	
44	6	6	7	7	2	2	
45	6	5	6	2	2	2	
48	5	7	2	1	2	2	
55	5	4	6	1	2	2	
46	6	0	8	0	2	2	
36	6	7	8	9	2	2	
69	8	7	2	2	3	2	Mainly reports physical issues, breathlessness as main problem and reason for anxiety. Low depression, but issues with adjusting to illness and anxiety.
71	8	2	2	0	3	2	Main issues are worry about how her disease affects family and adjusting and accepting the illness. Reports low anxiety and depression.
39	7	4	3	7	3	2	Mainly social work related issues, no emotional issues
62	7	7	4	0	3	2	Only issues with finance and work.
64	7	4	2	2	3	2	Mainly social work related issues, no emotional issues
1	8	6	5	8	3	3	
13	9	5	5	8	3	3	
3	8	8	8	5	3	3	
4	8	9	9	4	3	3	
7	9	7	8	5	3	3	
21	10	10	10	8	3	3	
22	8	7	10	8	3	3	
38	8	3	0	0	3	3	
40	8	5	9	7	3	3	
41	10	9	10	1	3	3	
51	10	10	1	4	3	3	
67	9	8	7	5	3	3	

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