YOUNG ADULTS' EXPERIENCES OF DIALYSIS AND KIDNEY TRANSPLANT DECISION-MAKING

SARAH OFORI-ANSAH

BSc (Hons), MSc Nephrology and Education,

MSc Clinical Research

http://orcid.org/0000-0001-5849-6609

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Abstract

Background

Young adults with end-stage kidney disease make decisions to select a renal replacement therapy choice with the support of healthcare professionals once their kidneys fail. However, little is known about how they experience dialysis and kidney transplant decision-making and the effects on their well-being.

Aim

The aim was to explore how young adults who are diagnosed with end-stage kidney disease experience dialysis and/or kidney transplant decision-making, understand the meaning of their lived experiences, and investigate the effects of decision-making and choice on their well-being.

Methodology

Interpretive phenomenology, informed by Heidegger's hermeneutic principles, was used to purposefully recruit young adults with end-stage kidney disease through social media. A qualitative design using semi-structured interviews were conducted and the data analysed using Braun and Clarke's thematic analysis approach.

Findings

Eighteen participants aged 18-30 years old were interviewed. Five themes developed from the analysis include: (1) world turned upside down; (2) experience of information delivery about options; (3) the experience of making my voice heard; (4) experiencing the new normal; and (5) the impact of decision-making and choice on well-being.

Conclusion and original contribution

This study illuminates our understanding of how young adults experience kidney therapy decision-making and their unmet informational and decisional needs. The majority struggle to cope due to the lack of support during the decision-making process. Kidney therapy decision-making and experiencing choice about therapies affect young adults' whole world and significantly impact their physical, psychosocial, and mental well-being. This thesis proposes a four-talk model, adding a new phase ('implement talk') to the existing phases (team talk, option talk, decision talk), to address some of the young adults' unmet decisional needs and better support their well-being during the decision-making process.

Keywords: Young adults; End-stage kidney disease; Shared decision-making; Interpretive phenomenology; Dialysis and kidney transplant.

Impact Pathway

Conferences attended	Dates
Oral and poster presentation at London South Bank University (LSBU) Doctoral Academy Postgraduate Doctoral Conference	July 2018, 2019, and 2020
Poster presented at UK Kidney Week	June 2019
Three Minute Thesis (3MT) competition at LSBU Doctoral Academy. Won the popular vote.	July 2019
Three Minute Thesis (3MT) competition at the LSBU Doctoral Academy. Won the first place. Selected for the national competition.	July 2020
Oral presentations at the 49th European Dialysis Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) International Conference	September 2021

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List of Abbreviations

A1-A3: Albuminuria grouping

AMED: The Allied and Complementary Medicine Database

APD: Automated Peritoneal Dialysis

ASRI: Adolescent Self-Regulatory Inventory

AYA: Adolescents and Young Adults

BAPN: British Association for Paediatric Nephrology

BNI: British Nursing Index

CAPD: Continuous Ambulatory Peritoneal Dialysis

CASP: Critical Appraisal Skills Programme

CINAHL: Cumulative Index to Nursing and Allied Health Literature

CKD: Chronic Kidney Disease

COMRADE: Combined Outcome Measure for Risk communication and treatment Decision-making Effectiveness scale

CPS: Control Preference Scale

DALYs: Disability-Adjusted-Life-Years

DARE: Database of Abstracts of Review

DH: Department of Health

eGFR- Estimated Glomerular Filtration Rate

EMBASE: Excerpta Medica Database

EMCARE: Excerpta Medica Care Database

ESKD: End-Stage Kidney Disease

GBD CKD: Global Burden of Disease Chronic Kidney Disease

G1-G5: Grouping of CKD

HCP: Healthcare professional

HD: Haemodialysis

ICHD: In-Centre Haemodialysis

KDIGO: Kidney Disease: Improving Global Outcomes

MEDLINE: Medical Literature Analysis and Retrieval System Online

NHS HRA REC: National Health Service Health Research Authority Research Ethics Committee

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

PD: Peritoneal Dialysis

PICO: Population, Intervention, Comparison, Outcome

PICOS: Population, Intervention, Comparison, Outcome, Study design

PMP: Per Million Population

PREM: Patient Reported Experience Measure

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PsycINFO: Psychological Information Database

RRT: Renal Replacement Therapy

SDM: Shared decision-making

UK: United Kingdom

WHO: World Health Organisation

YA: Young Adults

YLLs: Years of Life Lost

YLDs: Years Lived with Disability

Chapter 1 Introduction

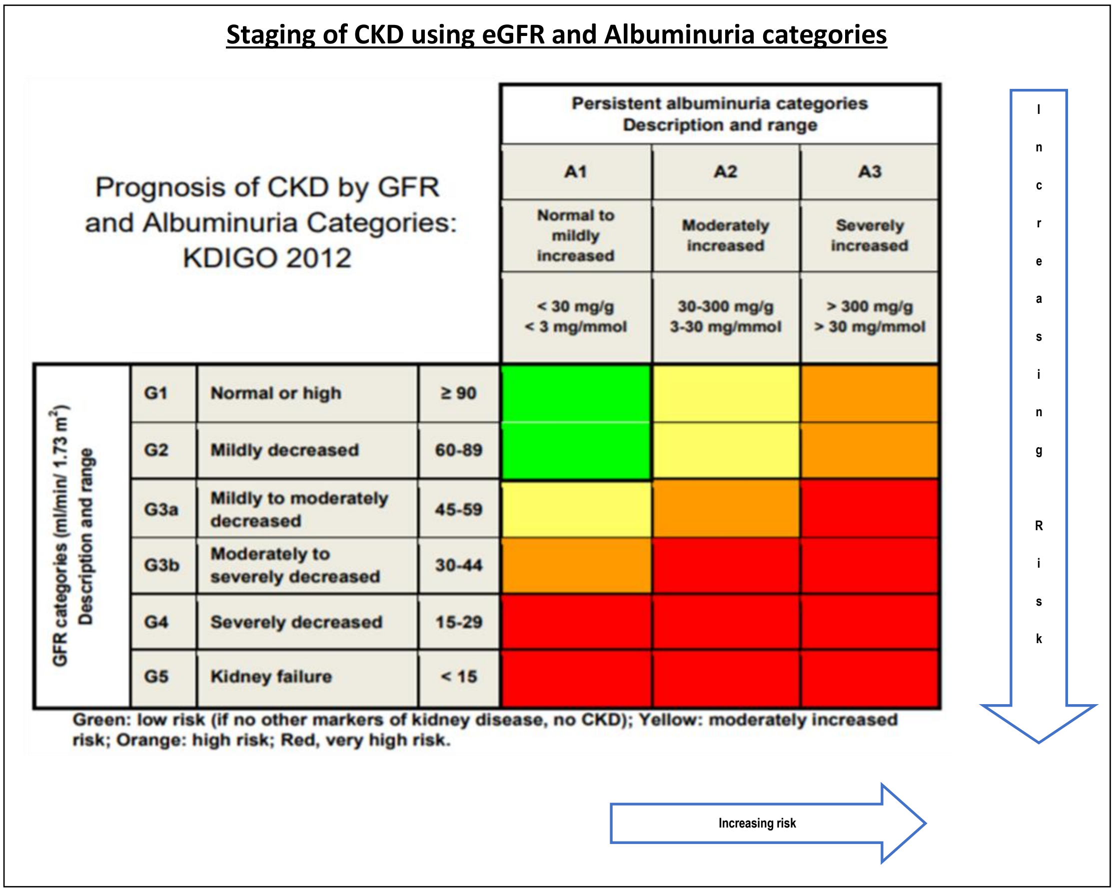
1.1. Introduction

The first chapter of the thesis discusses the background and rationale for this study. It provides an overview of chronic kidney disease (CKD) classifications, its management, preparation for renal replacement therapy (RRT) (dialysis, kidney transplantation and conservative care) and decision-making in line with existing national guidelines. The chapter also discusses some of the models used in healthcare decision-making and explores the transition and transfer of young adults into older adults' kidney services and the commencement of RRT. Finally, the rationale for the research topic, personal perspectives and context, are discussed and the chapter ends with an outline of the remaining chapters of the thesis.

1.2. Background: Chronic kidney disease definition and classification

Chronic kidney disease (CKD) is a long-term complex condition that affects the kidney structure or function for more than three months (Kidney Disease: Improving Global Outcomes (KDIGO), 2013; National Institute for Health and Care Excellence, 2021a). CKD is a global health problem and CKD is categorised according to the estimated glomerular filtration rate (eGFR) (group G1-G5) blood test and a urine test for albumin (protein) (A1-A3) categories (see Figure 1.1) (KDIGO, 2013; Levey *et al*., 2020).

Figure 1. 1 Staging of CKD using eGFR and Albuminuria



Staging of CKD using eGFR and Albuminuria categories

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012

				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				< 30 mg/g < 3 mg/mmol	30-300 mg/g 3-30 mg/mmol	> 300 mg/g > 30 mg/mmol
GFR categories (ml/min/ 1.73 m^2) Description and range	G1	Normal or high	≥ 90	🟩	🟨	🟧
	G2	Mildly decreased	60-89	🟩	🟨	🟧
	G3a	Mildly to moderately decreased	45-59	🟨	🟧	🟥
	G3b	Moderately to severely decreased	30-44	🟧	🟥	🟥
	G4	Severely decreased	15-29	🟥	🟥	🟥
	G5	Kidney failure	< 15	🟥	🟥	🟥

Green: low risk (if no other markers of kidney disease, no CKD); Yellow: moderately increased risk; Orange: high risk; Red, very high risk.

eGFR: Glomerular Filtration Rate G1-G5: Group 1 to Group 5 A1-A3: Albuminuria categories

Adapted with permission from Levey, A. on behalf of Kidney Disease: Improving Global Outcomes (KDIGO) and publisher (see Appendices 1 and 2)

The eGFR and albuminuria categories are used as a measure of the progression of CKD (G1-G5) (Figure 1.1) (Levey *et al*., 2020). Establishing the cause of the disease is an important part of the recommended diagnosis guidelines, as it enables effective management of the disease during the early stages (G1-G3) to slow down the disease progression (Kidney Disease: Improving Global Outcomes (KDIGO), 2013; NICE, 2021a).

The primary cause of CKD varies but the most common are hypertension and diabetes, depending on the setting (Barreto *et al*., 2016; Global Burden of

Disease Chronic Kidney Disease (GBD CKD) Collaboration, 2020). Other factors such as toxins, environmental problems, congenital disorders and immunological, genetic, and idiopathic causes (where the cause of CKD is unknown) may contribute to its development (NICE, 2021a). At CKD stage G4, preparation for RRT commences. People usually commence RRT at CKD G5 with an eGFR of 5-10 ml/min/1.73m^2 (NICE, 2018). Dialysis, kidney transplantation and conservative management are referred to as renal replacement therapies (NICE, 2021a) (see section 1.5 and Appendix 3 for explanation). CKD G5 is also referred to as end-stage kidney disease (ESKD) or kidney failure and used interchangeably in this thesis.

1.3. Incidence and prevalence of chronic kidney disease

The GBD CKD Collaboration (2020) reported that 697.5 million people globally were living with CKD (Stage G1-G5) in 2017. The global prevalence of CKD for all stages in 2017 was 9.1%, of which 5% accounted for CKD stage G1-G2, 3.9% for CKD stage G3, 0.16% for CKD stage G4, and 0.07% for CKD stage G5 (GBD CKD Collaboration, 2020). In the same report, all-age global prevalence of CKD increased by 29.3% between 1990 to 2017. The age-standardised prevalence of CKD was reported to be 1.29 times higher in females (9.5% [8.8-10.2]) compared with their age-related males (7.3% [6.8-7.9]) globally (GBD CKD Collaboration, 2020).

A health survey conducted in England in 2016 identified that 15% of adults aged 35 years had CKD stages G1-G5 and 7% were in stages G3-G5 (NatCen Social Research and UCL, 2017). The prevalence of CKD stages G3-G5 was higher

(34%) in people aged 75 years and above (NatCen Social Research and UCL, 2017). The prevalence of CKD (stage G4 and G5) population not on RRT at the end of 2019 (reported by 17 out of 70 UK adult kidney centres) was 21,368, a prevalence of 1,301 per million population (pmp) (UK Renal Registry, 2021). Of this number 79% were in CKD stage G4, 19% were in CKD stage G5 and 2% had an unknown CKD stage. Higher CKD prevalence was identified in males (55.3%) than females (44.7%) (UK Renal Registry, 2021). In the same report, 86.6% were White, 8.5% were Asian, 2.8 % were Black, and 2.1% were of unknown ethnicity. It is important to note that the actual number of prevalent CKD population would have been higher if all data from the 70 adult kidney centres were reported.

1.4. Prevention of CKD

CKD is a preventable and treatable condition but can either go undiagnosed in the early stages especially in people without symptoms for a long time or wrongly diagnosed while the disease progresses (Levin *et al*., 2013; GBD CKD Collaboration, 2020). The progression of CKD to ESKD and its associated risks can either be slowed, delayed, or prevented if detected early (Levin *et al*., 2013). People tend to seek help late or are referred late from primary care to a kidney centre in secondary care due to the silent nature of the disease which contributes to the unplanned start of RRT (Udayaraj *et al*., 2011). The late presentation of people with CKD to secondary care is a cause for concern as those who are diagnosed with CKD stage G5 or ESKD have limited time to make decisions about RRT choice and to be prepared for it (Udayaraj *et al*., 2011).

1.5. Management of CKD and preparation for RRT

CKD is managed according to the stage of the disease (KIDGO, 2013; NICE, 2021a). People with CKD stage G1-G2 and stable stage G3 (Figure 1.1) are managed mostly in the community by primary care doctors with diet, medication, and lifestyle changes to slow the progression of the disease (Lines *et al*., 2017; NICE, 2021a). Those at risk of progressive kidney disease and those with deteriorating kidney function are referred to a kidney specialist for further management (Lines *et al*., 2017; NICE, 2021a). Although CKD is managed with diet, medication, and lifestyle changes in the early stages G1-G3 of the disease, once the kidneys fail (CKD stage G5), it is managed with dialysis and kidney transplantation (NICE, 2018).

Patients who are predicted to start dialysis or receive a kidney transplant within twelve months must receive timely personalised information and education on the available therapy options and be supported to make RRT decisions (NICE, 2018). These patients are advised to decide which dialysis and kidney transplant choice they prefer and be prepared for it before they need to start their chosen dialysis or kidney transplant choice (NICE, 2018; KDIGO, 2020). Dialysis is the process of removing waste products, toxins, and excess fluid from the body to sustain the life of a patient with ESKD (KDIGO, 2013). There are two types of dialysis: peritoneal dialysis and haemodialysis (see Appendix 3 for an explanation). Depending on the choice of dialysis therapy, it can be performed at home, in a dedicated dialysis satellite centre within the community, or at a dialysis centre in a hospital.

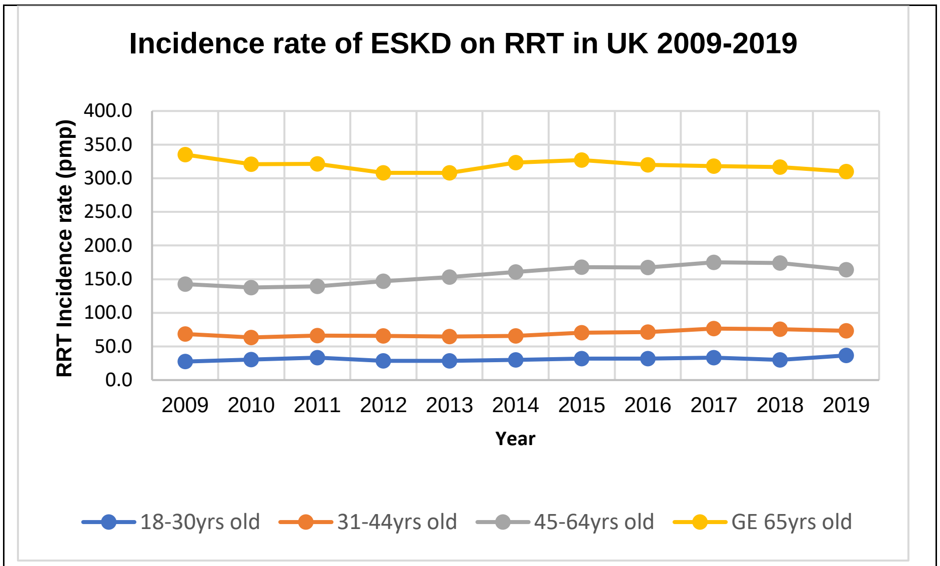
Patients who are suitable to receive a kidney transplant must decide whether they want to have a living donor kidney transplantation or to be listed on the national organ transplantation register (KDIGO, 2020; NICE, 2021a). If they do wish to have a living kidney donor, then they must find a suitable donor and be supported by healthcare professionals in the transplant workup process (KDIGO, 2020; NICE, 2018).

1.6. Incidence and Prevalence of RRT

The global age-standardised incidence rate of dialysis and kidney transplantation is 13.7 [12.6-14.9] per 100,000 population among males and 8.6 [7.9-9.3] among females, so 1.47 times greater among males than females (GBD CKD Collaboration, 2020). All-age incidence of dialysis and kidney transplantation increased by 43.1% and 34.4% respectively between 1990-2017(GBD CKD Collaboration, 2020). Among those in CKD stage G5, 0.011% accounted for kidney transplantation and 0.041% for dialysis (GBD CKD Collaboration, 2020). In the same report all-age mortality from CKD also increased by 41.5% between 1990-2017, with 1.2 million deaths occurring in 2017 (GBD CKD Collaboration, 2020). CKD was ranked as the 12th (previously ranked the 17th in 1990) leading cause of death globally in 2017 which is a cause for concern because some CKD causes are preventable (GBD CKD Collaboration, 2020).

In the UK, 7,945 adult patients started RRT in 2019 (Figure 1.2), a decrease of 1.6% from 2018 (7,959 adult patients) with an incident rate of 151 pmp compared with 152 pmp in 2018 (UK Renal Registry, 2021; UK Renal Registry, 2020). 63.5% of the incident RRT population were males (UK Renal Registry, 2021).

Figure 1. 2 Incidence rate of ESKD on RRT in UK

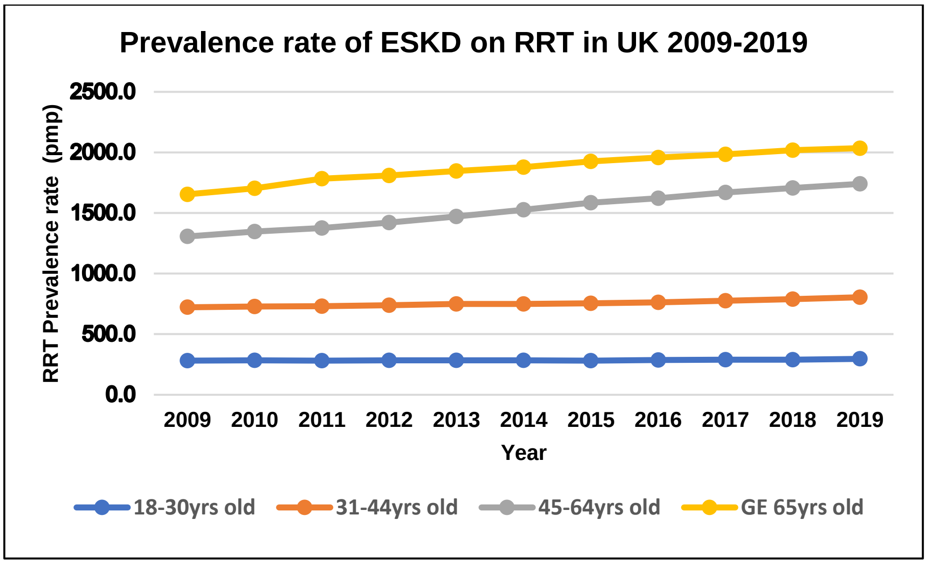


*Permission granted by UK Renal Registry Research Group to use data for Figures 1.2-1.4

pmp-per million population

In the same report, 68,111 adult patients were receiving RRT for ESKD by the end of 2019, an increase of 2.5% from 2018 (66,612). The prevalence rate was 1,293 pmp (1,272 pmp) for adults (Figure 1.3) (UK Renal Registry, 2021). At the end of 2019 there were 38,716 (56.8%) adults with ESKD in the UK who had a functioning kidney transplant compared with 37,302 (55.7%) adults in 2018, an increase of 1% (UK Renal Registry, 2021 and UK Renal Registry, 2020).

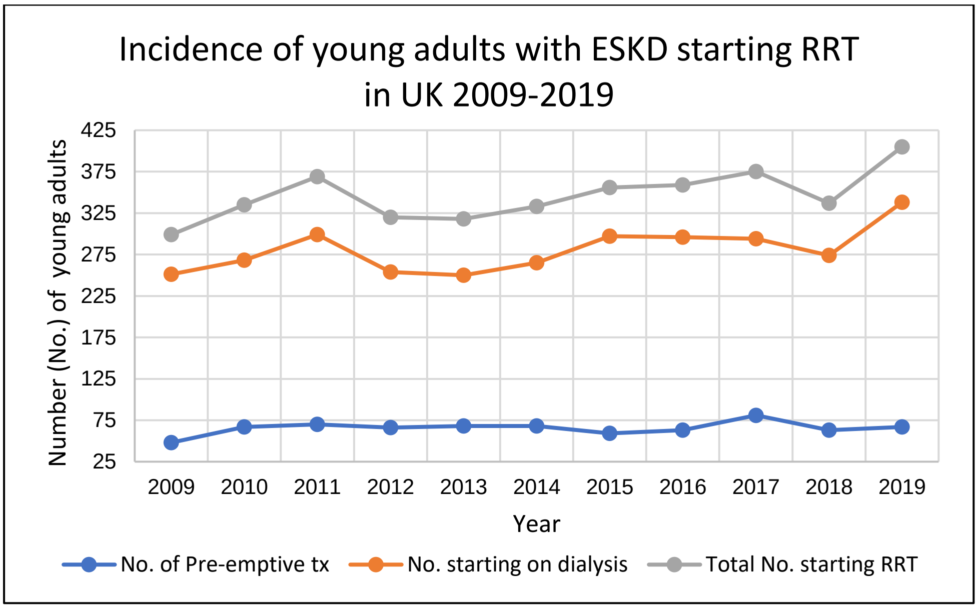
Figure 1. 3 Prevalence rate of ESKD on RRT in UK by age group



pmp- per million per population Permission granted by UK Renal Registry Research Group

The UK Renal Registry Report (2021) also highlighted that 405 young adults (YAs) started RRT in 2019, an increase from 2018 (337). In the same report 338 (274) YAs started dialysis and 67(63) had pre-emptive kidney transplantation in 2019 (Figure 1.4) (UK Renal Registry Report, 2021).

Figure 1. 4 Incidence of RRT among young adults with ESKD in UK



The incidence rate of RRT for YAs was 36.6 pmp and the prevalence rate was 296.1 pmp in 2019 compared with 30.2 pmp and 288.7 pmp respectively in 2018, which has steadily been increasing from 2009-2019 (Figures 1.2 and 1.3) (UK Renal Registry, 2021). The number of YAs who start haemodialysis as their first RRT compared with pre-emptive kidney transplantation continues to increase over the last decade. Decision-making in healthcare and the use of the three-talk model of shared decision-making (Elwyn *et al*., 2012; Elwyn *et al*., 2017) is discussed next.

1.7. Decision-making in healthcare

It was important to understand the term decision-making and its application in healthcare. Decision-making is a complex and multifaceted phenomenon, which is a central part of everyday activity undertaken consciously or unconsciously to manage and coordinate an individual’s actions (Peterson, 2009). Decision-making is also an “internal process by which a course of action or inaction is chosen from a set of two or more alternatives but may or may not result in actions” (McFall, 2015, p.7). People are motivated to make certain types of decisions based on their goals (Umeh, 2009). Likewise, in healthcare, people face decision-making during the trajectory of a disease and must choose from two or more alternatives which involve risk and uncertainty (NICE, 2021b).

Healthcare decision-making used to be medically led, initially driven by paternalistic and physician-as-an-agent models of decision making, a dominant approach used in the pre-1980 era, where doctors were responsible for decisions with less patient and carer involvement (Charles *et al*., 1999). The paternalistic approach was one directional with the doctor dominating the transfer of information and centred on the communication process in the doctor-patient encounter (Charles *et al.*, 1999). Behind this approach was the assumption that a single best treatment existed, and that the doctor knew the best treatment, evaluated good trade-offs between treatments and had a professional expectation to act in the patient's interest (Charles *et al*., 1999). This contributed to a power imbalance in the doctor-patient encounter and patients did not play active roles in their care and associated decisions.

In the physician-as-an-agent for the patient decision-making model, assumptions are made that knowledge and preferences are needed to enable the best expected decision (Charles *et al*., 1999). This approach involved the delegation of the patient's authority to the doctor who was seen to have more knowledge on technical expertise about the treatments, including the risks, and benefits than the patient to make decisions on their behalf (Charles *et al*., 1999). The patient was to share their preferences with the doctor to enable the doctor to act on their behalf as they would have done (Charles *et al*., 1999).

The doctor could not act as a perfect agent to make decisions for patients due to the information asymmetry between them because patients were unable to communicate their values and preferences to the doctor (Gafni *et al*., 1998). These models have been challenged over the years as they were perceived as less person-centred and resulted in power imbalances (Charles *et al*., 1999). This was because of the lack of patient involvement, asymmetry, and ineffective information exchange during the provision of decisional information to enable balanced decision-making (Charles *et al*., 1999).

Over the last two decades with the push for more patient rights and involvement in decisions about their treatment and care, different models such as informed and shared decision-making were proposed to support clinical decisions in practice (Gafni *et al*., 1998). The informed decision-making model assumes that the HCP transfers their technical expertise and knowledge about the benefits and risks of the treatment to the patient (Charles *et al*., 1999; Elwyn *et al*., 2016). The patient is now in the position of having the relevant knowledge in addition to their values and preferences to enable them to make an informed decision and communicate their choice to the HCP (Charles *et al*., 1999). Therefore, the patient has the authority to make their own healthcare decisions based on information that have been passed on to them by the HCP (Gafni *et al*., 1998).

1.7.1. Shared decision-making

Decision-making in healthcare is complex and involves several components such as awareness of options and choice, information exchange, deliberation of options, preference elicitation, and choice selection (Elwyn *et al*., 2017; NICE, 2021b). Guidelines for managing CKD recommend that HCPs work collaboratively with patients and/or their caregivers to discuss the available RRT options and support them to make decisions to select a preferred RRT choice (NICE, 2021a). This collaborative process is referred to as shared decision-making (NICE, 2021b). Shared decision-making (SDM) is a collaborative process where patients work together with their HCPs to reach a joint decision about their care (NICE, 2021b). Patients and their HCPs work together to select tests, treatments, or support packages and are supported to make decisions that are right for them based on their preferences and values (Elwyn *et al*., 2012).

SDM uses various processes to support the decision-maker to make better decisions based on the communication model of the HCP-patient encounter (Charles *et al*., 1999; Elwyn *et al*., 2010). Some SDM models do not make clear the theoretical framework informing their model, but describe what it is, the reason for its use, and the benefits to patients and HCPs. The concept of shared decision-making is discussed in-depth in chapter three of this thesis (see section 3.6.3). The decision-making context can be surrounded by much emotional and psychological distress which can be experienced by both patients and/or their families and sometimes HCPs (Lerner *et al*., 2015). Therefore, the guidelines recommend the psychological assessment of patients and the provision of appropriate support during the decision-making process (NICE, 2021b). Elwyn *et al*. (2014) suggest that emotional and psychological distress must be managed carefully during SDM. Involving people in decisions about their care has numerous benefits such as choosing appropriate treatments, improving health outcomes, and satisfaction with care (Savelberg *et al*., 2021; Joseph-Williams, 2017).

Evidence suggests that patients want to be involved in healthcare decisions but are unable to participate when they lack understanding, are not informed or feel less informed about the available options (Coulter *et al*., 2011; Makkar *et al*., 2019). The Kidney Patient Reported Experience Measure (PREM) highlighted experiences of low support and shared decisions (The Renal Association and Kidney Care UK, 2021). Although the decision-making experiences of older adults with ESKD are documented (Finderup *et al*., 2020; Ho *et al*., 2021; Saeed *et al*., 2019), the same cannot be said about YAs' experiences, with data on YAs' experiences mostly reported together with older adults' data (Levine *et al*., 2018).

Supporting people with ESKD to make an informed or shared decision to select dialysis and kidney transplant therapy is vital (NICE, 2021a).

1.8. Transition and transfer from paediatric to older adults' service

Adolescents and young adults' (AYAs) transition and transfer to older adult services occurs mostly between age 10 to 20 years (Kreuzer *et al*., 2015; NICE, 2016; Prüfe *et al*., 2017). Disparities between kidney centres on the age to begin and end transition and transfer from paediatric to older adult kidney centres have contributed to poor transitioning experiences, and worsening outcomes among YAs (Kreuzer *et al*., 2015; Prüfe *et al*., 2017). In the UK, the transfer from paediatric to adult kidney units occurs between ages of 16 to 18 years (Hamilton *et al*., 2018a). In Germany and Austria transfer mostly occurs at the age of 18 (Kreuzer *et al*., 2015). In other countries transfer occurs between age 19 to 20 years (Kreuzer *et al*., 2015; Prüfe *et al*., 2017).

The International Society of Nephrology (ISN) and the International Paediatric Nephrology Association (IPNA) (Watson *et al*., 2011) and NICE (2016) guidelines recommend that transition should occur before young people move from a paediatric to an adult service. The transition should include a process of initial planning, the actual transfer between services, and the provision of support throughout the process (Watson *et al*., 2011; NICE, 2016). Transfer occurs at the point where the responsibility for providing care and support to a YA moves from paediatric services to adult services (NICE, 2016). The transfer of AYAs from a familiar and nurturing environment (paediatric) to adult kidney service can mean moving them to an unfamiliar environment (British Association for Paediatric Nephrology (BAPN), 2009; Francis *et al*., 2017). Older adult kidney services are sometimes viewed as less empathetic, a discontinuation of the nurturing care previously received in their paediatric centres and can be a daunting experience for young people (Foster, 2015; Francis *et al*., 2017). Evidence suggests that the lack of preparation to receive YAs and the inadequate facilities at the adult kidney centres to cater for their needs, may have contributed to this belief (BAPN, 2009). However, promoting health self-efficacy and meeting the adult team before transfer has been reported to be associated with improved outcomes (Colver *et al*., 2018).

YAs living with long-term conditions such as CKD (Murray *et al*., 2014; Park *et al*., 2014), cancer (Hart *et al*., 2020; Smith *et al*., 2018), cystic fibrosis, asthma, and liver transplant (Morsa *et al*., 2018), and degenerative diseases (Mitchell, 2011) experienced worse outcomes and increased risk compared with their age-related healthy population. Among children, adolescents and older adults with CKD, YAs with CKD and receiving therapy are also worse off (Hamilton *et al*., 2017; Pankhurst *et al*., 2020; Park *et al*., 2014). YAs with CKD face challenges such as disruptions in education, growth development, and employment problems during the trajectory of the disease compared with older adults with the disease (Bailey *et al*., 2018; Foster *et al*., 2015; Hamilton *et al*., 2017; Murray *et al*., 2014).

Evidence suggests that people living with CKD experience psychological and social distress which can increase morbidity (Hudson and Chilcot, 2015; Zalai *et al*., 2012). Depression (Goh and Griva, 2018; Ng *et al*., 2015), and low quality of life (Gerson *et al*., 2010; Griva, *et al.*, 2016) has been reported among older adults. The psychosocial burden of the disease experienced among YAs with CKD is reported to be worse compared with children, adolescents, and older people with the disease (Bailey *et al*., 2018; Hamilton *et al*., 2017; Watson, 2014). Psychological distress has also been reported in young people with cancer (Smith *et al*., 2018), coronary heart disease, cerebrovascular disease and diabetes (Hudson and Chilcot, 2015) during treatment decision-making.

There are reported disparities and variations in the provision of psychosocial support and unmet psychosocial needs among people living with CKD (Harrington and Morgan, 2016; Seekles *et al*., 2018). This is a cause for concern not only for older people with CKD but also YAs, as those who face dialysis decisions following transfer from paediatric centres to adult centres could be worse due to unmet psychosocial needs (Nagra *et al*., 2015). Hamilton *et al*. (2018b) highlighted that YAs receiving dialysis or kidney transplant were twice as likely to experience a psychological disturbance and had worse psychosocial outcomes compared with older adults. The lack of preparation and readiness to receive YAs (Dwyer-Matzky *et al*., 2018) and the lack of dedicated YA clinics within older adult services, in addition to the burden of the disease, may have contributed to heightened fear and stress when they transfer to adult kidney centres (Foster, 2015; Kreuzer *et al*., 2015; Prüfe *et al*., 2017).

In the UK, 568 patients were transferred from paediatric kidney services to adult kidney services and commenced RRT between 1999-2008 (Hamilton *et al*., 2018a). The majority (82.1%) of these YAs (aged 16-30 years) started RRT in an adult kidney centre (Hamilton *et al*., 2018a). Among those aged 16-18 years, 63% (176) started RRT in an adult kidney centre and 37% (103) started in a paediatric kidney centre (Hamilton *et al*., 2018a). In the same report, 82% of YAs initially started dialysis (51.8% on haemodialysis and 30.2% on peritoneal dialysis) as their first RRT (Hamilton *et al*., 2018a). Only 14.1% received a kidney transplant before the need to start dialysis (known as pre-emptive kidney transplantation) (Hamilton *et al*., 2018a) despite it being recommended by NICE (2018). Among those who started on dialysis, 72.9% of 18-24-year-olds later went on to receive a kidney transplant (Hamilton *et al*., 2018a). This finding supports the UK Renal Registry Report (2021) of a high haemodialysis start among YAs with ESKD aged 18-30 years (Figure 1.4). An initial high start of dialysis and low receipt of kidney transplantation among YAs were also reported in Australia and New Zealand (Krischock *et al*., 2016), Germany and Austria (Robinski *et al*., 2016), Australia (Ritchie *et al*., 2012), and USA (Dahlerus *et al*., 2016).

In response to the problems faced by young people when they move into older adult services, guidelines were developed to help address these challenges in the UK (BAPN, 2009; Department of Health, 2008; Department of Health, 2011; NICE, 2016) and internationally (Watson *et al*., 2011; White *et al*., 2018). These guidelines encourage planned preparation, familiarisation with the new older adult environment, knowledge development, involvement of therapy decisions, and the provision of support for YAs before and after transferring to adult care (BAPN, 2009; Department of Health, 2008; Department of Health, 2011; NICE, 2016; Watson *et al*., 2011; White *et al*., 2018).

The loss of a healthy life is felt more among YAs with CKD than older adults with the disease (Hamilton *et al*., 2018a). YAs who developed CKD and progress to ESKD in young adulthood are worse compared with YAs who had the disease in childhood and adolescence (Ritchie *et al*., 2012). Jackson (2014) asserts that people with chronic illness grieve for the loss of healthy life and the severity of grieving is associated with the severity of their illness, which requires psychological support. It is possible that YAs with long-term conditions who face decision-making also experience grief.

Although most YAs later received a kidney transplant (Hamilton *et al*., 2018a), the reason for the high number starting haemodialysis compared with less pre-emptive kidney transplantation is not well understood as it is not well-known how decisions about the RRT were made. Also, there is less data on YAs' experiences because their data tends to be included with older adults' data (Hamilton *et al*., 2018a; Levine *et al*., 2018). Due to the lower percentage of YAs with CKD compared with older adults (Figures 1.2 and 1.3), they can easily go unnoticed and receive less attention (Levine *et al*., 2018). YAs have unique needs such as engagement in healthcare decisions and self-management and they face different challenges compared to children, adolescents, and older adults (Bailey *et al*., 2018; Hamilton *et al*., 2017; Hamilton *et al*., 2018b).

1.9. Young adults with CKD/ESKD

This study refers to people aged 18 to 30 years as young adults. The acceptable age of the majority when a child becomes an adult and has full legal capacity in Europe, is age 18 years except for Scotland where full capacity starts at age 16 years (European Union Agency for fundamental rights and Fundamental Rights Agency (FRA), 2017). The European Union (EU) uses the term youth to describe people aged beyond 18 years and YAs up to age 30 years (FRA, 2017). Different terms and age ranges are used to describe adolescents (10-19 years), young people (10-24 years) and youth (15-24 years) (United Nations Department of Economic and Social Affairs (UNDESA), (2013). Erikson’s stages of psychosocial development age highlighted by McLeod (2018) suggests that young adulthood occurs between the ages of 20 to 40 years.

The EU Strategy for Youth has used the term youth to refer to teenagers and young adults between the ages of 13-30 years (FRA, 2017). These different age ranges and overlapping age boundaries create confusion about the age range for YAs. In the UK, the age of 18 years recommended by FRA (2017) is accepted as the start of adulthood although transitioning and transfers can occur between ages 16 to 18 years. After careful consideration of the different terminologies and age ranges for adolescents, youth and young adults and the overlapping age boundaries, this study adopted a broader age range of 18 to 30 years to represent YAs (FRA, 2017).

Among YAs aged 18 to 30 years old there is little differentiation in terms of their management according to age in kidney care centres (Murray *et al*., 2014). This has resulted in the isolation of YAs who struggle to fit into the older adult population (Murray *et al*., 2014). YAs face challenges during the young adulthood developmental period as they prepare for adult life which needs recognition by healthcare service providers (Bailey *et al*., 2018; Care Quality Commission Report, 2014; Hamilton *et al*., 2017). The Care Quality Commission Report (2017) highlighted that many young people with complex needs experienced a lack of transition planning, no indications for future wishes, hope or aspirations. In the same report young people lacked understanding of the transition process due to poor information about the changes to expect at adult services and lacked preparation (Care Quality Commission Report, 2017).

Young adulthood is a period when complex decision-making abilities are maturing and there is also an increase in responsibilities and independence (Halpern-Felsher *et al*., 2016). YAs living with CKD G1-G5 can struggle to accept their diagnosis, and prognosis, and can feel overwhelmed with the burden of managing the long-term illness, compared with children and older adults with CKD (Lewis and Marks, 2014; Ritchie *et al*., 2012; Tong *et al*., 2013; Zhong and Melendez-Torres, 2017). Murray *et al*. (2014) highlighted that YAs with kidney disease experience slow progression in their developmental milestones compared to their healthy age-related group, because of the effects of the disease. Unfortunately, the majority of YAs with CKD are at a critical stage in their education and employment where they require support to enable them to self-manage the disease and to participate in decision-making during the journey of the disease (Murray *et al*., 2014; Zhong and Melendez-Torres, 2017). YAs with CKD/ESKD experience decisions such as dietary decisions, reduced fluid allowances, and RRT decisions, which form part of the management of the disease (Levey *et al*., 2013).

1.10. The global impact of living with CKD

CKD is recognised as one of the public health burdens due to the increasing number of people diagnosed and living with the disease globally and has a high morbidity and mortality rate, despite it being considered as mostly preventable and treatable (GBD CKD Collaboration, 2020). The burden of people living with CKD world-wide in terms of lost ‘healthy life’ is referred to as Disability-Adjusted-

Life-Years (DALYs) (World Health Organisation (WHO), no date). DALY is a summary measure that shows the overall burden of a disease where one DALY refers to the loss of one year of full health or ‘healthy life’ (WHO, no date). The World Health Organisation highlighted in 2016 that the DALYs associated with kidney disease and that associated with cancer, cardiovascular disease, diabetes, and neurological conditions, had increased significantly from 1990-2015 (GBD 2013 DALYs and HALE Collaborators, 2015).

Living with CKD can be debilitating in the advanced stages (G4-G5), especially among young adults with the disease, and can also affect family members and close relations (Seekles *et al*., 2018). The GBD CKD Collaboration (2020) reported that CKD resulted in 7.3 million Years Lived with Disability (YLDs), 35.8 million Disability-Adjusted-Life-Years (DALYs) in 2017, reflecting the burden of CKD. The mortality referred to as Years of Life Lost (YLLs) due to CKD was 28.5 million in 2017 (GBD CKD Collaboration, 2020). CKD stage G5 and dialysis accounted for high numbers of YLDs, 40%, and 22% respectively in 2017, even though stages G1-G3 are more prevalent. CKD due to Type 2 diabetes mellitus, hypertension, and unknown causes contributed to the DALYs globally among people aged 40 to >70 years. Among those aged 15-29 years, CKD due to glomerulonephritis, Type 1 diabetes and unknown causes contributed to high DALYs (GBD CKD Collaboration, 2020).

1.11. Rationale for the study

Despite evidence-based guidelines, the transition and transfer of YAs to older adult services continue to raise challenges in the UK (Care Quality Commission

Report, 2014; Care Quality Commission Report, 2017) and internationally (Kreuzer *et al*., 2015; Prüfe *et al*., 2017). Not all AYAs go through a transition service before or after transfer from paediatric to older adult services, and some struggle to engage with adult health services (Fegra *et al*., 2014; Murray *et al*., 2014). The disparities and variations in the management of AYAs from paediatric to adult kidney services nationally (Gair, 2016; Hamilton *et al*., 2018a) and internationally (Kreuzer *et al*., 2015; Prüfe *et al*., 2017; Watson *et al*., 2011) have contributed to healthcare problems among YAs.

Studies have highlighted that around the time of transitioning and following transfer to older adult services there is increased risk in non-adherence to medication, therapy regimens, poor and non-attendance at clinic, high unexpected loss of kidney transplant, and lack of engagement in services (Levine *et al*., 2018; Nagra *et al*., 2015; Prestidge *et al*., 2012; Weitz *et al*., 2015). Reports of increases in preventable hospitalisation within the first three to four years of transferring to an adult service have also been highlighted (Samuel *et al*., 2014).

These elevated risks of non-adherence, the loss of kidney transplants, and preventable hospitalisation are associated with poorer outcomes among YAs compared with children and older people with CKD (Bailey *et al*., 2018; Diáz-González de Ferris *et al*., 2017; Hamilton *et al*., 2018a; Weitz *et al*., 2015). Behavioural changes have also been reported among YAs with cancer and diabetes who transitioned to adult services (Hynes *et al*., 2016; McGrady and Pai, 2019). Although guidelines (NICE, 2016; NICE, 2021b) and policies (Härter *et al.*, 2011; Coulter and Collins, 2011) promote patients' rights to participate in healthcare decision-making, the embedment of shared decision-making in routine care is yet to be achieved (Härter *et al*., 2017; Joseph-Williams *et al*., 2017).

NICE (2021b) guidelines highlight the need for healthcare providers and HCPs to recognise patients in decision-making, educate people about their healthcare needs and promote SDM. Gafni *et al*. (1998) assert that for a preference-sensitive decision about treatment with alternative options that involve trade-offs to occur, complete knowledge of the risks and benefits of each treatment option and its cost (knowledge component), and patient preferences and values (the utility function) must be satisfied. Health literacy which is the ability of a person to read, understand, evaluate, and use the health information received to improve their health (Coulter *et al*., 2011), is an important aspect of decision-making and self-management. Low health literacy has been reported among older CKD population (Levine *et al*., 2018) and is associated with poor adherence to the RRT regime (Fraser *et al*., 2013; Green *et al*., 2013) and poor health outcomes (Berkman *et al*., 2011; Levine *et al*., 2018), but that of YAs remains limited.

Although evidence suggests a higher start of dialysis compared with pre-emptive kidney transplantation among YAs (Hamilton *et al*., 2018a; UK Renal Registry, 2021), no studies have explored why this occurs. There are only limited studies that have specifically explored young adults' experiences of dialysis and kidney transplant decision-making or how they make dialysis and kidney transplantation decisions to understand their needs (Ofori-Ansah *et al*., 2022), which is discussed in chapter two of this thesis. Therefore, research is needed to explore how YAs make decisions to select their preferred dialysis and kidney transplant choice to understand their decision-making preferences and experiences.

1.12. Study interest

1.12.1. Personal experience in kidney care

My interest and motivations in conducting this research project stems from my professional experience as a kidney nurse and previous research that I have conducted. I have professional clinical experience in managing people with CKD, providing education about kidney therapy options, and supporting them to explore, make decisions about their options and how they receive therapy. It was in this clinical role of managing and supporting adults with different stages of CKD (G1-G5) and modalities such as advanced CKD, post-transplant, nephrology, and rare kidney diseases that I became aware of the challenges experienced by YAs and their families. Over the years, it became clear during my interactions with YAs with CKD, who had either been transferred from a paediatric unit or had presented directly to the adult kidney centre from primary care, that there were challenges with managing their care.

My observation of YAs include poor clinic attendance, increased rates of non-attendance, non-adherence to medication regime, lack of engagement with therapy decision-making and fear of dialysis therapy. This behaviour pattern often led to an increase in their emotional burden, risks, and complications of the illness in certain situations with profound consequences (Ferris *et al*., 2015). YAs generally experience a variety of emotions during their developmental milestones when faced with challenges (U.S. Department of Health and Human Services, 2018). However, these emotional disturbances are heightened when a YA is faced with a chronic illness like CKD that has implications for their life and this worsened when their condition progressed to ESKD (Tunnicliffe *et al*., 2016; Wilson and Stock, 2019). The observed lack of engagement with therapy decision-making process among YAs in practice often resulted in a less timely selection of dialysis choices. YAs' needs can only be addressed if kidney professionals understand their experiences.

My discussions with some YAs highlighted that their needs were different from older adults with kidney disease; they perceived these needs as unmet, and they required a personalised approach to manage their needs. YAs expressed fear of coming to the kidney unit, as being one of the few YAs in the unit, they did not feel they belonged there. Many YAs struggled to attend clinics as they tried to fit work, education, social life, and family needs around their appointments. Most of them struggled to engage with decision-making because they were either asymptomatic or denied the kidney disease had progressed to ESKD. YAs wanted to live normally like their peers and the majority preferred to live as though they did not have kidney disease due to a lack of understanding of the disease and its progression. YAs' needs were sometimes less well understood by the multi-professional team involved in their care.

I became aware of variations and disparities in the provision of YA kidney services which resulted in health inequalities in kidney healthcare management across different areas of the UK (Gair *et al*., 2016; Caskey and Dreyer, 2018). Apart from being a minority among other adult groups, YAs also had less focus at the Renal Registry level, their data were included in older adults' reports, making them less visible until recently (Hamilton *et al*., 2018a). Therefore, it was important to explore YAs' experiences as this can help understand what their needs are and address some of the kidney health inequalities they experience.

I bring to this research my knowledge and professional experience of managing YAs with CKD which makes me an insider, exploring an area I have familiarity with; therefore, my objective is to stay neutral and avoid biases which is discussed further in sections 3.21 and 3.22. At the same time, I see myself as an outsider as a researcher, with a limited understanding of YAs' lived experience of making dialysis and kidney transplant decisions and how it impacts them. It was important not to take things for granted as an insider, but to embrace openness in my quest to explore and understand YAs lived experiences of decision-making.

1.12.2. Project and research experience

My passion to understand YAs' needs and support grew stronger, and I became an advocate for YAs in my local kidney unit. It was during my clinical work as a project lead for NHS Kidney Care quality improvement projects (2012-2014), that I attended a session on transition care for adolescents and YAs which confirmed my interest. My aim was to explore how best YAs could be supported to develop their knowledge and understanding of their diagnosis, how the disease may progress, and the therapies required. This is important for engagement and participation in decisions about YAs' care and timely selection of renal replacement therapy. I shared the idea with lead consultants and like-minded colleagues leading to the creation of a transition clinic within our unit, away from the normal clinics to address some of YAs' needs.

In 2015, I conducted a research study to understand the experiences of decision-making among adult patients with CKD G4 and G5 and their caregivers as part of my MSc in Clinical Research study. People aged 18 to 42 years old did not participate in the study although it was open to them. This limitation of the study in addition to the observed patterns from the professional experience of managing YAs with CKD motivated me to explore their decision-making experiences. The intention to research this area was discussed with other healthcare professionals in our kidney unit and our local CKD patient user group. Consulting users of healthcare services and the public, referred to as Patient and Public Involvement (PPI), is an important part of the research process (INVOLVE, 2012).

PPI allows researchers to seek patients' views and use their views to inform their decision-making about areas to be researched and be involved in different aspects of the research process (National Institute for Health and Care Research (NIHR), 2021). This ensures the research study has a focus on what matters most to patients rather than only the researcher's aspiration (NIHR, 2021). It also means working in partnership with health and care professionals for everyone's benefit. The research idea was welcomed as both the kidney patient user group and the kidney health professionals felt it was an unmet area that required exploration. The initial aim of the research was to understand young adults' engagement with dialysis and kidney transplant decision-making. I also wanted to understand the support available to them and elicit their views on what could be done to make their experience better.

It was during this period that I came across the PhD scholarship programme, to which I applied and was awarded the scholarship to conduct this research study. Further discussions were held with our local peer support group on the research idea before starting the PhD programme. Following the commencement of the PhD programme, a formal involvement group of people with experience in making RRT decisions as young people was set up to discuss the research question and ideas to firm the research question which is discussed in the methods section in chapter three (section 3.14) of the thesis under Patient and Public Involvement.

1.13. Research question, aims, and objectives

The research question for this study was: How do young adults with end-stage kidney disease experience dialysis and/or kidney transplant decision-making?

Aim

The aim was to explore how young adults who are diagnosed with end-stage kidney disease experience dialysis and/or kidney transplant decisions, understand the meaning of their experiences, and investigate the effects of decision-making and choice on their well-being.

Objectives

The objectives were to:

a. Understand how young adults engage with and make dialysis and/or kidney transplant decisions.
b. Explore young adults' preference for decision-making and identify factors that influence young adults' dialysis and/or kidney transplant choice selection.
c. Explore the effects of dialysis and/or kidney transplant decision-making and choice on young adults' well-being.
d. Elicit young adults' views on what could have been done differently to enhance their experiences of decision-making and receiving dialysis and/or kidney transplant therapy.

1.14. Context for the study: COVID 19 Pandemic

The study was affected by the global onset of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS CoV-2), also referred to as COVID-19, which spread rapidly worldwide and was declared a pandemic in mid-March 2020 by the World Health Organisation (WHO) (2020). The COVID-19 pandemic resulted in global lockdowns, including in the UK, to restrict the movement of people and reduce the transmission of the disease (Anderson *et al*., 2020). The UK experienced its first COVID-19 pandemic lockdown at the end of March 2020, and this impacted on individuals' lifestyles due to limited movement and social contact with people. At the time, I was waiting for research and development approval from a National Health Service (NHS) hospital site to recruit extra participants for my study. Rapid adaptations and redesigning of healthcare services including staff redeployment to meet the demands of healthcare delivery occurred internationally including the NHS in the UK (Kanavaki *et al*., 2022).

In the UK, the National Institute for Health and Care Research (NIHR) in March 2020 directed that the National Institute for Health and Care Research Clinical Research Network (NIHR CRN) had stopped the NHS site setting up new or existing studies that were not nationally prioritised COVID-19 studies at NHS and Social care sites. As my study was not considered a nationally prioritised COVID-19 study, the study could not be undertaken at the NHS site.

This dynamic and rapidly changing situation also affected the educational system worldwide (Schleicher, 2020). The delivery of education in schools including higher education was affected, as all non-essential in-person meetings were either reduced, moved online, or stopped in the UK (Department for Education, 2020; Public Health England and Department for Education, 2020). The progress of doctoral studies, for example, study set up, recruitment, data collection and use of the library and other facilities were severely affected. Online doctoral supervision was adopted which provided me with support for my studies. Fortunately, the social media recruitment had increased in December 2019 whilst waiting for the NHS Health Research Authority approval and I had conducted interviews with eighteen participants by January 2020, when Covid-19 was on the increase. As it was less likely for the study to be set up on the NHS site and I now had sufficient participants through social media recruitment, a decision was made with my supervisory team to stop further recruitment and to analyse the data already collected.

The COVID-19 pandemic affected all health service providers worldwide including kidney care services. For example, an increase in the incidence and prevalence of kidney disease was reported (Pecly *et al*., 2021; Uribarri *et al*., 2020). The renal workforce was among other healthcare professionals whose morale and well-being were affected because of the sustained pressure and burden of providing kidney services because of the COVID-19 pandemic (Beckwith *et al*., 2021; Mc Keaveney *et al*., 2021). Although the CKD management guidelines recommend that healthcare professionals (HCPs) use a shared decision-making approach to support patients and/or their caregivers or families during RRT decision-making (NICE, 2021a), the COVID-19 pandemic made it challenging to provide the service. Kidney health professionals rapidly had to adopt new ways of providing kidney services during the pandemic such as patient education and supporting therapy decision-making (Sever *et al*., 2021).

1.15. Summary

Research is needed to understand YAs' experiences of dialysis and kidney transplant decision-making. Although there is literature on the experiences of living with CKD and ESKD, there is less literature about how YAs experience dialysis and kidney transplant choice selection. Exploring YAs' dialysis and kidney transplant decision-making experiences would enhance the understanding of how they engage with the decision-making process, their preferences for decision-making, and the factors that influence their decisions.

1.16. Structure of the thesis

The doctoral thesis is structured to guide the reader chronologically through the various elements of the project arranged in chapters. The introduction chapter has introduced CKD and its management concerning existing guidelines to give the reader a better understanding of the participants' experiences of making dialysis and kidney transplant decisions to select a renal replacement therapy and some epidemiological overview. The chapter also provided context for the study.

Chapter 2 Literature review: This chapter presents how an integrative literature review of primary articles on YAs with long-term conditions was performed and highlights the findings from the review in the form of the themes identified. The chapter discusses the findings and how the knowledge gap was used to inform this research study.

Chapter 3 Methodology and methods: This chapter discusses how the study was conducted to generate data and how the data were analysed.

Chapter 4 Findings of the study: The themes identified from the data analysis and the interpretation of YAs' dialysis and kidney transplant decision-making experiences are presented.

Chapter 5 Discussions: This chapter discusses the findings with the integrative literature review and other existing evidence on the research topic and how it aligns with the three-talk model of shared decision-making and Heidegger's hermeneutic phenomenological principles.

Chapter 6 Conclusion: This chapter concludes the thesis. It discusses this study's contribution to new knowledge, the implications for practice and policy, recommendations for future research, the strengths and limitations of the study and the dissemination of the study findings.

Chapter 2 Literature Review

2.1. Introduction

This chapter provides a critical review of existing literature on YAs' decision-making experiences concerning treatment or therapy choices. The purpose of this review was to contextualise the research study by appraising the existing literature on the research topic, summarise the findings and identify the knowledge gap informing the research study. The chapter explains the literature reviewing approach, the search strategy, and how the primary articles selected were appraised to produce the synthesis of the topic. The knowledge gap identified and links to the theoretical framework are also explained.

2.2. Rationale for choosing integrative literature reviewing process

An integrative review was chosen to conduct the literature reviewing of primary articles that explored YAs' experiences of treatment or therapy decision-making to provide a comprehensive body of evidence. An integrative literature review method is a process used to synthesise knowledge from past empirical research or theoretical literature involving diverse methodologies such as experimental and non-experimental research to understand the contexts, the processes used, and the phenomenon of interest (Whittemore and Knafl, 2005). It was important to consider the different types of literature reviewing approaches and decide which one would be appropriate to use. The literature reviewing techniques considered were narrative review (Jahan *et al*., 2016), scoping review (Pollock *et al*., 2021) and integrative review (Whittemore & Knafl, 2005).

Narrative review can be used to discuss broad topics, history, and other development issues or their management, to help update practitioners and for educational purposes (Green *et al*., 2006). A narrative literature review can be used to examine theory, contexts, and physiological perspectives in a thoughtful way (Green *et al*., 2006) and takes a less formal approach compared to other literature reviewing methods (Jahan *et al*., 2016). Fink (2014) argues that such reviews tend to be conducted with a broad question, no selection criteria, are subjective, and without any methodological approach, explaining how articles may have been chosen. The quality of articles may not have been well critiqued and does not allow for independent reproducibility due to their subjectiveness (Fink, 2014), therefore, a narrative review was not used.

Scoping review was also considered; although not used, it is important to explain the reasons. Scoping review is an approach that is gaining attention within health and social science disciplines to provide narrative evidence (Pollock *et al*., 2021). Scoping reviews tend to be used as a quick way to explore broader topics to map existing literature of an area of interest regarding the volume, nature, and characteristics of the primary research (Arksey and O'Malley, 2005). It is commonly used to scrutinise the extent, range, and nature of research activity of a topic on a broader level where the topic of interest is not widely reviewed (Pham *et al*., 2014). Scoping review has been used to explore emerging evidence that may be less understood, for example, Allobaney *et al*. (2020) scoped the literature to map the extent of nursing research related to COVID-19. Quanwan and Zhang (2019) used scoping review to explore problem-solving based interventions for informal caregivers.

However, due to its broad scoping boundaries and amount of data explored, the quality of the evidence in the primary papers is often not assessed nor addresses the issue of synthesis, rather it provides a narrative or descriptive account of the research available (Arksey and O'Malley, 2005). Munn *et al*. (2018) assert that scoping review may be appropriate if the focus is to identify certain concepts or characteristics in the primary studies, map, or discuss these concepts or characteristics. Scoping review was not used as the purpose of this literature review was to explore what the decision-making experiences of young adults with long-term conditions were, to produce a synthesis of the evidence and identify the knowledge gap to inform this study.

The integrative literature reviewing approach was chosen because primary research of an interesting topic with different methodologies can be critiqued and synthesised in an integrated way, resulting in the generation of new ideas, perspectives, and knowledge on the topic reviewed (Torraco, 2005). An integrative review contributes to clinical and evidence-based practice, for example, in nursing science and practice, research, and health policy initiatives, to provide various perspectives on a topic of concern like decision-making (Whittemore and Knafl, 2005). Decision-making has been explored via different approaches (Brown *et al*., 2022; Elwyn *et al*., 2012).

Therefore, it was important to use a reviewing method that will allow the combination of different methodological approaches to understand the decision-making experiences of YAs with long-term conditions. The use of the integrative reviewing method enabled the presentation of varied perspectives of evidence

(Russell, 2005). The integrative review aimed to generate an understanding of the experiences, perspectives, and knowledge of YAs' decision-making. The strength of the integrative literature review lies in its ability to include diverse methodologies to generate new knowledge (Torraco, 2005; Whittemore and Knafl, 2005). It is an organised and structured process that allowed the identification of the relevant body of literature to answer the research question, provide a strong scientific body of evidence and a holistic understanding of the topic (Whittemore and Knafl, 2005). However, the inclusion of primary studies with diverse methodologies can give rise to possible biases, inaccuracies, and lack of rigour when poorly conducted (Whittemore and Knafl, 2005). A structured approach needed to be followed as Cook *et al*. (1997) argued that the quality and worth of a literature review were dependent on the reviewer's ability to minimise errors and biases. This review has followed the well-recognised five-stage approach described by Whittemore and Knafl (2005).

2.3. Stages of the integrative review

The review involves the following five stages; problem identification, literature search, data evaluation, data analysis, and presentation of findings (Whittemore and Knafl, 2005), (see Table 2.1).

Table 2. 1 Stages of the integrative literature review process

	Stages	Description
1	Problem identification	Clear identification of the research problem that the review is addressing was decided at the initial stage. The question and aim were formulated to provide a clear focus and boundaries for the integrative reviewing process (Whittemore and Knafl, 2005).

2	Literature search	The search strategy, search terms, inclusion and exclusion criteria, were developed using the Population (patient), Exposure, Outcomes, and Study type (PEOS framework). The criteria for inclusion and exclusion to screen the literature aided the process. The combination of keywords and phrases based on the PEOS framework concepts was used to retrieve relevant articles from the different databases.
3	Data evaluation	Primary studies with different methodological approaches (quantitative, qualitative, and mixed method studies) that met the inclusion criteria were appraised and their quality evaluated according to methodology, theoretical rigour, and data relevance using different evaluation tools.
4	Data analysis	An iterative process involving data reduction, data display, data comparison, conclusion drawing, and verification of themes, as recommended by Whittemore and Knafl (2005), was followed during the data analysis. Data extracted from primary sources were coded, categorised, and conceptualised to develop a thematic synthesis to answer the review question.
5	Presentation or synthesis of results	Synthesis of themes generated from the data analysis is presented in an integrated way to highlight the findings and the knowledge gap informing this study.

2.3.1. Stage 1: Problem identification

Clear identification of the research problem that the review is addressing is needed at the first stage. Therefore, the research problem was identified, followed by the determination of the target population, concepts of interest, and a suitable sampling frame. The formulation of the question, aim, and objectives are essential to provide a clear focus and boundaries for the integrative review process (Whittemore and Knafl, 2005). The review question was: *what are the decision-making experiences of young adults with long-term conditions?* The aim was to produce a synthesis of the evidence and identify the knowledge gap to inform this study. Having identified the review question and goal for the review, the search strategy used to review primary articles is explained in section 2.3.2.

2.3.2. Stage 2: Literature search

The use of a defined search strategy and search terminologies enhanced the rigour of the reviewing process as it ensured that the relevant databases are used to retrieve the primary articles (Cooper, 2017). A systematic search process was used to find primary literature that has explored the experiences of treatment decision-making of YAs with long-term conditions. The initial search was conducted between June and December 2018, and then updated in 2020 and in August 2021 to ensure that any new research on the topic was included in the review. Table 2.2 shows the broader search criteria for the population used for the literature search using the PEOS framework.

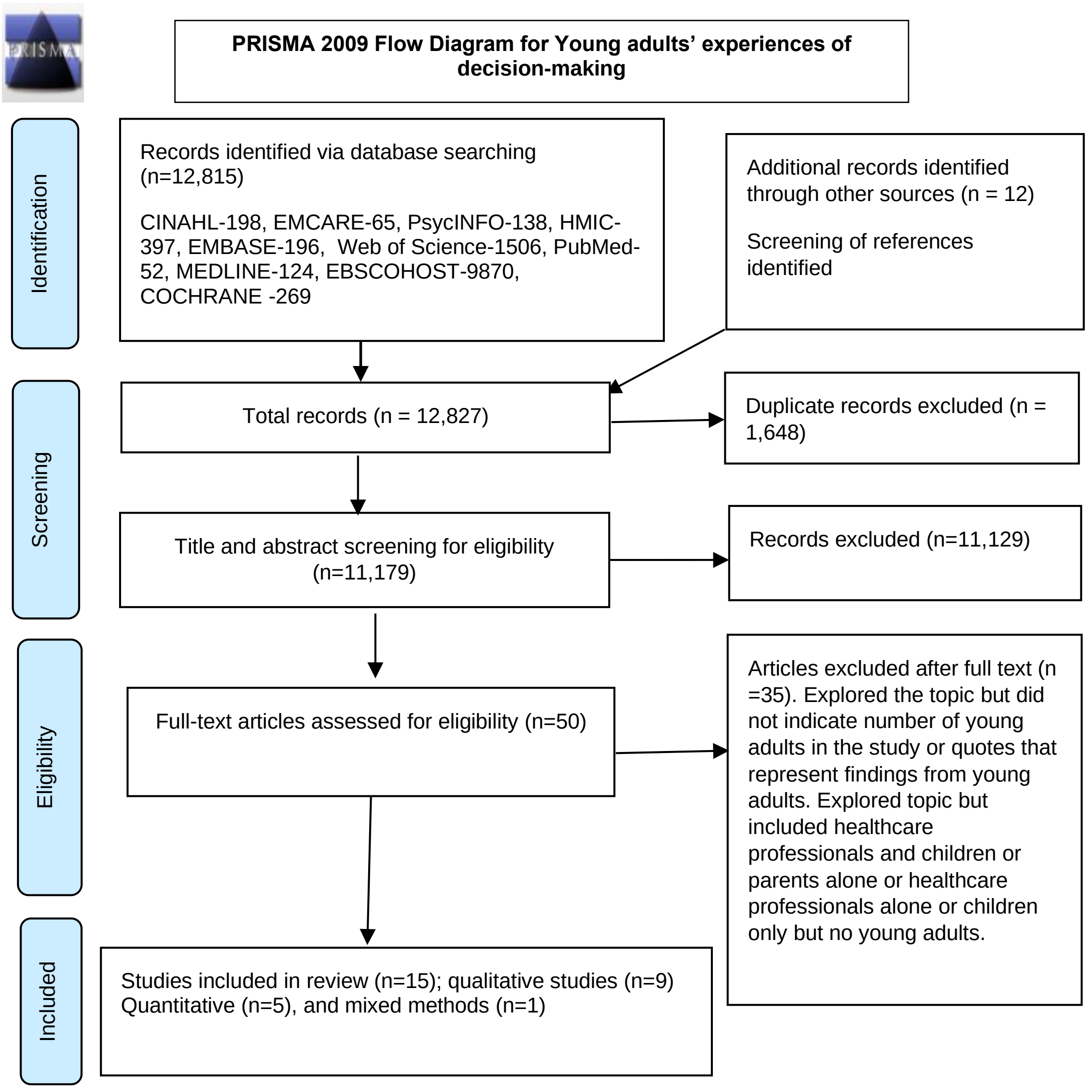
Table 2. 2 Search criteria

PEO framework and description		Inclusion criteria	Exclusion criteria
Patient/ Population (P)	Young adults aged 18 to 30 years.	Young adults [adolescents, young people, youth, teenagers] with long-term conditions and/or end-stage kidney disease (ESKD), aged 18 to 30 years. Studies were included if in addition to young adults included other groups or people such as children, adolescents, parents/family, and healthcare professionals.	People aged <18 years or above 30 years. Young adults in CKD stages 1-3 and young adults without long-term conditions. Studies were excluded if they focused only on children, adolescents, older adults, parents/family, and healthcare professionals.
Exposure (E)	Kidney failure /End-stage kidney disease (ESKD) /long-term conditions	Studies that explored decision-making experiences of young adults with long-term conditions and/or ESKD. Explored involvement, participation, views, or perceptions about treatment and therapy decision-making. For example, renal replacement therapies (RRT), or kidney failure therapy options such as dialysis (haemodialysis (HD), or In-centre haemodialysis (ICHD), satellite haemodialysis; peritoneal dialysis (PD), continuous ambulatory peritoneal dialysis (CAPD), automated peritoneal dialysis (APD), home dialysis), or kidney transplantation (living or deceased donor kidney transplantation), or other therapies for long-term conditions like cancer, diabetes, and asthma treatment.	Studies were excluded if they did not focus on treatment decision-making or decision-making but focused on young adults with CKD stages 1-3, without long-term conditions, or on conservative management or end-of-life issues.
Search terms		'Young adults' or 'young people' or 'adolescents' or 'teenagers' or 'youth'. 'Kidney failure' or 'chronic kidney disease' or 'end-stage renal disease' or 'end-stage kidney disease' or 'long-term conditions' or 'Decision-making', 'Shared decision-making'.	

		‘Choice selection’ or ‘patient experiences’, or ‘treatment decision-making’ or ‘views’ or ‘perceptions’ or ‘involvement’ or ‘participation’ or ‘engagement’ in decision-making. ‘Renal replacement therapy’ or ‘dialysis’ or ‘peritoneal dialysis’ or ‘home haemodialysis’ or ‘home-based therapies’ or ‘kidney transplant’, or ‘haemodialysis’, ‘cancer therapy’, ‘diabetes therapy’.	
Outcome (O)	Experiences of therapy decision-making	Studies that focused on experiences, views, perspectives of treatment decision-making, and the effect of decision making on well-being.	Outcomes focused on end-of-life treatment decision-making, withdrawal from dialysis, experiences of living with long-term conditions or quality of life.
Study design/ types included		Quantitative, qualitative, mixed methods, randomised control trials, thesis, and peer reviews.	Non-peer reviewed articles and editorials, commentaries, opinion papers.
Publication types		Abstracts, full text, published in English language between 2010 to 2021.	Published before 2010 or after 2010 and not in English.
Databases			
Allied and Complementary Medicine Database (AMED) British Nursing Index (BNI) Cochrane Library of Systematic Reviews Cumulative Index to Nursing and Allied Health Literature (CINAHL) EBSCOHOST EMCare Excerpta Medica database (EMBASE) Web of Science Medical Literature Analysis and Retrieval System Online (MEDLINE) Psychological Information database (PsycINFO) Public Medical Literature Analysis and Retrieval System Online (PUBMED)			

A combination of phrases, keywords, and MESH terms where applicable and Boolean operations such as ‘OR’ and ‘AND’ were used to combine search terms to conduct title and abstract search of databases (see Table 2.2). Hand-searching of abstracts retrieved from the databases and reference lists of retrieved papers was conducted to identify other relevant articles. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) process (Moher *et al*., 2009) was used to refine the steps of the literature search to retrieve a total of fifteen articles (Figure 2.1).

Figure 2. 1 PRISMA Diagram flow chart



Having discussed the literature search, an explanation of how the data were evaluated is provided in the next section.

2.3.3. Stage 3: Data evaluation

The fifteen studies, nine qualitative, five quantitative, and one mixed method study (Table 2.3), were published in English language between 2010 to 2021 and from eight countries. These countries were Australia (n=1), Europe (n=1, included 36 countries including UK), Ireland (n=1), New Zealand (n=1), South Korea (n=1), Taiwan (n=1), UK (n=3) and USA (n=6). One study (Van Biesen *et al*., 2014) included participants from lots of countries. Studies explored a range of decision-making experiences such as views, perspectives, and experiences of decision-making, decisional self-efficacy, decisional conflict, decisional support, and factors influencing treatment or therapy decisions (Table 2.3). Authors (Chen *et al*., 2018; Coyne and Gallagher, 2018; Pyke-Grimm *et al*., 2020; Zee *et al*., 2018) were contacted for the actual numbers of YAs in their study if it was published less than five years ago.

Table 2. 3 Data extraction sheet describing primary articles

Author(s), year, and country	Aim and type of Intervention	Study Population, Sample size (n= young adults) and Age range (years)	Study Design	Data collection approach and survey scales (quantitative studies)	Key findings/ results	Limitations	Quality Assessment
Calestani *et al*. (2014) UK	Explored experience, views, and perspectives of patients waiting for kidney transplant listing	People with end-stage kidney disease on the transplant waiting list and those not listed. 53 participants (n=4) Age range= 23-73 years	Qualitative (Did not specify the type of qualitative approach used)	Semi-structured interviews	Variation in the provision of information about dialysis therapy options and the transplant listing process. Lack of information and understanding of the transplant listing process was reported which also influenced participation in decision-making. Varied decision-making experiences were highlighted. Family and friends influenced the choice decision.	The authors did not explore how decisions on kidney transplant listing occurred. Sampling bias limited the sampling population from the multiple sites (kidney units) and weakens the conclusion made. No quotes supporting the themes were from people for whom interpreters were used during interviews which reduces the representativeness of the supporting evidence from minority ethnic backgrounds.	Moderate
Coyne and Gallagher (2011)	Explored children and young people who are in hospital	Children and young people with fractures, appendicitis,	Qualitative (Descriptive approach)	Focus group and single interviews	AYAs had varied preferences for receiving treatment information about illness and options. Some felt ignored as communication about disease and	The study included the decisional experiences of children with acute illness in addition to chronic illness	Strong

Ireland	experiences of participation in communication and decision-making.	constipation, and infection (n=28) and children with chronic illness (asthma, diabetes, cystic fibrosis, and sickle cell) (n=27) 55 participants [of which 9 are 14-18 years] (n= not stated) Age range 07-18 years			treatment options were directed to parents instead of them. They also had varied preferences for their decisional roles and roles of significant others involved in decision-making. The lack of involvement in decision-making resulted in shock, anger, disappointment, confusion, and betrayal.	although the experiences are different. The study did not explore how participants made their treatment decisions. Not all findings could be attributed to YAs.	
Chen *et al*. (2018) Taiwan	Explored decisional conflict and its influencing factors on choosing dialysis modality in patients with end-stage renal disease.	People with end-stage renal disease 70 participants (n=3) Age range 23-90 years	Quantitative (Predictive correlational cross-study)	Survey Scale used - Dialysis knowledge scale, decision self-efficacy scale, social support scale, and decisional conflict scale	Varied information delivery experiences. One-third of participants received limited information or lacked information on the available treatment options. Moderate confidence in making an informed choice was highlighted. Decisional conflicts and how to implement choice decisions were experienced by some participants. Decisional conflict was associated with	Sampling bias existed. Results were not generalisable. Casual relationships between decisional conflict and factors measured were not determined. The impact of decisional conflict on treatment outcomes and patient adjustment was not accounted for.	Moderate

					age, dialysis knowledge, decision self-efficacy, family, and professional support.		
Devitt *et al*. (2017) Australia	Elicited the accounts of patients' illness experiences including effects on family life, views on transplant, and their satisfaction with health services.	People with CKD (90% were receiving in-centre haemodialysis) 146 participants (n=5) Age range 20 - >70 years	Qualitative (Narrative approach)	Face-to-face narrative-interviews	Most participants from indigenous backgrounds experienced communication problems with their clinicians. The majority lacked awareness of the kidney transplant choice. Cultural and religious beliefs hindered the acceptance of the kidney transplant choice, which some negotiated to get buy-in and family support among those who became aware of kidney transplantation. Concerns of donor consequences post-transplant resulted in the preference for cadaveric donation instead of living donation.	The study underestimated the difficulties the indigenous people of Australia experienced concerning kidney transplantation. Sampling bias as patients with less confidence, distress, or confusion may not have volunteered to speak to a stranger (researcher). Diverse social, cultural, and treatment context.	Moderate
Hart *et al*. (2020) UK	Described the decision-making experiences of adolescents with chronic illness and their parents and the extent to which they agreed.	AYAs with cancer and their relations. 33 participants (15 relations and AYAs n=18) Age range 16-24 years	Qualitative (Descriptive approach)	Semi-structured interviews	Most AYAs experienced difficulties processing the news of cancer diagnosis due to being extremely unwell at the time of diagnosis. Distress and quick acceleration in clinical activity following diagnosis impeded the absorption of treatment-relevant information. Most AYAs preferred to defer decisions to health professionals when they had to make choices about front-line treatment (clinical	The sample had more males compared to females. The source and prevalence of regrets were not explored by the study. Findings were subject to recall bias. The presence of close relations could have affected the openness to share details of their decision-making experiences.	Strong

					trial treatments). Parents/caregivers tried to compensate for AYAs' limited engagement with treatment-relevant information. However, they had conflicting priorities and their own information needs.		
Kim and Choi (2016) South Korea	Explored the experiences of Korean adolescents who have undergone kidney transplantation.	AYAs with transplant. 9 participants (n= 2) Age range 12-18 years	Qualitative (Descriptive approach)	Semi-structured Interviews	AYAs felt they were not invited or considered as decision-makers forcing them into a passive role. They lacked knowledge and received less information about transplant treatment options and practicalities of the surgery to be able to decide on the kidney transplant option. Experienced a lot of emotions that resulted from the practicalities of undergoing a transplant surgery, due to body image and feeling different. AYAs felt isolated at school as they lived with a lot of restrictions, which impacted on self-esteem and identity.	Small sample size, more adolescents compared to young adults therefore, not all the results may reflect YAs' experiences of decision-making. The authors did not examine how decisions were made or how involvement in decision-making affected their well-being. Lack of exploration of how their culture affected the decision-making process.	Moderate
Mack *et al*. (2019) USA	Evaluated cancer treatment decision-making among AYAs, including decisional	AYAs with cancer and their oncologists. 203 participants (n=152)	Quantitative (Type of design not stated)	Survey Survey scales- Decision preference scale, Hospital	Varied preference of decisional roles, ranging from active, collaborative to passive (where decision-making was deferred to significant people). The majority of adolescents and young adults held the roles they wished relative to	Sampling was from hospital and community settings, with one hospital having limited diversity. Findings from the hospital settings may not be representative of those in	Strong

	preferences, engagement, and decisional regrets.	Age range 15-29 years Oncologist =99		Anxiety and Depression Scale (HDAS), Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale, and the Trust in physicians scale questionnaires. Oncologists completed questionnaire on participants' prognosis	parents and oncologists when making cancer treatment decisions. One-quarter of participants regretted initial treatment decisions, with heightened regret among those with limited trust and understanding of their oncologist. Baseline regrets were also associated with anxiety and depression.	community settings. There was less participation of people from ethnic minority background, therefore their views are still limited. The association between clinical, communication factors and treatment regrets could not be presumed as causative factors. Survey responses could be the reflection of patients and not objective descriptions, as communication interactions were not directly observed. Multiple statistical analyses performed could have resulted in false-positive findings.	
Miano *et al*. (2020) USA	Described the degree of decisional control AYAs preferred in complex medical decisions.	AYAs with non-oncological and oncological conditions 46 (24 non-oncology and 22	Quantitative (A cross-sectional descriptive correlational design)	Survey Survey scales-Control Preference Scale (CPS), CollaboRATE	High preference for collaborative (39%) or shared roles (34%) for decision-making compared with other roles. No statistical differences between decisional control preference and other variables (age, gender, race or education). Participants with oncology diagnosis compared to non-	Results are limited to similar tertiary pediatric hospitals and not generalisable. The possibility of response bias may have affected reported scores. The presence of many variables existing among oncology and	Moderate

		oncology) participants Age range 18-39 years		Tool, Decisional Self-efficacy Scale and Adolescent Self-Regulatory Inventory (ASRI), Healthcare Climate Questionnaire (HCCQ), and Multidimensional Scale of Perceived Social Support (MSPSS).	oncology participants preferred less decisional control (passive roles). Oncology patients diagnosed recently preferred passive roles compared to those who wanted shared or active roles. Higher SDM scores were reported in recent medical encounters by oncology group than non-oncology group. The greater the time from diagnosis the greater the self-efficacy. High degree of support was reported in the oncology group compared to non-oncology group. There was positive relationship between decision self-efficacy and self-regulatory skills, perceived autonomy, social support, and perceived shared decisions.	the non-oncology group could have hindered the detection of statistically significant differences. Study was under powered to detect statistical differences. Use of multiple scales could affect the interpretation of results.	
Mitchell (2014) UK	Explored perspectives and experiences of disabled young people with degenerative conditions as they	Disabled AYAs with degenerative conditions 10 participants (n= not stated)	Longitudinal Qualitative study	Semi-structured interviews	Participants felt involved in medical treatment decision-making choices and adopted different decisional roles. Participants preferred information heuristics and collaborating with other people whilst engaging in complex processes of weighing up different	Small sample size with limited ethnic diversity. The impact of culture on young people with degenerative conditions during decision-making, their decisional preferences and behaviours, were not explored. Exploring	Strong

	faced significant medical interventions and engaged in the decision-making process.	Age range 13-22 years			decisional factors which they viewed as important. Decision-making about the medical interventions was perceived as giving away their independence, autonomy, and quality of life and influenced their decisions. Consideration of parental wishes during decision-making about the intervention led to either an acceptance or rejection of the intervention to reduce the burden on their parents.	decision-making experiences of different types of medical situations could affect the interpretations of the findings.	
Pyke-Grimm *et al*. (2020) USA	Explored and described AYAs' experience with cancer treatment decision making.	AYAs with cancer. 16 participants (n= not stated) Age range 15-20 years	Qualitative Focused Ethnography	Semi-structured interviews and informal participant observations.	Receipt of diagnosis had a negative impact and led to a range of emotions e.g., anger, sadness, fear, shock, and inability to retain information. Participants sought more information (from family and the internet but rarely from peers) to gain knowledge about illness, treatment options, and what to expect. Participants had preferences for an active, collaborative, or passive decisional role.	Small sample size from one setting and limited representation of ethnic minority groups. The presence of parents could have affected the openness about experiences during the interviews. Potential bias about communication and trust issues as participants may have chosen to focus more on the positives than negatives.	Moderate
Shay *et al*. (2018) USA	Explored medical decision-making preferences and factors that may	AYA Cancer survivors (Leukaemia, Lymphoma,	Mixed methods study	Survey with two open-ended questions	Varied decisional preferences. 90% of survivors wanted to be involved in treatment decision-making. 20% (6) preferred autonomous decision-making,	Findings cannot be generalised as it was a pilot study and not powered. Low response rate (8.6%) due to low participation	Weak

	make the medical decision-making process difficult for young adult cancer survivors. It also examined survivorship needs and concerns.	sarcoma, and others including Germ cell) Participants n=30 Age range 18-39 years	(Cross-sectional design)	Survey scale- Developed an online REDCap survey.	while 43% (13) preferred to share decision with their doctor and their family. 17% (5) wanted to make decisions with their doctors alone while 10% (3) wanted to make decisions together with family. However, 10% (3) did not want to be involved in decision-making but preferred their family to make decisions on their behalf. 39% of older young adults (23-39 years) compared with 6% of younger adults (18-22 years) had a preference to make autonomous decisions. Younger adults (53%) preferred to make decisions together with their doctor and their family compared with older young adults (31%). Areas that YAs perceived made medical decision-making difficult or made them anxious included uncertainty about which option to choose, fear of receiving bad news, fear of discomfort and family involvement. Information, trust in the medical team, internal and external	which may be why the authors referred to the study as a pilot study. Lack of clarity of qualitative approach used. Although a mixed methods approach was used there is a lack of clarity because authors just mention a two staged design approach was used.	

					support were considered as areas that could make medical decision-making easier for YA cancer survivors.		
Van Biesen *et al*. (2014) Europe (involving 36 countries including the UK)	Explored European patients' perceptions about information, satisfaction about information and education on the different modalities and their involvement in the modality selection process.	People with CKD (53% HD and 38% had functioning transplant graft) 3867 participants (n=245) Age range Not stated	Quantitative (Type of design not stated)	Survey Survey scale - Designed and validated their own survey scale.	Useful information on CKD and therapy options were received by most of the participants (78%), but (38%) could not recall they had been given any information. 75% of participants felt involved in the decision on therapy choice while others had no free choice due to medical comorbidities (29%) or having inappropriate housing (22.8%) among those who wanted home therapy. Although 51.2% were confident to choose a treatment modality, 48% felt they could not select a choice or know their choice.	The sample size was undetermined, and the study was not statistically powered to detect a difference. Selection bias among the multiple countries taking part and representativeness of the population could not be explored. The survey response rate was not reported due to the differences across participating countries. Recall bias could have occurred and may have affected the results.	Moderate
Walker *et al*. (2016) New Zealand	Described patients and care values, beliefs, and experiences when considering home dialysis treatment modalities.	People with CKD Stage 4 and 5 and end-stage renal disease on home dialysis therapy. 43 participants (n=3)	Qualitative study (Type of design not stated)	Interviews	Less information was received on therapy options and some participants reported a lack of decisional power. Others gained confidence in making choices through the support and trust from clinicians and receiving reassurance from peers. Factors influencing choice include the desire to sustain relationships, minimise social	The dominance of home dialysis therapy in the country of study may have led to a bias of representation of other therapy options. Researcher bias due to clinical role and being known to participants may have affected	Moderate

		Age range 22-79 years			isolation, reduced lifestyle disruptions, sustain employment, avoid relocation, and maximise survival.	the correct presentation of their experiences.	
Weaver *et al*. (2015) USA	Investigated the medical decision-making preferences of adolescent oncology patients	Adolescents with cancer 40 participants (n=not stated) Age range 12-18 years	Qualitative (Grounded theory approach)	Interviews	Adolescents preferred decisional roles ranging from active to passive involvement. 12.5% (5) felt their decisional preferences varied too much based on the situations. 42.5% (17) preferred to remain fully active, 22.5% (9) preferred active middle role and 22.5% (9) preferred passive bystander role. 77% of adolescents preferred to share the decision-making role than to be the ultimate decision-maker. They valued parental and HCPs’ supportive roles during decision-making.	The study did not examine decisional preferences on choice confidence, decisional conflict, and psychosocial outcomes.	Moderate
Zee *et al*. (2018) USA	Assessed participants' perceptions of the dialysis modality decision-making process and compared the impact of their	People receiving Peritoneal Dialysis (PD = 614) and In-Center Haemodialysis (ICHD =1346). Multi-centred study	Quantitative (Type of design not stated)	Survey Survey scale- Decisional needs assessment scale, decisional regret scale,	Varied informational experiences were reported. More PD participants (93%) compared with ICHD (66%) felt choice was offered. PD participants felt they were provided with enough information, understood the differences between the options and were satisfied with choice compared with those receiving ICHD. ICHD participants felt less informed, less	Sampling bias may have existed. Less YAs participated compared to older adults, therefore not all experiences could be attributed to YAs. Part of a multi-centre study and unable to explore the perceptions of patients about how the involvement of other	Strong

	chosen modality on their lives.	1978 participants (n=51) Age range Not stated		and the COMRADE scale.	confident and less satisfied compared with PD participants. PD participants highlighted the involvement of significant others (HCPs, spouses, and partners) in the dialysis modality decisions compared with ICHD participants. Participants reported moderate to high impact of dialysis on their lives. However, 60% lacked knowledge about the disadvantages of the dialysis modality while more than 50% lacked access to peers at the time of modality decision making.	people in their PD training influenced their choice. The direction of the impact of dialysis may be speculated as the survey questions focused on the extent to which participants felt affected but did not explore if the perceived effects were positive or negative. Possible existing confounding differences between PD and ICHD participants may have affected the outcomes as it was not explored.	

The participants in the selected studies were in three main categories of long-term conditions (Table 2.4) with a total of 6,614 participants, of which 6,590 were patients and 24 were either caregivers or family members. Of the 6,590 patients, 750 were adolescents and young adults and 18 children (aged between 7-10 years).

Table 2. 4 Categories of disease

Category of disease	Authors	Number of studies
Cancer	Coyne and Gallagher, 2011; Hart *et al*., 2020; Mack *et al*., 2019; Miano *et al*., 2020; Pyke-Grimm *et al*., 2020; Shay *et al*., 2018; Weaver *et al*., 2015.	7
Degenerative diseases	Mitchell, 2014	1
Kidney disease	Calestani *et al*., 2014; Chen *et al*., 2018; Kim and Choi, 2016; Devitt *et al*., 2017; Van Biesen *et al*., 2014; Walker *et al*., 2016; Zee *et al*., 2018.	7

Appraising and evaluating the quality of studies in an integrative review method is complex due to the inclusion of diverse primary studies that have used different methodologies (Whittemore and Knafl, 2005). There is no gold standard for calculating quality scores to evaluate and interpret the quality of articles for the integrative review method (Whittemore and Knafl, 2005). Whittemore and Knafl (2005) suggest that quality scores could be used based on either the sampling frame used, or the existing appraisal tools used to assess the quality of specific research methodologies.

The articles were assessed for their quality (Table 2.3) and comprehensiveness of reporting using the Critical Appraisal Skills Programme (CASP, 2018) for qualitative studies, Centre for Evidence Based Management (CEBM) critical appraisal (2014) checklist for cross-sectional (survey) studies, and the Mixed

Methods Appraisal Tool (MMAT) (Hong *et al*., 2018). The CASP, CEBM and MMAT tools were used to assess the robustness of reporting, credibility or trustworthiness, dependability, transferability, reliability, validity, and generalisability, and the quality of the primary articles included in the review.

The overall quality assessment of primary articles was of strong to moderate quality, with the majority (nine) of moderate quality and one of weak quality but no study was excluded (Table 2.3). The age of participants (Table 2.3) ranged from 12 to 39 years old in most of the studies but one study in addition to YAs included children (7-18 years old) (Coyne and Gallagher, 2011). Six studies with people living with kidney disease had more older adults compared to YAs aged between 18 to 90 years old. The overall mean age was not calculated because not all studies reported the mean age of participants.

Table 2.5 shows a summary of the survey scales used by quantitative studies. Most of the data collecting instruments used in studies were validated and reliable. Authors who developed their survey scales validated them.

Table 2. 5 Summary of the survey scales used in quantitative studies

Author	Data collection method	Instrument scale	Type of assessment performed
Chen *et al*. (2018)	Survey	Dialysis knowledge scale, decision self-efficacy scale, social support scale, and decisional conflict scale.	Knowledge of dialysis treatment options, self-confidence to make treatment decisions, available support during decision-making and decisional conflict.
Mack *et al*. (2019)	Survey	Decision preference scale, Hospital Anxiety and Depression Scale (HDAS), Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale, and	Assessed decisional preferences and roles, psychological factors, peace of mind, and communication of quality.

		the Trust in physicians scale questionnaires	
Miano *et al*. (2020)	Survey	Control preference scale (CPS), CollaboRATE Tool, Decisional Self-Efficacy Scale and Adolescent Self-Regulatory Inventory (ASRI), Healthcare Climate Questionnaire (HCCQ), Multidimensional Scale of Perceived Social Support (MSPSS)	Identified decision role preferences, assessed SDM experience, self-efficacy for decision-making, and self-regulatory skills. Perceived autonomy and perceived social support were also assessed.
Shay *et al*. (2018)	Survey and Interview	Developed an online REDCap survey and modified preference control scale	Assessed medical decision-making preferences and survivorship of cancer and needs.
Van Biesen *et al*. (2014)	Survey	Designed own survey scale	Assessed experiences of information delivery, treatment decision-making, and satisfaction with treatment and care.
Zee *et al*. (2018)	Survey	Decisional needs assessment scale, decisional regret scale, and the COMRADE scale	Assessed decisional needs, and experiences with dialysis modality.

The process and the steps used to analyse the data from the primary articles are next presented.

2.4. Stage 4: Data analysis

The data analysis provided a thorough and unbiased interpretation of the primary resources and a synthesis of the evidence (Whittemore and Knafl, 2005). The analysis involved four stages: data reduction, data display, data comparison, conclusion drawing, and verification of themes (Whittemore and Knafl, 2005). Data from the primary studies were extracted, coded, categorised, and summarised into an integrated conclusion about the research problem (Cooper, 2017). Data were initially extracted from the results of one primary study using a line-by-line approach and coded into different themes to create a coding framework. The remaining fourteen articles were then coded into the framework to create a matrix for each of the classifications and any new codes identified added to the list, which was not previously included.

2.4.1. Data reduction, display, comparison, conclusion drawing and verification of themes

The data extracted were aligned with common methodologies and coded into the framework and the contrasting patterns of importance were noted in the display. The coded data from the individual primary sources were grouped to allow visualisation, clustering of codes, and noting of the patterns or themes and the possible relationships across the data to set the scene for comparing the data (Table 2.6) and the interpretation of the data.

Table 2. 6 Summary of thematic coding framework

Summary of the thematic coding framework															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Themes	**Calestani *et al*. (2014)**	**Chen *et al*. (2018)**	**Coyne and Gallagher (2011)**	**Devitt *et al*. (2017)**	**Hart *et al.* (2020)**	**Kim and Choi (2016)**	**Mack *et al*. (2019)**	**Mitchell (2014)**	**Miano *et al*. (2020)**	**Pyke-Grimm *et al*. (2020)**	**Shay *et al*. (2018)**	**Van Biesen *et al*. (2014)**	**Walker *et al*. (2016)**	**Weaver *et* al. (2015)**	**Zee *et al.* (2018)**
Decision-making	√	×	√	×	√	√	√	√	√	√	√	√	√	√	√
AYAs preference for decision-making	×	×	√	×	√	×	√	√	√	√	√	×	×	√	√
Active decision -making	×	×	√	√	×	×	√	×	√	√	√	×	√	√	√

Passive decision-making	√	×	√	×	√	√	√	×	√	×	√	×	×	√	√
Shared decision - making	×	×	√	×	×	×	√	×	√	√	√	×	√	√	√
Choice selection	√	√	√	√	√	×	√	×	×	×	×	√	√	×	√
Lack of choice	√	×	√	√	×	×	√	×	×	√	×	√	√	×	√
Decisional conflict	×	√	×	√	×	×	×	×	×	×	×	×	×	×	×
Decision regrets	√	√	×	×	×	√	√	√	×	×	×	×	√	×	√
Defer medical decisions	×	×	×	×	√	×	√	×	×	×	×	×	√	×	×
Involvement and engagement in	×	√	√	√	×	√	×	×	√	√	√	×	√	√	√

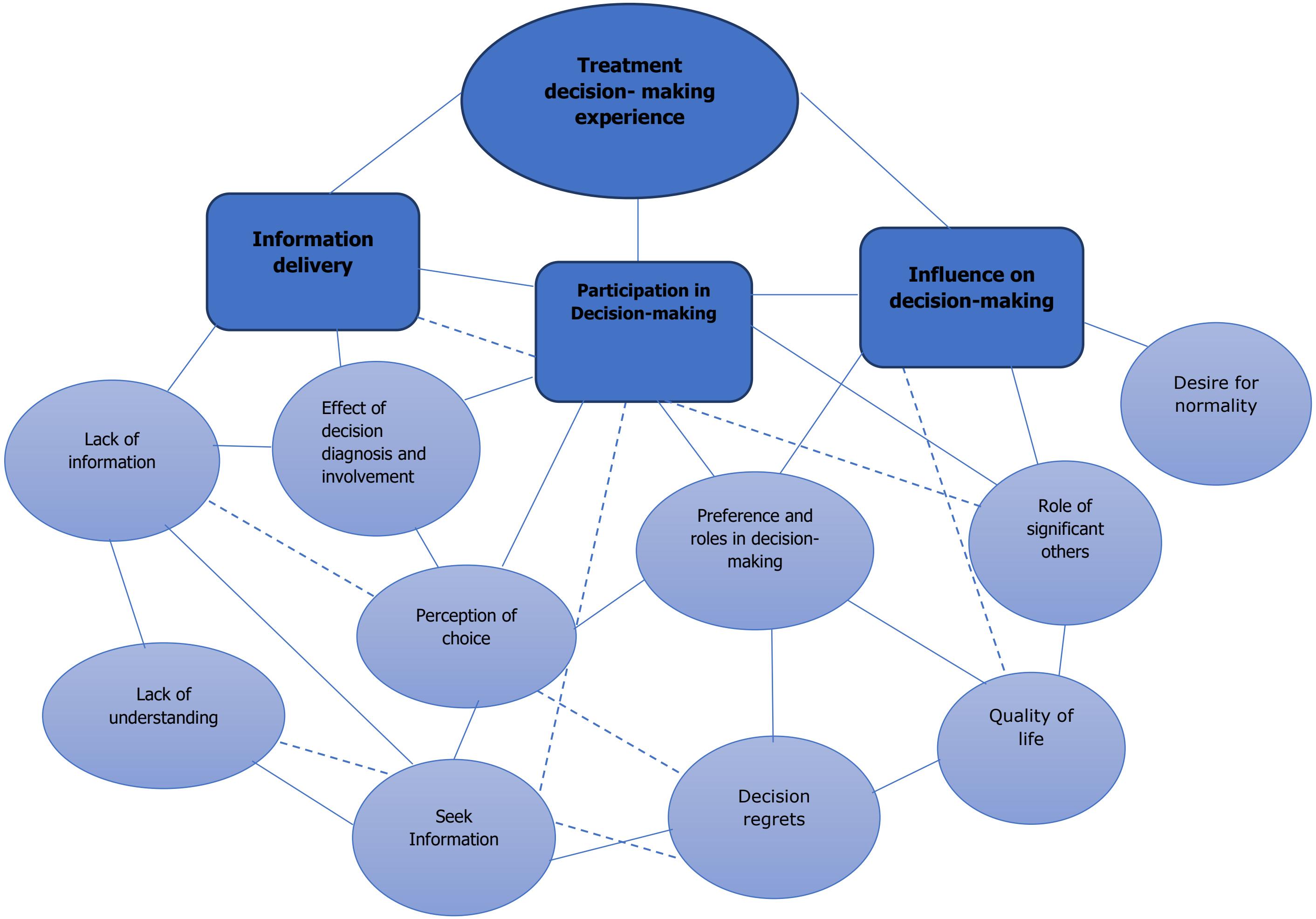
decision-making															
Role of parents/ family in decision-making	×	√	×	√	√	×	√	√	×	√	√	×	√	√	√
Role of healthcare professionals in treatment decision-making	×	×	√	√	×	×	√	×	√	√	√	×	√	√	×
Relationships building	×	×	√	√	×	√	×	×	×	√	×	×	√	√	×
Emotions displayed at receiving treatment	×	×	√	×	√	√	√	×	×	×	×	×	×	×	×
Shock at decision-making	×	×	√	×	√	×	×	×	×	×	×	×	×	×	×

Influence on decision-making	×	×	√	√	×	×	√	√	√	√	√	√	×	√	×
Information delivery	√	√	√	√	√	×	√	×	×	√	×	×	√	√	√
Absorbing information	√	×	√	√	√	×	√	√	×	√	×	√	√	√	×
Engaging with information	√	×	√	√	√	×	√	√	×	√	×	√	√	√	√
Lack of information and understanding of options	√	√	√	√	√	×	√	√	×	√	×	√	√	√	√
Parental role in information delivery	×	×	√	×	×	×	×	√	×	×	×	×	√	√	√
Communication	×	×	√	√	×	√	×	×	×	√	×	×	×	×	√

Cultural issues	×	×	×	√	×	×	×	×	×	×	×	×	√	×	×
Peer involvement	√	×	×	√	×	×	×	×	×	×	×	×	√	×	×

The identified patterns and themes were used to develop a conceptual mapping of themes (Figure 2.2) of the identified patterns among the themes and how they relate to each other. The conceptual mapping provided clarity of the patterns from the emerging themes or concepts which was used to develop higher clusters of themes that relates to each other to ensure sound interpretation of the data analysed (Whittemore and Knafl, 2005).

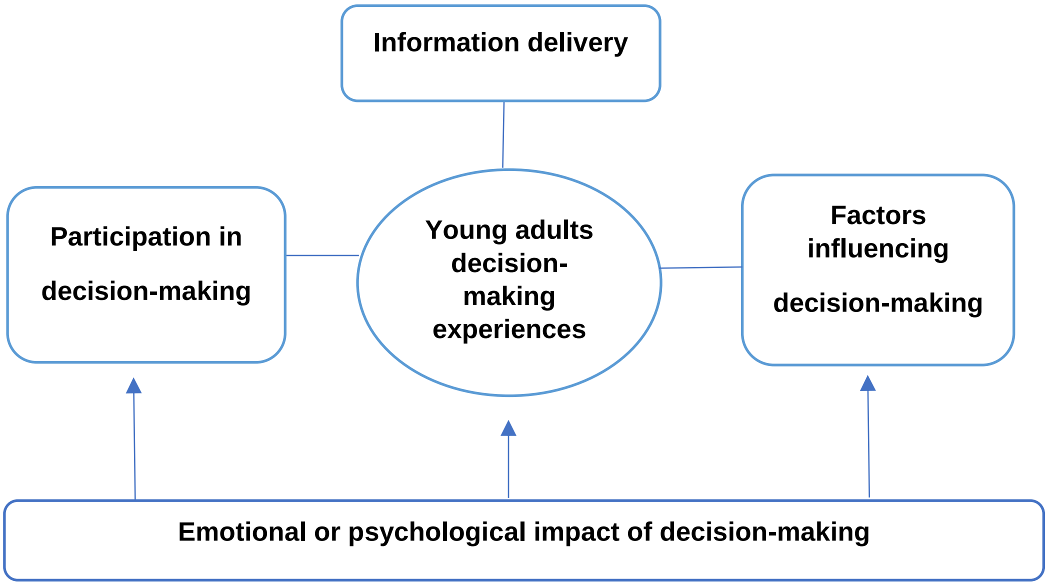
Figure 2. 2 Mapping of thematic relationships



The final phase of the data analysis process moved the interpretation from the description of patterns and relationships to a higher level of abstraction and subsuming of the particulars to the general. For example, the commonalities and differences among coded themes were highlighted and the patterns and processes were also isolated from each small set group to allow generalisation of the dataset. Miles and Huberman (1994) encourage a continual revision of conclusion or conceptual models that have been developed to reach a final tuning.

The final review themes (Figure 2.3) were grounded in the data to confirm the accuracy, credibility, and confirmability of the themes and allowed the themes to be verified from the primary data sources. The themes also demonstrate how they answer the review question.

Figure 2. 3 Final review themes



Having explained the literature search, how the data were evaluated and analysed, an integrated synthesis of the final themes is presented below.

2.5. Synthesis of themes

There were variations in how studies described their sample population. Some studies referred to their samples as adolescents and YAs while others referred to them as adults. Generally, some studies referred to people aged between 10 to 19 years as adolescents and people aged 16 to 25 years as YAs (six studies). Other studies included the age range between 18-39 years as YAs (two studies) and greater than age 18 years as adults (seven studies) (see Table 2.3).

Studies focused on communication, decisional roles and treatment decision-making informed by the concepts of SDM (Miano *et al*., 2020; Weaver *et al*., 2015) or implied the use of informed decision or SDM concepts (Hart *et al*., 2020; Calestani *et al*., 2014; Zee *et al*., 2018) or prospect theory of decision-making (Mitchell, 2014). Others include concepts of communication in health decision-making (Coyne and Gallagher, 2011), self-efficacy theory (Chen *et al*., 2018; Pyke-Grimm *et al*., 2020) or decisional regrets (Chen *et al*., 2018; Mack *et al*., 2019) while the remaining studies lacked clarity of the concepts or theories informing their studies (Devitt *et al*., 2017; Kim and Choi, 2016; Shay *et al*., 2018; Van Biesen *et al*., 2014).

The four main themes identified in Figure 2.3 and subthemes are:

- Information delivery (subthemes: provision of health information, health literacy, and health information-seeking behaviour)

- Participation in decision-making (subthemes: perception about choice, preferences and roles in decision-making and roles of significant others)
- Factors influencing decision-making
- Emotional or psychological impact of decision-making

2.5.1. Information delivery

Studies reported that information delivery formed an important part of receiving diagnosis and treatment/therapy decision-making. Three subthemes, provision of health information, health literacy, and health information-seeking behaviour, are presented below.

2.5.1.1. Provision of health information

The provision of treatment information was integral to the understanding of diagnosis and treatment options, management of the long-term condition, engagement and participation in decisions and care (Calestani *et al*., 2014; Hart *et al*., 2020; Mitchell, 2014; Van Biesen *et al*., 2014; Walker *et al*., 2016; Weaver *et al*., 2015; Zee *et al*., 2018). Information on available options was communicated by HCPs mostly doctors and nurses but YAs supplemented the information received.

Provision of information varied across studies but mainly through verbal explanations via individual discussions with HCPs or given information leaflets, or a combination of both (Calestani *et al*., 2014; Mitchell, 2014; Pyke-Grimm *et al*., 2020; Walker *et al*., 2016; Weaver *et al*., 2015). The amount of treatment information delivered varied across studies as it was perceived as, lacking, limited, enough or too much. For example, Zee *et al*. (2018) reported participants on peritoneal dialysis (PD) received enough information on available options which was explained in a way that was easier to understand than those on haemodialysis (HD), which contrasted with other studies (Hart *et al*., 2020; Van Biesen *et al*., 2014) where less information was received.

The situational context, the timing of information provision, how information was communicated, and the discussions of treatment options enhanced or hindered YAs' ability to absorb and understand the information received. YAs struggled to engage with treatment-relevant information due to how it was presented, the timing of delivery and the situational contexts at that time (Calestani *et al*., 2014; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020). Participants avoided or disengaged with information perceived to be difficult or complex to understand (Coyne and Gallagher, 2011; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020). Hart *et al*.'s (2020) study highlighted that YAs purposefully disengaged from information that could bring emotional distress although it was relevant to treatment decision-making.

On the contrary, some participants in Calestani *et al*.'s (2014) study felt unable to concentrate or absorbed much information at the time when information was received. Therefore, giving less details about options and at a slower pace was preferred. Some participants were more concerned about the long-term impact of treatment on their life than the short-term side effect (Hart *et al*., 2020). Some YAs preferred limited exposure to information that had the potential to cause emotional effects (Coyne and Gallagher, 2011; Mitchell, 2014). Another factor that affected the assimilation of information was that sometimes the information was communicated very quickly, or the content was found too complex to understand (Calestani *et al*., 2014; Devitt *et al*., 2017; Mitchell, 2014; Walker *et al*., 2016).

The provision of too much information over a short period resulted in a lack of depth, confusion, and fear (Devitt *et al*., 2017; Mitchell, 2014; Pyke-Grimm *et al*., 2020). Therefore, less information was preferred (Mitchell, 2014, Calestani *et al*., 2014). On the contrary, others preferred more information on treatment options than the lack of it (Pyke-Grimm *et al*., 2020). For example, information received on treatment options was considered either less than expected (PD (27%) and in-centre haemodialysis [ICHD] (25%) respectively) or more than what participants (PD (9%) and ICHD (11%)) had wanted (Zee *et al*., 2018).

Indigenous people in Australia who experienced communication problems with the way information was delivered felt HCPs used their power to restrict patients' access to relevant information (Devitt *et al*., 2017). In other situations, YAs wanted information to be directed to them instead of their parents and with less medical jargon (Coyne and Gallagher, 2011; Hart *et al*., 2020). YAs reported being left behind or were either asked to leave the room or their parents were taken to separate rooms while discussions were held without them causing them to worry (Coyne and Gallagher, 2011; Hart *et al*., 2020; Kim and Choi, 2016).

Treatment information framed in the context of benefits and risks or the good and the bad was perceived as enabling YAs to reach decisional clarity and guided their tolerance level of options discussed (Weaver *et al*., 2015). In contrast, Mitchell (2014) reported choice was framed as supporting or inhibiting independence and/or autonomy. Communication approaches such as listening, advocating, and provision of encouragement with hope by HCPs were considered supportive behaviours (Weaver *et al*., 2015).

Only one study reported that participants' understanding was checked during the decision-making process which provided YAs with the opportunity to share their decision-making preferences with HCPs (Weaver *et al*., 2015). YAs with positive information experiences were satisfied with the communication and provision of information as it was explained to them in a way that was easy for them to understand (Chen *et al*., 2018; Hart *et al*., 2020; Mitchell, 2014; Van Biesen *et al*., 2014; Walker *et al*., 2016; Zee *et al*., 2018).

2.5.1.2. Health literacy

Health literacy varied as YAs reported a lack of information, and difficulty engaging with and understanding the treatment options, across studies (Calestani *et al*., 2014; Chen *et al*., 2018; Devitt *et al.,* 2017; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020; Walker *et al*., 2016; Zee *et al*., 2018). Chen *et al*. (2018) highlighted that 37% (26) of participants lacked dialysis therapy options education at the start of dialysis. Similarly, people receiving ICHD felt less informed than those receiving PD (Devitt *et al*., 2017; Zee *et al*., 2018). In contrast to Chen *et al*. (2018) and Zee *et al*.'s (2018) studies, Devitt *et al*. (2018) highlighted that almost half of the participants from an indigenous background were uninformed, did not understand certain aspects of the therapy information received or could not understand their kidney care team.

Calestani *et al*. (2014) highlighted that most participants lacked an understanding of the transplant listing process. Participants in Devitt *et al*.'s (2018) study lacked understanding of the transplant listing eligibility criteria, the transplant procedure, and its associated risks. Others struggled to understand information on home dialysis therapies received because the written information was complex, not easily understood, and were overwhelmed by the medical jargon (Walker *et al*., 2016). For example, some participants with a degree qualification could not understand the information received on therapy options (Walker *et al*., 2016).

The lack of understanding of the treatment information was associated with disempowerment, lack of decisional power, or ability to share or make informed decisions (Walker *et al*., 2016; Devitt *et al*., 2017). Participants for whom English was a second language were worse off as they felt lost and embarrassed by their inability to read and understand the information provided (Walker *et al*., 2016; Devitt *et al*., 2017). YAs wanted clear, easy, simple, and visual information on treatment options that enhanced understanding, especially on the practicalities and the risks of treatment (Coyne and Gallagher, 2011; Calestani *et al*., 2014; Devitt *et al*., 2017; Walker *et al*., 2016). Others preferred information to be provided in a step-by-step approach per the progression of the long-term condition to avoid information overload (Calestani *et al*., 2014; Walker *et al*., 2016).

2.5.1.3. Health information-seeking behaviour

Health information-seeking was an initiative taken by some YAs to develop their knowledge about treatment choices and enabled them to make an informed choice or share in decision-making. YAs looked for alternative information sources for example, family opinions or searched the internet when they lacked information to supplement what has been received (Calestani *et al*., 2014; Coyne and Gallagher, 2011; Hart *et al*., 2020; Mitchell, 2014; Pyke-Grimm *et al*., 2020). Although some YAs sought information from their peers (Calestani *et al*., 2014; Mitchell, 2014; Zee *et al*., 2018), others rarely involved their peers or friends (Coyne and Gallagher, 2011; Devitt *et al*., 2017; Pyke-Grimm *et al*., 2020).

Compared with those with cancer, YAs with kidney failure and degenerative diseases found talking to their peers beneficial in enabling their understanding of the treatment options (Calestani *et al*., 2014; Mitchell, 2014; Zee *et al*., 2018). Others preferred information either on a need-to-know basis only (Calestani *et al*., 2014; Pyke-Grimm *et al*., 2020) or just enough information but not overwhelming to enable them to improve their knowledge and make the right decisions (Coyne and Gallagher, 2011; Calestani *et al*., 2014; Mitchell, 2014). The desire for more information declined once participants were satisfied with the information acquired (Pyke-Grimm *et al*., 2020). Satisfaction with treatment choice was linked with better information received and an understanding of the options available (Chen *et al*., 2018; Mitchell, 2014; Van Biesen *et al*., 2014; Walker *et al*., 2016*;* Weaver *et al*., 2015; Zee *et al*., 2018).

2.5.2. Participation in decision-making

Studies used treatment decision-making and shared decision-making interchangeably to refer to treatment decisions or the type of decision-making that participants experienced. The treatment decision-making was impacted by (i) lack of information and (ii) understanding. The complexity and diverse decisional preferences and roles were reflected in YAs' decision-making experiences. Although most YAs felt involved in treatment decision-making, their preference for decision types, decisional roles, and level of involvement varied (Calestani *et al*., 2014; Coyne and Gallagher, 2011; Chen *et al*., 2018; Devitt *et al*., 2017; Hart *et al*., 2020; Mack *et al*., 2019; Mitchell, 2014; Pyke-Grimm *et al*., 2020; Walker *et al*., 2016; Weaver *et al*., 2015; Zee *et al*., 2018). Three subthemes are discussed next: perceptions of choice, preferences and roles in decision-making, and roles of significant others in decision-making.

2.5.2.1. Perceptions of choice

Treatment decision-making was framed into categories such as easy or difficult/ hard, intermediate, minor or major, and small or big concerning how it impacted their life, future, and outcome (Coyne and Gallagher, 2011; Pyke-Grimm *et al*., 2020; Van Biesen *et al*., 2014; Walker *et al*., 2016; Weaver *et al*., 2015; Zee *et al*., 2018). In contrast with other studies, Mitchell's (2014) study reported that participants categorised the decisions as reversible or irreversible which influenced the level and role of participation. Decision-making was also perceived as supportive if it had either fewer or greater consequences for life-threatening decisions (Calestani *et al*., 2014; Coyne and Gallagher, 2011; Hart *et al*., 2020; Mitchell, 2014; Weaver *et al*., 2015). The perceived freedom to choose a preferred option was associated with the satisfaction of therapy (Van Biesen *et al*., 2014).

Although most YAs felt they had a choice there was limited room for negotiation about the choice offered to them (Hart *et al*., 2020; Calestani *et al*., 2014) while others felt they lacked choice (Kim and Choi, 2016; Van Biesen *et al*., 2014; Walker *et al*., 2016; Zee *et al*., 2018). Those on PD compared with those on in-centre haemodialysis, felt they were offered a choice (Van Biesen *et al*., 2014; Walker *et al*., 2016). Many YAs wanted to be involved in decision-making, but others preferred selective involvement (Pyke-Grimm *et al*., 2020). Some participants felt rushed when they received the kidney transplant call as they had to leave everything they were doing to attend the hospital for the transplant surgery, leaving them puzzled and fearful (Kim and Choi, 2016).

Lack of involvement in treatment decision-making was highlighted across studies (Calestani *et al*., 2014; Coyne and Gallagher, 2011; Mack *et al*., 2019; Pyke-Grimm *et al*., 2020; Van Biesen *et al*., 2014). Limited interaction time between HCPs and participants resulted in a lack of depth during choice discussions (Calestani *et al*., 2014). The lack of information on the transplant listing process hindered participation in discussions and the ability to make informed or shared decisions (Calestani *et al*., 2014; Devitt *et al*., 2017). Although clinicians suggested to patients with kidney failure to speak to their family about the need for a kidney donor, some participants questioned the moral basis for risking the life of a family member or a close friend (Calestani *et al*., 2014; Devitt *et al*., 2017).

Some YAs expressed feeling guilty to ask or did not want to be blamed should the donor come to harm or suffer problems later in life (Calestani *et al*., 2014; Devitt *et al*., 2017). Others did not want to be spoilers of another person's life or be indebted to their kidney donors for the rest of their life or to be controlled by them (Devitt *et al*., 2017). Therefore, some preferred to be assessed for suitability and to be listed on the national organ transplant register instead of risking a family member or friend's life (Calestani *et al*., 2014; Devitt *et al*., 2017).

Decisional regrets were associated with a preference for decisional involvement (Chen *et al*., 2018; Mack *et al*., 2019; Zee *et al*., 2018). Mack *et al*. (2019) reported over a quarter (47 out of 195) of participants experienced decisional regrets following initial treatment choice at baseline with similar rates at four and twelve months. More in-centre haemodialysis patients (11%) compared with PD patients (6%) experienced decisional regrets (Zee *et al*., 2018). However decisional regrets were less likely to occur among YAs who trusted their oncologist completely and felt their oncologist understood what was important to them (Mack *et al*., 2019). The degree of decisional conflict was associated with the level of education, work status, and dialysis education but not with gender or marital status (Chen *et al*., 2018; Mack *et al*., 2019). The decisional conflict was significantly associated with age in Chen *et al*.'s (2018) study, which contrasted with Mack *et al*.'s (2019) study. While dialysis knowledge, decisional self-efficacy, family, and HCPs' support were also predictors of decisional conflict, the higher the decisional conflict scores, the greater the uncertainty about implementing the dialysis choice made (Chen *et al*., 2018).

2.5.2.2. Preferences and roles in decision-making

YAs weighed up outcomes and distinguished between the different types of decisions they faced and categorised them as small or minor, intermediate, big/major, or life-threatening (Coyne and Gallagher, 2011; Hart *et al*., 2020; Mitchell, 2014; Pyke-Grimm *et al*., 2020). How YAs perceived and categorised the type of decision to be made influenced their preferred decisional roles and level of involvement and this varied across studies (Coyne and Gallagher, 2011; Mack *et al*., 2019; Hart *et al*., 2020; Kim and Choi, 2016; Pyke-Grimm *et al*., 2020; Weaver *et al*., 2015; Zee *et al*., 2018).

Decision-making preferences and roles were dynamic and not static as the preference for involvement in treatment decisions and roles evolved over time because those who initially preferred not to be involved, became involved (Mitchell, 2014; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020). The roles assumed by YAs during decision-making changed over time (Coyne and Gallagher, 2011; Hart *et al*., 2020; Mitchell, 2014; Pyke-Grimm *et al*., 2020). YAs' decisional roles assumed during treatment decision-making ranged from passive, active, shared, or collaborative (Coyne and Gallagher, 2011; Mack *et al*., 2019; Miano *et al*., 2020; Shay *et al*., 2018; Pyke-Grimm *et al*., 2020; Weaver *et al*., 2015). Although YAs had a preference for either active, passive, or shared/collaborative roles in decision-making, not all YAs participated in their preferred roles during decision-making (Hart *et al*., 2020; Kim and Choi, 2016; Pyke-Grimm *et al*., 2020; Mack *et al*., 2019). On the contrary, oncology participants who had less time since diagnosis were more likely to have passive control on decisional preference than those non-oncological participants with more time since diagnosis to consider decisions (Miano *et al*., 2020).

An active decisional role was preferred when YAs wanted to be the primary decision-maker (Coyne and Gallagher, 2011; Hart *et al*., 2020; Kim and Choi, 2016; Pyke-Grimm, 2018; Mack *et al*., 2019; Mitchell, 2014; Miano *et al*., 2020; Shay *et al*., 2018). YAs accepted the decisional roles and responsibility, considered expert advice and recommendations, asked questions, did their research, weighed up the options, and shared in decisions. However, others felt robbed of their role as they were not considered a decision-maker (Kim and Choi, 2016). Decisional preference per ethnic group, sex, age, education, cancer type, or whether new or relapsed disease did not affect decisional roles (Mack *et al*., 2019; Miano *et al*., 2020; Shay *et al*., 2018; Weaver *et al*., 2015).

Passive decisional roles were expressed when there was a preference for parents and/or HCPs to make therapy decisions on YAs' behalf (Coyne and Gallagher, 2011; Hart *et al*., 2020; Miano *et al*., 2020; Shay *et al*., 2018; Pyke-Grimm *et al*., 2020). YAs who assumed passive roles felt doctors knew best as they were the experts, had the skills, and trusted them to do what was better for them (Coyne and Gallagher, 2011; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020; Weaver *et al*., 2015) while others felt their parents knew best compared to them (Coyne and Gallagher, 2011; Mitchell, 2014; Hart *et al*., 2020). Others felt forced to assume passive roles as they were not invited to participate in decision-making nor were their views elicited (Coyne and Gallagher 2011; Kim and Choi, 2016; Pyke-Grimm *et al*., 2020). Passive decisional roles and preferences were also assumed where YAs either avoided taking part in decision-making or felt too overwhelmed, or too ill to participate.

Preference for sharing or collaborating with others in decision-making occurred when decisions were made together by YAs and HCPs or in collaboration with their parents after reaching a consensus agreement on the preferred option (Calestani *et al*., 2014; Chen *et al*., 2018; Coyne and Gallagher, 2011; Hart *et al*., 2020; Mack *et al*., 2019; Mitchell, 2014; Miano *et al*., 2020; Pyke-Grimm *et al*., 2020; Shay *et al*., 2018; Weaver *et al*., 2015; Zee *et al*., 2018). Zee *et al*. (2018) highlighted that PD (95%) and in-centre haemodialysis (84%) participants, and their nephrologists agreed on the type of dialysis choice.

More than half (58%) of AYAs preferred to make decisions in collaboration with their oncologist (Mack *et al*., 2019), while 10 out of 16 made major decisions using collaborative decision-making (Pyke-Grimm *et al*., 2020). Autonomous and sharing in decision-making with other people were considered vital in enabling YAs to reach the right decision (Mitchell, 2014). In Weaver *et al*.'s (2015) study, YAs preferred to maintain a continuous active role (42.5%), while 22.5% preferred intermediate or middle active roles, however, 12.5% of participants could not generalise their decisional preference as it varied so much depending on the decision situation.

Decisional roles were not associated with decisional regrets when adjusted for age (Mack *et al*., 2019). Time played an important factor in the decision quality as YAs who did not need to make early treatment decisions felt they had time to consider the decision to be made (Coyne and Gallagher, 2011; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020). Although age was not associated with the type of decisional role, the extent to which an active role was performed varied according to age (Coyne and Gallagher, 2011; Hart *et al*., 2020; Mack *et al*., 2019; Mitchell, 2014; Pyke-Grimm *et al*., 2020).

2.5.2.3. Role of significant others

Studies reported parents/family, peers and HCPs played supportive roles in decision-making (Coyne and Gallagher, 2011; Chen *et al*., 2018; Devitt *et al*., 2017; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020; Shay *et al*., 2018; Walker *et al*., 2016; Weaver *et al*., 2015; Zee *et al*., 2018). The supportive role of HCPs were valued by AYAs (Coyne and Gallagher, 2011; Pyke-Grimm *et al*., 2020; Weaver *et al*., 2015). However, more than half of the AYAs did not want parental involvement in decision-making (Mack *et al*., 2019). People on in-centre HD reported more spouses/partners participated in treatment decisions compared with other family members and friends (Zee *et al*., 2018). Family and HCPs exhibited action-oriented activities and attitudes that were perceived to promote YAs' involvement in treatment decisions, freedom to decide, and the ability to make the correct choice (Coyne and Gallagher, 2011; Hart *et al*., 2020; Weaver *et al*., 2015).

Action-oriented activities of parents included asking difficult questions on mortality and risks, seeking information, explaining treatment-relevant information, and encouraging participation in treatment discussions (Coyne and Gallagher, 2011; Hart *et al*., 2020; Weaver *et al*., 2015). Parents looked out for YAs' best interest, advocated, and protected them during diagnosis and treatment decisions (Coyne and Gallagher, 2011; Hart *et al*., 2020; Mitchell, 2014). For example, parents sat in consultations, checked their feelings and thoughts, shared family opinions about choices, and sometimes advocated for oncologists to talk directly with YAs instead of them (Hart *et al*., 2020; Weaver *et al*., 2015). Decisional confidence of YAs was linked to parents providing insightful knowledge about the therapy options (Weaver *et al*., 2015).

Despite these supportive roles, some YAs felt their parents sometimes prevented them from being given a certain type of information that they considered fearful or could cause emotional harm or distress (Coyne and Gallagher, 2011; Kim and Choi, 2016; Mitchell, 2014; Weaver *et al*., 2015). Other YAs felt parents sometimes prevented their involvement in choice discussions as they could not ask questions or express their views about how they felt or their preferences as they conflicted with that of their parents (Coyne and Gallagher, 2011; Pyke-Grimm *et al*., 2020). Parents provided safety nets during treatment decision-making, especially in decisions considered major (Coyne and Gallagher, 2011; Hart *et al*., 2020).

Family also played a significant role in kidney transplant donation decisions (Calestani *et al*., 2014; Chen *et al*., 2018; Walker *et al*., 2016). Some participants in receipt of kidney transplants felt anger towards their mother post-kidney transplantation irrespective of whether they donated a kidney to them or not, as they were perceived as too overprotective of them (Kim and Choi, 2016). Others described their mothers as being anxious about them, constantly reminding them to be careful, and in extreme cases, some were advised about their future such as not to marry because of their health, resulting in some living secret lives away from their mother’s watchful eye (Kim and Choi, 2016).

Building trust in HCPs was valued when considering therapy choices, especially where the outcome was uncertain or carried serious risks and consequences (Calestani *et al*., 2014; Coyne and Gallagher, 2011; Pyke-Grimm *et al*., 2020; Walker *et al*., 2016). HCPs perceived to be trustworthy were able to help participants with a limited support network to overcome the vulnerability associated with performing home dialysis therapy (Walker *et al*., 2016). Others felt positive support from HCPs enhanced their ability to cope with the therapy and appreciated their involvement (Coyne and Gallagher, 2011; Hart *et al*., 2020; Weaver *et al*., 2015).

2.5.3. Factors influencing decision-making

Factors that influenced treatment decision-making included trust, maturity, cognitive ability, emotional maturity, independence, quality of life, desire for normality, family, and the ability to work. Perceived independence, the nature of the procedure (invasiveness) and its impact (whether it is reversible or not) on life influenced decision-making about medical devices needed to sustain life (Mitchell, 2014). Family and friends influenced living donor kidney transplant decisions (Calestani *et al*., 2014; Devitt *et al*., 2017) and dialysis choices (Walker *et al*., 2016). Normalcy in life and avoidance of constraints of dialysis drove the desire to be listed for a kidney transplant (Calestani *et al*., 2014). Trusting the source of information about treatment options provided some degree of certainty or assurance for YAs although some felt doctors sometimes gave selective or biased information (Coyne and Gallagher, 2011; Devitt *et al*., 2017; Mitchell, 2014; Pyke-Grimm *et al*., 2020). Established relationships with HCPs enhanced engagement with information exchange as YAs felt able to ask questions about the information received and made informed or shared decisions (Coyne, and Gallagher, 2011; Mitchell, 2014; Pyke-Grimm *et al*., 2020; Weaver *et al*., 2015).

Participants from an indigenous background (Aboriginals and Torres of Straits Islanders) with cultural and religious beliefs against accepting another person's organ into their body (because it was considered a taboo and associated with a bad omen), had to negotiate these cultural and social beliefs to get buy-in from community leaders or family (Devitt *et al*., 2017). Participants who became knowledgeable about the benefits of kidney transplants and desired to receive a kidney transplant took positive steps to educate their families about kidney transplantation to gain their approval (Devitt *et al*., 2017). HCPs also influenced dialysis modality decisions based on their advice and framing of discussions (Walker *et al*., 2016; Zee *et al*., 2018). Others refused offers from families because of their concern they could also develop kidney disease, while some felt making a direct request to the family was associated with a lot of emotions and preferred not to do so (Devitt *et al*., 2017).

The desire to maintain cultural and social engagements also influenced choice decisions. Participants from an indigenous background in New Zealand, the Māori, and Pacific Islanders preferred home dialysis because they wanted to participate in community activities like church, community meetings, and family functions (Walker *et al*., 2016). The desire for free time and the ability to drink and eat what they preferred influenced the type of dialysis choice (Zee *et al*., 2018). The perceived limitations of dialysis therapy on life influenced kidney transplantation decisions as it provided a sense of freedom and normalcy

(Calestani *et al*., 2014; Kim and Choi, 2016). Half of the people with degenerative disease refused to undergo certain procedures due to their inability to socialise with friends (Mitchell, 2014). Being treated like an adult influenced participation in treatment decision-making as YAs felt they were taken more seriously by clinicians when they turned age 18 years (Pyke-Grimm *et al*., 2020). The invasiveness of the therapy, the perceived impact of life-sustaining interventions, the quality of life, maintaining health, and the acceptable level of perceived risks were traded against each other based on what mattered most to YAs (Mitchell, 2014).

2.5.4. Emotional or psychological impact of decision-making

Studies did not directly explore the emotional or psychological impact of decision-making on YAs, with the exception of Mack *et al*. (2019) who used the hospital anxiety and depression scale to explore regrets, at diagnosis, four months, and 12 months. The authors reported an association of baseline regret at the time of diagnosis with increased anxiety (54% among those with regret and 29% among those without) and depressions (39% versus 20%) at four months but not at 12 months (Mack *et al*., 2019). However, they did not make a direct relationship between anxiety and depression in decision-making (Mack *et al*., 2019).

A number of other studies did highlight emotional or psychological effects on YAs, though not associated with decision-making specifically. Studies reported that YAs expressed shock, fear, anxiety, extreme distress, and mixed feelings following receipt of a cancer diagnosis due to the thought of possible death (Coyne and Gallagher, 2011; Hart *et al*., 2020; Pyke-Grimm *et al*., 2020). On the contrary, others felt relieved to have a diagnosis with the hope to be receiving the right treatment (Hart *et al*., 2020). Other studies reported some participants hid their diagnosis from friends due to fear of being rejected by peers (Coyne and Gallagher, 2011; Kim and Choi, 2016). Reports of some YAs developing a pragmatic mindset devoid of emotions to focus on getting better were also highlighted (Hart *et al*., 2020). Some studies reported that the acceptance of the new way of living by YAs enhanced the adoption of active lifestyles and positive perspectives of their situations (Kim and Choi, 2016; Hart *et al*., 2020; Mitchell, 2014).

Perceived kidney transplant donor outcomes, cultural, and religious beliefs hindered participants' ability to discuss kidney transplant options with their families (Devitt *et al*., 2017). Fear of losing a transplanted kidney and transplant not lasting a lifetime caused some participants to live in uncertainty (Kim and Choi, 2016). Overall, although studies highlighted the impact of receipt of diagnosis and outcomes of treatment, there was less consideration of the direct link between emotions described by the participants and the decision-making. These studies focused on the decision itself but not specifically on YAs' perceptions about how the decision-making affected their emotions.

2.6. Discussion

This integrative review highlighted the complexity of decision-making (Byrnes *et al*., 1999) experienced by YAs with long-term conditions. YAs continue to be worse off compared with adolescents and older adults in treatment decision-making (Neinstein *et al*., 2013; Park *et al*., 2014). Despite the national and international evidence-based guidelines (NICE, 2016; Watson *et al*., 2011) on transitioning and transferring from paediatric to adult services, that recommend that YAs be provided with quality information and be supported in decision-making, this review highlights that not all YAs in the selected studies experienced this. Although YAs in this review were diagnosed with different conditions such as cancer, kidney disease, and degenerative disease, they all had to make life-saving decisions despite the different situational and social contexts. Each of the four review themes will now be discussed in more detail.

2.6.1. Information delivery

Information delivery and communication were a pivotal part of receiving a diagnosis and the decision-making process across all studies. Information sharing is fundamental to HCP-patient communication during the decision-making process (Elwyn *et al*., 2012; NICE, 2021b). Quality time spent during the information exchange and the deliberation of treatment options enable the development of a patient's understanding of the available options and the ability to share in decision-making (Elwyn *et al*., 2012).

This integrative review highlights YAs' need for information to enable them to improve their health literacy to gain awareness of their choice and available treatment options before they could effectively participate in discussions. The lack of or inadequate health information delivery highlighted in this integrative review contributes to the challenges experienced by YAs during treatment decision-making and falls short of national and international guideline recommendations on health literacy (Levin *et al*., 2013; NICE, 2021b). These guidelines (Levin *et al*., 2013; NICE, 2021b) recommend the provision of personalised information on the risks, benefits, and consequences of each option and for HCPs to make clear any associated uncertainties. This is because the receipt of quality information can improve YAs' health literacy and promotes participation in decision-making and the lack of it affects health outcomes (Levine *et al*., 2018). This supports the findings of the integrative literature review as YAs with limited information or those who lacked understanding disengaged with information considered disturbing.

The lack of information on available options has been reported by eighteen studies in a systematic review of older people with CKD and their carers (Morton *et al*., 2010a). Information exchange in most of the studies reviewed was a one-way approach with HCPs leading the information delivery and falls short of the SDM principles (Charles *et al*., 1999). Charles *et al*. (1999) assert that information sharing should be a two-way approach, where the HCPs share all the relevant information necessary for the decision task and present it in a way that people can easily understand during the HCP-patient encounter. Joseph-Williams *et al*. (2014) and Elwyn *et al*. (2012) reiterate the need for HCPs to share all relevant decision information and to elicit patients' values and preferences during discussions of treatment options.

Building quality relationships and trust during the clinical encounter was a precursor to enabling better information sharing and exchange (Elwyn *et al*., 2012) which was highlighted in this review. The perceived unequal level of participation during options information sharing due to the situational context and timing of the provision of information placed YAs in a disadvantaged position. Reports of feeling unwell, being under the influence of medication, or feeling overwhelmed with events, which hindered the absorption or making sense of the information by YAs in this review, resulted in dissatisfaction. Morton *et al*. (2010a) highlighted in their review (ten studies) that participants felt too unwell to absorb the information provided.

Coulter and Collins (2011) assert that people become dissatisfied when they are less informed about treatment options, decision-making, and care. The inadequate information delivery and the communication of it across studies resulted in a lack of satisfaction, whilst those with a positive experience of information delivery were more satisfied. However, the studies in the review did not elicit YAs' views about the impact of this ineffective way of providing information. The timing of the information delivery and how it was framed were considered as either enablers or barriers to engaging with or absorbing information. Having an adequate set time to share decision-relevant information is important during the SDM process as it avoids rush which then leaves people feeling unsupported in the encounter (Elwyn *et al*., 2012; Joseph-Williams *et al*., 2014). The inadequate information delivery and the desire for quality information influenced YAs' information-seeking attitudes.

2.6.2. Participation in decision-making

The integrative review highlights the complexity of therapy decision-making as it is not linear nor does it just involve two people; instead, it is cyclical, multi-relational, contextual dependent on the situational and social context, and can be emotion-laden (Elwyn *et al*., 2014). Janis and Mann (1977) asserted that decision-making involves conflict, and it is this conflict that brings a degree of stress to the decision-making process, which in turn determines a person's ability to make a good or bad decision.

Janis and Mann (1976) argued that this stress relates to the worry an individual has about the objective (personal and material) and subjective losses with the potential to lower self-esteem. YAs are still developing their autonomy and independence (Davies *et al*., 2015) as reflected in their decisional preferences and roles in decision-making in this integrative review. The lack of understanding of choice or perceived inability to make treatment decisions during the HCP-patient encounter affected YAs' confidence to participate in decision-making.

Halpern-Felsher and Cauffman (2001) assert that an individual can make a competent informed health decision if the person understands the purpose of the treatment, the procedures involved, possible risks, alternative options, and likely outcomes. Although YAs preferred to be involved in treatment decision-making, not all YAs felt able to make competent decisions as they did not meet all the elements for competent decision-making highlighted by Halpern-Felsher and Cauffman (2001). Reports of limited understanding of the practicalities involved in treatment choice, the inability to weigh the risks and benefits, and not being considered as an equal partner in decision-making have been highlighted in adult decision-making (Joseph-Williams *et al*., 2017).

Some YAs gained experience and understanding by learning from HCPs and took a more active role in treatment decision-making as time passed and supports a social constructivist approach to learning. Social constructivism has the notion that people learn because of their interaction with their environment and knowledge is constructed as the learner makes sense of their experience of their world (Crotty, 2003). Vygotsky (1978) argued that knowledge is co-constructed within a social environment during the process of social interaction through dialogue and interaction with others. The same could be said of YAs as they co-constructed their knowledge of choice options during their dialogue and interaction with people such as HCPs, family, and peers within the decisional context as they made sense of the decision task.

Morton *et al*. (2010a) echoed the findings of the integrative review as ten studies in their systematic review reported that older patients felt rushed to make decisions. Although most YAs in this review felt they had a choice, others felt they lacked a choice which is supported by the findings by Dahlerus *et al*. (2016) where one-third of the participants lacked choice as they felt the dialysis modality choice was not theirs. The decision-making context faced by YAs was interpreted as choosing between lifesaving treatment versus death or giving up autonomy or independence in aspects of their life. Morton *et al*. (2010a) support the finding as older patients and carers felt they confronted mortality as they had to choose between life and death, which is reiterated by other studies (Harwood and Clark, 2013; Tong *et al*., 2009).

Decisional preferences of YAs were dynamic as they changed based on their ongoing situations with a majority wanting active and collaborative roles. These findings contrasted with Knopf's (2008) findings, where most adolescents and parents preferred passive roles as opposed to active roles. The situational context such as how sick YAs felt, their understanding of the situation, and personal circumstances affected the actual level and roles assumed (active, intermediate, or passive) compared with their preferred roles during decision-making. Pyke-Grimm *et al*. (2020) highlighted that AYAs did not always participate at their preferred level which contrasts with Mack *et al*.'s (2019) study, where participants were involved at their preferred level, which echoed earlier findings by Unguru (2011).

Supportive roles of parents and HCPs highlighted in this integrative review have been reported by other studies (Day *et al*., 2016; Gessler *et al*., 2019; Morton *et al*., 2010b). Grinyer's (2003) assertion that AYAs look to others for support during decision-making, especially when they have serious illnesses, supports the findings of this review as AYAs valued parental, HCPs, and occasionally friends' or peers' opinions. Findings from Gessler *et al*. (2019) also reiterate how AYAs draw on the skills, knowledge, and practices of family members with decisional experiences, to develop an informed knowledge of options, which enhanced their decision ability. Although parents advocated YAs' access to information and involvement, there were conflicts of interest of decisional preferences, roles, and desire for information between parents and YAs highlighted in this review and reported by other studies (Day *et al*., 2016; Gessler *et al*., 2019).

Despite these supportive roles, not all YAs received support from HCPs during decision-making, which relates to the findings of lack of preparation and support that AYAs experience during the journey of the illness (Kreuzer *et al*., 2015; Krischock *et al*., 2016; Prüfe *et al*., 2017). The desire for greater autonomy in decision-making was reported across studies and relates to Smith *et al*.'s (2011) suggestion that decisional autonomy increases among young people as they transition into adulthood. Although decisional self-efficacy among YAs was examined, most studies reported that YAs lacked the ability to determine the right choice when the decision task was perceived as a big or major decision and carried profound consequences. However, YAs who understood the decision task, options, and its consequences played a more active role in decision-making, which is echoed by other studies (Day *et al*., 2016; Gessler *et al*., 2019; Knopf, 2008).

2.6.3. Factors influencing decision-making

The type of decisional task, situational context, age, family, the impact of treatment on life (short and longer-term), maintaining independence, ability to work, trust in HCPs, relationship with HCPs, and quality of life influenced YAs' participation in decision-making. These factors highlighted in the integrative review support other studies (Dahlerus *et al*., 2016; Harwood and Clark 2013; Morton *et al*., 2010b; Murray *et al*., 2009). Although studies in the review highlighted that YAs trusted their parents and HCPs to look out for their best interests based on their experiences and expertise due to uncertainty of choice, they were unable to determine whether YAs were willing to take higher risks. These findings support Zinn's (2015) notion of trust, where an individual relies on others when there is uncertainty about choice, and were echoed by Harrington and Morgan (2016) who reported that older kidney transplant patients expressed their complete trust and faith in their medical team, but the trust did not mean they were willing to take higher risks.

The lack of information and understanding of the available therapy choice, fear, the perceived consequences of outcomes, and the burden of treatment on the family following an intervention, was a barrier to engaging with the decision-making process or making a certain type of choice by YAs in the review. This finding supports Murray *et al*.'s (2009) study, that factors such as fear, a self-perceived burden to family, lack of knowledge and understanding, poor professional interpersonal skills, and personal characteristics were barriers to participation in decision-making among older patients with ESKD.

Halpern-Felsher *et al*. (2016) assert that AYAs' decision-making is influenced by parental monitoring to prevent risky health-related decisions and risk-taking, and resonates with what Kim and Choi (2016) reported about the watchful eyes of parents which resulted in conflicts and living of secret lives by some AYAs in this integrative review. Halpern-Felsher *et al*. (2016) highlighted that cultural and religious beliefs that encourage autonomy influence decision-making and supports the findings of this integrative review. Cultural beliefs influenced the choice of home dialysis and kidney transplant modality (Devitt *et al*., 2017; Kim and Choi, 2016; Sheu *et al*., 2012; Walker *et al*., 2016).

The building of good relationships and respect for the patient and their interdependence with others in the decision environment enhances the support of an individual's decisional role (Elwyn *et al*., 2012). Age and cognitive maturity determined the type of decisions and preferred level of involvement in treatment decisions and have been highlighted by other studies (Coyne *et al*., 2014; Pyke-Grimm *et al*., 2019; Zwaanswijk *et al*., 2011). Weaver *et al*. (2015) did not find any association between age and treatment decision-making. The findings of the review reflect inconsistencies in treatment decision-making in clinical practice and unmet needs, which falls short of the recommended guidelines on patients' rights and involvement in decision-making (Department of Health, 2016; NICE, 2021b).

2.6.4. Emotional and psychological impact of decision-making

Although the decision context can bring inherent emotional and psychological distresses (Elwyn *et al*., 2012), none of the studies in this review specifically explored how decision-making affected YAs emotionally or psychologically. Studies in this review reported YAs' expression of sadness at the receipt of life-changing diagnoses and facing the life-saving therapy but did not explore the impact of the decision-making process on their well-being nor the psychosocial support provided to YAs. Assessing the psychosocial needs and providing the appropriate support during participation in decision-making is recommended (KDIGO, 2013; NICE, 2021b). Service providers and HCPs must seek to incorporate psychological support as part of the decision-making process rather than being separate. This will ensure that all YAs receive psychological support starting from diagnosis and through the journey of their disease without having to request psychological support, therefore breaking barriers associated with seeking psychological support and maintaining their well-being.

2.7. Knowledge gap

Although decisional preferences of YAs with cancer and degenerative diseases are known, those of YAs with kidney disease are still limited and research is needed to explore them (Ofori-Ansah *et al*., 2022). Findings from this integrative review highlight there is little literature with a specific focus on YAs' decision-making experiences and they have unmet informational and decisional needs (Ofori-Ansah *et al*., 2022). Most studies did not examine the experience of how participants made their decisions. There is a lack of understanding of the content of the information provided and how YAs' knowledge was assessed during the treatment discussions to check their understanding of the information received and it is important to investigate it.

Decisional regrets were highlighted by some studies but the reasons for these regrets were neither examined nor were the support systems available to them explored (Chen *et al*., 2018; Mack *et al*., 2019). Causal relationships between decisional conflict and the factors measured could not be determined (Mack *et al*., 2019), therefore, research is needed to investigate decisional conflicts and their impact on patient adjustments and treatment outcomes. Decision-making experiences of YAs from ethnic minorities across studies remain limited (Calestani *et al*., 2014; Mack *et al*., 2019; Mitchell, 2014)**.** None of the studies explored the psychological needs of YAs or the support received during the decision-making process, as inadequate support was experienced by most YAs

(Hart *et al*., 2020; Kim and Choi, 2016; Miano *et al*., 2020; Pyke-Grimm *et al*., 2020; Shay *et al*., 2018). This knowledge gap reflects YAs' unmet needs during the decision-making encounter which needs to be explored (Ofori-Ansah *et al*., 2022).

2.8. Strengths and limitations of the integrative review

The strength of this review lies in the ability to combine studies with different methodological (quantitative, qualitative, and mixed methods) approaches that have explored the decision-making experiences of YAs with long-term conditions. The findings can be transferred to similar situations but are not generalisable. Most of the studies reviewed combined the findings of AYAs or older adults therefore, not all information could be extracted for only YAs. The majority of studies on kidney patients were over the age of 30 years thus not all the findings could be associated with YAs' experiences of dialysis decision-making.

Other limitations include recalling and sampling bias as the majority of the studies were retrospective and relied on the participants' ability to recall past experiences in the qualitative studies. Selection biases may have resulted in a misrepresentation of the disease group as most studies included mostly adolescents rather than YAs. The use of multiple statistical analyses in quantitative studies could introduce a false-positive conclusion in some of the studies.

2.9. Knowledge this review adds to existing body of evidence

This integrative literature review has filled an important gap in knowledge about YAs' treatment decision-making experiences. YAs' decision-making is complex, with various aspects as it is intertwined with personal, emotional, and cultural sensitivities which require further exploration (Ofori-Ansah *et al*., 2022). Limited literature with a specific focus on how YAs made treatment decisions, especially among those with kidney disease, was identified (Ofori-Ansah *et al*., 2022). The reason for this was that YAs data in most studies were combined with children, adolescents, or older adults with long-term conditions. YAs' psychosocial needs and the support received during engagement in the treatment decision encounter are limited and require further exploration through research (Ofori-Ansah *et al*., 2022). Therefore, the decisional needs of YAs remain limited and less understood but have specific needs.

The published review by Ofori-Ansah *et al*. (2022) identified the following; there is little literature with a specific focus on YAs' decision-making experiences, especially those with kidney disease. YAs treatment decision-making appears to be a complex process with many different facets intertwined with personal, emotional, and cultural sensitivities. The decision complexity varied across situations and among different YAs and careful navigation is needed to support their needs during decision-making. Planned preparation of patients is important in ensuring that patients are ready to receive the information and able to participate in decision-making.

Eliciting feedback from YAs and/or their family to ascertain their understanding of information can improve HCPs' awareness of their knowledge and understanding and address any knowledge gap (Ofori-Ansah *et al*., 2022). Empathetic communication and timely preparation of YAs and parents/family before receiving treatment information and offering psychosocial support (NICE, 2021b) could promote engagement with the decision-making process and absorption of information. A good patient-HCP relationship promotes trust during treatment decision-making encounters (Brennan *et al*., 2013). Without an understanding of patients' circumstances, HCPs are likely to get it wrong during the decision-making process of what matters most to YAs (Joseph-Williams *et al*., 2017). Assessing YAs' psychosocial needs during the decision-making process could identify the most vulnerable YAs who need support.

2.10. Conclusions from the integrative review

The integrative review highlights that YAs' unmet decisional needs, such as ineffective communication, understanding of the decision-making process, the practicalities involved in performing therapy, and psychosocial support, must be addressed to enhance the engagement with the decision-making process. YAs experienced suboptimal information delivery, poor communication of long-term conditions, and available treatment options, which hinders the development of knowledge, understanding, and efficient involvement in treatment decisions. YAs have decisional preferences and roles but not all were able to participate in their preferred role and level and should be supported to do so during decision-making.

Inappropriate timing of information delivery and communication about diagnosis and options contributed negatively to YAs' ability to absorb and make sense of the information provided. Quality information is needed to enable YAs to make quality treatment decisions. Framing of decisional information to convey the risks and benefits of treatments could facilitate YAs' ability to weigh their options and contribute to decision-making. HCPs need to develop risk communication and decision-making skills that promote relationship building and reduce associated fear. HCPs must be aware of YAs' informational needs and take the necessary step to elicit their preferences and what matters to them as this improves satisfaction.

2.11. Linking the literature review to the theoretical framework for the study

In this integrative review, the majority of the studies explored treatment decision-making experiences, decisional roles or evaluated treatment decision-making and alluded to the use of principles of shared decision-making. Studies reported the desire for shared and collaborative decision-making. SDM was endorsed internationally following the declaration of the Salzburg statement of shared decision making in 2010 which called on HCPs and researchers to recognise the "ethical imperative to share decisions with all patients whatever their level of health literacy" (Salzburg Global Seminar, 2011, p.1). HCPs are expected to encourage a two-way flow of information sharing in clinical encounters with patients by providing quality information, based on risk communication guidance that enables patients to ask questions, explain their situations, and express their preferences (Salzburg Global Seminar, 2011).

Following the declaration statement, research, and policies to promote its routine use were instituted internationally to promote SDM in routine healthcare decisions (Härt *et al*., 2017). In the UK, SDM has become one of the pinnacles in person-centred care (Sanderson *et al*., 2019). It has been incorporated in various policies and guidelines (Härt *et al*., 2017; NICE, 2021b). Implementation research programmes of SDM have also proposed models of what SDM consists of and should look like (Joseph-Williams *et al*., 2019). Although there are other SDM models such as the Informed Medical Decision Foundation model (2012) and the SHARE model (The Agency for Healthcare Research and Quality, 2018), these models follow the same SDM principles. The difference lies in the number of steps in the SDM process. However, the three-talk model of SDM is the most referenced in the literature (Joseph-Williams *et al*., 2019).

2.12. Young adults and preferences for shared decision-making

Goal setting has a bearing on decision-making and occurs in the early stages of decision-making (Umeh, 2009). YA decision-makers may have different goals (intrinsic or external) and motivational drives for decision-making. Intrinsic goals (such as satisfying inherent psychological needs and personal satisfaction in doing an activity) and extensive goals (such as receiving rewards for achieving their activity) impact how decisions are made (Umeh, 2009). A person can be motivated to pursue intrinsic goals as opposed to extrinsic ones, which are perceived as less interesting (Umeh, 2009). Therefore, a YA decision-maker may be less driven to act on extrinsic goals, which are externally derived, as they are perceived as less attractive (Ryan and Deci, 2000).

YAs may exhibit both competence and incompetence during decision-making, due to variations in how they weigh risks and benefits and rationalise their thinking during decision-making (Mann *et al*., 1998). Umeh, (2009) asserts, that

YAs’ decision-making is influenced by choices that are readily accessible rather than abstract information. Developmental psychologists posit that rationalistic thinking and abstraction continue to develop until early adulthood (Mann *et al*., 1989; Halpern-Felsher and Cauffman, 2001). Social psychologists (Mann, 1977; Feldman, 2001) see decision-making as a social event because the decision-maker can be influenced by social factors (peers or groups) during the decision-making process.

Halpern-Felsher and Cauffman (2001) examined the similarities and differences between adolescents’ and YAs’ decision-making competence and found that YAs were more likely to seek advice and consider the risks and benefits associated with the decision. Others have suggested that it takes longer for YAs to mature in their risk-taking behaviours and decision-making ability (Ormond *et al*.,1991; Petersen and Leffert, 1995), therefore raising questions about their decision-making competence before adulthood. People employ different decision-making strategies or preferences when faced with decision-making. Preferences used in health decision-making could impact positively or negatively on health outcomes and YAs are no different (Halpern-Felsher *et al*., 2016). SDM is age-dependent and takes longer and some YAs prefer a defensive avoidance decision-making strategy, where they either distort or ignore the facts and shift responsibility to others, especially when faced with decisions that cause stress or anxiety (Cramer, 2012). However, evidence suggests that YAs committed to a course of action, will actively weigh the pros and cons during engagement in decision-making (Mauriello *et al*., 2007; Drahovzal, 2007) and are likely to act if the pros outweigh the cons (Medvene, 2007).

Research using a decision-making questionnaire based on the conflict-theory model (Mann, 1977) and Myers Briggs Type Indicator (Myers *et al*., 1998) suggest that some young people make irrational decisions without carefully appraising their options and preferences for decision-making. YAs use different decision preferences and styles, especially for emotion-laden decisions which may have a high impact on their health outcomes (Janis and Mann, 1977; Mann, 1989; Umeh, 1998). The use of the three-talk model of SDM allowed the study to identify motivating factors of YAs during the dialysis and kidney transplant decision-making and how they experienced it.

2.13. Summary of chapter

This chapter explained the process of an integrated synthesis and critically discussed the review findings, within the themes of information delivery, participation in decision-making, factors influencing decision-making, and emotional and psychological effect of decision-making. This chapter identified the knowledge gap in the literature that informed the research study and the research question, aims and objectives (see chapter 1 section 1.13) and explained how it links to the theoretical framework of the study. Chapter three will discuss the methodology and methods of this study.

Chapter 3 Methodology and methods

3.1. Introduction

This chapter will discuss the philosophical (ontological and epistemological) positioning and rationale, paradigmatical (theoretical) perspective, methodology, and methods including ethical considerations during the conduct of the study. The chapter will also discuss the analytical approach used for the data analysis and reflexivity and will conclude with a summary. These elements influence how the study was framed and conducted from the designing stage to the end of the study. The rationale and choice of the hermeneutic phenomenological approach influenced by Heidegger's (1962) principles will also be discussed. The sampling, recruitment, ethical considerations, data collection, data analysis approach, and the trustworthiness of the process are discussed.

Crotty (2017) encourages researchers to consider the methodology and methods they propose to use for their study and the justification of their choice by exploring the following questions:

What epistemology informs the chosen theoretical perspective and the conceptual framework? (Addressed in section 3.2)

What theoretical perspective underpins the chosen methodology? (Addressed in section 3.3-3.4)

*What methodology underlines the choice and use of methods? (*Addressed in section 3.5)

*What method is proposed for the data collection? (*Addressed in section 3.8)

Therefore, the epistemological stance taken, the paradigmatic choice that informed the methodology and the methods used in this study are explored in this chapter. Having a philosophical assumption and methodological approach ensures that the appropriate method is used to gather data for the study as this strengthens the trustworthiness of the study (Holloway and Todres, 2005).

The epistemology informing the theoretical perspective underlying the methodology, and the proposed data collection methods form the conceptual framework underpinning this research study (Ravitch and Riggan, 2017). This conceptual framework is a way of linking my interest, goals, philosophical positioning, situated context, setting, theories, and the proposed methods used to explore the research question (Ravitch and Riggan, 2017). It was important to explore the epistemological and ontological (philosophical) perspectives that informed the chosen theoretical perspective and the conceptual framework for this study. I will now explore the philosophical perspectives and my positioning in the next section.

3.2. Philosophical perspectives

This section explains my positioning on the nature of reality (ontological perspective), what I know about reality and how it can be verified (epistemology) (Crotty, 2017). This study explored a social phenomenon: the lived experience of dialysis and kidney transplant decision-making and the meaning of the experience to the participants, which is influenced by different beliefs and values. Having a philosophical perspective is important because my understanding of reality and how knowledge about this reality would be generated influences the chosen methodology and my account of the knowledge generated (data analysis) about the experiences (Crotty, 2017).

Researchers take different philosophical stances such as ontology, and epistemology (see sections 3.2.1-3.2.2) which influences the choice of the methodology used to explore the phenomenon of interest (Creswell and Poth, 2018; Kivunja and Kuyini, 2017; Savin-Baden and Major, 2013) and frames the research topic (Naughton and Rolfe, 2010). My ontological position is next discussed.

3.2.1. Ontological positioning

Ontology is concerned with the study of being (reality) or the understanding of the social world (Crotty, 2017). Scotland (2012) explains ontology as the assumptions made to believe that something is real or makes sense. Ontology deals with the question about the form and nature of reality or what is there that can be known (Creswell, 2013). Guba and Lincoln (2005) assert that two main ontological positions, realism and relativism, are assumed by researchers. Realism ontology assumes that reality exists outside the mind or consciousness and is aligned with objectivist epistemology and the positivism paradigm. Relativism ontology has the notion that reality is subjective and differs from person to person (Guba and Lincoln, 2005; Neuman, 2003), and is aligned with a constructivist epistemology and an interpretivism paradigm (Scotland, 2012). I take the relativist's position because I believe that reality is subjective, therefore each participant’s experiences of dialysis and/or kidney transplant decision-making will differ from each other.

3.2.2. Epistemological positioning

Epistemology deals with the nature of knowledge (Matthew and Ross, 2010) or the researcher's understanding of what it means to know (Gray, 2018) and how we know things (Guba and Lincoln, 1994). It addresses the question about what the nature of knowledge is and the relationship between the knower and the would-be knower or what can be known (Langdridge, 2007; Killam, 2013). It was important for me to understand how this reality or truth can be known (Cooksey and McDonald, 2011) and to use the appropriate research method to collect the data, produce that knowledge and justify it.

An interpretive paradigm was chosen for the study as it was considered a better way of generating knowledge about YAs' decision-making experiences and aligns with my constructivist epistemological position. The interpretive paradigm was compatible with the focus of the study, research question, aim and objectives, and the data generated are grounded in the participants' narratives. I am part of the research inquiry and the findings generated are the resultant interaction of the dialogue between the researcher and the participants (Creswell, 2013). The interpretivism paradigm chosen will be discussed in section 3.3.1 of this chapter.

Diverse ways of knowing such as objectivism (reality exists to be discovered), subjectivism (people impose meaning on objects), and constructivism (people construct meaning) are used by researchers (Matthew and Ross, 2010). Objectivism asserts that a single reality exists out there to be discovered, which is independent of our consciousness, aligned to the positivist paradigm (Gray, 2018), and uses quantitative methods to explore this reality (Matthews and Ross, 2010). Subjectivism on the other hand assumes that an object in a person’s world does not contribute to the generation of meaning or knowledge but the meaning is imposed on the objects by their subjects and not formed because of the individual’s interactions with the objects within their world (Crotty, 2017).

Constructivism assumes a relativist ontological reality where reality can be understood in the “form of multiple, intangible mental constructions, which are socially and experientially based, local and specific in nature” (Guba and Lincoln, 1994, p.110). The term constructivism is used interchangeably with social constructivism or constructionism, which can create confusion with its usage (Crotty, 2017). In contrast to other epistemological stances discussed, constructivists assert that truth and meaning are created by people through their interaction with their world but do not exist in some external world (Crotty, 2017).

Constructivism is aligned to an interpretive or social constructivist positioning (Crotty, 2017; Gray, 2018). Constructivists have the belief that there is an active relationship between the object of investigation (participants) and the investigator (researcher) therefore the findings are the results of their creation. Rogers and Pilgrim (2005) highlight that constructivism as a dominant position within sociology holds a fundamental belief that reality is not already established and awaiting discovery, but rather is transitional because of a person’s actions, thus reality is constructed. Guba and Lincoln (1994) suggested that reality is socially constructed and what exists depends upon the understanding of that reality (or multiple realities) and its socially produced knowledge. People always try to make sense of their experiences and question what reality is (Spinelli, 2005) to understand their experiences. As a researcher, I become part of the investigation as I engage in dialogue with the data that are created.

Constructivist epistemology emerged as a better way to generate knowledge to understand young adults' lived experiences of decision-making and align with the interpretivist paradigm. This is because human beings construct the meaning of their experiences from multiple perspectives such as their beliefs and values (Gray, 2018). This perspective enabled me to explore young adults' lived experiences of dialysis and kidney transplant decision-making and contributed to the generation of knowledge. Decision-making is a social construct and subjective, therefore, the chosen paradigm should explore these social interactions. Having explored the philosophical perspectives, I will now discuss the rationale for ontological, epistemological, and theoretical positioning.

3.2.3. Rationale for ontological, epistemological, and theoretical positioning

Crotty (2017) asserts that the chosen paradigm for a study should align with the epistemology and the methodology for conducting the study. In the conduct of the study, I pondered whether social reality exists independently of human interactions and interpretations. A constructivist stance was adopted which underpinned the interpretivist approach. My constructivist epistemological and relativist ontological positioning was compatible with the interpretivist paradigm chosen for the study because of my viewpoint that reality is subjective and individually constructed. Kivunja and Kuyini (2017) assert that assumptions are made that the beliefs of an individual form the basis of their social reality.

I hold the view that each YA's experience of dialysis and kidney transplant decision-making is influenced by their beliefs and forms the basis of their interpretation and understanding of that experience. I believe that the YAs in this study will construct the meaning of their decision-making experiences as they reflect on them. The reality of a YA's experience of dialysis and kidney transplant decision-making does not exist independently of others but is intertwined with their interrelationships with people and the things within their social world. The lived experience of a person is subjective as it has multiple perspectives and no one's experience is the same but differs from one person to the other because it is constructed through their interactions with their world, informed by their beliefs and values.

3.3. Choosing a paradigm

It was important to examine the theoretical perspective that underpins the chosen methodology, as suggested by Crotty (2003). Killam (2013) asserts that research is driven by a set of beliefs or worldviews which is known as the paradigm, the way of thinking about or viewing the world, and forms the basis for what a researcher does when conducting a study. The term paradigm refers to "a set of basic beliefs that provide the principles for understanding the world and the basic principles underpinning research in the social sciences" (Langdridge, 2007, p.3). These paradigms are associated with different ontological, epistemological, axiological, and methodological perspectives (Guba and Lincoln, 1994). The paradigms accept basic assumptions, beliefs, norms, and values (Kivunja and Kuyini, 2017), which are based on trust (Langdridge, 2007).

With this understanding of a paradigm, the study was guided by the chosen interpretive paradigm, assumptions, beliefs, values, and norms. Although different paradigms exist, the two main options are positivism and interpretivism (Gray, 2018). As the focus of the study was to explore the meaning of YAs' lived experiences of dialysis and kidney transplant decision-making, these subjective meanings cannot be achieved using a positivist or quantitative approach driven by objective reality. Neither would the use of statistical analysis be able to draw out the subjective meanings of the experience, therefore positivism or a quantitative approach was not used. Instead, the interpretivism paradigm was chosen for this study and will now be discussed.

3.3.1. Interpretivism paradigm

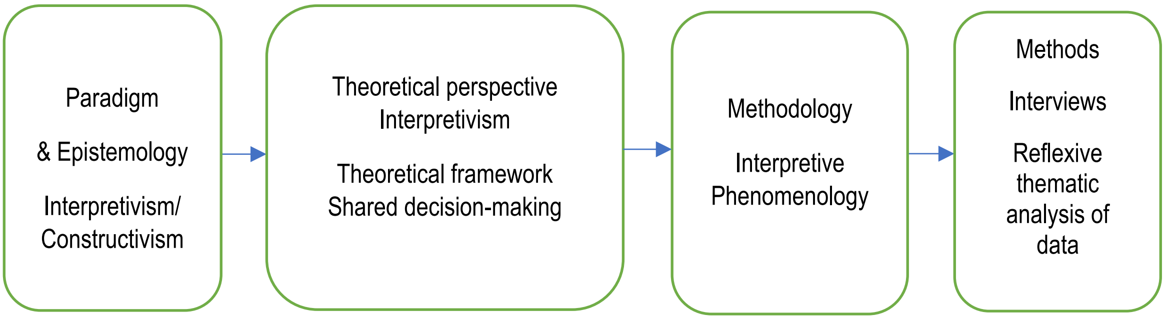
The interpretivism paradigm, which employs inductive reasoning, using naturalistic ways to either generate theory or explore people's experiences, has its roots in anthropology, sociology, and philosophy, and aligns with qualitative research approaches (Creswell, 2013). Its view of reality is subjective and multiple, which is psychologically and socially constructed based on natural occurrences (Creswell, 2013). The interpretivism paradigm is informed by constructivist epistemology and aligns with social constructivism (Creswell, 2013). It uses diverse ways to explore the participants' (young adults) world to understand the meaning of people's social interactions, look for patterns and develop themes through reflexivity (Creswell, 2013). Social constructivists believe that reality is socially constructed because it allows the researcher to explore how a social phenomenon (decision-making) is constructed to understand its meaning (Alvesson and Skoldberg, 2018).

The interpretive paradigm aligns with different methodologies such as ethnography, narrative, grounded theory, phenomenology, and interpretative phenomenological analysis (IPA) (Savin-Baden and Major, 2013). Ethnographic inquiry is concerned with shared and learned patterns of culture-sharing groups (Leach, 2014). It can be used to describe and interpret participants' shared patterns of values, behaviour, and language within a culture-sharing group (Gray, 2009). Ethnographic researchers tend to spend significant time in the natural setting of communities for some time to understand the participants' cultural world (Creswell, 2013). Data are generated through careful observations, field notes, and interviews of evolving contextually lived realities identified in the participants' world (Creswell, 2013).

Narrative inquiry uses the story of people to produce data in a narrative form (Hoshmand, 2005 cited in Butina, 2015). Creswell (2013) asserts that narrative inquiry describes participants' experiences in chronological order. The approach has been used in different disciplines, such as education (Rivas-Flores, 2019), nursing (Elmir *et al*., 2017) and social science (Mathias *et al*., 2021) to gain an understanding of historical experiences, culture, identity, and the narrator's lifestyle (Bleakley, 2005). Grounded theory is concerned with theory generation of social processes, interactions, or actions through multiple stages of data generation and is grounded in the views of participants (Charmaz, 2006; Corbin and Strauss, 2015). It uses the constant comparison of data and theoretical sampling to maximise similarities and differences of information generated from a systematic or constructivist approach (Creswell, 2013). Phenomenology inquiry (interpretive) focuses on the lived experience of a phenomenon and is concerned with meaning-making and how meaning is interpreted from the experience (Langdridge, 2007).

After careful consideration of the different methodologies, a phenomenological (interpretive) approach was chosen for this study, and the rationale for choice is explained in section 3.4. Ethnography, narrative, and grounded theory approaches were not used because the study does not seek to explore YAs' culture of therapy decision-making or develop a theory of their social processes or interactions or present their lived experiences in chronological order. This study seeks to explore and understand the meaning of participants' lived experiences of dialysis and kidney transplant therapy decision-making, therefore, interpretive phenomenology was adopted. Interpretive inquiry uses different methods such as observations, interviews, journals, or artefacts (objects of cultural and historical significance) to generate data and is grounded in participants' narratives. Having explained my philosophical positioning, the paradigm and the theoretical perspective that informed the study, a diagrammatic representation of all these elements and how they relate with the methodology, can be seen in Figure 3.1.

Figure 3. 1 Conceptual framework adopted from Crotty (2003)



Now that I have identified the paradigm, the rationale for the chosen methodology is discussed.

3.4. Rationale for chosen methodology

The study aimed to understand the meaning of YAs’ lived experiences of dialysis and kidney transplant decision-making therefore Heidegger’s interpretive phenomenological approach was chosen. The phenomenological approach was used because it focuses on the lived experience of an individual and is aligned with the interpretivism paradigm. The use of the phenomenological approach allowed the exploration of the phenomenon surrounding decision-making and the understanding of the meaning of that phenomenon from YAs’ perspectives. An interpretivist approach was chosen because it focuses on understanding and meaning-making of a person’s experience and aligns with qualitative research (Crotty, 2017).

The choice of the interpretive paradigm and phenomenological methodology was influenced by the research question, aim, and objectives (see chapter 1, section 1.13). The reality of YAs’ dialysis and kidney transplant decision-making experiences is not there to be discovered. Instead, it will be constructed and interpreted through their social interactions occurring with the subjective elements in YAs’ world of decision-making. The lived experiences of dialysis and kidney transplant decision-making are socially situated and culturally derived therefore the chosen interpretivism paradigm must allow the understanding of the socially, culturally, and historically situated interpretations of the participants’ experiences (Crotty, 2017).

Phenomenology from Heidegger's perspective is to "let the things that shows itself to be seen from itself in the same way it shows itself" (Heidegger, 1962, p. 38). Heidegger based his phenomenology on the concept of Dasein (human being) (Heidegger, 1962). Decision-making of treatment choice is the phenomenon that was explored in this study to understand what it meant for YAs when they faced dialysis and kidney transplantation decisions. YAs can only understand their experience that appears to their consciousness, and it is this experience that is narrated by each participant to give the researcher access to that experience.

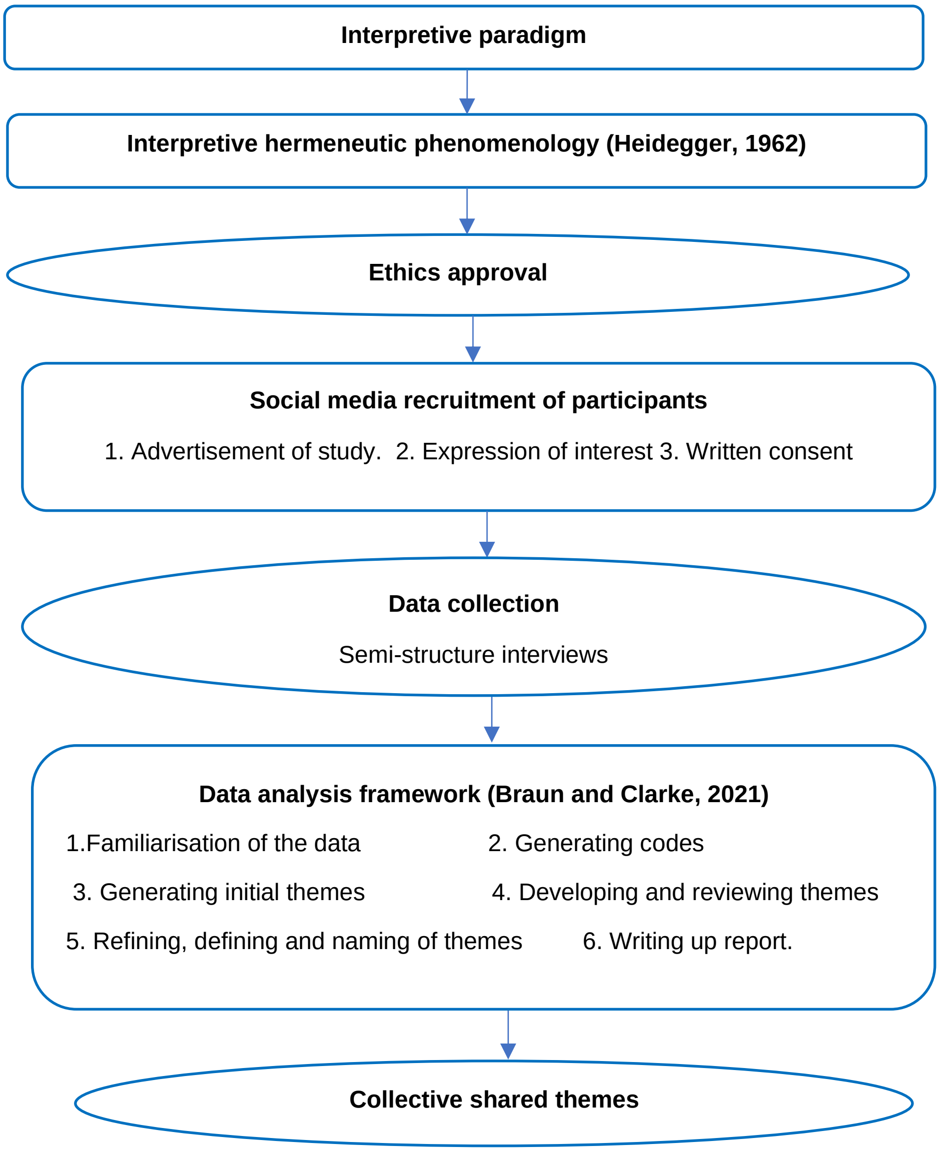
The meaning given to things always has something to do with the person and the meaning system they use, as it would have with the thing itself (Spinelli, 2005). A YA's view of the reality of making a dialysis and kidney transplant decision is embedded in their experiences and cannot be separated from the actual reality perceived. It was through this reality that the meaning of the experience was constructed, realised and the study emerged. Heidegger (1962) argued that our understanding of Being is through our experiences of a phenomenon and being-in-the-world is informed by prior existential things which means the understanding of our existence or being is through interpretation.

Although the world and the objects within it may seem meaningless in themselves, Merleau-Ponty (1962) argues that they have embedded meanings. YAs with kidney failure faced with dialysis and kidney transplant decisions are related to their world and the things within it because people are always related to their world (Crotty, 2017). An individual's relatedness to their world makes them conscious of the things within their world (Langdridge, 2007). Through the conscious engagement with their world and the interactions with the objects within it, the meaning of those interactions and their experiences of it can be interpreted and understood (Merleau-Ponty, 1962).

A YA’s lived experience of dialysis and/or kidney transplant decision-making could be informed from multiple perspectives, such as their personal, social, cultural, and psychological viewpoints. Therefore, embracing multiple views of reality enhanced the exploration of the decision-making phenomenon from multiple perspectives to help understand their lived experience of decision-making. The constructivist’s stance enabled the researcher to choose the methodology and study design that is compatible with the specified objectives, the type of evidence to be gathered, and how the data collected were analysed to answer the research question (Matthews and Ross, 2010).

Now that I have explained the rationale, it is important to consider the methodology that guided the study and how data were collected to generate the knowledge, in a diagrammatic representation (see Figure 3.2).

Figure 3. 2 Study Methodology and methods



3.5. Methodology

The methodology is about how the researcher discovers knowledge, systematically gains understanding, and is driven by ontological and epistemological beliefs (Killam, 2013). Having considered the different methodological approaches, phenomenology (Heideggerian interpretive phenomenology) was adopted. The methodology is the design of the study that guides and shapes the choice of the methods used to gather data to explore the phenomenon (decision-making) and must align with the epistemological and the interpretive perspectives chosen (Savin-Baden and Major, 2013). The methodology provides a theoretical perspective linking that research question to the methods (Savin-Baden and Major, 2013). Although different methodological approaches such as grounded theory, ethnography, and narrative inquiry, could have been used, instead phenomenology was chosen as it suited the research aims. Phenomenology focuses on the lived experience of a phenomenon and is concerned with meaning-making and how meaning is interpreted from an experience (Langdridge, 2007).

3.5.1. Phenomenology

Heideggerian interpretive phenomenology was adopted as the study was interested in how YAs with ESKD experienced and made sense of their world (therapy decision-making) which the study seeks to understand and aligns with the interpretive paradigm. Heidegger argued that the task of phenomenologists is to explore and understand how people experience everyday life (Heidegger, 1962). Phenomenology draws on Husserl, a German mathematician, whose philosophical writings date back to the 18th century. Over the years, phenomenology has been developed by other philosophers like Heidegger, Sartre, and Merleau-Ponty (Spiegelberg, 1982). Kant, a German philosopher, asserted that an individual's mind can never know "the thing itself" but can only know it as "it appears" to them ["the phenomenon"] (Spinelli, 2005, p.6).

The word "phenomenology" is from the Greek word "phain-omenon" which means "appearance" or "that which shows itself" and was used by various philosophers in the mid18th century (Spinelli, 2005, p. 6). The word “phenomena” means “the appearances of things, as contrasted with the things themselves as they really are”, where a phenomenon is anything that appears to a person in their conscious experience (Spinelli, 2005, p. 6). Phenomenology is concerned with the understanding of human experiences and behaviours and has been used in other disciplines such as health and social care (Evans, 2018; Langdridge, 2007).

Phenomenology has its roots in philosophy and psychology and has the viewpoint that reality is embedded in an individual’s experience (Lopez and Willis, 2004) and is indivisible from the actual reality being perceived (Spinelli, 2005). Different strands of phenomenology exist which are linked to the two main ones, descriptive and interpretive phenomenology (Larkin and Thompson, 2012). Phenomenologists express a common interest in the human experience to explore the essence and interpret the meaning of a lived experience, despite their different opinions (Creswell, 2013). Although descriptive and Interpretative Phenomenological Analysis was not used, a brief explanation is provided to support the reasons for my chosen methodology (see Table 3.1).

Table 3. 1 Types of phenomenological methodologies and rationale for not using

Types of methodologies and rationale for not using		
Type of methodology	Explanation of possible use	Rationale for not using
Descriptive phenomenology	Descriptive, also known as transcendental, phenomenology seeks to describe and to understand the essence of an individual’s experience in the way it appears to our consciousness, in its own terms and aims to	Descriptive phenomenology was not used because I bring my experience, knowledge, beliefs, and values to the research and these cannot be bracketed.

	achieve transcendental subjectivity (Smith *et al*., 2009). Influenced by Husserl ideology and based on Franz Brentano's philosophical idea of intentionality ("the internal experience of being conscious of something", Dowling, 2007, p.132) which became one of the main concepts in descriptive phenomenology (McGraft, 1986). Husserl proposed that the inquirer (researcher) should bracket themselves or suspend their assumptions and presuppositions of the taken-for-granted activities to concentrate their attention on the experience itself (Smith *et al*., 2009). Since then, other phenomenologists like Heidegger (1962), Giorgi (1970; 2009), Merleau-Ponty (1962), and Moustakas (1994) have further developed phenomenology.	It is this view of reduction, bracketing, and techniques of bracketing that has caused ongoing debates among phenomenologists (Crotty, 2017; Denzin and Lincoln, 2013). My presuppositions and assumptions play a key role in illuminating the meaning and understanding of a phenomenon, therefore cannot be bracketed in trying to understand a phenomenon or an experience, as suggested by Heidegger (1962). My past knowledge and experience of kidney disease and its treatment would be a guide for the inquiry. Through this lens, the right questions about the experience were asked to gain insight into how YAs experienced dialysis and kidney transplant decision-making.
Interpretative Phenomenological Analysis (IPA)	IPA is an interpretive phenomenological approach that can be used to explore and analyse the lived experiences of people to gain understanding and the meaning of their experiences (Peat *et al*., 2019). IPA is based on three theoretical perspectives: phenomenology, hermeneutics (interpretation), and ideography (particular aspects of an experience). It seeks to describe and interpret the lived experience of an individual with a focus on the uniqueness of particular situations within the participant's experience that have significance (Smith *et al*., 2009).	IPA was not used as it requires in-depth interviewing with a smaller number of participants to achieve the deep meaning of an experience, which may require multiple interviewing of participants to understand the experience (Smith *et al*., 2009). IPA could have been used but it was not because the study wanted to gain a broader collective understanding of the participants' experiences which involved a larger sample than the smaller number required for IPA.

The chosen methodology will now be discussed.

3.5.2. Interpretive phenomenology and the rationale for choice

Interpretive phenomenology chosen for this study is based on the hermeneutic philosophical principles that resulted from Heidegger’s philosophical perspective of phenomenology, which contrasted with Husserl’s. Heidegger based his phenomenology on hermeneutics, the philosophy of interpretation of literary work and historical texts (Smith *et al.*, 2009). Hermeneutics is derived from the Greek word “hermeneuein”, meaning “to interpret” or “to understand” (Crotty, 2003, p.87). Hermeneutic phenomenology as a philosophy is concerned with human existence as it is experienced, the meaning-making of an individual’s lived experience and the processes involved (Langdridge, 2007; Larkin and Thompson, 2012; Lauterbach, 2018). The term hermeneutic phenomenology has been used interchangeably or in combination with interpretive phenomenology (Lauterbach, 2018). The term interpretive phenomenology is used in this study.

Hermeneutic phenomenological ideologies are believed to have started in the early 18th century, from the work of two philosophers, Kierkegaard (1813-1855) and Nietzsche (1844-1900), who argued that a person should be understood in terms of their “individual, concrete, and subjective existence” (Cooper, 2003, p.5). Kierkegaard and Nietzsche’s ideologies were further developed by philosophers like Husserl (1960), Heidegger (1962), Gadamer (1960), and Sartre (1948), and became part of the phenomenological method by the twentieth century to explain the human lived existence and experience (Cooper, 2003). Hermeneutic theorists like Heidegger argue that existence proceeds essence, because “man does not possess existence, but he is existence” (Misiak and Sexton, 1973, p.72).

The emphasis on existence emanates from the Latin verb “existere” which means to “stand out” or to “emerge” or “to become” (Misiak and Sexton, 1973, p.72). Therefore, a person’s unique or particular experience of a phenomenon stands out from our “universal givens” (Spinelli, 2005, p.108). These universal givens are the everyday things we experience in our world, which are taken for granted (Spinelli, 2005). In this study, YAs’ experiences of dialysis and kidney transplant decision-making stands out from their world of living with ESKD as it is linked to their existence. This is because the type of decisions that inform their choice of dialysis and kidney transplant therapy is inter-related with their survival and living with ESKD, therefore, this experience will have a particular significance or meaning to them which the study explored.

Heidegger, a student of Husserl moved away from Husserl’s epistemological focus of discovering and describing the essences of a phenomenon (experience), to an ontological focus on the human experience of ‘Being’ and the meaning of ‘Being’ (Heidegger 1962). Interpretive phenomenology was developed by Heidegger through his application of hermeneutic principles using the concept of being in the world instead of knowing the world (Reiners, 2012). Heidegger based his philosophy of understanding the reality of Being on the concept of “Dasein”, *a* German word for “existence” or “being there” which he also used as a person or a subject to explain his phenomenological philosophy (Langdridge, 2007, p.30). In his writings on “Being and Time”, Heidegger asserted that “Dasein always understands itself in terms of its existence”, because “existence is the determining character of Dasein” (Heidegger, 1962, p.33). Heidegger argued that an “individual’s understanding of their existence is through Being and the understanding of Being is through the experience of encountering a phenomenon within their world” (Heidegger, 1962, p.38). For Heidegger, the phenomenological experience is about meaning, “let that which shows itself be seen from itself” (Heidegger, 1962, p.38). Therefore, to understand the phenomenon such as decision-making, the researcher must go back to the thing itself, the root of that experience (Finlay, 2011). In this study, the understanding of ‘Being’ concerns the lived experience of dialysis and kidney transplant decision-making which is rooted in YAs’ narratives and perspectives of their experiences.

Heidegger argued that any understanding of an experience is interpreted because the nature of Beings (people) is to make sense of (interpret) their world (Spinelli, 2005). Similarly, any understanding of YAs' experiences is interpreted through their interaction with other entities in their world of decision-making. Interpretive phenomenology enables the researcher and participants to co-explore and develops their understanding of the phenomenon being explored. Heidegger argued that Dasein (person) as an entity does not just exist among other entities but is in relationship with itself and seeks to understand it because the “understanding of Being is itself a definite characteristic of Dasein’s Being” (Heidegger 1962, p.32).

Heidegger asserted that there are “basic structures or existentialities that characterises Dasein’s being” which is “fundamental to its existence and experience of the world” (Heidegger 1962, p.33). It is through these existentialities that we understand our state of Being as humans (Heidegger, 1962). These existentialist features include freedom and the limitations that come with it, engagement and encounter with the world and others, temporality (relating to time), and meaning/meaninglessness (Spinelli, 2005; Finlay, 2011). These basic structures have psychological implications on how an individual may choose to live their life (Spinelli, 2005).

Heidegger’s ideologies on temporality, facticity, authenticity, mood, being-towards-death, care, being-with, and discourse (Spinelli, 2005; Finlay, 2011) are vital to understanding YAs’ world of decision-making experiences. Heidegger argued that human beings cannot be separated from the world they live in and their way of perceiving their experience, therefore rejecting Husserl’s idea of bracketing (Langdridge, 2007). Rather, the way of perceiving an experience should be seen through its cultural and historical context (Langdridge, 2007). Heidegger (1962) considered the greater depth of meaning that came from interpretation. Interpretive phenomenology involves the researcher and the researched. The closest to gaining access to the participants' experiences is through the reflective interpretation of their lived experiences. Through this interpretive lens, meaning and understanding of YAs' decision-making experiences would be achieved.

The interpretive phenomenological methodology has been used to explore people’s experiences and their inter-relatedness with their world such as its historical, cultural, psychological, and social situatedness, to gain understanding and meaning of those experiences (Langdridge, 2007; Smith *et al*., 2009). Chan *et al*. (2015) used it to explore students’ lived experiences in diverse learning contexts. It has also been used in podiatry (Bridgen, 2017), postmodern therapists (Chan, 2010), and nursing (Abu Ali and Abushaikha, 2019). Mendes

(2018) used it to explore the impact of critical illness news on family while Heravi-Karimooi *et al*. (2017) used it to understand the lived experiences of elderly patients with coronary artery disease. Nakamura (2018) used it to explore young adults' experiences of resilience. The use of interpretive phenomenology enabled the understanding of YAs' inter-relatedness with their historical past, cultural, and social situatedness as well as the psychological impact to gain understanding and meaning of their experiences.

Understanding an experience is to interpret it and not just to describe it and language helps us to understand our experience of the phenomenon experienced (Langdridge, 2007). For Heidegger, language and understanding are inseparable, because it is "only through our language or interpretation, that our being-in-the-world is manifested and understood" (Finlay, 2011, p. 52). Language is influenced by culture and history and is perceived as the house of meaning through which people interpret their experience of the world (Smith *et al*., 2009). Similarly, the language used by participants was vital in bringing forth the interpretation and meaning of YAs' experience of decision-making. Heidegger asserts that "whenever Dasein (a person) tacitly understands and interprets something like Being, it does so with time as its standpoint" (Heidegger, 1962, p.39). This means that people (YAs) understand and interpret their experience concerning a particular time as a standpoint or reference.

Heidegger further explained that time should be conceived "as the horizon of all understanding of Being (experience) and for any way of interpreting it" (Heidegger, 1962, p.39). Likewise, YAs will interpret their experiences with particular time points during their decision-making. A hermeneutical understanding is also historical understanding, where the horizon of the past and present come together because the world is experienced through language, and it is through language that horizons of understanding, the meaning of our world, and experience are derived (Gadamer, 1989; Gadamer, 2006). To understand the meaning of YAs' decision-making experiences, both the researcher and participants must meet in this zone of horizons of understanding, which occurs through dialoguing with the text of YAs' narratives because participants' pasts and cultural situatedness are interlinked with time. Next to be discussed is the theoretical framework underpinning the study.

3.6. Theoretical framework underpinning the study

The evidence for shared decision-making (SDM), the rationale for selecting the three-talk model of SDM as the theoretical framework, and how it was applied in this research study, are presented. The integrative literature review in chapter two presented the complexity of decision-making that YAs faced. Qualitative studies that explored YAs' decision-making experiences alluded to the use of shared decision-making while the quantitative studies used different decisional scales and frameworks to assess behaviour and experiences of the shared decision-making process.

3.6.1. Historical perspective and theoretical models of decision-making

The history of decision-making can be traced back to Pascal and de Fermat, mathematicians in the seventeenth century, tasked with solving a mathematical problem [the Sisyphean task] (Edwards, 1982). Pascal and de Fermat came up with a probability function to solve the problem, where they proposed that “the value of a future gain should be directly proportional to the chance of getting it” (McFall, 2015, p.4). This led to the development of the first model of decision-making; the expected value theory, which was inspired by Pascal’s proposition (McFall, 2015). These mathematical models of decision-making led to the development of other decision-making approaches in economics, social psychology, political science, moral, motivational, and health decision-making literature (McFall, 2015). As a result, various theoretical decision models were developed to deal with some of the challenges experienced by the decision-maker.

3.6.2. Types of decision-making theories

The theoretical decision-making models are categorised into three main groups: normative, descriptive, and prescriptive theoretical models and each of these has various theoretical frameworks which are used in multiple settings including healthcare settings (Schwartz, 2016).

3.6.2.1. Normative theories of decision-making

Normative decision-making theories are based on logic (Gold *et al*., 2011). It has been used to explain how people reason, and make judgements and decisions based on rational choice theories such as the expected value theory, expected utility theory, the concept of risk, ignorance, and uncertainty (Halpern-Felsher *et al*., 2016; Schwartz, 2016). Researchers have used them to inform the development of descriptive theories of decision-making (Gold *et al*., 2011).

3.6.2.2. Descriptive theories of decision-making

Descriptive decision theories are used to explain the cognitive and affective processes the decision-maker goes through to make decisions (Bell *et al*., 1999; Schwartz, 2016). Examples of these theoretical frameworks include the theory of planned behaviour (Ajzen, 1980; Montano and Kasprzk, 2015), theory of reason (Montano and Kasprzyk, 2008), prospect theory (Mishra *et al*., 2012), subjective expected utility theory (Ronis, 1992) and health belief models (Janz and Becker, 1984; Rosenstock *et al*., 1988; Champion and Skinner, 2008). These theoretical models are used to predict risky behaviours or explain how people make judgements and decisions (Mishra *et al*., 2012), and examine how a decision-maker’s behaviour can be moderated (Bekker, 2009).

3.6.2.3. Prescriptive theories of decision-making

Prescriptive decision-making theories were developed to reduce the inherent bias in the normative and descriptive decision theories and models using various strategies to motivate better thinking and information processing (Bekker, 2009). Prescriptive decision theories provide a set of rules for combining beliefs (probabilities) and preferences (utilities) to aid the choice of a decision option (Pitz and Sachs, 1984) and are viewed as value-focused thinking (McFall, 2015). These theories and models have been applied in multiple contexts and settings (Bekker, 2009) and informed the development of the three-talk model of shared decision-making (see section 3.6.3). The complexity of decision-making is reflected in the use of different theoretical models and frameworks used to explore aspects of YAs' experiences and attitudes during decision-making (Zee *et al*., 2019; Zinn, 2015).

3.6.3. Shared decision-making model in healthcare

The SDM model of decision-making is based on the communication model of the clinician-patient encounter and informed by the prescriptive decisional theories (Charles *et al*., 1997; Elwyn *et al*., 2010). Although the conceptual definition of SDM varies in the literature (Charles *et al*., 1997; Makoul and Clayman, 2006; Elwyn *et al*., 2010; Coulter and Collins, 2011; NICE, 2021b), the commonly agreed minimum characteristics are those proposed by Charles *et al*. (1997). The four main characteristics for SDM (Charles *et al*., 1997) to occur includes the following:

a) The HCP and patient should be involved in the treatment decision-making process.
b) Both HCP and patient (but can include others) should share information with each other.
c) Both should take the necessary steps to participate in the decision-making process by expressing treatment preferences.
d) A treatment decision is made, both agree on the treatment and implement it.

These fundamental elements of SDM were further refined by researchers (Coulter and Collins, 2011; Elwyn *et al*., 2012). They suggested that evidence-based information provision on all available options, outcomes, uncertainties, and decision support counselling, should form the core part of SDM (Coulter and Collins, 2011; Elwyn *et al*., 2012). It is important that an individual fully understands the risks, benefits, and consequences of other options available during the deliberations about the options in the decision context (NICE, 2021b).

3.6.3.1. Concepts of shared decision-making

SDM has at its core the ethical principles of self-determination, autonomy, and relational autonomy (Elwyn *et al*., 2012; Gulbrandson *et al*., 2016). Ryan and Deci (2000) posit that self-determination theory focuses on intrinsic tendencies that protect and preserve a person's well-being. Self-determination is operationalised by supporting patient autonomy through the development of good clinician-patient relationships, respecting individual competencies, and interdependence on others (Elwyn *et al*., 2012; Gulbrandson *et al*., 2016). Relational autonomy posits that an individual's decision-making is always related to interpersonal relationships and mutual tendencies because an individual is not a self-governing agent who is entirely free (Mackenzie, 2008; Walker and Ross, 2014). Elwyn *et al*. (2012) assert that self-determination and relational autonomy should be balanced with the principles of beneficence and justice.

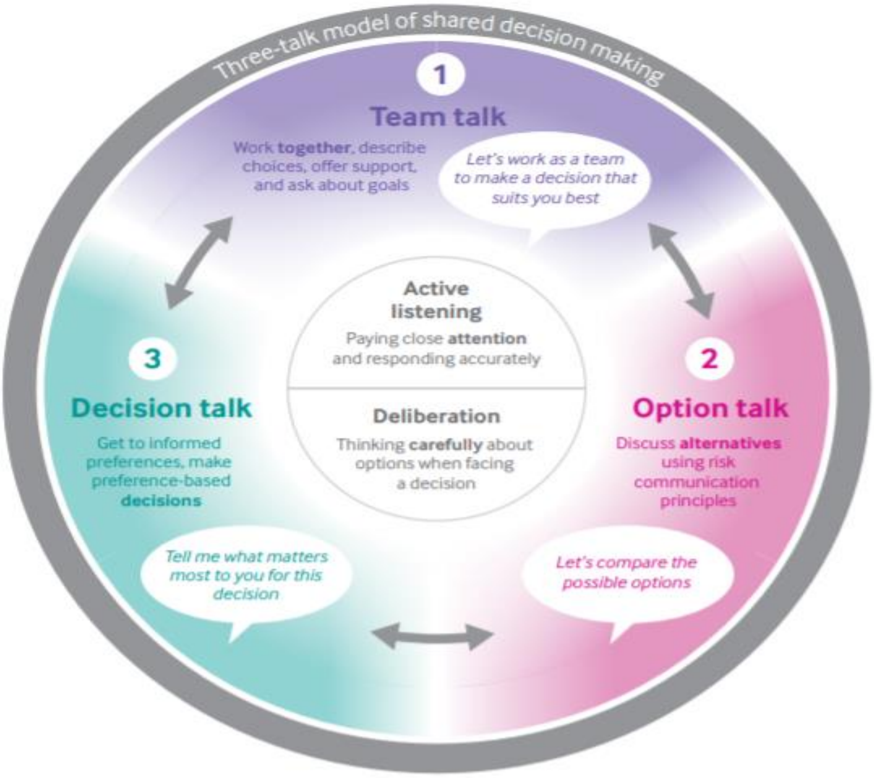
SDM can improve patients' knowledge and understanding of illness and treatments and improve medication adherence and health outcomes (Coulter *et al*., 2011; Joseph-Williams *et al*., 2017). Kew *et al*. (2017) highlighted that SDM may improve quality of life and asthma control, improve the use of inhalers, improve satisfaction with care, and empower patients to make choices. There is a need to find a balance between HCP power and patient choice for an equipoise during SDM (Quill and Brody, 1996). Elwyn *et al*. (2012) proposed that to achieve SDM, the tasks should help confer agency. Agency is the ability of an individual to act independently and make their own free choices (Gafni *et al*., 1998). An individual's autonomy must be promoted during decision-making in the HCPs-patient encounter (Entwistle *et al*., 2010). Some HCPs however believe they do not possess the skills, logistics and time to practice SDM, whilst others believe the patients do not want to be involved in their care (Joseph-Williams *et al*., 2014).

3.6.3.2. The three-talk model of shared decision-making

Elwyn *et al*. (2012) translated the conceptual descriptions of SDM into a three-step model of decision-making for practical use in routine practice consisting of three main interrelated steps: choice talk, option talk, and decision talk. The concepts and models of the three-talk model SDM have recently been updated since its development in 2012 following discussions and surveys of HCPs from different specialities in healthcare settings internationally, patients, carers, and stakeholders with changes (Elwyn *et al*., 2017). In the updated three-talk model of SDM (see Figure 3.3), the choice talk has been changed to team talk and a new and easy-to-understand pictorial diagram of the processes was included (Elwyn *et al*., 2017). The three-talk model of SDM involves (1) collaboration (2) active listening and (3) deliberation during the treatment discussions (Elwyn *et al*., 2012; Elwyn *et al*., 2014).

The model also acknowledges the psychosocial, emotional, and cultural factors that could influence the deliberation process on options (Elwyn *et al*., 2012; Elwyn *et al*., 2014). The psychosocial and emotional and cultural factors must be managed effectively during the dialogue (Elwyn *et al*., 2012; Elwyn *et al*., 2014). The new three-talk model consists of three key phases: (1) team talk, (2) option talk, and (3) decision talk (Elwyn *et al*., 2017). The team talk phase creates awareness of the need for decision-making where the individual is made aware that choices exist, provides support, and identifies and explores the person's goals concerning their health problem (Elwyn *et al*., 2017).

Figure 3. 3 Three-talk model of shared decision-making (Elwyn *et al*., 2017)



The option talk phase involves comparing alternatives and uses risk communication principles to discuss alternative options and trade-offs. The decision talk refers to the task of arriving at a decision that reflects a patient's informed preferences which have been guided by their experience and HCPs' expertise (Elwyn *et al*., 2012). These are incorporated during the deliberation on options to select the preferred treatment choice (Elwyn *et al*., 2012). The three-talk model of SDM is an interactive process of engagement, discussion, and collaborative deliberation of available treatment options (Elwyn *et al*., 2014). Elwyn *et al*. (2014) have highlighted five constructs: (a) constructive engagement, (b) recognition of alternative actions, (c) comparative learning, (d) preference construction and elicitation, and (e) preference integration that informs the collaborative deliberation process of the three-talk of SDM.

Constructive engagement occurs during the dyadic or more dialogue between the HCP and the patient (young adult) within a safe environment to explore the treatment options and considers the core values of respect, empathy, and curiosity about each other's view (Elwyn *et al*., 2014). The recognition of alternative actions is where participants recognise the existence of relevant, alternative potential courses of action that should occur during SDM. Comparative learning allows the HCP and participants to compare alternative courses of action where patients learn about possible alternatives through the facilitation of knowledge transfer by clinicians on the benefits and disadvantages of each alternative course of action and compare each of them (Elwyn *et al*., 2014). HCPs must be open to the individual and/or relations where there is insufficient knowledge on the benefits and harms of treatments, and judge how much information should be delivered because more is not always better (Elwyn *et al*., 2014).

Preference construction and elicitation is a complex process through which patient preferences are formed and constructed based on the attributes of the alternate course of action, appraisal of the process, procedures, and their preference for short and long-term outcomes using analytical and non-analytical approaches (Elwyn *et al*., 2014). The authors argue that appraisals of future actions are dependent on personal motivation, context and multiple contributing factors and preferences changed as new understanding is generated (Elwyn *et* *al*., 2014). Preference integration is a process where views, priorities, and opinions of both the patient and HCPs are considered explicitly and awareness of the course of actions that can be taken to agree on a choice. Collaborative deliberation of treatment options improves patients' and carers' understanding of their options and supports them to select a preferred choice (Elwyn *et al*., 2014).

In the UK, the three-talk model of SDM has been recommended for use in routine NHS settings although this is still yet to be fully embedded (NICE, 2019a). The difference between SDM and other models is that both the patient and clinicians are active and equal partners with each viewed as an expert contributing their expertise (Coulter and Collins, 2011). It acknowledges the psychological, social, and emotional factors that may influence the deliberation of options and recommend effective management of it during the deliberation dialogue (Elwyn *et al*., 2012). SDM has been used in various healthcare settings such as diabetes (Branda *et al*., 2013), stroke (Brown *et al*., 2014), emergency care (Hess *et al*., 2015; Holland *et al*., 2016), and kidney disease (Finderup *et al*., 2020; Hart *et al*., 2019; Robinski *et al*., 2016).

The three-talk model of SDM has been used to inform the development of the Shared Decision-Making-Dialysis Choice (SDM-DC) tool for people facing a dialysis modality choice decision-making in four hospitals with kidney centres in Denmark, which enhanced their involvement in the decision-making (Finderup *et al*., 2019). Participants who received the SDM-DC intervention reported an 80% SDM score and choosing home-based treatment had a higher knowledge score (84%) than hospital-based treatment (75%) (Finderup *et al*., 2020). An observation of the decision-making process of 76 clinical consultations (26 pre-dialysis consultations and two consultations each of 25 patients with breast cancer) using the three-talk model of SDM, highlighted the complexity of the decision-making process which was characterised by multiple and multi-stage decisions (Joseph-Williams *et al*., 2019). The authors observed that the option talk phase was an evolving situation, which was increasingly responsive and tailored to individual needs and decisions were often delayed (Joseph-Williams *et al*., 2019). Joseph-Williams *et al*. (2019) suggested the use of planning decisions to reflect this process.

The use of SDM has shown improvement in patients' knowledge of treatment options (Waterman *et al*., 2019*;* Bailey *et al.*, 2016; Stacey *et al*., 2017a), adherence to treatment (LeBlanc *et al*., 2015) and engagement in decision-making and care (Stacey *et al*., 2017a; Robinski *et al*., 2016). SDM has been used in patient-HCP communications (Robinski *et al*., 2016; Waterman *et al*., 2019), managing risk (Harrington and Morgan, 2016) and reduction in health disparities (Durand *et al*., 2014). Despite the drive nationally and internationally to embed SDM in routine patient care it continues to be a challenge (Härter *et al*., 2011; Makarov *et al*., 2016; NICE, 2021b). The difficulty of SDM embedment has been due to the resistance of health professionals to use it in routine care and other practical barriers (Joseph-Williams *et al*., 2019).

3.7. Application of shared decision-making as a theoretical framework

People get exposed to a lot of information whether from internal or external sources during decision-making and use inherent finite cognitive processes to select the right information, and store and retrieve them for future use (Bekker, 2009). Similarly, YAs with chronic illness can be exposed to a lot of information, which can be overwhelming, and may select the information they perceive as appropriate and use them to inform their decision-making later, as highlighted in the integrative review (chapter two of the thesis). The closest way to understand how YAs experienced dialysis and kidney transplant decision-making is by using a decision-making model such as the three-talk model of SDM as a framework to explore their experiences.

The three-talk model of SDM was used to guide the data collection for the study as it is a tested model used and recommended by NICE (2021b) to be used in healthcare decision-making about treatment and care. The concepts and the process of the three-talk model guided the interviewer in exploring YAs' experiences of dialysis and kidney transplant decision-making. The findings of the study will be aligned with the three-talk phases of the three-talk model of SDM to understand how their experiences relate to the key stages: team, option, and decision talk experienced. It will enhance the meaning of the different situational contexts of the YAs, the effects of the decision processes on YAs, and how these were experienced. Although the decision-making experience will not be observed in the clinical setting, the reflective account of YAs about their experience will enhance the meaning of their experiences and whether SDM occurred or not. Aligning these concepts to the findings will enable the study to identify the gaps in its application and will be added to the knowledge and evidence building of the use of the three-talk model of SDM in routine care.

Understanding the concepts of SDM will allow the examination of the meaning of YAs' decision-making experiences and how they appraised the process (Elwyn *et al*., 2014). The concepts of SDM will be used in the discussion chapter in the wider context of decision-making. It could be argued that meaning-making, a quest for a favourable understanding of a situation and its implications (Park, 2013), is important in SDM. Human beings are meaning-making people; therefore, we try to make sense of and interpret our everyday experiences with our world (Smith *et al*., 2009; Langdridge, 2007). People construct their beliefs and preferences for events, which are influenced by their information-processing capacity to enable them to generate an effective response to a decision task and it is possible that YAs will do the same (Payne and Bettman, 2004). During preference elicitation of SDM, an individual is influenced by multiple contributing factors in addition to their personal motivation and the decision context to appraise the overall situation, which can lead to changes in their preferences as new understanding is generated (Elwyn *et al*., 2014).

The above exploration of the theoretical decision theories and models has highlighted the complexity of decision-making as various strategies and styles are used to inform a type of decision-making and response. The choice of a particular theory or model is informed by personal, situational, and environmental factors and the expected outcome of the decision encounter. Although descriptive theories, such as the health belief models and the protection motivation theories, are used to understand and predict health decision-making behaviours and identify psychological factors that contribute to it (Ogden, 2012), these do not explore the whole experience of the individual.

Prescriptive theories have shown a range of techniques that enhances good thinking and how the decision-maker can be supported to make appropriate decisions. Decision-making in YAs is influenced by multiple factors such as social, and emotional competence, perceived self-efficacy, emotional burden, and how it might affect their life. The three-talk model of SDM is widely used in healthcare and is currently recommended for use in clinical practice (NICE, 2021b). It can offer the needed support to YAs if used appropriately, hence was chosen for this study. The model was used to inform the development of the interview questions during data collection, and aligned with the findings and discussions.

3.8. Methods

The methods used in the conduct of the study are discussed in this section. Researchers use different techniques (methods) to collect and analyse data that are aligned with their research question (Creswell and Poth, 2018). Interpretive hermeneutic phenomenology has no set methods used to explore a phenomenon (van Manen, 2014); hence, a range of activities could be used as it acknowledges that no one approach is suitable for all phenomena (Goble and Yin, 2014). This study used semi-structured interviews informed by the three-talk model of SDM (Elwyn *et al*., 2014) as a guide to exploring and understanding participants' experiences of decision-making (Figure 3.3). The researcher must anticipate the issues that can arise during the conduct of the study such as ethical issues, the sampling strategy, and how data can be collected and analysed (Creswell and Poth, 2018). This section discusses the context for the research, identification and recruitment of participants, the sampling methods, eligibility, sample size, patient and public involvement, ethical approval, and collection of data. The identification and recruitment of participants will now be discussed.

3.8.1. Identification and recruitment of participants

YAs with ESKD aged between 18-30 years old were specifically chosen as the integrative literature review (in chapter two) highlighted a research gap in their decision-making experiences. Evidence suggests there are variations in healthcare for children and young people, which differs across regions in the UK (Cheung *et al*., 2013) and those with ESKD are no different (Gair, 2016). It was important to get a broader perspective of YAs' experiences of making dialysis and kidney transplant decisions irrespective of their location in the UK. Most YAs engage with social media because of its ease to use and accessibility (Auxier and Anderson, 2021) and provides opportunity for social connection (Keles *et al*., 2019). Therefore, social media recruitment strategies, using networks such as Twitter and Facebook (section 3.8.2), were chosen as the means to identify and recruit potential participants to the study to enable the perspectives of YAs from different kidney centres in the UK. Participants opted into the study by contacting the researcher via email, text, or telephone to express their interest to participate in the study.

3.8.2. Social medial recruitment

Social media (Facebook and Twitter) was used to recruit participants to this study. Social media has been increasingly used for health research (Berry and Bass 2012; Kayrouz *et al*., 2015; Whitaker *et al*., 2017) and clinical trials (Glickman *et al*., 2012). Social media has successfully been used to recruit adolescents, YAs, and other underserved populations to research studies (Amon *et al*., 2014; Gorman *et al*., 2014; Ince *et al*., 2014; Loxton *et al*., 2015). Social media was used to recruit YAs with type 1 diabetes for an interventional trial study (Mason *et al*., 2018). Ramo and Prochaska (2012) used Facebook to recruit YAs who are ex-smokers and concluded that it was cost-effective and a viable way of assessing the health behaviours of YAs. Harris *et al*. (2014) reiterated the findings of the cost-benefit of using social media compared to the traditional random sampling methods in their study which recruited young women for health surveys. Gorman *et al*. (2014) used a diversified (social media, local hospital referral, and word of mouth) approach to recruit YA female cancer survivors to their study and reported that nationally, social media and internet recruitment yielded the highest number of participants compared to the other approaches.

Although social media recruitment can provide wider access to potential participants, increase participation, and save time and money, it has challenges. Clinical trials that used social media and internet recruitment suggest challenges with violation of study protocols in randomised control trials, for example, exposure of blinded participants due to the formation of close bonds and asking leading questions about the trials (Glickman *et al*., 2012). Participants may share experiences after their participation in a study with their followers. While it can promote positive participation, it also can result in negative experiences like giving advice that deters other potential participants (Glickman *et al*., 2012). Recruitment of participants can also be challenging especially in underserved groups. Wisk *et al*. (2019) recruited fewer YAs compared to other recruitment strategies in their randomised control study to assess the effectiveness of a behaviour intervention to prevent weight gain. Sanchez *et al*. (2020) highlighted the decrease in sample representativeness while Reuter (2020) highlighted the challenge of having limited options to verify demographic information of participants, the ability to manage participants, the lack of training and resources for researchers.

Gatekeepers, such as moderators and leaders of national kidney patient charities including Kidney Care UK, the National Kidney Federation (an umbrella organisation for local kidney groups), and YA kidney patient associations, were contacted via email and telephone and study information was shared with them. Influential YAs with social media presence were also contacted. Following an agreement with the gatekeepers and influential YAs with a social media presence, the study poster (Appendix 4) was sent to them and posted on their Twitter, Facebook, newsletters, and bulletins. Twitter and Facebook were the main social media sites used to recruit the majority of the participants.

Following the receipt of an interest to take part in the study, potential participants were assessed for suitability and those who met the inclusion criteria (see section 3.9.1) were sent the participant information sheet (PIS) (see Appendix 5). Participants who contacted the researcher by text or phone were then asked to send their email address for the researcher to send the PIS to them, following the initial explanation of the study. Interested participants were encouraged to contact the researcher with their questions about the study and those who did, received answers to their questions. If they were still willing to take part, following receipt of the PIS, they were asked to send available dates to attend an interview.

Participants had no less than 48 hours to decide if they wanted to take part in the study by contacting the researcher following receipt of the PIS.

Once the interview date and type of interviewing approach (virtual via Skype or face-to-face) had been agreed, the study consent form (see Appendix 6) was sent to each participant to complete and return to the researcher via email before the interviews occurred. Participants were provided with an incentive (reimbursement for their travel or a gift card of £20 depending on their choice) as an appreciation for their time for taking part in the study. Following participation in the study, participants were asked to email their address to enable the researcher to send their £20 gift card. All participants informed the researcher following the receipt of their £20 gift cards.

3.9. Eligibility

The study recruited YAs with ESKD who had made decisions about dialysis and/or kidney transplant choice and are in receipt of dialysis or kidney transplant therapy. The following inclusion and exclusion criteria were used to determine the eligibility of participants.

3.9.1. Inclusion criteria

The inclusion criteria were:

i. YAs diagnosed with ESKD for more than three months, aged 18-30 years inclusive and living in the UK.

ii. Had made a decision about renal replacement therapy and subsequently received haemodialysis or peritoneal dialysis or kidney transplant.
iii. Could recall past information about their decision-making experiences.
iv. Could communicate in English as interpreters were not available.
v. Could voluntarily give their consent to take part in the study.

3.9.2. Exclusion criteria

YAs were not eligible if they were aged below 18 years or above 30 years of age and

i. Had not made a dialysis or transplant decision
ii. Could not recall information about their decision-making experiences
iii. Were unable to voluntarily give their consent, communicate in or understand English.

Having presented the eligibility criteria for the study, the sampling method used will now be discussed.

3.10. Sampling methods

The sampling method chosen by the researcher must be theoretically consistent with the qualitative paradigm (Smith *et al*., 2009). Purposeful sampling, which is the selection of a specific population, community, or group of people with certain demographic characteristics and experiences like age, disease, or people with similar knowledge, experience, or perspective of the phenomenon being explored, was chosen for the study (Gray, 2018; Creswell and Poth, 2018).

Purposeful sampling enabled the recruitment of YAs with similar experiences and offered specific insight into their experiences of making dialysis and/or kidney transplant decisions. YAs with ESKD aged between 18-30 years old were specifically chosen as the integrative literature review (in chapter two) highlighted a research gap in their decision-making experiences. Although the purposeful sampling approach allowed the study to hear the experiences of different YAs in the UK, it could also lead to sampling bias due to the deliberate focus on a particular population (Gray, 2018). Next discussed is the sample size for the study.

3.11. Sample size

There is no specific sample size for qualitative studies including phenomenological studies, as the appropriate size for qualitative studies continues to be an ongoing debate (Morley and Cathala, 2019). Considerations are given to the richness of the individual cases, level of analysis, and reporting (Smith *et al*., 2009; Tappen, 2016). Factors such as the nature of the research topic, scope of the study, number of interviews per participant, the quality of the data, the usable data, the methodology, and the design of the study influenced the estimation of the sample size to achieve data saturation (Morse, 2000). Mason (2010) and Charmaz (2006) suggest that the concept of data saturation, which is where there is no added information to the topic being discussed, should guide the researcher in selecting an appropriate sample size. Miles *et al*. (2013) recommend a sample size of 15-30 interviews.

Polkinghorne (1989) also suggests that between five to twenty participants with the same experience of a phenomenon are appropriate for phenomenological studies. A sample size of about 20 participants is usually needed for qualitative studies (Charmaz, 2006; Crouch and McKenzie, 2006). A sample size of 20 participants was considered a suitable size to gain a rich and in-depth understanding of the decision-making phenomenon and achieve data saturation. As this is a phenomenological study, the focus was on meaning-making and understanding YAs' experiences on the individual and collective levels. Therefore, the sample size chosen should be managed to avoid excess data at the risk of an in-depth data analysis and interpretation (Smith *et al*., 2009).

Although twenty participants were recruited, two dropped out due to illness. The remaining eighteen participants were considered adequate to achieve rich and in-depth data to understand the decision-making phenomenon. This sample size was manageable as opposed to a smaller sample size. The use of a smaller sample size could risk achieving rich data (Flick, 2006) and a larger sample size could affect the data quality (Onwuegbuzie and Leech, 2007). The data collection method is next presented.

3.12. Data collecting method

Data collection was via either face-to-face or Skype interviews using an interview guide (Appendix 7).

3.12.1. Interviewing

Interviewing is a way of systematically gathering knowledge during the interaction between the interviewer (researcher) and interviewee (participant) in a qualitative study (Brinkmann and Kvale, 2015). Interviews are “conversations with a structure and a purpose where careful questioning and listening is used to obtain thoroughly tested knowledge, which goes beyond our everyday spontaneous exchange of views” (Brinkmann and Kvale, 2015, p.6). The interviewing approach provided “access to the context of the participants to behaviour” that allowed the researcher to “understand the meaning of their lived experience” (Seidman, 2006, p.10). Interviews are a good way of engaging in conversations with study participants to try to understand their world from their perspective and the meaning of their experiences (Savin-Baden and Major, 2013).

Brinkmann and Kvale (2015) assert that “alternation occurs between the knowers and the known, between the constructors of knowledge and the knowledge constructed, between actors who enact the conventional context of the interview and the context that organises what the actors say” (p.5). Brinkmann and Kvale’s (2015) explanation of what happens during the interviewing context relates to the phenomenological approach used for this study and the co-construction of knowledge that occurs, as both the researcher and participants bring into the research context their world of experiences. Schostak (2006) argues that interviewing is not a simple tool that can be used to generate data because it is a place where views may clash, therefore skills are required.

The ‘*inter-view’* was about seeing the participants’ world through hearing their stories, their opinions, reasons, and arguments and the use of words to provide views into different worlds, as well as the researcher's world (Brinkmann and Kvale, 2015). Seeing the participant's world through hearing their stories related to the thing itself, the phenomenon (dialysis and/or kidney transplant decision-making) that the researcher was interested to explore (Spinelli, 2005). The use of interviews enabled the researcher to carefully question participants and through active listening probe more in-depth using clues provided to ask further questions to clarify issues and promote the conversation. Now that the interviewing approach has been explained, the interview method used will next be discussed.

3.12.2. Interviewing method

Different interviewing methods such as informal, structured, unstructured, and semi-structured interview methods are used by researchers in qualitative research (Rapley, 2012). Savin-Baden and Major (2013) assert that the type of interview used during a study is influenced by the research approach guiding the study.

3.12.3. Phenomenological interviewing approach

As this study used an interpretive hermeneutic phenomenology, the interviewing technique needed to align with the interpretive approach and methodology. The focus of this study was to understand participants' experiences of their treatment decision-making and the use of a semi-structured interviewing technique allowed the exploration of the experience. A phenomenological way of interviewing is a form of a semi-structured interview that focuses on an in-depth interviewing approach and is grounded in the principles of phenomenology (Schutz, 1967). Marshall and Rossman (2011) assert that phenomenological interviews are a type of in-depth interview grounded in the theoretical tradition of phenomenology. Phenomenological interviewing covers three phases: a focus on life history, details of the experience, and reflection of the interviewing process (Seidman, 2006).

The focus on the life history phase of the interview is where the participant's experience is put into context while the experience detail phase relates to the specific experience the researcher is exploring (Seidman, 2006). The participants' experience of the decision-making cannot be separated from their past life because it has a bearing on their experiences and illuminates the meaning of their experiences. The reflection on the meaning phase is based on the life history and experience phase and reflects what that experience means to the participant (Seidman, 2006). Getting the context of the participants' experience was important to the interpretation of the data and the understanding of the experience (Dey, 2005).

Jennings (2005) asserts that the success of an interview is dependent on establishing a rapport, which is a social relationship that centres on the genuineness, trust, and respect for participants. Rapport was developed during the recruitment process, which established trust and facilitated the dynamic flow of conversation during the interviewing process (Brinkmann and Kvale, 2015). Interviewing is a form of social interaction based on conversations (Warren and Karner, 2015). The social interaction provided the opportunity to explore the decision-making phenomenon and generated an in-depth understanding of participants' experiences (Wengraf, 2001). Participants were made aware of what was expected of them and had a willingness to share their experiences of decision-making with the researcher (Tierney and Dilley, 2002). The interviewing process enabled the researcher and the participants to co-construct knowledge of their decision-making experience.

The reflective account of participants' embodied experiences is paramount to enable my understanding of the phenomenon (decision-making) under investigation (Lauterbach, 2018). Interview in hermeneutic phenomenology uses a conversational approach as a way of exploring and developing a rich exploration of the phenomenon (van Manen, 2016). Probing during the interview allowed me to clarify and understand the meaning of YAs' experiences (Seidman, 2006). Engaging in active listening ensured full attention was given to participants while interpretive listening was performed to get clarification from the participants (Jennings, 2005). Data collection was guided by the concept of saturation, the point where no new information is gathered as the researcher hears and sees similar information being repeated over and over again (Lincoln and Guba, 1985). However, some interpretive phenomenologists hold the belief that interpretation is never-ending as it is dynamic, therefore, has less emphasis on data saturation (Smith *et al*., 2009).

3.13. Interview guide

An interview guide forms an integral part of interviewing as it provides a list of questions and areas that need exploring during the interview (Kajornboon, 2005).

The interview guide (Appendix 7) provided a structure for the in-depth interviews (Brinkmann and Kvale, 2015) therefore ensuring that the interview guide was clear and void of ambiguity (Kajornboon, 2005). The interview questions enable the gathering of information on what the participants did (behaviour), thought (opinions, attitudes, values), felt, know (knowledge) and what they may have seen, heard, and touched (senses) concerning their decision-making experiences (King *et al.*, 2018). The World Health Organisation (2002) suggests that the researcher should identify the appropriate topics and questions, draft the questions, decide on the level of details, have a list of probes or prompts, pilot the questions, and address or revise the guide, as necessary.

The interview guide covered different questions and areas of the phenomenon explored and was aligned with the stages of the three-talk model of shared decision-making (see section 3.6.3.2) to guide the conversation. The in-depth phenomenological interviewing allowed the use of loosely pre-set open-ended questions, supplemented by further questions which arose during the interviews in response to participants’ comments or reactions (Savin-Baden and Major, 2013). The researcher was able to probe deeper in response to participants' comments or reactions, followed new ideas, and kept the discussions focused within the time frame to gain in-depth insight and meaning into the participant’s experience (Brinkmann and Kvale, 2015).

The challenge with this method is that questions not included in the guide but need exploring could go unexplored if they do not come into the conversation (Savin-Baden and Major, 2013) and relies on the researcher’s interviewing skills to ensure that the flow of discussions generates rich and thick data. A test interview was carried out using the interview guide with one supervisor before the interviews commenced, with no change in the interview guide.

3.14. Patient and Public Involvement

Patient and Public Involvement (PPI) brings rich experiences and expertise into the research discussions and gives the researcher a different perspective of the intended area of study (INVOLVE, 2012; NHS England, 2015). It was important to get the views of people with ESKD with experience of making RRT decisions as young people. Through word of mouth by the researcher and another kidney professional (supervisor) and meeting with a local kidney peer support group, three people with experience in making dialysis and kidney transplant decisions as young people expressed interest to be part of the steering group. The steering group formed was made up of three people with ESKD and three healthcare professionals (the researcher and two supervisors).

PPI was undertaken to get a different perspective of the intended research study and to ensure that the research question had the correct focus (INVOLVE, 2012; Hickey *et al*., 2018). The steering group met in June 2018 to discuss, shape and finalised the research question. A brainstorming exercise with the group highlighted the experiences of YAs during the dialysis and kidney transplant decision-making process, and the need for research to explore their psychosocial and mental well-being impact during their trajectory of the disease, especially at decision-making. The group agreed that the study should explore the decision-making experiences of YAs, the psychosocial impact, and YAs' well-being and this was incorporated in the study. Following the initial meeting, other influential YAs with RRT decision-making experience contributed ideas to the recruitment process. The group was also involved in the recruitment (see section 3.8.2) and dissemination of the findings (see section 6.10).

3.15. Ethical considerations

It was important to consider possible ethical issues that could arise during the conduct of the study and for the necessary steps to be taken to address them. The ethical issues considered are addressed below.

3.15.1. Ethical approval

Creswell and Poth (2018) recommend that researchers should consider all ethical issues that can arise during the study. The ethical principles considered during the research process included autonomy (self-determination), respect for the participants, beneficence (doing good), justice, and non-maleficence (doing no harm) (Tappen, 2016). These principles were adhered to during the study. Considerations were given to doing no harm to participants, self-determination, privacy, unequal power, discussing sensitive issues, anonymity, and confidentiality. The study was approved by the Health and Social Care Ethics Committee of the London Doctoral Academy London South Bank University, ETH1819-0029 (Appendix 8) in 2019. Due to the initial slow response to recruitment, and feedback from the PPI group and influential YA kidney patient groups, a review of the recruitment criteria was undertaken. As a result, minor amendments to the inclusion criteria (removed the years of decision-making experience) were made to the study protocol and was approved by the University.

In August 2019, recruitment through social media was slow therefore a decision was made to seek ethical approval from the Health Research Authority (HRA) so that further participants could be recruited from the NHS. Despite favourable HRA approval from the London Research Ethics Committee in 2020 (Appendix 9) to recruit further participants, recruitment via the NHS was suspended due to the SARS-CoV-2 (COVID-19) pandemic. The recruitment via social media gradually improved and by December 2019, twenty participants had been recruited but two dropped out due to illness. The eighteen participants had been interviewed by end of January 2020. Due to the ongoing COVID-19 pandemic and the national lockdowns and my scholarship time running out, a decision was made to stop further recruitment from the NHS in September 2020. The next session will discuss the potential ethical issues considered.

3.15.2. Self-determination and autonomy

Self-determination and autonomy relate to decisional autonomy that enables a person to decide whether to take part in the study or not (Cardol *et al*., 2002). Self-determination considers the ability of a person to think, choose, decide, and act independently (Hammar *et al*., 2014). To enhance a YA's self-determination and autonomy, the study was advertised using a poster advert and video on social media platforms (Facebook and Twitter) with easy accessibility to YAs. The poster advert (Appendix 4) detailed how interested people could voluntarily take part in the research, by contacting the researcher via email or telephone to opt into the study (see section 3.8.2). This ensured that there was no coercion in the recruitment process and that interested participants were able to self-determine and make autonomous decisions to take part in the study.

3.15.3. Respect and privacy

Research participants were treated with respect and their privacy was protected as they were assured that their involvement in the study will not be disclosed to anyone apart from the researcher and supervisors who will have access on a need-to-know basis only. Interviews (face-to-face or virtual) were held at a suitable time and place as per participants' preferences. To ensure transparency, all participants were made aware that any disclosure of information that related to professional misconduct, abuse or harm will invoke the safeguarding of adults' policy (Department of Health and Social Care Act, 2021) as the researcher has a duty of care as part of her professional code of conduct (Nursing and Midwifery Council, 2018).

3.15.4. Trust

Trust is essential in qualitative research studies especially where interviews are conducted, to enable participants to openly share their experiences with the researcher who is considered an outsider (Lobiondo-Wood and Haber, 2018). Participants develop trust when they engage in a research study, therefore it was essential for the researcher to maintain this mutual trust established throughout the study (Lobiondo-Wood and Haber, 2018). The researcher ensured that participants' well-being came before the study, therefore ensuring they received all the information about their participation in the study. Counselling and advocacy system were put in place to minimise any emotional discomfort during and after interviewing participants.

3.15.5. Power relationships

Inherent power imbalances can exist during the participant-researcher interactions when people participate in a research study, especially during the interview where the participant is asked questions by the researcher (Creswell and Poth, 2018). It was important to manage and reduce this imbalance by being honest and truthful to participants about what was involved in the study, and what would happen during their participation in the study (Lobiondo-Wood and Haber, 2018). The participant's individuality and autonomy were respected during the collection of the data while recognising my own subjective lens (Creswell and Poth, 2018).

Strategies taken to reduce the influence of power imbalances in the recruitment process are documented in the PIS (Appendix 5). Participants opted into the study and participated as equals as they self-determined their life stories they shared without any coercion, voiced out their concerns and were given a contact at the University should they have any complaints. Participants were made aware they could withdraw from the study at any time, but any data collected two weeks after interviews would be retained.

3.15.6. Confidentiality and consent

The confidentiality of participants was maintained throughout their participation. Each participant was assigned a unique identification number and identifiable information such as consent forms (Appendix 6) were anonymised so that the interview data could not be traced back to them. These identifiable data and all interview data including sound files generated during the study were stored in separate folders on a password-protected laptop and University cloud storage. The researcher adhered to the information governance and data protection act (Data Protection Act, 2018 and General Data Protection Regulations (GDPR), 2018) and policies of the University. Only the researcher and supervisors had access to the non-identifiable data on a need-to-know basis. Anonymised names will be used for quotes in publications to avoid data being traced back to participants (see section 4.2).

3.15.7. Discussing sensitive issues

Some YAs may perceive discussing treatment choice as a sensitive issue, therefore, supportive measures were put in place (see Appendix 5) to ensure that participants who may become distressed during the interviewing process were supported. Before interviews were conducted, the participants were asked to have a named person and their telephone number who they may wish to speak to, should they become upset during the interview. It is possible for some YAs to experience discomfort or upset while talking about their experiences, therefore participants were observed during interviewing for non-verbal clues of discomfort. Interviews were paused to give time for participants who became upset while sharing their experiences to recover in a small number of situations. Following recovery, interviews were resumed as per the participant's preference but none of the participants had a need for psychological support.

3.16. Data collection

The researcher organised and conducted interviews with participants after receiving their consent to be interviewed. The interviews were audio-recorded digitally which allowed the researcher to concentrate on the discussion and the dynamics of the interview. Transcripts were sent to each participant to confirm the interview content, as this strengthens the credibility of the data. This is because participants are part of the research process and count as member checking (participant validation) of the data content (Birt *et al*., 2016). Therefore, it was important for them to check the authenticity of the transcribed information about their experiences. The length of the interviewing time of participants ranged from 31.20 to 101.21 minutes with an average duration of 57 minutes (see Appendix 10). The transcribing of the data collected is next considered.

3.17. Transcribing

Transcribing is a complex interpretive process where attention is given to the details of the oral speech and the written text (Brinkmann and Kvale, 2015), which is the first step in data analysis (Savin-Baden and Major, 2013). The conversational interaction between the two physically present people is abstracted and fixed in a written form, different from the evolving conversation that occurred between the researcher and the participants during the interview (Brinkmann and Kvale, 2015). The meaning of transcription from a linguistic viewpoint is the “translation from an oral language to a written language where the construction involves a series of judgements and decisions” (Brinkmann and Kvale, 2015, p. 204).

The interview data were translated verbatim by the researcher from an oral discourse into a written discourse during the transcribing process (Brinkmann and Kvale, 2015). This step was done with accuracy as it is vital to enhancing the researcher’s understanding of YAs' decision-making experiences. Bailey (2008) asserts that the goals of a study, the philosophical and methodological assumptions of the researcher influence the contents of the transcripts. The participant’s tone, pacing, timing, pauses, and verbal tics such as um, erm, and ah were noted during the transcription as they hold vital clues for the interpretation of the data in addition to the words spoken (Savin-Baden and Major, 2013). This is because meaning may not be in just what a participant says but also in the way it is said (Bailey, 2008). The data analysis framework considered is next discussed.

3.18. Data analysis

The study adopted Braun and Clarke’s (2021) six-phase thematic analysis approach as it is flexible and suitable across different epistemological and theoretical perspectives. Their thematic method was recently updated and renamed reflexive thematic analysis (reflexive TA) (Braun and Clarke, 2019). There are different approaches to analysing qualitative data which are underpinned by different paradigms and theoretical frameworks (Creswell and Poth, 2018). Making decisions about the choice of data analysis method can be challenging especially for novice researchers (Evans, 2018) because of the similarities of the process used yet having differences (Braun and Clarke, 2013).

Although, other analytic approaches such as content analysis, narrative analysis, framework analysis, and interpretative phenomenological analysis were considered initially, they were not used as they have different foci (Creswell and Poth, 2018; Savin-Baden and Major, 2013). A summary of the analytic methods considered and the reasons for not choosing them has been explained in Appendix 11. I will now explain the rationale for choosing Braun and Clarke's (2021) reflexive TA approach.

3.18.1. The rationale for choosing Braun and Clarke's (2021) reflexive thematic analysis

Crotty (2017) asserts that the chosen analytical approach must align with the paradigm, methodology, and methods of the study to ensure consistency in the processes undertaken to generate knowledge. Crotty (2017) explained that the choice of the analysis approach tends to be driven by the researcher's views and values on how knowledge would be generated, the theoretical underpinning of the methodology, and the methods used for the research study. As this study was informed by constructivist epistemology, interpretive paradigm, and interpretive methodology, the chosen analytical approach must be compatible with the epistemology, interpretive paradigm, and methodology.

The data analysis aimed to make sense of and interpret the meaning of YAs' lived experiences of dialysis and/or kidney transplant decision-making. Therefore, this knowledge would be best generated inductively from the raw data rather than deductively from a theory. Reflexive thematic analysis (TA) was chosen as it is flexible and not aligned to a specific theoretical or epistemological perspective and compatible with different paradigms and methodological approaches (Braun and Clarke, 2017). TA is generally used for analysing, identifying, and reporting patterns or themes within qualitative data (Braun and Clarke, 2013; Maguire and Delahunt, 2017; Jugder, 2016). The term TA is viewed as a broad term for various analytical approaches whose focus is to identify patterns of meanings within qualitative data (Braun and Clarke, 2013).

TA has been used broadly in qualitative analysis to mean different things which have contributed to some of the confusion about its usage (Javadi and Zarea, 2016; Terry *et al*., 2017; Vaismoradi *et al*., 2013). For example, TA has been viewed as a phenomenological method (Guest *et al*., 2012) or used interchangeably with content analysis and discourse analysis (Terry *et al*., 2017; Braun and Clarke, 2017). Despite these perceptions, there are different versions of TA (Boyatzis, 1998; Javadi and Zarea, 2016) that share some theoretical flexibility, but differ in the techniques used to produce themes and are underpinned by different philosophies (Braun and Clarke, 2013).

Reflexive TA is a data analysis method that offers theoretical flexibility and not a methodology (Braun and Clarke, 2013). The theoretical flexibility relates to the perception that “the search for, and examination of, patterning across language does not require adherence to any particular theory of language, an explanatory meaning framework for human beings, experiences or practices” (Braun and Clarke, 2013, p.3). This means that reflexive TA is suited for use from essentialist to constructionist paradigms, across different theoretical frameworks and methodologies (such as interpretive phenomenology) to analyse and identify patterns, and meanings of an experience within the data (Braun and Clarke, 2013).

Reflexive TA can be used within different frameworks to explore different types of research questions such as questions that relate to people's experience, views or perceptions, or the construction of meaning or understanding of an experience (Braun and Clarke, 2014), which this study is about. Reflexive TA is used across applied, behavioural, and social sciences (Braun and Clarke, 2019). It has also been used to analyse case studies (Cedervall and Åberg, 2010), literature reviews (Cruzes and Dybå, 2011), lived experiences (Rance *et al*., 2017) and phenomenological studies (Smith *et al*., 2009). Reflexive TA was used because it was compatible with the constructivist epistemology, interpretive paradigm, methodology, and methods of the study.

Reflexive TA suited the exploration and understanding of the meaning of a lived experience (Braun and Clarke, 2014). Another reason for its adoption was the structured analytical process as it provided a systematic way to explore and identify the patterns of meaning across the data that addressed the research question and objectives (Braun and Clarke, 2021). Reflexive TA can analyse complex experiential contexts and phenomena (such as decision-making) to provide rich interpretation and meaning of the experience (Braun and Clarke, 2013; Maguire and Delahunt, 2017). To understand and interpret the meaning of participants' lived experiences of dialysis and kidney transplant decision-making, the analysis must be grounded in the participants' situational contexts.

The meaning of an experience in hermeneutic phenomenology always relates to particular contextual situations, hence, meaning is contextually bound (Hekman, 1984). Therefore, the analysis that was performed had to be grounded in the participants’ contexts to develop a rich interpretation which reflexive TA offered. Using reflexive TA allowed the exploration of meaning and the analytical interpretation of participants’ experiences from multiple perspectives, such as the timing of situated events, psychosocial effects, and their socio-cultural interrelationships of the experience. Reflexive TA recognises the researcher’s involvement in the analytic process and uses reflexivity to make open the researcher’s influence on the analytic process (Braun and Clarke, 2019).

The system of meanings within interpretive phenomenology is the subject of how a person experiences and constructs their world (Patterson and Williams, 2002). This hermeneutic assumption is also held by social constructionism, which asserts that people construct the meaning of their social interactions within their world (Crotty, 2003). The researcher takes this viewpoint, that YAs with ESKD who experience dialysis and kidney transplant decisions would construct the meaning of their experience from multiple perspectives as they interact with their intersubjective world during treatment decision-making. The research question is about understanding how YAs experienced dialysis and kidney transplant decision-making. Therefore, the analytic approach chosen should have this experiential focus to analyse YAs’ lived experiences of dialysis and kidney transplant decision-making from multiple viewpoints. Having explained the rationale for choosing reflexive TA, I will now discuss how the analysis was conducted.

3.19. Data analysis process

Data management is important during the analysis process and the researcher must decide whether a manual method (for example, the use of paper, pencils, markers, and post-it-notes) or software tools such as NVivo is needed, and how they intend to use it in their research. Qualitative Data Analysis Software (QDAS) tools such as NVivo have been used to store, manage, and analyse data in qualitative research (Jackson and Bazeley, 2019). Jackson and Bazeley (2019) suggest that the use of software tools such as NVivo should be informed by the research aim and not the ease of use or familiarity. Bailey *et al*. (2018) used NVivo to analyse data for their systematic literature review while Zamawe (2015) used it to code transcripts and audio files and write reflexive notes.

Despite the advantages of using NVivo, it can be challenging especially for a novice researcher. While the use of NVivo for data management and analysis was considered initially, it was not used. As a novice, my experience of using NVivo for my integrative literature review was less successful than expected as I struggled to navigate around aspects of the programme during the analysis of data. Despite spending a lot of time extracting data from primary papers and coding them I struggled to manage the complexity of the process and had to resort to a manual method to complete the analytic process. Therefore, NVivo was not used as I felt less confident being able to interrogate the data iteratively to generate themes like the manual method. Other computer software tools such as Microsoft Word and Excel were used during the data analysis of this study.

An iterative process was used to perform inductive analysis from the raw data using Braun and Clarke’s six-phase reflexive TA approach (Braun and Clarke,

2021) to identify themes. This involved a rigorous process of (i) familiarisation with the data; (ii) coding; (iii) generating initial themes; (iv) developing and reviewing names; (v) refining, defining, and naming themes; and (vi) writing-up an interpretive report of the analysis (Table 3.2). The analysis process is iterative where the researcher moves backwards and forth between the different phases of the analysis (Braun and Clarke, 2021). These repetitive movements allowed the researcher to assume the hermeneutic circle (in hermeneutic phenomenology) to gain an understanding and the meaning of the participants' experiences (Patterson and Williams, 2002; Pietkiewicz and Smith, 2014).

Table 3. 2 Braun and Clarke's (2021) six phase analysis approach

Phases of analysis	Description
1. Familiarisation with the data (section 3.19.1)	Reading and re-reading the data while listening to the audio-recorded data for familiarisation and immersion of the data and noting of initial analytic ideas.
2. Coding (section 3.19.2.)	Generation of succinct labels or codes of the entire dataset that identify important areas of the data which are relevant to answering the research question. These initial codes capture individual meanings or concepts associated with sections of the data identified to be of interest. Relevant data extracts are also identified. Both coded data and the relevant data extracts are then collated for later analysis.
3. Generating initial themes (section 3.19.3)	Examination of codes and collated data to identify significant broader patterns of meaning which constitute potential themes. This phase is an active process involving the compilation of clustered codes that share core concept. Codes are re-coded by identifying similarities and patterns within the data and themes constructed. The collation of data relevant to each theme is reviewed for viability by mapping their interrelationships and connections to the identified patterns.
4. Developing and reviewing themes (section 3.19.4)	Candidate (main) themes are checked against the dataset to ensure that the themes make sense in relation to the coded extracts and full dataset to tell a convincing and compelling story. The themes are refined and mapped to ensure they fit together to answer the research question.
5. Refining, defining, and naming themes (section 3.19.5)	Detailed analysis of each theme is developed to identify the scope and focus of the story it conveys and to ensure each theme is built around a strong concept and decide on the informative name of each theme.

6. Writing up (section 3.19.6)	The final phase of bringing together the analytic narrative and data extras to produce a coherent and persuasive account of the data and contextualising it with existing literature.

3.19.1. Phase 1 Familiarisation with the data

This is the first phase of the analysis where the repetitive reading of the transcripts was performed to allow immersion and familiarisation of the data (Braun and Clarke, 2021; Maguire and Delahunt, 2017). Finlay (2011) argues that interpretation of meaning starts from data gathering and analysis, as meaning is not randomly imposed or imported from an outside source but constructed. The data were read and re-read while listening to the audio recording initially, which allowed the researcher to relive the interviewing moment, noting the moods, tones, initial codes, and thoughts about the data. Initial thoughts about the data, codes and patterns identified were noted on the transcript in Microsoft Word (see Appendix 12). The repetitive reading was the start of letting the phenomenon of interest from the participants' experiences appear to me as I imagined the participants' experiences to develop deep and initial knowledge about the data (Braun and Clarke, 2021).

The interpreting of the data captured Heidegger's notion of appearing, which is an important part of interpretive phenomenology (Smith *et al*., 2009). Interpretation is about uncovering the meaning of a lived experience from participants' situated context (Finlay, 2011). This is because the experience always presents itself in a manner that is at the same time self-concealing (Moran, 2000). This familiarisation process allowed the researcher to move between an insider and outsider perspective to gain an understanding of the experience (Pietkiewicz and Smith, 2014).

3.19.2. Phase 2 Generating codes

Phase 2 is where the coding (semantic or latent) of items of interest to the study identified from the data were conducted to capture specific and particular meanings within the dataset (Braun and Clarke, 2021). The process of coding allows a close examination of the data through critical listening of the recordings and marking of visual images or reading of the text (Savin-Baden and Major, 2013). Coding is a process where the researcher defines what the data are about (Charmaz, 2006) and forms the building blocks for creating themes (Braun and Clarke, 2006; Braun and Clarke, 2021). The study is concerned with understanding a lived experience, therefore, an inductive approach was taken to construct the codes, and no pre-set coding was used.

A detailed line-by-line coding of all the data was performed to capture segments of the data of importance to the experience that related to the research question. The semantic (captured "explicitly-expressed meaning") and latent (focused on deeper "conceptual level of meaning") (Braun and Clarke, 2021, p. 57) codes were created and segments of the data that described key moments of the lived events were extracted and noted. All coded items were then collated in Microsoft (MS) Excel, then organised under broader headings to capture the experience, and organised into meaningful groups (see Appendix 13). Questions were asked about the data during the analysis to illuminate the researcher's understanding of the text which provided helpful interrogation of the data and enhanced interpretation and meaning of participants’ experiences.

3.19.3. Phase 3 Generating initial themes

Phase 3 of the analysis began after all the codes and data extracts had been collated (Braun and Clarke, 2021). The identified patterns, attitudes, perceptions, interactions, and meanings about the experience from the data set provided codes for the patterns of themes (Savin-Baden and Major, 2013). The different codes were grouped into potential meaningful patterns of themes and the collation of all the relevant extracts for the identified themes was done. Through this interpretive and analytic process, consideration of how the different codes could be combined or grouped to create an overarching theme for similar codes and nuances was thought about. Questions were asked about the relationships between codes, themes, and the different levels of themes to understand how they fit together to tell the story of the participants' experiences.

The patterns or initial themes were then categorised and clustered by looking at how often they were coded using MS Excel and colour-coding (Appendix 14). Connections were searched among the codes for commonality and opposing relationships and grouped to form candidate (main) themes while others were grouped to form subthemes (Braun and Clarke, 2021). The codes were then displayed using visual mapping for theme generation, development, and review. This phase ended with a collection of candidate (main) themes and subthemes (see Appendix 15) and data extracts setting the scene for the fourth phase of the analysis.

3.19.4. Phase 4 Developing and reviewing themes

Developing and reviewing candidate (main) themes occurred in phase 4 which was done in two levels (Braun and Clarke, 2021). All the collated extracts for the themes and identified themes were re-examined to see if the main themes formed a coherent pattern. Where a main theme did not fit, it was moved to another category where it best fitted or shared similar concepts. Where codes fitted in more than one category, it was re-examined and put in the categories that best described the experience. The themes were refined and renamed under broader overarching themes or separated where necessary when the theme did not fit together, to create new candidate themes.

All the categories of the main themes and subthemes were explored for meaning in the light of the experience and how they answer the research question. Patton (2015) asserts that the use of internal homogeneity and external heterogeneity is a good way for judging the categorisation. The themes were checked for consistency and coherency to ensure they fit together to provide meaning and interpretation of the decision-making experience and clear distinctions between the themes. Following the reviewing and refinement of all themes, a thematic map of the themes was created (see Appendix 16). The mapped candidate themes were checked for accuracy to ensure that the themes reflected the meaning of the decision-making experience for the whole data and tell a coherent story about the experience to ensure the validity of the individual themes (Braun and Clarke, 2021).

3.19.5. Phase 5 Refining, defining, and naming themes

The candidate themes were defined and named to identify what each theme is about and the aspect of the experience it captures in phase 5 (Braun and Clarke, 2021). The collated data extracts of each were examined and organised into a coherent and consistent account with narratives written about them highlighting the key areas of interest about the experience. Each theme and subthemes identified were reviewed for the interrelationship among them and demonstration of any hierarchy of meaning of the experience after which the final themes were concluded (see Appendix 17). The remaining themes were further examined and defined to conclude the final subthemes (see Table 4.1).

Interpretivists assert that “any description of a lived experience has to be seen in the context of that participant’s experience” therefore a contextual interpretation was needed (Finlay, 2011, p.112). The interpretation was needed to bring out how meaning occurs in the participant-related context, the researcher, and the whole research (Finlay, 2011). Understanding within hermeneutic phenomenology occurs with the fusion of horizons (Koch, 1995). Koch asserts that the fusion of horizon is the “dialectic between the pre-understanding of the research process, interpretive framework and the resources of information” (1995, p. 835) which was important to enable the understanding of participants’ decision-making experiences. Through going back and forth during the analytic process the hermeneutic circle was engaged as the part became part of the whole and the whole became part as the researcher tried to make sense of participants’ sense making during the researcher-participant co-construction of knowledge (Smith and Osbourn, 2003).

3.19.6. Phase 6 Writing up

Phase 6 is the final analysis which began after the final themes and subthemes were concluded (Braun and Clarke, 2021). This phase involves thinking about how participants’ stories of decision-making could be crafted to tell a coherent story about their experiences bringing the themes together in an analytic narrative and using the data extracts to produce an interpretive report of the experience. A selection of vivid examples from the data extracts that tell the participants' experiences of dialysis and kidney transplant decision-making was performed (see sections 4.4-4.8.3). These extracts were the participants’ own words which supported the reported themes and subthemes to tell a congruent and coherent story and give the meaning of YAs’ dialysis and kidney transplant decision-making experiences. The reporting of the analysis and how meaning was interpreted is presented in chapter four of this thesis. I will now discuss measures taken to ensure the quality and trustworthiness of the analysis process.

3.20. Trustworthiness of data

The strength of a qualitative inquiry lies in the richness of data generated and the ability to deal with complex issues (Creswell, 2013). Trustworthiness relates to the validity and reliability of the process used to conduct the research (Lincoln and Guba, 1985). Validity is one of the ways for qualitative approaches to determine the trustworthiness, authenticity, and accuracy of the data generated from the participants, the researcher’s standpoint, and readers of the account (Creswell, 2013) and highlighted by Noble and Smith (2015). The use of the interpretive phenomenological approach and reflexivity allowed the researcher to be open about personal biases that may have influenced the process (Noble and Smith, 2015).

Trustworthiness relates to the rigour (see section 3.20.1) taken to conduct the study and whether the findings are believable. It was important to ensure the truthfulness of the findings, their authenticity, and their quality (Cypress, 2017). Trustworthiness also relates to the credibility and dependability of the process used in conducting this study as well as the transferability of the findings (Creswell, 2013). Yardley (2008) suggests four broad principles for determining the validity of a study: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance, which are discussed in depth (see sections 3.20.1-3.20.5).

3.20.1. Rigour of analysis

Rigour is a way of expressing the attributes that relate to the quality of the qualitative research process (Sandelowski, 2002). The concepts of credibility, dependability and transferability were used to evaluate the rigour of the study (Streubert and Carpenter, 2012). Ensuring rigour requires commitment and demonstration of sensitivity to the context (Smith *et al*., 2009) and the theoretical constructs (Tracy and Hinrichs, 2017) by the researcher. Commitment and sensitivity were demonstrated by engaging with participants as equals, respecting and accommodating their individuality, establishing rapport with them, and managing the power dynamics during the interviewing process. This led to the development of trust, which was maintained throughout the study. The research data were collected ethically and analysed systematically, which aligned with the theoretical constructs informing the study and ensuring rigour of the study

(Tracy and Hinrichs, 2017). Member checking, which is the process where study participants check the credibility of the data and/or results of a qualitative study, was used to enhance its rigour (Brit *et al*., 2016). Each participant verified and confirmed the content of the data (transcripts) that was returned to them as the true reflection of their experiences shared with the researcher.

Smith and McGammon (2017) argued that the use of member checking may be an ineffective way of verifying the data due to the researcher's inability to ascertain that each participant truly checked the data and the lack of reporting of any identified disagreements. However, member reflections, which is a practical way of exploring the authenticity and managing any contradictions within the data generated and/or its interpretation is recommended (Schinke *et al*., 2013). Member reflections allowed discussions with participants about how to manage any discrepancies within data and/or its interpretation if identified as a way of generating additional data and insight to ensure rigour of the study (Schinke *et al*., 2013). No contradictions were identified within the data generated. Keeping an audit trail of how the analysis was conducted, a systematic process that allows other researchers and readers to follow the analytic process, adds to the rigour of the study.

3.20.2. Credibility

The credibility of a qualitative study lies in the truthfulness of the findings, which is demonstrated in how data were analysed and interpreted (Creswell, 2013). The credibility of the analytic process lies in its sensitivity to the context, commitment, rigour, transparency, the coherency of the narrative produced, and the importance, and impact of the analysis (Finlay, 2002a). The interpretations and final themes were grounded in the data to ensure that the claims of the research are contextual as this strengthens its claims (Creswell, 2013). The researcher's supervisory team checked the analytic process and themes identified to ensure the themes are coherent and consistent, which indirectly audited the process.

Patton (2015) asserts that the credibility of the researcher is also vital because the researcher is the main person who collects and analyses the data. The detailed processes undertaken during the conduct of the study have been documented in this thesis, which demonstrates transparency and openness and adds to its credibility (Tracy and Hinrichs, 2017). Being open about my professional background and knowledge of kidney disease and its treatment options to my participants, the reason for the study, and what was expected of them, also adds to the credibility. This openness enhanced trust in the researcher-participant relationship during the conduct of the study.

The process of the study was presented at School Panel Review meetings where the research processes and progress were thoroughly scrutinised by independent researchers. Presentations at the university's doctoral student conferences and peers during doctoral support meetings provided another opportunity for the study to be critiqued and scrutinised, which also added to its credibility. Monthly briefing to my supervisory team also provided another layer of credibility to the study as ideas and processes were challenged, which offered the researcher the opportunity to critically evaluate the progress and ensured clarity and efficient conduct of each stage of the study.

3.20.3. Dependability

Dependability is concerned with the reporting process used to undertake the study to enable other researchers to see what has been done, the consistency and coherency between the data and findings (Lincoln and Guba, 1989). Qualitative researchers employ diverse ways to check for the accuracy and consistency of their findings to improve the reliability of the study (Creswell, 2013). For example, the participants checked the content of data collected while other research members checked the themes for consistency and achieved agreement on the final themes (Gibbs, 2007). The documentation of the study process from its setup to the conclusion, describing the processes involved and how the study was conducted in this thesis, demonstrates transparency of the study and makes the study dependable (Smith *et al*., 2009).

Yardley (2008) maintains that a good qualitative study demonstrates sensitivity to the context. The systematic approach used for the data analysis ensured a thorough interpretation of the data was achieved (Yardley, 2008). The validity of this study also lies in the rationale for interpretive phenomenology methodology, the methods for data collection, and the data analysis approach, which ensured sensitivity to context (Smith *et al*., 2009). The auditing process also strengthened the credibility of the systematic processes, which ensured that the themes developed were coherent and consistent, demonstrating sensitivity to the decision-making context.

3.20.4. Confirmability

Confirmability relates to how the findings and interpretation are grounded in the data collected, therefore, the researcher ensured that findings and interpretation related to the data generated (Liamputtong, 2013). The degree of fit between the underpinning theoretical framework and the conduct of the research study shows the coherence of the elements of the research process (Yardley, 2000). The knowledge added to the existing body of evidence, recommendations made and the implications for clinical practice reflects the impact and importance of this study. Finlay (2011) asserts that interpretation is needed to bring out meanings from the context because the meaning of a phenomenon tends to be either implicit or hidden.

The interpreting of data was captured as the researcher allowed things to appear during the data analysis, as suggested by Heidegger (the notion of ‘appearing of things’*)* as an important part of interpretive phenomenology (Smith *et al*., 2009). Ricoeur (1991) argues that life becomes just a biological phenomenon when it lacks meaning and interpretation, therefore it was important to ensure the correct interpretation of the data was achieved to bring the meaning of the overall experience. Grounding the interpretation of the data in the participants’ narratives and the researcher’s lens of professional knowledge and experience helped to illuminate the meaning and understanding of YAs’ experiences during the analysis and confirm the findings.

3.20.5. Transferability

Transferability is about whether the findings of the study can be applied to similar situations or contexts as a qualitative study deals with smaller samples

(Liamputtong, 2013; Lewis *et al*., 2014). Transferability is considered synonymous with the generalisability of findings used in quantitative research (Lewis *et al*., 2014). Lincoln and Guba (1985) argue that the researcher has the responsibility to provide sufficient evidence to make transferability judgements possible. This thesis provides a description of the phenomenon and contexts to the study in chapter 1 which allowed the comparison of occurrences of the phenomenon of interest described in the thesis. The integrative literature review in chapter 2 highlighted that there are less studies with a specific focus on YAs with ESKD dialysis and kidney transplant decision-making experiences.

This chapter 3 has provided a description of the methods used, such as setting, type of sampling, recruitment strategy, the eligibility criteria, and the data collection approach. This provides a thick description about how the study was conducted to offer the readers of this thesis an understanding of the study settings and connections to their social contexts, therefore enabling the readers to make judgements about its transferability (Lincoln and Guba, 1985). This would allow the readers to make informed judgements about whether the findings of this study are applicable to other situations and contexts (Jeffrey *et al*., 2005).

Although the findings of the research may not be generalisable due to the small sample size, they can be transferrable to similar contexts (Creswell, 2013; Liamputtong, 2013; Lewis *et al*., 2014). This current study provides evidence of understanding about how YAs with ESKD experienced decision-making, and this can be used to compare or conduct future work in this area, or in similar contexts such as YAs with other long-term conditions (like diabetes, cancer, asthma etc), who face treatment decision-making. I will now discuss my personal reflections and reflexivity to demonstrate transparency and my influence on the conduct of the study, which is key in interpretive phenomenology.

3.21. Personal reflections

In this section, I will explore the subjectivity and the concept of reflection in qualitative studies and my personal reflection of the research process focusing on interview and analysis process. The conduct of qualitative research involves subjectivity, which informs the choice of the research area, methodology and the interpretation of the data (Ratner, 2002). The subjective nature of qualitative research is acknowledged in qualitative literature which relates to how researchers position themselves in relation to the phenomenon and the participants experiencing it (Roulston, 2010).

The researcher reflects on their values and what they bring to the research study and how the research has influenced them (Ratner, 2002). Finlay (2002a) asserts that subjectivity although viewed sometimes as a problem in a qualitative study can be transformed into an opportunity through reflection and reflexivity. The terms reflection and reflexivity are sometimes used interchangeably to describe the reflective process in qualitative research although they are different (Ben-Ari and Enosh, 2011). Reflection and reflexivity concepts should be viewed in a continuum and both ends should be acknowledged (Finlay, 2002a).

Although there are different explanations for reflection in the literature it is centred on three main areas: “reflection as an inspection of one’s values and beliefs;

reflection as a liminal position between the studied phenomenon and analytical distance of the phenomenon; and reflection as a means of understanding the construction of one's identity" (Ben-Ari and Enosh, 2011, p.3). Driscoll (2001) asserts that the reflective process allows the researcher to "uncover and expose thoughts, feelings and behaviours that are present in a period of time" (p.96). The reflective process involves a conscious and active engagement of the researcher's dual role as an insider (with professional knowledge) and outsider (researcher), which requires constant movement between the two roles during the generation of knowledge (Ben-Ari and Enosh, 2011). Disclosing my dual role and my chosen position (researcher) during the conduct of the study enhanced the interviewing process as I understood the context and showed a lot of empathy. For reflection to take place, an experience of a phenomenon should first occur (Driscoll, 2007).

Moon (2004) highlighted the sequential stages of the reflective process which begins with having the experience, recognising the need to resolve and clarify an issue as we review and recollect our feelings including our emotional state. The process also involves the processing of ideas, and knowledge, identifying possible transformation and possible actions (Moon, 2004). The researcher is influenced by their participants and vice versa (Nakkeeran, 2010) due to the shared space during the conduct of the research (Bourke, 2014). I kept a diary where I reflected on my feelings, observations and thoughts during the data generation and analysis, decisions made, and the actions taken to enhance the transparency of the research processes. Journaling and the use of reflective diary have been used mostly in education (Alt and Raichel, 2020), and other professions, for example nursing, to explore the learner's experience (Hwang *et* *al*., 2018). Reflective journaling is a process where the researcher makes notes about their thoughts, feelings, decisions and actions during the conduct of the study, as they reflect on their experiences (Vicary *et al*., 2017).

The use of a reflective journal enabled active learning as it allowed me to reflect on the research processes (Thorpe, 2010). Reflective tools, such as structured models of reflection (John, 2013; Driscoll, 2007), are used to promote deeper reflection of self and experience. Driscoll's What model of structured reflection (2007) was used to explore aspects of my experiential learning. The model consists of (i) What? -describe the event (ii) So what? - analyse the event and (iii) Now what? -proposed action following the event. I first reflected on my values, beliefs and what I bring to the research study at the beginning of my PhD journey:

Excerpt from the diary: Who am I and what do I bring to the research? I am a renal nurse with a lot of experience in kidney disease and its management. I am going to research an area where I have practical and theoretical knowledge about kidney disease and therapy options. My professional experience and knowledge will be beneficial to the study as they will enable me to ask the right questions to explore young adults' experiences. I must be open-minded and avoid biases. I believe reality is subjective and has multiple facets, it is part of everyday life and how far reality can be explored depends on what the individual decides to share. (15/4/2019)

Knowledge and experience gained in managing kidney disease informed my interaction with participants as a professional insider during the interview because of the sensitivity of the topic. Recognising my own biases that I bring to the research context shaped how I engaged with the research process and related with the participants (Bourke, 2014).

Through using Driscoll's What model of structured reflection (2007), I was able to step back from the experience to "ponder, carefully, and persistently the meaning of it to the self through the development of inferences" (Daudelin, 1996, p.39). I reminded myself of the need to be open and neutral as a professional insider and avoid making assumptions without clarification due to my familiarity with the setting. I pondered on my observations, feelings, views, and actions during and after post-interviewing. I was able to make sense of the participants' non-verbal communication observed.

I was surprised about the level of emotions expressed by one of the participants as she shared her experiences which made me feel uncomfortable during my first interview:

Excerpt from the journal: "*very emotional throughout as she tries to withhold her tears, pinching both eyes to hold back tears but sometimes smiling. Deep grief reliving these very traumatic experiences. Lack of understanding of therapy and the feeling of being thrown in at the deep end with minimal support." (01/05/2019)*

I became concerned about the participant as she relived the experience because it felt as if it had just happened. A lot of grief and pain and mixed emotions were expressed, which made me think about how facing treatment decision-making had affected her emotions as she relived the experience. It felt that some of the emotional issues were not fully resolved. As a professional insider, I could see how low health literacy about options at the time had contributed to some of her experiences.

As a researcher (outsider), I realised that facing a dialysis decision was a big decision to make. I showed a lot of empathy and compassion as I monitored the situation closely. I wrote in my journal:

"I feel so sorry about her experience and saddened by it. I asked myself, how did they get it so wrong? as one with professional knowledge. I am concerned about her emotional state and wish I am in the same room with her to comfort her. I can't as this is a virtual interview and can only monitor the situation closely. I asked the participant from time to time if everything was okay because of the mixed emotions making sure it was still okay to continue with the interview. Although she answered yes, I listened with a watchful eye to detect when to stop the interview. I suggested that we pause the interview to give her time to recover which she reluctantly accepted before we continued. I am aware of my own struggle but gathered the boldness to ask that we pause the interview for a while." (01/05/2019)

Schon (1991) asserts that reflection can occur in-action (during the experience) and on-action (after the experience). Reflection in action made me uncover my feelings, why I felt that way and thought about what to do to manage the ongoing situation. My sadness may have been due to my motherly instinct. Secondly, as a professional insider, I realised some of the issues could have been avoided. Fales (1983) assert reflective learning occurs during reflection, a process that allows internal examination and exploration of an issue of concern that is triggered by an experience, which allows the creation and clarification of meaning in terms of self and which may bring about change in conceptual perspective.

The interviewing context was dynamic and being attuned to the situation enabled me to take prompt actions. Through reflection, I was able to resolve this inner conflict as I gained more insight into the experience. This learning was applied to the remaining interviews. My confidence grew as I probed participants' experiences, pausing the interview when needed to give them space while being supportive. YAs verbalised that talking about their experiences with me was therapeutic for them, as suggested to them by their counsellors for those who were receiving psychological support. I learnt to balance my desire to probe deeper and ensure it did not cause distress. The participants felt touched by the empathy and compassion shown which I believe enhanced their trust in me and to share their experiences. Despite these emotive experiences all the participants completed the interviews and were provided access to psychological support.

Reflecting on my experience is a way of evidencing the transparency and rigour of this qualitative study (Vicary *et al*., 2017). The learning from these experiences added value to the study as it highlighted the importance of understanding YAs' experiences and making their voices heard. I noticed that some participants occasionally would ask my opinion about their experiences, however, reiterating my position as a researcher (outsider) and not a healthcare professional prevented bias and I encouraged them to speak to their kidney care team. Post reflection after all the interviews allowed me to note the emerging pattern among participants' stories.

Finlay (2011) asserts that an individual's lived experience consists of various facets and subjective interactions which have been refracted through different lenses to make sense of that experience. Interpreting a phenomenon in hermeneutic phenomenology is important as the researcher constructs their interpretations of participants' experiences in relation to the phenomenon experienced (Band-Winterstein *et al*., 2014). The interpretation of the experience comes from both the researcher and the participants as they engage in constant dialogue during the analysis of the data and co-construct the meaning of the experience (Finlay, 2011; Smith *et al*., 2009). Through reflexivity the researcher demonstrates their influence on the interpretation of the data, which is discussed next.

3.22. Reflexivity

Reflexivity allows the researcher to explore their positioning and to understand how it contributes to knowledge construction (Swaminathan and Mulvihill, 2018). Reflexivity is a mental process (Smith *et al*., 2009). Finlay defines reflexivity as "the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied to move beyond the partiality of our previous understandings and our investment in particular research outcomes" (Finlay, 2003, p.108).

Common variations of reflexivity in qualitative research include introspection; (ii) intersubjective reflection; (iii) mutual collaboration; (iv) social critique (v) discursive deconstruction depending on the researcher's aim and focus (Finlay, 2002b). Reflexivity as introspection uses the researcher's own reflections, intuitions and thinking as primary evidence (Moustakas, 1994). Reflexivity as intersubjective reflection allows the researcher to examine mutual meanings that emerge from the research relationship where "self-in relation-to-others becomes the aim and objective focus" (Finlay, 2002b). Reflexivity as mutual collaboration "enlist research participants as co-researchers and vice versa" (Finlay, 2002b, p. 216). Reflexivity as a social critique acknowledges the tension that arises from "different social positions" such as gender, race, and class (Finlay, 2002b, p.220).

Reflexivity as a discursive deconstruction is where “attention is paid to the ambiguity of meanings in the language used” and its “impact on moods of presentations” (Finlay, 2002b, p.222).

Having considered the various reflexive models, reflexivity as introspection was chosen as it suited my research study and enabled me to explore my own emotional and mental processes to gain new insights. The reflexive process began with having an intense interest, that I am passionate about (understanding YAs’ decision-making experiences) which Moustakas (1990) asserts it calls out to the researcher. Reflexivity allowed the researcher to acknowledge her involvement in the research study as opposed to bracketing. Finlay (2002a) asserts that reflexivity is a thoughtful, conscious self-awareness analytic process. Reflexivity was performed intentionally to critically analyse the knowledge generated and the researcher’s experiences to achieve a deeper understanding of the meaning that the participants gave to their experiences, behaviours, and assumptions of their world of decision-making (Moon, 2004; Schwandt, 1997). The reflexive experience is presented in three stages: pre-research, data collection, and data analysis stage (Finlay, 2002a).

3.22.1. Pre- research stage

The process of reflexivity starts from the conception of the study (Finlay, 2002a). Beginning my research with the exploration of my experience enabled me to embrace my own humanness as the basis of my psychological understanding (Wash, 1995). Finlay (1988) cautions on the need for balance when using introspection, to avoid wallowing in subjectivity or engaging in legitimised emoting. Introspection was used to develop interpretations and insight of the experience and to make clear the “link between knowledge claims, personal experiences of the participants and the researcher and the social context” (Finlay, 2002b, p.215). I reflected on both the topic and my relationship with the topic as a professional insider and a researcher.

Privileged with knowledge about the stages of kidney disease, its management, and the need for decision-making when the kidney fails, I was aware of the potential challenges this brings to people living with the disease. Through researching existing literature and the lived account of patients during my engagement with the kidney failure PPI group, the clarification and firming of the research question was established. Being reflexive related to my continuous subjective self-awareness of the research processes and my influence during the conduct of the study as this enhanced the trustworthiness of the research (Finlay, 2002b).

Interest, motivations, and assumptions were explored to enable me to focus on the phenomenon to be researched with openness and avoided things that could divert this attention. I considered my role as a professional insider and as a researcher and how the two roles could be managed during the conduct of the study to avoid role conflict by being open to the participants of my researcher position. I acknowledged that as a researcher, I am part of the construction of knowledge as I bring my values, beliefs, and philosophical assumptions into the research context which was made open in this chapter through my reflexivity (Finlay 2002b).

3.22.2. Data collection stage

It was important to reflect on how my knowledge and experience influenced the interviewing process. Situated in a dual position of being in the participant's experience of decision-making and yet an outsider of that experience (Ben-Ari and Enosh, 2011), I moved in between the two perspectives to understand YAs' experiences of dialysis and kidney transplant decision-making. This gave me a deeper understanding of myself and that of my participants concerning the decision-making experience (Finlay and Gaugh, 2003). My knowledge and experience of chronic kidney disease and its management enabled me to negotiate those sensitivities that arose during the interviews and to support participants as they relived their experiences of dialysis and transplant decision-making.

It prepared me to ask the right questions and probe more where needed during the interviews and interrogated the data through my professional lens of experience to illuminate my understanding of YAs experiences. I took steps to avoid becoming biased or justifying the behaviours of HCPs or judging participants; instead, my professional knowledge and experience allowed me to listen carefully as YAs narrated their stories and showed empathy as I probed their experiences to understand their decision-making experiences.

The use of Driscoll's (2007) What? structured reflective approach provided me with the opportunity to reflect-in-action and reflect-on-action, to examine my perceptions and feelings and why I may have felt that way. Through this process, I identified the heightened emotions displayed by the participants as they relieved their decision-making experiences and acted promptly as needed. For example, I realised during my first interviewing that reliving the experience, brought up a lot of emotions that the participant had not fully dealt with at the time and was able to offer the participant the space by pausing the interview when the person was overcome by emotions. I considered the data collection to be sensitive as it brought back some of the traumatic events from the past (Morse, 2010) in YAs' lived experience of therapy decision-making which had to be managed. Through reflexivity, I reflected on my interviewing experiences and learnt from them, as I incorporated the learning from one interview situation into subsequent interviews to enhance my interviewing skills (Driscoll, 2007).

The interviews were very emotive as participants displayed a lot of emotions such as sadness, grief, frustration, and anger and tears were shed during the interviews. These emotions reflected how YAs felt at the time when they faced the decision-making process reliving those moments. Although I expected some emotions to be expressed, the intensity of it was less anticipated. It felt like these emotions were not fully resolved by most of the YAs. I was relieved to hear from some of the YAs that they were already receiving psychological support during the interviews. My priority was to ensure that the participants were supported, therefore, I paused interviews if a participant felt emotionally overwhelmed until they felt ready to continue. Participants were offered the opportunity to call their named support contact if they wished, however, none of them felt the need to do so.

Despite, the various emotions observed, all the participants completed the interviews. Being reflexive enhanced the researcher-participant relationship as the participants saw me as friendly, understanding and interested in their experiences and therefore felt confident to share their experiences. All participants were given contact for psychological support, provided by renal councillors through a national Kidney Charity (Kidney Care UK). In a few cases where I had concerns about a participant, a telephone follow-up call occurred three days after the interview to ensure they were okay. Having encountered a lot of emotive situations during my professional practice, I had the skills to manage the emotional contexts that ensued. Debriefing the interviews with my supervisory team also ensured that I was supported.

I was aware that power imbalances can occur during the interviewing of participants and made conscious efforts to put participants on an equal level as they were experts in their experience. I showed interest in the participant’s story as it was narrated, empathised, and showed humour when required in the researcher-participant social context (Gough, 1999). The use of rapport enabled me to gain trust as I showed respect for the participants which reflected my genuineness and passion to understand what mattered most to the participants. The meaning of participants’ experiences was negotiated between the researcher and the participants in that particular social context of decision-making (Finlay, 2002b). The reflexive analysis during the data collection allowed the identification of how the data collected was influenced by the method used and the emerging researcher-participant relationships during the interview context (Gough, 1999).

3.22.3. Data analysis stage

As a researcher, I believe YAs constructed the meaning of their decision-making experiences, which was embedded in their cultural and historical setting (Creswell and Poth, 2018). An individual's way of knowing their world is influenced by different sources such as their values, personal experiences, beliefs, other people, and the meaning derived is from their social interactions (Matthews and Ross, 2010). Therefore, their view of reality, which is socially constructed, was from multiple perspectives (Matthews and Ross, 2010; Creswell and Poth, 2018). As a researcher, I also bring my own bias, meaning, and understanding into the research, which shapes the interpretation which was acknowledged during the reflexive analysis (Gray, 2018). The qualitative paradigm chosen aligned with my epistemological position and theoretical perspectives (Lincoln *et al*., 2011) and may have influenced how the data were analysed.

The knowledge created during the research study was the result of the researcher's interactions and dialogue with the YAs' narratives of their lived experiences of making dialysis and kidney transplant decisions (Finlay, 2011; King *et al*., 2019). These interpretations were filtered through a spatial-temporal (relating to space and time) lens arising from my cultural and historical areas while bringing other contemporary ideas (Finlay, 2011). Reliving the interviewing time through reflection during the data analysis benefited the analytic process because it enhanced my ability to interrogate the data, interpret them and gain a deeper understanding through reflexivity. I attuned myself to participants' shared embodied experiences, and my intersubjectivity with the participants, in trying to understand their world (Finlay, 2011). I also constructed my social reality through the interpretation of the research findings, therefore, becoming part of what is being researched (Gray, 2018).

Using Driscoll's reflection model, I was able to relive the interviewing time to explore the participants' experiences concerning what happened when YAs faced decision-making as they relived their experiences. I also examined what I saw, how I felt, acted, and responded and what the participants did during the interviewing time as I analysed the data, which enhanced the meaning and interpretation of participants' experiences. Driscoll and Teh (2001) assert that these three elements interact within the different stages of an experiential learning cycle, where the individual has an experience and then purposefully reflects on aspects of it to discover what has been learnt and actions the new learning from the experience (Driscoll, 2007). The data collection and data analysis process was an experiential learning experience for me.

My critical self-reflections, views, and feelings formed part of the research data, and it was important for me as a researcher to acknowledge this (Gray, 2018). Through reflexivity and self-reflection, I was able to acknowledge and reduce my influence to ensure the participants' voices were heard. It was important not to allow my knowledge of treatment options, decision-making, and my professional experience to hinder the interpretive process. Instead, this was used as a lens for interpreting and making sense of YAs' experiences to make their voice heard. Immersing oneself in reflexive analysis takes time, and commitment and can be uncomfortable as it exposes how the researcher may have negatively and positively affected the research process (Finlay, 2002b). However, it is necessary to be open about how I have influenced the research because it adds to the trustworthiness of the research process.

3.23. Summary of chapter

This chapter explained the epistemological and ontological positioning and how it influenced the rationale for using the interpretive paradigm, the choice of the methodology underpinning the study, and the methods used to generate knowledge. The chapter also discussed the ethical issues considered, the quality and credibility of the research process, and how the data were analysed to understand the meaning of young adults' lived experiences of dialysis and kidney transplant decision-making. I also discussed how being reflexive enabled me to critically analyse my involvement in the study processes. The report of the findings of the analytic process is presented in chapter four to complete the interpretation of the data in the form of themes.

Chapter 4 Findings

4.1. Introduction

Chapter 4 presents the findings to the research question: How do young adults with end-stage kidney disease experience dialysis and/or kidney transplant decision-making? The study aimed to explore YAs', who are diagnosed with ESKD, lived experiences of making dialysis and/or kidney transplant decisions, to understand the meaning of their lived experiences and the effects of decision-making and choice on their well-being. The presentation of the findings includes analytical comments of the researcher's interpretation of the meaning of YAs' lived experiences of decision-making. The findings are presented as five overarching themes and subthemes to provide an understanding of how YAs engaged with and made dialysis and kidney transplant decisions.

The first two themes present the findings of YAs' experience of a world turned upside down and the experiences of information delivery about options. These themes relate to YAs' experiences of receiving a diagnosis/prognosis of CKD/ESKD, the awareness of future dialysis and kidney transplant decisions, and their engagement with options information delivery. The third theme focuses on YAs' experiences of being involved in decision-making, their decisional preferences and roles in decision-making, the importance of family, friends and others, and the reasons that influenced their choice selection presented under the experience of making my voice heard.

The fourth and fifth themes focus on YAs' experiences of receiving dialysis and kidney transplant therapy, the impact of decision-making and choice on YAs' well-being, and how they coped. The chapter will also highlight how the themes relate to Heidegger's (1962) hermeneutic existential principles of being-in-the-world as YAs experienced the decision-making phenomenon. The chapter will conclude with a summary of the findings. First, the demographic profile of the participants is presented.

4.2. Demographic profile of participants

A total of 39 expressions of interest were received via email and text from people with ESKD who had seen the study advert on Facebook (27), Twitter (6), local kidney group website (2) and word of mouth (4). Of the 39 expressions of interest 20 were recruited and two withdrew due to illness. A total of 18 participants with ESKD in receipt of dialysis and kidney transplant therapy were recruited and interviewed (Appendix 10). Initial diagnosis of chronic kidney disease ranged between stages G2 to G5 at different ages during childhood (5), adolescence (2) and young adulthood (eleven).

Participants comprised 50% males (9) and 50% females (9) with a mean age of 25.4 years (median age of 25.5 years) ranging between 18 to 30 years and from seven out of nine regions in England and one from Scotland. Participants were from different ethnicities; White (13), African (1) and Asian (4). At the time of the interview, nine participants were in either part-time or full-time employment, four were unemployed and 5 (higher education [4] and college [1]) were in education. Pseudonyms were used to protect the participants' identity and a short description of each participant is provided in Figure 4.1.

Figure 4. 1 Description of participants

Participants' description sheet

Aaron is a 29-year-old man who was diagnosed with ESKD from birth and was in tertiary education and developing his acting career. Received his first kidney transplant in childhood but failed in his young adulthood and faced treatment decision-making.

Ben is a 25-year-old man who was in his final year of college when he became unwell and was diagnosed with ESKD. Ben had never experienced any serious illness prior to his diagnosis. He had to temporarily put his education on hold.

Charlie is a 26-year-old man who was on a gap year abroad and had never experienced any serious illness until he was diagnosed with ESKD due to a rare disease. As a result, he had to stop his gap year and returned home for treatment. Currently in higher education.

Dave is a 28-year-old man who was diagnosed with ESKD from birth. He received a living donor kidney transplant in childhood and in tertiary education developing his career.

Ella is a 24-year-old woman who developed ESKD in childhood. She received a deceased donor kidney transplant which failed after six months and faced dialysis decision whilst in education.

Fred is a 24-year-old man who was working when he was diagnosed with ESKD and had never experienced any serious illness in his life. English was not Fred’s first language, therefore he sometimes struggled as he interpreted the information first in his native language to understand the information and then retranslate it back to English.

Georgia is a 26-year-old woman who had CKD stage G3 due to an autoimmune condition during her first year at university and progressed slowly to ESKD.

Harry is a 29-year-old man who had never had any serious illness until his diagnosis with ESKD in his early adulthood. He was not in education or working at the time.

Jess is a 22-year-old woman diagnosed with CKD in childhood but progressed slowly to ESKD in young adulthood. She works part-time and was in college at the time.

Joe is an 18-year-old man who was diagnosed with CKD since childhood but progressed to ESKD in early young adulthood. He was in education at the time.

Linda is a 28-year-old woman who was working part-time and in university education when she was diagnosed with ESKD. She had never had any serious illness prior to receiving the ESKD diagnosis.

Mina is a 29-year-old woman who worked and supported her family financially and had never experienced serious health problems. She was diagnosed with ESKD in young adulthood. Temporarily had to stop work to focus on her health and later continued to work whilst receiving RRT.

Nally is a 23-year-old woman who was diagnosed with CKD G4 in her early young adulthood but progressed to ESKD after two years. Although she received a perfectly matched living kidney transplantation it failed soon after the transplant. Since then, she suffered many complications due to her rare reaction to dialysis therapy. She had to change her job because of the impact of the disease.

Paul is a 28-year-old man who until his diagnosis with ESKD had not experienced any serious illness. Paul was working at the time of diagnosis and did not consider ESKD as anything major initially and was looking forward to going back to work.

Sharon is a 22-year-old woman who was diagnosed with CKD in her childhood but progressed slowly to ESKD in her late adolescence. She was in education at the time.

Steve is a 21-year-old man who was diagnosed with ESKD due to a rare genetic disease. This affected his relationship with his family, and he moved out of his home. He was not in education at the time.

Rita is a 30-year-old woman who was diagnosed with CKD stage G2 in her adolescence and progressed slowly to CKD stage G4. Following her marriage, she had a planned pregnancy which was monitored closely but progressed to ESKD 28 weeks into her pregnancy. Rita was working before this but had to stop work.

Zoe is a 25-year-old woman who was diagnosed with CKD stage G3 when she was pregnant. Following the delivery of her child, she later went on to develop ESKD. She had not experienced any serious illness prior to the diagnosis and was working at the time.

4.3. Presentation of the findings

Five main themes and thirteen subthemes were generated from the data analysis (see Table 4.1).

Table 4. 1 Themes and subthemes

Theme 1 World turned upside down Subtheme 1.1 Change of self-identity Subtheme 1.2 The experience of life thrown off track
Theme 2 The experience of information delivery about options Subtheme 2.1 Communication and understanding of choice options Subtheme 2.2 The experience of health information-seeking
Theme 3 The experience of making my voice heard Subtheme 3.1 Engaging in decision-making as equal Subtheme 3.2 The importance of family, friends, and others Subtheme 3.3 Reasons influencing decisions about choice

Theme 4 Experiencing the new normal Subtheme 4.1 Experience of receiving dialysis and kidney transplant therapy Subtheme 4.2 The experience of feeling different Subtheme 4.3 Searching for the meaning of the new normal experience
Theme 5 The impact of decision-making and choice on well-being Subtheme 5.1 The psychosocial effect of decision-making and choice Subtheme 5.2 Keeping sane and not going crazy Subtheme 5.3 Enhancing my decision-making

The first person is used to bring out the researcher's voice as I am part of the whole data (hermeneutic circle) during the analytic interpretive process to understand the participants' experiences of decision-making. My understanding of YAs' experiences of dialysis and kidney transplant decision-making is demonstrated by the illustrative excerpts from the interviews and the use of the participants' own words (quotes) in this chapter. My interpretation of data helped to contextualise the findings and how the individual experiences of YAs contributed to tell a story about their collective decision-making experiences to ensure the coherence and trustworthiness of the findings (see section 3.20.7). Driscoll's What model of structured reflection (2007) was used as a framework for reflection during the analytic process to enhance my reflexivity (see sections 3.22-3.22.3). The reflexive comments provided in this chapter gives the reader an understanding of the analytic and the interpretive comments made during the analysis process. Theme one will now be presented.

4.4. Theme 1 World turned upside down

This theme is concerned with how YAs articulated their experiences following their awareness of the need for dialysis during receipt of diagnosis and prognosis of CKD/ESKD. There are two subthemes: change of self-identity and the experience of life thrown off track. Charlie’s expression:

> *“I was having a good time and I was happy, and suddenly all that has changed. …So, it kind of turned my world upside down...” (Charlie, M, 26 years)*

illustrates the experiences of many YAs. This is because YAs experienced changes in their life which made their world turn upside down.

4.4.1. Subtheme 1.1 Change of self-identity

YAs articulated the beginning of their decision-making experiences to the time they initially became aware of the need for dialysis and/or kidney transplant therapy following diagnosis/prognosis of ESKD. The common perspective among YAs was that they experienced a change in their self-identity and life. Two-thirds of the participants (Ben, Fred, Charlie, Georgia, Mina, Nally, Paul, Harry, Linda, Steve, and Zoe) who received diagnosis/ prognosis in their early young adulthood described the change as sudden which in some cases was not considered to be serious until after diagnosis. Most YAs received the diagnosis during young adulthood, whilst some YAs (Aaron, Dave, Ella, Jess, Joe, and Sharon) had the disease in childhood or adolescence (Rita).

YAs experienced a change in their ability to function and perform daily tasks because of their physical limitations and weakness. The perceived changes and multiple losses experienced that occurred around that time affected YAs emotionally and they struggled to understand why their life had changed. Fred’s experience illuminates how a change in his self-identity happened suddenly:

> *"I was working in [pizza shop] ... I just noticed that I was really getting weak like I can't do anything. Like I cannot lift my hands properly* sometimes *and I get very slower than everyone. I was like in pace with everyone, but I got really slow and then I thought it was like maybe flu or something else so take a week off. I did that then I was totally useless [laughs but looks upset] and then I went to doctors." (Fred, M, 24 years)*

Fred used the expression "totally useless" to illustrate a change in his self-perception and self-identity because of the loss of health. Charlie also expressed:

> *"…it came as a little bit of a shock to me; from being a healthy fit person, who was hiking all the time, to sort of suddenly you know, having this new life of taking medication all the time and all that sort of stuff and knowing that somewhere in the future I will need dialysis and transplant… [looking very sad]…it was really quite shocking and erm a bit overwhelming really." (Charlie, M, 26 years)*

The expression "from being a healthy fit person, … to having this new life of taking medication all the time" describes Charlie's awareness of the change in his self-identity from being a healthy fit person to a person who is sick and incapacitated. The comparison of his past lifestyle to the new lifestyle demonstrates the changes that occurred.

The change in self-identity was long-term and permanent due to their lost health. Likewise, Fred said:

> "*I was really like active, running a lot and then doing things and then all of a sudden, I feel like I can't do anything."* (*Fred, M, 24 years)*

Thus, he compared his past self with his present to demonstrate his functionality and the changes that occurred. The use of "I can't do anything" links back to Fred's previous use of "totally useless" as imagery to illustrate the change, thus illuminating the understanding of the impact of the change of his self-identity experienced.

The realisation of the sudden change in self-identity which is how YAs felt about themselves because of kidney disease was difficult to assimilate. Many YAs experienced fear, anxiety, confusion, and uncertainty when they received the diagnosis/prognosis and were told of the need for an RRT decision. Charlie's expressions of "really quite shocking" and "a bit overwhelming really" reveals how the information affected him. Irrespective of whether it was sudden or gradual they all were emotionally affected because of the change in their self-identity. Sharon who had known from a young age that she would need dialysis at some point said:

> *"…I always knew that I will need one [kidney transplant] but my progression was very slow… I didn't have it until when I was sixteen, …it came as a shock because I was not expecting it." (Sharon, F, 22 years)*

Different phrases or words were used to illustrate how YAs felt when they realised the change in self-identity, performance, and functionality, and experienced a loss of health. For example, Fred used: "I was really upset", "thought different" and “emotional”. While Joe expressed: “it was nerve-racking”. Other phrases such as: “I found it really hard” (Georgia); “it was just kind of scary and confusing” (Steve); “anxious and nervous” (Ben); or “it all came as a surprise…” (Mina). These expressions conveyed the effect of receiving news of a diagnosis/prognosis of ESKD and the need for dialysis and/or kidney transplant therapy which caused their perception of their self-identity to change. YAs either wept or looked sad as they relived that moment of realisation that their once healthy self-identity was lost. The change in their self-identity marked the beginning of a new self-identity (a weak and incapacitated self). The emotional grief expressed by YAs was associated with the permanency of the change in self-identity. At the same time, some felt their family did not realise the change was permanent.

Most YAs like Linda could not believe their healthy self-identity would one day change forever within a short space of time and were impacted by it. Linda expressed:

> *“I was kind of just in shock. Because I didn’t think anything like that would happen…” (Linda, F, 28 years)*

Many YAs struggled to understand the changes due to the presence of ESKD, which has caused their perception of their self-identity to change. This was worse among those who were diagnosed in their young adulthood compared with those who had it in childhood. This is illustrated by Mina’s experience: “*I really struggled for a long time to get my head around it.” (Mina, F, 29 years)* whilst Harry said: *“it took me a while for it to sink in”. (Harry, M, 29 years)*

The inability of some YAs to get an explanation of how they got ESKD, which in turn caused a change in their self-identity, led to frustration and anger. Zoe who was overcome with emotions said:

> *"I had a biopsy, and they haven't been able to actually figure out why this is happening. So, there is no disease, so there is kind of nothing like that. [weeping]." (Zoe, F, 25 years)*

Linda however, felt confused:

> *"…it was just kind of confusing as to why I have got it, and then I wanted to know what happened to the kidneys… Because they never explained what happened to them, yes. They just said there was no cause of what happened that they could explain to me.… that is what kind of happens and they don't really know why. And it was just like no one knows what has caused it. Like it made it harder to explain to myself what has happened". (Linda, F, 28 years)*

The expression "it made it harder to explain to myself" sums up Linda's frustration or understanding and difficulty to accept a diagnosis (identity change) and the lack of closure as also experienced by Mina:

> *"We don't know, erm they don't know why I've got kidney failure. It was never discovered. I just have it, which is kind of frustrating in a way because I don't really have an answer to it." (Mina, F, 29 years)*

These expressions shows that experience is not isolated but intersect with the YA life. For example, internal struggles and frustrations to understand why the presence of ESKD had brought a lot of changes in their body as they lost their previous healthy self and experienced a change in their self-identity. Not knowing why they got the ESKD made it difficult for YAs to find closure.

Some YAs experienced guilt and self-blame. For example, Paul who felt his dad thought his behaviour might have contributed to the development of ESKD expressed:

> "*…my dad was a little bit convinced that maybe some of the supplements I was taking had done it [caused the ESKD]. …he at one point also thought…maybe me being vegetarian might have caused it…. which I mean wasn't particularly helpful, to be honest. …during the time I thought I must have done this to myself because there is no family history. Erm, I must have given myself kidney failure by taking those supplements and things like that erm, so I did start to convince myself that was the case." (Paul, M, 28 years)*

Although Paul believed the assertion that he may have brought ESKD on himself because of his lifestyle, the biopsy report revealed that was not the case and he felt relieved. Collectively, YAs expressed a lot of grief as they relived that moment, from the observations made during the interviewing time.

YAs expressed how the changes to self-identity affected their families who struggled to understand the change in their self-identity, which is illustrated by Mina's experience. Mina said:

> *"I think they've [parents] struggled to understand it……my dad…was upset as well when my doctor finally said that this is a long-term thing. This is it,*

> *it’s going to you know have a change in her life, so he was upset about that.” (Mina, F, 29 years)*

Reflective box dated 30th of January 2020

This reflection was written at the end of the participants' interviews as I thought about their experiences. Each YA’s story is different, yet it was similar. YAs were going about their normal life when they became ill and were faced with major decisions-dialysis and/or kidney transplant therapy that would affect their life forever. I tried to understand the trajectory of YAs' decision-making experiences as I began to imagine the scene of YAs' situated events. I felt I shared the temporary space of receiving a diagnosis and being aware of the need for dialysis and/or kidney transplantation and the experiences that followed. This is because the narration of their experiences was so vivid as if it had just happened. The observed emotions during the interviews revealed the intense grief they had endured.

Managing YAs’ emotions was my priority, as I paused to give them time when they were overcome by emotions and sobbed until they felt ready to continue. Giving YAs that space and time to recover from their emotions and being there for them and reiterating to them it was okay and I understood them enhanced the trust. I was happy with how I dealt with YAs’ emotional situations as they felt comforted and supported. Being a parent myself I felt their expression of grief and fears when they lost their once healthy self-identity and faced an unknown future.

During the interviewing time, although I sometimes felt sad, I acted ethically and professionally as I showed a lot of empathy to the YAs who expressed a lack of understanding of why their healthy self-identity had changed overnight and their future was uncertain and in limbo. As I pondered over their experiences, as a mother, I understood YAs' expressions about the self-blame experienced by some of their parents who felt helpless as they watched their children experience a loss of their once healthy self-identity and face a threat to their future. At the same time, I could not understand why many did not receive psychological support to help manage the emotions experienced at the time.

On a positive note, I was glad that some YAs later found psychological support and were able to accept their situational events. This is why a multidisciplinary approach when breaking such sensitive information to YAs and working collaboratively to offer the needed support during that time is important. I feel the study was timely as it provided me with an insight into the lack of sensitivity with which some healthcare professionals inform people about diagnosis and/or prognosis that has profound consequences to changing one's situation and the therapy that awaits them.

4.4.2. *Subtheme1.2 The experience of life thrown off track*

The experience of life thrown off track is how YAs expressed the effect of the changes and perceptions about the future. Most YAs at the time of the decision-making were engaged in either education, travelling, employment, or starting a family. YAs felt their lives were thrown off track because of the threat to their immediate and future life. Most participants had to either put their education, career, or work on hold. The physical effect of ESKD experienced, reduced YAs' ability to participate in active activities because of the lack of strength, and they felt their life was thrown off track, as illustrated by Fred's experience:

> *"I cannot play ice hockey; I cannot do anything I like. I cannot go for beer outside with my friends anymore. …Well, I was able to do most of the things [previously], but I couldn't because like I had no strength to do" (Fred, M, 24 years)*

Others felt their plans for their life had to be changed because of ESKD and future therapy. Drawing on Charlie's experiences, he could no longer continue with his gap year. Charlie's plan to stay abroad and work was interrupted by the changes to his health and he had to return home to England:

> *"…I could see that all those plans would fall apart, which I knew. So, it was obviously very, very, very sad... because it completely changed things, like the course of my life really. Everything that I had planned up to that point was just sort of thrown off track." (Charlie, M, 26 years)*

Likewise, stopping work temporarily was difficult for Mina because she financially supported her parents and had a perceived fear of losing her job:

> *"…I was working before then, …and suddenly I was told… that was it, stop for a while and I think that is hard for me… Having to always think about my health...but there is always the future which I'm not thinking about it now, just focussing on my health right now." (Mina, F, 29 years)*

Several YAs lived with the uncertainty of their future, and like Mina, their health became a priority. Zoe associated having dialysis with putting her life on hold, because of the perceived interference with work and family life:

> *"…I work full time, I have a daughter, and I never wanted to do haemodialysis …I didn't really want the distractions to my day where I happen to go into the hospital a few times a week…. I kind of didn't want dialysis to be my whole life and everything works around that." (Zoe, F, 25 years)*

The concept of life thrown off track also relates to YAs putting careers and education on hold or stopping completely, which was difficult to accept. For example, Aaron's transplanted kidney received from his dad as a child had failed in his young adulthood and he faced decision-making. This meant he had to put his teaching and acting career on hold because of dialysis:

> *"…it was very hard-hitting because at the time I was training to be a primary school teacher… I was really enjoying myself and it was a great experience. I've been teaching drama for many years before, but I thought this would be an opportunity to kind of further my career, and the way it hit me, …it was very hard-hitting, very difficult to hear that …. I am going to have to put everything on hold and start this new treatment." (Aaron, M, 29 years)*

The use of "very hard-hitting" and "very difficult to hear that" illustrates the difficulty of YAs accepting that their career or work had to be put on hold to start dialysis or undergo kidney transplantation. It also reflects the enormity of RRT and its impact on their life.

Those YAs in full-time education (Dave, Charlie, Ella, Jess, Joe, Linda, and Sharon) experienced disruptions with their academic work because of the constantly changing situations. Progress of education milestones went off track due to absenteeism because of hospital appointments, admissions, and receiving therapy. Joe said:

> *"I struggled generally about it. When you hear about dialysis or kidney transplant, erm you know that in the future your life will be affected… I was studying for my GCSEs, and I was scared that it might just come very soon, that it could affect me during my GCSEs or after I start college so I was scared that it might affect my course." (Joe, M, 18 years)*

The perceived interruptions caused some YAs like Joe to feel the RRT could interfere with his GCSEs or college work. Jess's experiences illustrate how she dropped out of college because of kidney transplant surgery:

> *"…it was a struggle because I was trying to work at the time and being at college. So, I had to tell my employer about having a kidney transplant in three weeks and I had to drop out of college because of it". (Jess, F, 22 years)*

The experience of life thrown off track also relates to the inability to do academic tasks due to constant interruptions caused by poor health. Some YAs (Charlie, Dave, Georgia, Jess, Joe, Linda, and Sharon) struggled to meet the academic workload, and in some cases, this affected their GCSE or Advanced Level exams, hindering their future career progression. Dave said:

> *"…throughout education, it's been a constant struggle with me and the kidney… Erm is just that constant, … I found that when I take time off, I miss only a day, even let's say in the morning and I'm like, I'm so far behind in my work already. So then even from day one, I'm playing catch up, and then it's just kind of only get worse if I'm unwell. … even when I've done my best, I'm still failing" (Dave, M, 28 years)*.

Dave's experience provides a deeper understanding of YAs' experiences of life thrown off track. Many YAs felt their best was not enough as they were still failing to achieve academic milestones compared with their healthy peers. YAs often had to change their career pathways. Dave went on to say:

> *"…especially university and stuff like that…I failed my A-levels, so I had to drop out of those. So, I went to college instead to do BTEC and stuff like that. …my GCSE maths I had to retake it three times, once was from the ward. The second time I failed was because of hospital because I missed so much, I did my best, but it was just kind of I'm not able to do it." (Dave, M, 28 years)*

Sharon said:

> *"I started it [kidney transplant workup] when I was revising for my GCSE, so it was a bit of a difficult time to do it but I kind of have to just get through it. So, I ended up having to only take maths exams…I happen to have all my other exams as course work that went towards my grades." (Sharon, F, 22 years)*

Another concept of the experience of life thrown off track also relates to YAs' perceptions regarding their inability to enter an intimate relationship, marry, or have a family because of the disease. Many YAs had the desire to have a relationship, marry and have children as did their healthy siblings, but could see this future potential going off track. Aaron said:

> *"…when you see erm so and so that I've known for how many years old and they've gone on got married and now they are expecting their first child and all of these things that I obviously want, and it's quite difficult in that sense…I was single as well at the time which is like difficult. …I've seen that with my brother, …he got married and had his first child, all of these are things I like." (Aaron, M, 29 years)*

Rita said:

> *"…before I fell pregnant, I had a lot of pre-pregnancy planning with my consultant and her joint obstetrician… I was monitored all the way through my pregnancy. Everything was okay but then when I got to 28 weeks pregnant my kidneys went to end-stage. So, I was given two options, I could either start dialysis two hours a day and see how long we could prolong the pregnancy for, or I could have the baby delivered there and then at 28 weeks with the hope of not needing dialysis for a bit longer." (Rita, F, 30 years)*

Rita felt her experience of motherhood was threatened as she had to decide to either start dialysis in exchange for prolonging the pregnancy and having a healthy baby or having a premature baby which might mean starting dialysis later.

The perceived underachievement of life goals in their adulthood milestone compared with their healthy age-related peers contributed to the experience of life being thrown off track. Harry explained:

> *"…I was only 20 when I was diagnosed, and I haven't fully lived my life yet. I haven't experienced anything… and everyone else at my age are already way ahead in terms of being an adult and things like buying a house and settling down and things like that. So, I'm being held back, and I am trying to get back to a normal quality of life." (Harry, M, 29 years)*

YAs struggled to understand and make sense of why their world had suddenly turned upside down due to the experience of multiple changes and losses. The experience of multiple changes in the body led to a change in their self-perception and self-identity. They lost their previous healthy fit self and had a new identity of being sick and incapacitated, which in turn, affected their performance of daily activities of living. YAs experienced a life thrown off track as their education, career, employment, and family had to either be delayed, put on hold, or stopped. The cumulative experiences of the changes in YAs' self-identity and the experience of lives thrown off track made their world turn upside down. To make decisions, YAs needed to ask questions, adjust, and accept their ESKD diagnosis/prognosis.

4.5. Theme 2 The experience of information delivery about options

This theme concerns YAs' experiences of receiving information on therapy options, the development of their knowledge, and understanding of the options which occurs during the option talk phase of SDM. There are two subthemes:

communication and understanding of choice options, and the experience of health information-seeking. Most YAs had multiple experiences of information delivery linked to the different decisions they had to make. Experiences of information delivery were diverse and were overall perceived as either lacking, suboptimal, or fairly good.

4.5.1. Subtheme 2.1 Communication and understanding of choice options

This subtheme explores the situational contexts, absorption of information, quality of the information, the variety of the content of information and the impact of the information received on YAs. Multiple experiences of communications about choice options were described which was linked to the type of therapy decisions made. Mixed experiences of information delivery and understanding of therapy options were highlighted.

i) *Exploring situational context*

To understand the meaning of YAs' experiences of communication of options information, it was necessary to explore their situational contexts. It was important to examine the language used to describe the situational events of their present world as the interactions had a bearing on their past and future. YAs' experience of receiving options information, their understanding of the information, and their ability to use the options information to develop their knowledge and make better decisions, related to their health literacy.

Information delivery was either planned or unplanned and delivered by healthcare professionals (nurses or doctors). Planned information delivery occurred during one-to-one, or group patient education sessions. Unplanned sessions occurred ad-hoc during routine clinic appointments or hospital admission. Over one-third of participants reported they received information on options during hospital admission, and often this was the first time they had received any information, which is illustrated by Mina's experience:

> *"…I really didn't have treatment options as such, erm because my function was so bad… the next day, I was… sent to another hospital to a renal ward and that is where I started dialysis. … so, I didn't really, really have much time to be like what do I do in terms of treatment." (Mina, F, 29 years).*

Time and situational events influenced the quantity and quality of therapy options information delivered, which can be related to Heidegger's notion of temporality (Heidegger, 1962). Temporality relates to our understanding of a present situation which has a bearing on our past and projection of the future (Heidegger, 1962). The perceived availability or limitation of time was associated with whether the individual could deliberate on the information, gain understanding, and use the information to consider their choice.

Planned information delivery of options information was associated with multiple receipts of options education based on their kidney function. Zoe explained:

> *"So, over the years I went back every kind of few months [voice continues to sound like she is weeping whilst talking], to see how things were going and*

> *how things were. Things will kind of drop and go back up, drop, and go back up [swallowing saliva to control emotions and tears] and we got nearer to the point where we had to talk about dialysis… she [the doctor] informed me and gave me all the information straight away." (Zoe, F, 25 years)*

ii) *Absorption of information*

The provision of information about therapy options whilst feeling unwell and trying to get over the shock of diagnosis/prognosis of EKSD affected the absorption of information. Mina said:

> *"… they [health professionals] did [tears flowing again] but I don't think I was taking it in. I don't think I really understood it because it was [silence], it [dialysis] had to happen there and then like on the day. … I didn't really, they did explain but it wasn't going in my mind." (Mina, F, 29 years).*

Mina's expression: "I don't think I was taking it in" and "it wasn't going in" conveyed a sense of an inability to concentrate, absorb and assimilate the options information at the time. Ben also expressed:

> *"Not much knowledge because it was a shock to me. I was still trying to get over the fact that I had kidney failure as it happened so suddenly to me." (Ben, M, 25 years)*

The state of feeling unwell and shocked, and the environment (ward) impacted YAs' ability to develop their knowledge and understanding of the therapy options.

iii) *Quality of information*

Among YAs who had time gaps between initial awareness of needing dialysis and/or kidney transplantation and the start of dialysis therapy, some lacked or experienced suboptimal information delivery. Drawing on the experiences of Charlie and Rita who had time gaps (eighteen months and eighteen years respectively), they all lacked timely information about their options in their first decision-making experiences. Charlie emphasised the lack of discussions of therapy options and their effect on his life:

> *"Erm to be honest it didn't really. Erm there wasn't any discussions about it [options] at all. Erm, it was more or less when I was in hospital, and I had to make a decision there and then…. So, erm I didn't have any real information about the different options, about how it will impact my life. … so, there wasn't really any education information of it." (Charlie, M, 26 years)*

Similarly, Rita expressed:

> *"…I didn't really know much to be honest. I found that throughout my kidney disease journey I wasn't really told anything… I never was even told anything about dialysis. ... Even when I did my pregnancy planning dialysis wasn't mentioned that there could be a possibility... I remember one of the nurses said to me do you not know what dialysis is? And I said no. I said I know it's going to help my kidneys, but I don't know what it's going to do. They (dialysis nurses) told me the machine do that, what is gonna happen and that…, I didn't know anything whilst I was there until it was literally happening…" (Rita, F, 30 years)*

Despite the years that Rita had lived with kidney disease and had a planned pregnancy with her kidney doctor and obstetrician, she did not know about dialysis until just before she started dialysis.

Reflective comments dated 4th November 2020

This reflection was written during my analysis of the data. It became clear to me that irrespective of the situational contexts and time gaps, there appears to be a trend of a lack of effective patient education about therapy options. Interpreting their experiences through my professional lens as a professional insider, I could see significant opportunities were missed to develop YAs' knowledge. Hearing YAs' stories made me reflect on advanced kidney care patient education and the possible variations of the service across different kidney units in the UK. What was most striking to me was the similarities of their individual experiences of communication about treatment options although they were from different kidney centres.

This made me wonder how HCPs engaged with YAs' education on therapy options as the kidney disease progressed. On the other side, it made me also question if YAs did not want to hear about it due to fear because many emotions were displayed as YAs relived the information delivery moments. While it may be easy for an HCP to provide therapy option information to a young person, for a YA, where, when, and how it is communicated as well as its relation to their future life is important as highlighted in the integrative literature review.

In contrast, some YAs experienced planned patient education sessions, either a group, one-to-one education sessions, or a combination of both. For example, Zoe, who in addition to receiving one-to-one discussions, also attended group, education said:

> *"...She [consultant] was more like okay, I think we need to look at the dialysis options and I think I had. Erm, I had to go to a dialysis meeting… where they kind of explained the different type of dialysis erm [pause] and what happens to your body that kind of thing. And the point of that was to kind of educate people a bit more about what your options are" (Zoe, F, 25 years old)*

Planned education on their options was vital to enable YAs to develop their knowledge and their understanding of therapy options.

Among those with childhood CKD, some reported that despite the awareness of the need for future kidney transplantation, information only started to occur in early young adulthood which is illustrated by Jess' experience. Jess said:

> *"…I was probably about seven when I was told that I needed a kidney transplant some point in the future, but they didn't know when. And it wasn't until I was twenty-one that they told me that I would need a kidney transplant. …so, it wasn't until I turned eighteen that I started getting more information about the transplant." (Jess, F, 22 years)*

The options information was perceived as one-sided and unbalanced because of its focus on benefits with little or no information on the risks, the practical performance, or implications on life. Nally explained:

> *"…they said right we need to make a decision…they just give me all these positives about peritoneal dialysis. They didn't tell me about home haemo, they erm didn't tell me about any other option it was just PD. Erm, so they went through all the positives erm they didn't tell me about the negatives and erm that was it. … Erm so every option that they give you, it hones into the positives. It's very one-sided erm and that's the way it's been really." (Nally, F, 23 years)*

Some YAs expressed they felt the information delivered did not meet their needs as there was a lack of information on the effects of disease and therapy on their life. For example, Zoe expressed her thoughts:

> *"…we never really kind of had any mortality kind of discussion or anything like that. Because [teary voice] it was always, yes well you are going to go dialysis or have a kidney transplant, so we've never been like you are going to die [holding back tears]. …the PD nurses were a bit more [flashed face and weeping], …I felt they were a bit more harsh to me with reality [laughing but tearful] and they were kind of like [silence] and that was the time I really realised how I guess severe it was, life- changing stuff…Yeah, I definitely wasn't informed." (Zoe, F, 25 years)*

However, Nally said:

> *"…it was talked extensively about the transplant, but they never talk about what happens when the transplant fails [long silence]. You know they don't talk about that 1% of people that will have renal vein thrombosis, erm [the*

> *tone of voice and facial expressions conveys a sense of anger]. They don't talk about how it will make you feel, they don't talk about how it makes your family feel [voice drops, looking sad but then suddenly raises the tone of voice and shows anger and frustration while speaking], or all the horrendous things you would have to go through after that." (Nally, F, 23 years)*.

YAs felt although kidney transplant was presented as a better alternative to dialysis, there was less focus on the risks involved. For example, a minority of people could experience worse outcomes or experience living donor transplantation failure soon after transplant surgery (which Nally experienced).

> *Reflective box dated 26th September 2019*
>
> *I recall at the time of the interview hearing Nally's story of the immediate graft failure of the living donor kidney transplantation. I thought about the difficulties she and her family experienced because of the lack of information of such outcomes and its management and the lack of support. Interpreting this through my professional lens, it felt like HCPs focused on the best outcome for living donor kidney transplantation as maybe they did not want to scare people. Although there is an exceptionally low possibility of immediate kidney transplant failure, this might not be talked about during patient education. I felt complete openness about all the pros and cons associated with each choice is important as this would better prepare people for what is to come and avoid issues like what Nally and her family experienced.*

iv) *Variety of the content of information*

The content of options information received, and mode of information delivery varied among YAs. Information on options was delivered through talks and discussions or a combination of a talk and video during the education sessions. Some YAs received information on all available therapy options while others received information on either one or two of the options. Extra resources like leaflets, booklets, and video materials on therapy options received helped participants develop their knowledge. For example, Harry said:

> *"I think they provided me enough knowledge because they gave me leaflets and things like that. They also sent me to specialist nurses that I could speak to about dialysis as such. … and they also presented to me like a short television programme or some video...we were taken to a small room in the hospital, and we were shown a video of what dialysis will be like and things like that." (Harry, M, 29 years)*

v) *The effect of the information received on YAs*

The content of the therapy options discussed brought fear and anxiety and affected YAs' engagement with the information received. For example, Fred became more afraid as he read the information leaflets and imagined it.

> *"Oh, they gave me a lot of leaflets and for me to read… A lot of leaflets I had [laughing], yes, I was reading. And the more I was reading the more scared I got because it was like when I read, I imagine like it, I can kind of imagine it like. Because of my many language barriers like I have to visualise it with one language and then interpret." (Fred, M, 24 years)*

Fred's expression "the more I was reading, the more scared I got" conveys the impact the content had on him as he engaged with the information, a view shared by other YAs. Fred's situation was worsened possibly because of the language barrier. Likewise, Steve also echoed the sense of fear when he received options information:

> *"…I was also scared about what was going to happen in the long term, I wasn't sure. Because obviously at the time I wasn't very educated on kidney disease or anything. I was just, it was just so scary. I think like everything about it." (Steve, M, 21 years)*

The fear and anxiety experienced caused others to disengage with the options information received as they put it at the back of their minds to avoid being worried or burdened by the thoughts of it. Georgia expressed:

> *"Like I just didn't want to think about it. Like I just felt like if you don't think about it the better. Yeah, I hadn't ignored it, I hadn't ignored what was going to happen, but I didn't think about it, …Because if I knew it was coming all that time, I think it would have probably stressed me out a lot more." (Georgia, F, 28 years)*

Not wanting to think about the need for future renal replacement therapy, contributed to some YAs becoming more impacted by the information when they faced decision-making.

vi) *Mixed experiences of understanding of options information*

Mixed experiences of understanding options information were identified. YAs sometimes just went along with suggested options which is illustrated by Linda's experience. Linda said:

> *"I just went along with it because I really didn't understand what was going on." (Linda, F, 28 years)*

However, Zoe expressed:

> *"But again, like I said, I didn't really understand what that [treatment options] entailed. It was more just like I said, it was based on what it's going to have the least impact on my life [sounding tearful] …they had a model, and they were like showing me more where the catheter goes. But I'd never seen PD being done on someone or what it looks like or feels like or anything like that. So, I still felt very out of the loop… I wish I understood the process more and what would actually happen…" (Zoe, F, 25 years)*

Most YAs were driven by the need to survive as they were overwhelmed with the situational events. They did not have the space to deliberate properly on the options information received neither did they understand the information. YAs like Linda and Zoe preferred to go along with what HCPs suggested would have the least impact on their life. The content was sometimes difficult to understand which is illustrated by Zoe's experience where she wanted the options information to be explained to her as if she was a five-year-old to enable her to understand. Zoe said:

> *"…I think sometimes some of the nurses maybe take it for granted, that they understand it and they maybe think they are explaining it well. But I*

> *kind of needed it to be explained to me as if I was like five [laughing]. … instead of talking to me like I am an idiot. Or it's kind of explaining it but not really…it will be better if they've been through it themselves but obviously, you can't. It's really difficult when they [nurses], erm they know it and it's easy for them, but I don't..." (Zoe, F, 25 years)*

YAs felt HCPs were often unable to relate to their informational needs to help them to understand the options information, especially during their first encounter with options information delivery. Some felt that if HCPs experienced kidney disease themselves, they would be able to relate to their needs.

Most YAs felt information delivery during their second and third decision-making encounter was better. Rita expressed:

> *"…it was planned my PD and… I was given lots of information about that. I knew exactly what it was, I went to the education session about it, and I felt a lot more prepared on PD than I did for haemo… I went in there to their training room and one of the nurses showed me... Like they've got a dummy with the PD tube in … so they showed me what that would look like…and they explained what an exchange is, so I was prepared... that was really good, that was really good." (Rita, F, 30 years)*

Similarly, Nally felt satisfied with discussions during her second kidney transplant:

> *"Erm he [transplant surgeon] gave me all the likelihoods, erm he showed me a specific study. He showed me the likelihood of the transplant surviving five years, it was like the kidney could survive ten years,*

> *compared to a good match transplant…And then he just said go away and make your decision, erm which I did…" (Nally, F, 23 years)*

Sharon also had a positive experience:

> *"…they told me all about what it was…and showed me what it was and explained everything to the machine and how it works, like how I will feel afterwards. Erm, I got to know the nurses that are there. It's all quite a nice experience in that sense. They were so prepared." (Sharon, F, 22 years)*

Among those who transferred from paediatric to adult kidney service, a minority (Aaron, Ella, Jess, Joe, and Sharon) of them lacked confidence and felt nervous to engage with clinicians or ask questions therefore information was given to YAs with their parents present. Jess said:

> *"…my mum used to come with me quite a lot because I was quite nervous, quite shy, I didn't like speaking up to the doctors myself. Erm and obviously having moved from the children's bit to the adult's bit, quite old, erm I was lacking the confidence really. So, the information that I was given, it was more given to my mum who then gave it to me as well." (Jess, F, 22 years)*

Jess expressed her transition from paediatrics to adult service where her mum was involved in consultations. As moving to adult kidney service was a new experience, she was yet to develop the confidence to independently attend clinics on her own.

Overall, the experience of communication and understanding of options varied and was inconsistent across geographic areas. Communication was often poor because of the situational context, lack of absorption of information, poor quality and variation in information. The content of options caused fear and anxiety, as well as a lack of real choice, which was made worse by poor transitioning to adult services. The lack of or suboptimal information and lack of understanding experienced conveyed an experience of ineffective health education and inequalities during the information delivery resulting in low health literacy. This perceived low health literacy of options contributed to the development of health information-seeking which is next presented.

4.5.2. Subtheme 2.2 The experience of health information-seeking

The experience of health information-seeking relates to how YAs searched for extra information where lacking or suboptimal, to supplement what they had received. The lack of information, understanding and peer support motivated most YAs to search for information about choice options and the practicalities involved. YAs desired to hear from peers with practical experiences. Resources used include searching online and speaking to family members, friends, and peers with first-hand information about therapy options.

Others spoke to doctors and nurses within and outside their healthcare team. For example, Ben said:

> "*…there was a lot of information I gathered as I was so young and terrified at the time. But having all that information and looking online and researching about it and looking at videos that gave me full confidence of*

> *what was going to happen and basically my lifestyle at that point" (Ben, M, 25 years)*

Ella also expressed how she accessed information:

> "*I found a lot of my information from the patients rather than doctors and nurses… I did a lot of google searches [laughing]… I looked on the internet a lot, not just mainly for social but how dialysis makes you feel [laughing], what you can do on dialysis and things like that." (Ella, F, 24 years)*

Some YAs felt they gained more information from peers and independently through information searching.

Through independent health information-seeking, many YAs became aware of national kidney charities and kidney patients' social media platforms which enhanced their knowledge about the practicalities involved:

> *"…a lot more now since I started dialysis and had a baby, definitely a lot more now. … Like I think erm a lot of that is due to myself and also many of them is due to the fact that I'm part of Kidney Research Facebook group and Kidney Care UK …now ten months later I know loads about it because I've researched it myself. …If you don't ask you don't know, but back then I didn't know anything…" (Rita, F, 30 years)*

However, some YAs became aware of the potential fake news and preferred to use trusted sites like local and national kidney charities. Rita expressed:

> *"…mainly Kidney Care UK, Kidney Research, and things like that, just like, I try, I don't google things. I made sure I don't google things because I know google can tell you incorrect information." (Rita, F, 30 years)*

The lack of access to peers with dialysis and kidney transplant experience also motivated information-seeking behaviours as they felt their clinicians could not provide experiential knowledge. Zoe said:

> *"So, I wanted to hear some more positive [burst into laughter] and uplifting versions of where people have gone on it with their lives and have had jobs that kind of thing on PD to realise that it will still, I will just be a new normal, but it will still be normal. Erm, you know it wouldn't…make my life terrible or anything like that [sounding tearful] …I definitely felt better hearing other people's versions of it. Because I'd only heard the doctor and one of my best friends." (Zoe, F, 25 years)*

Although hearing other people's experiences were helpful, some were not. Zoe went on to explain:

> *"…the forums that I found were things like I hate dialysis stuff, …so a lot of people were saying very, very, negative things you know. My life is ruined because of dialysis and erm I didn't feel great going into it but there weren't a lot of positive conversations out there…" (Zoe, F, 25 years)*

The lack of and suboptimal information from HCPs, coupled with the lack of understanding of the practicalities involved, resulted in health information-seeking. Through their health information-seeking, YAs often improved their knowledge and understanding of kidney disease and therapy options. Receipt of peer support was empowering and supportive in allaying some of their fears. YAs felt knowledgeable, empowered, and confident to engage in meaningful decision-making. This experience links to theme three which is presented next.

4.6. Theme 3 The experience of making my voice heard

This theme is concerned with YAs' experiences of their engagement and involvement in dialysis and/or kidney transplant decision-making to explore choice options which occur in the option and decision talk phase of the three-talk model of shared decision-making. This theme discusses YAs' roles, their preferences, how the choice was selected, the involvement of other people and reasons influencing choice decisions. YAs were involved in multiple decision-making contexts but not always invited to the decision context as equals. This theme has three subthemes: engaging in decision-making as an equal; the importance of family, friends, and others; and reasons influencing decisions about choice. Engaging in decision-making as an equal is now discussed.

4.6.1. Subtheme 3.1 Engaging in decision-making as an equal

YAs assumed active or passive roles in decision-making which resulted in passive, autonomous, or collaborative/shared decisions. YAs' level of involvement was dynamic and progressed over time as their knowledge and understanding of the therapy options improved. YAs often lacked the awareness that choice existed and that they had the right to select their preferred options during therapy discussions. This lack of awareness influenced their roles and level of participation, especially during their first decision-making encounter.

Drawing on Nally's experience, her lack of awareness of the right to select a choice disempowered her from participating as an equal in decision-making:

> *"…It makes me angry now [looking very angry] …because at that time I didn't know. Like I didn't realise that I should have a choice. So, if you don't realise it, you are not so upset or angry about it because it [choice] was never there. …and it is only as I kind of progressed and had that knowledge for myself could I then argue back. I think what makes it easier for me as well is because I come from a science background, so they can't, they can't put wool over my eyes, I know what they are talking about. …as I progressed through I kind of found my voice a little bit but not everybody does. … there is no decisions, absolutely no decisions. …only with experience do you start realising that there is a choice. …if you have no sense to go forward to make your own choice, then choice is made for you." (Nally, F, 23 years)*

Many YAs like Nally felt robbed of their decisional power as they just accepted the choice suggested to them by clinicians. Gaining knowledge about their rights and roles in decision-making empowered them to find their voice to advocate for themselves later on. The repetitive use of the phrase "there is no decision" conveys Nally's feelings about the lack of choice experienced, which was expressed by other YAs too.

Fear and anxiety influenced the passive role YAs assumed in decision-making. Drawing on Ben's experience a passive role was assumed due to fear:

> *"Erm at that time I was very scared and nervous of what was going to happen to me, …so I went with their decision…"* (Ben, M, 25 years)

Similarly, shock and limited understanding made Paul assume a passive role and let things happen, as did other YAs during their first encounter with decision-making:

> *"…it was all quite shocking, I didn't really know what was going on, I got a little bit, I don't know maybe passive and just let things happen…I just accepted it, erm I just went with it. So maybe I didn't ask many questions as I should have done."* (Paul, M, 28 years)

Reliving the experience, Paul like other YAs felt asking questions could have enlightened their understanding and developed the confidence to determine their choice.

Ella, who as a child had her decisions made by her parents, experienced the transfer of power from her parents to herself to make her own decisions in her young adulthood:

> *"…I was only a child then…and my parents made most of my decisions. So, once I turned eighteen, I started to do my decision and stuff. …I did have a kidney transplant, but it wasn't a good match and just didn't work, and that decision I wasn't involved in at all…so I made the decision this time, yeah, it was up to me."* (Ella, F, 24 years)

YAs felt the way discussions about options were framed made them accept suggested dialysis choices by HCPs, which is highlighted by Paul's experience:

> *"…so, the way it was sort of presented to me was…if you do HD [haemodialysis] you need to go to the hospital three times a week for as long as you're doing it. Erm, so they really recommended against it [haemodialysis], and they heavily recommended PD [peritoneal dialysis] because you can do it from home basically and you can do it when you are asleep, so it doesn't take too much of your time. …I really didn't have time to think about it to be honest." (Paul, M, 28 years)*

YAs like Paul felt the best option was to go with the HCP's suggestion due to the lack of experience and limited time to consider options. Likewise, Nally who had already experienced a failed living donor kidney transplant and developed anaphylaxis during haemodialysis, felt indirectly forced to accept the suggested choice:

> *"… it's kind of like will be in a room for an hour, and I didn't know if I wanted to, then they will say yeah but think about this, think about how good it will be. Think about how well you are dialysed, …. They [clinicians] just force me to say yes with all these brilliant ideas of how it was going to be like and eventually I did say okay because I had no choice. … they are very convincing, …and I still knew that I didn't want to do it erm, but I went on with it and erm it was a disaster, erm it was an absolute disaster (feeling relieved and excited)." (Nally, F, 23 years)*

Inner conflicts about ownership of choice were experienced. The lack of ownership of choice decisions was also linked to the perception that they were not listened to during deliberations and discussions about the options. There was a perceived superiority of HCPs and a lack of power by YAs to refuse suggested options. Nally’s expression “they [HCPs] are very convincing” shows the perceived influence of HCPs and power. Nally was pleased that PD therapy did not work, which she expressed as a disaster related to the severe complications experienced which led to her admission to the intensive care unit. Nally felt vindicated but regretted not speaking out earlier as this would have averted this complication.

In contrast, other YAs felt that a choice was offered, and they were able to take active roles, ask questions, and make their voice heard. Drawing on Ella’s experience where the choice was offered to either stay on PD or transfer to haemodialysis following a split of the PD tube, she chose haemodialysis:

> *“…they [clinicians] did say to me that I was able to go back on PD but if I prefer, I can transfer over to haemodialysis and I made the decision to move over to haemodialysis. …they [clinicians] said the [kidney] wasn’t a good match for me. Erm, they did say to me that if you still wanted it, you may still have it but there is somebody else that it is a better match for. And at that point, I was like I have already had one failed one, and I don’t want my second one to be not so good either, even though I will be on dialysis for so many years, so I did say no to that one.” (Ella, F, 24 years)*

Becoming more knowledgeable and gaining an understanding of the treatment options enabled YAs to make trade-offs before decisions were concluded. For example, when Nally received another kidney donor offer but was not a good match, she was not prepared to take the higher risk of accepting a poorly matched kidney:

> *“I essentially had three choices. The first one was to accept a really bad matched kidney directly…the second option was to go in the pool paired exchange. And the third option was to not accept any kidney from my step mum and hopefully get on the cadaver list and then eventually get a transplant. …So that is when I did have some decisions, I had to make my decisions. It was like you are really sick and you need a transplant now or…you wait and potentially die. …it was very equal weighting, … in the numbers of pros and cons. ...when I started speaking to people the pros list kind of went up a little bit because they had other ideas as well.” (Nally, F, 23 years)*

Engaging as an equal gave YAs control over the choice decisions as illustrated by Rita’s experience when she faced a kidney transplant decision:

> *“…I’m still breastfeeding as well, and I know that due to the medication I have to stop breastfeeding when I have my transplant. But breastfeeding is really, really important to me because I had loads of problems to start with from the beginning. So, I wanted to breastfeed my baby at least until she is one year old, that’s my choice and I don’t want this [transplant]. …I guess that is about control and I want a bit of control over something else. …so, I’m going down the live donor route at the moment.” (Rita, F, 30 years).*

Collaborative and shared decisions were also experienced by YAs, which is illustrated by Zoe’s experience where she felt what mattered to her [work and family] was explored:

> *"…For both of us that was like the least disruptive version [teary voice again] where I could technically kind of carry on with my life with some limitation but erm like the day-to-day wouldn't be erm centred around dialysis." (Zoe, F, 25 years)*

Mutual understanding and agreeing on an option considered with YAs resulted in collaborative and shared decisions, although Zoe preferred the decision to be made by her doctor with her involvement:

> *"…I will prefer for that decision to be made by her [doctor] with my involvement…" (Zoe, F, 25 years)*

Zoe lacked decisional efficacy and therefore gave her decisional power back to her doctor, which contrasted with Rita's experience where she made the final decision.

Understanding the risks involved in their decision empowered YAs to own the decisions they made. YAs' engagement with decision-making varied and some could not always participate as an equal. As time progressed, some later improved their knowledge, gained confidence, and were able to advocate for themselves and make their voices heard. YAs often had important people (family, friends, and others) with whom they discussed their options, and this subtheme is presented next.

4.6.2. Subtheme 3.2 The importance of family, friends, and others

This subtheme concerns the supportive roles of family, partners, peers, friends, academic teachers/lecturers, employers, and HCPs in the trajectory of decision-making. Family and partners played a key role in the deliberation and decisions about therapy options as they acted as proxies for information, opted to be donors, and supported the management of therapies, while academic teachers/lecturers and employers played supporting roles.

For some participants family was an integral part of the decision-making process. Joe's experience was that he felt his family enabled him to have different perspectives of his situation and felt assured that he could still carry on with his life goals:

> *"…they all made me feel like it's not something to be worried about. It is something that could happen, but it would not affect you as much as you think. Even if I do have a transplant or have to go on dialysis you can still carry on with your life. They showed me so many people in the world that it happened to them, and they were living their normal life. It made me feel a bit relieved more than anything that even if I don't have a transplant, I will go to dialysis, I will be able to continue studying and reach where I want to reach." (Joe, M, 18 years)*

Looking at their situation from different perspectives helped YAs to appraise their situation and feel confident to face their future.

Family and friends played a significant role in YAs' decisions about kidney donation. Asking family or friends to donate a kidney was considered a big issue because of the perceived risk of putting another person's life in danger. YAs were reluctant to ask or accept kidney donor offers from family as they did not want to put them through that experience. Drawing on Harry's experience, he felt living kidney donation was a big request:

> *"…I don't have any family members or friends that were eligible or fit enough to donate… So, it's a lot for someone to take on to donate for you when they don't need to, so of course, no one came forward… [long silence]. Yeah, I mean it's a big thing for someone to sacrifice a kidney when it can affect them quite significantly as well, with the risk of operation and things like that." (Harry, M, 29 years)*

In contrast, YAs were excited when donors were identified as being suitable, as illustrated by Linda's experience who was overjoyed to receive four donor offers; her mum, sisters, and a family friend (nurse) were all perfectly matched donors, an unusual occurrence:

> *"So, I had four people offering to donate and all four of them were matches. …So, it was both my sisters, mum, and the transplant nurse [named omitted] was a match. So that was exciting and a very positive part of it, we were all of a sudden having all these choices. A lot of people don't have that. …I had all these matches that was very exciting because that wasn't that common… Because she [mum] always said to me without a doubt, she wants to do it…I never asked them to donate they just got checked up all four of them." (Linda, F, 28 years)*

Peers with experiential knowledge helped participants to understand the practical aspects of therapy options. Joe felt reassured that he was not alone through the experience because he saw and heard from other peers' experiences:

> *“…they [clinicians] give you a youth person’s list that you can talk to them…you can contact them whenever you have a problem. …it was just different people with the same problems, and we discussed our problems and how you are feeling. So, it made me relieved that you are not the only person with the problem. … you realise that there are other people with other conditions in addition to their kidney problems and it makes you feel like if they can do it then you can also do it.” (Joe, M, 18 years)*

YAs in education and employment felt their school and employers supported their decision-making as they accommodated their needs. Planned support packages included the provision of education materials and offering YAs time to attend haemodialysis therapy and kidney transplant surgery. Jess's experience was that her school provided opportunities that enabled her to make up for the lesson missed:

> *“The school did a few things, erm they made sure that I needed the time for the things that I need. And what they did as well is because they knew that I wouldn’t be able to sit most of my exams, they then pulled me out of those lessons, and I had more time to focus on the lessons that I’d missed in the days that I was in hospital… they were quite helpful with it all. So, it was good.” (Jess, F, 22 years)*

The support from the school was valued because they supported Jess’s therapy decisions. Similarly, Mina’s employer supported her therapy decisions and made allowances for her to fit dialysis around her work:

> *"…I've been able to fit it around work where I just go in later and leave later. So, I've got a bit more flexibility than maybe some jobs would have, so I guess I'm lucky in that." (Mina, F, 29 years)*

However, the work situation could have been different if she did not have the flexibility or was not already in employment.

YAs wanted their voice to be heard during discussions about therapy options as they did not feel they were often heard. The lack of awareness of choice, knowledge and understanding of options and what was expected limited YAs' ability to take active roles in decision-making. YAs relied on their interdependencies of family, partners, and peers during deliberations of options decision-making. Family, partners, peers, and HCPs contributed in diverse ways to support participants during therapy decision-making. Employers and teachers offered flexible working and learning time and were valued. The lack of elicitation of YAs' preferences and values hindered their ability to make known to the HCPs what mattered most to them during the decision-making process in the decision talk phase. Next presented are reasons influencing decisions about choice.

4.6.3. Subtheme 3.3 Reasons influencing decisions about choice

This subtheme presents the reasons that influenced YAs' decision-making during their deliberation of the options. The theme explores what mattered most to YAs as they considered their options and how they weighed up and made trade-offs during their deliberations of options. Personal, social and other reasons influenced decisions about choice. The personal reasons were the desire for normalcy, independence, regaining control, freedom, the impact of choice on their daily life and future and personal choice. The social reasons include work-life balance, the ability to socialise, education, the ability to travel, family life, and the perceived burden of therapy on the family. Other reasons included the performance of therapy, safety, and quality of life. These issues that mattered to YAs needed to be elicited and communicated to the healthcare team for YAs' voices to be heard.

The desire for normalcy influenced YAs' choice of therapy as they preferred therapy with the least distraction to their daily life, which is illustrated by Zoe's experience. Zoe said:

> *"…at first, the plan was to get me a transplant, before I would even have to go on dialysis, so I kind of skip that altogether. …Erm I kind of didn't want dialysis to be kind of my whole life and everything works around that. I wanted it [dialysis] to work around my life as it is now…" (Zoe, F, 25 years)*

Family life also influenced the decision-making of others. Drawing on Rita's experience, her priority was to have a healthy baby, be at home with her child, and enjoy motherhood:

> *"…I chose dialysis so that we could prolong the pregnancy and we got another four weeks out of it which was amazing. …home treatment was the one priority …, I first started on CAPD, and the idea was to make sure it fits around my life and fit it around my baby…" (Rita, F, 30 years)*

Being at home and spending quality time with her baby influenced her dialysis decision and it was important to Rita.

The impact of therapy on the wider family also influenced the choice of therapy, which was illustrated by Jess's experiences as she considered the impact of therapy on her family, and this influenced the choice of kidney transplantation:

> *"…I think really the impact it would have on my family life. If I had been on dialysis erm and having to go to the hospital a lot more because I have a younger sister, I think if I had to do that, it would have had a bigger impact on me and my family and me and my boyfriend and me and my friends." (Jess, F, 22 years)*

Maintaining independence and control also influenced decision-making. For example, Mina wanted to maintain independence and be in control and this influenced the choice of PD:

> *"I'm someone who is independent, and I didn't want to go to the hospital three times a week. It wasn't convenient. I wanted to go back to work and the PD option that they discussed with me erm seems to be the best thing to do to get back to work and to have my own independence and kind of fit it around so to speak as much as I could around my time. …I think for me is having that control [long silence] that's what is important to me. I lost some of that erm with having kidney failure, so it's like trying to get some of that back." (Mina, F, 29 years)*

The desire for freedom also influenced the consideration of a choice during decision-making. Drawing on Rita's experience, she wanted to have the freedom to do things that mattered to her life. Rita said:

> *I just want freedom; I just want freedom again." (Rita, F, 30 years)*

The repetition "I just want freedom" conveys the importance of having the freedom to spend time on other issues in life. YAs needed to be supported to find a therapy that could offer them their desired freedom.

The dislike of needles and phobia of blood also influenced choice decisions which are illustrated by Zoe and Steve's experiences. Zoe's dislike of needles influenced her preference for therapy without the use of needles. Zoe said:

> *"… I just didn't like the thought of the needles." (Zoe, F, 25 years)*

whilst Steve who had a phobia of blood expressed:

> *"…it was the fact the I will not be seeing blood that was the main factor for me. I was really scared of like blood. …I was scared about [haemodialysis], I have a phobia for blood. It's quite scary for me personally because at the time I had a huge phobia." (Steve, M, 21 years)*

Some YAs did not want their body image to change and preferred therapy with minimal change to body image. For example, Aaron considered the effect of permanent dialysis access on his acting career:

> *"I went for the line option because I didn't really want too many kind of cosmetics, erm I didn't want a fistula because I thought it would affect my acting career for the future." (Aaron, M, 29 years)*

The ability to continue working, education and the ability to socialise with family and friends also influenced decision-making. For example, Zoe who had a child and worked full time, preferred an option that would allow her to continue working. Zoe said:

> *"My choice was very much based on that [work] and how much work-life balance that I have [stressing that point, in a teary voice tone], rather than the science that was behind, what would work better..." (Zoe, F, 25 years)*

The ability to work and be productive was vital to YAs who were employed and influenced their decisions. Zoe emphasised how important her work was for her and did not want a therapy that will interfere with it.

The ability to continue education was important to YAs who were in education and influenced decision-making about choice. For example, Joe considered the effect of therapy on his education, social, and family life and it was important to him to get his voice heard:

> *"…I was thinking about studying, …thinking about which type of dialysis will be better for me in terms of my studies and managing my kidney failure. …social life for example, if I'm going to the hospital three times a week, then that will take my social life away, family, friends…all these things is what I considered…" (Joe, M, 18 years).*

The ability to travel for holidays with family and friends was important in considering choice. Drawing on Rita’s experience, she considered therapy that would allow her to travel to see family and friends:

> *“…being able to travel was a big thing…because my husband is from [name omitted, Eastern European Country] and we normally go twice a year to go and visit his family, and friends. …So, I just like wanna be able to just get on the plane and go somewhere again and not have to dialyse, and not have to plan...” (Rita, F, 30 years).*

Travelling was important for some YAs like Rita as it had been a part of the family life.

Safety and quality of life also played a vital role in the consideration of choice, which is illustrated by Harry’s experience. Harry expressed:

> *“I think it was about like how safe it was to be on haemodialysis and how it prolongs your life to prepare you for a kidney transplant if you are eligible for it. …because I wanted to try to extend my life as much as I could …but the motivation was that I want to have a better quality of life. …So, my decision was that I would rather die on the operation table than being on dialysis.” (Harry, M, 29 years)*

Areas that mattered most to some YAs were their safety and their quality and quantity of life.

Reflective Box Dated 18th February 2021

This reflection is based on my dialogue with the data as it became apparent that YAs preferred active involvement and being the decision-maker who can make autonomous decisions. There was a lack of awareness that choices exist therefore some were unsure of their roles, and whether they could make their voice heard. There seem to be ongoing conflicts and power dynamics in the decision context. Many felt they were not invited to the decision-making as an equal and struggled to make their voice heard. YAs considered several reasons that mattered to them, weighed their options, and made trade-offs as they preferred therapy with minimal effect on their life and family.

Family, peers and other people like academic tutors and employers made adjustments for them which they were grateful for. It appears what HCPs thought was best for YAs was not the same as YAs felt sometimes. It appears that in some situations HCPs failed to hear YA's voice and this resulted in decision conflicts as the choices suggested were not what they wanted but lacked the confidence to speak their mind. There seems to be very little deliberation and elicitation of YAs' preferences. At the same time, I was relieved because I felt this was why this study was so important as it would make YAs' voice heard. It feels that lack of information and roles to play in decision-making made some YAs assume passive roles. Most YAs later were empowered to ask questions and were able to communicate their preferred choice to their HCPs, so their voice was heard in second and third decision-making.

Personal reasons (such as normalcy, freedom, independence, control, body image, family life and personal preferences) and social reasons (work life, education, socialisation, safety and quality of life) influenced YAs' decisions about choice. HCPs needed to elicit these aforementioned reasons for YAs to be supported to make the best decision that is based on what mattered most to them in the option and decision talk phases. However, less deliberations and a lack of elicitation of what mattered most to YAs meant they were unable to communicate them to HCPs. Having presented the YAs' engagement with decision-making and how the choice was selected, I will now present YAs' experience of the new normal life.

4.7. Theme 4 Experiencing the new normal

The experience of living with ESKD made YAs feel different and not normal compared with their healthy aged-related peers. The lack of understanding of the experience of the new normal life resulted in a search for the meaning of it. This theme has three subthemes: experience of receiving dialysis and kidney transplant therapy; the experience of feeling different; and searching for the meaning of the new normal experience. It was also vital for YAs to accept the need for dialysis and/or kidney transplant therapy and that it was a permanent change to their life before decisions were made. However, some YAs made decisions without understanding what it really meant to their life regarding long-term dependence.

4.7.1. Subtheme 4.1 The experience of receiving dialysis and kidney transplant therapy

This subtheme presents the implementation of the agreed choice and the preparation to transition from carefree life to initiating dialysis and kidney transplant choice and the adaptation made in life. This subtheme relates to the preparation for and the practicalities of receiving the agreed therapy. The experience of making decisions about a preferred choice has a direct relationship and effect on what happens during receipt of the agreed therapy.

Many YAs struggled to make the transition from being a carefree person to depending on dialysis or receiving a kidney transplant to keep them alive as they were not ready for it. For example, some YAs who opted for home therapies like PD were not aware that they needed a storage space to store dialysis consumables. Zoe said:

> *“Let’s say I had the surgery and then I went home, and a few days later they came with this massive lorry with loads and loads and loads of stuff that I needed to do dialysis, machine, and all that stuff. And I didn’t have any idea of how much room I needed for this stuff. So, we had to clear up one of the cupboards when I was really unwell.” (Zoe, F, 25 years)*

Zoe lacked information about the need for storage space or the delivery of dialysis items hence was unprepared to receive the delivery of items and felt overwhelmed. The timing of the delivery was perceived as inappropriate as she was unwell following the PD access surgery.

Dialysis therapy was perceived as the new normal, but unacceptable due to the harshness of the therapy, which caused YAs to experience fear, anxiety, and in some cases depression. Drawing on Fred’s experience, dialysis therapy was unacceptable to him although his symptoms were relieved initially:

> *“…it was unacceptable to be fair at the start. I didn’t really go as well [silence]. I was like in a weird position. …thinking damn things [very upset and expressing desperation]. Then recently I started to understand it that it was for my own good. So, I started feeling better since I have been going there. …I stopped at one point because I was like super anxious, and I was like no I don’t want it anymore and it’s just like a waste of my time and everything. It takes so much of my day [showing his dislike and frustration]. Yeah, I didn’t go for about two weeks till I guess someone tells the police and there was like six police officers who took me in [laughing] to hospital after like two weeks…” (Fred, M, 24 years)*

YAs also expressed a lot of frustrations when they experienced dialysis due to the uncertainties experienced, and the quantity of time spent on performing the dialysis therapy. Fred’s expression “…and it’s just like a waste of my time and everything. It takes so much of my day” conveyed the impact of dialysis on YAs’ life and the lack of understanding of why they had to be subjected to such an experience. As a result, some YAs did not adhere strictly to the dialysis regimen, as illustrated by Fred’s experience of stopping therapy.

YAs adapted and adopted new normality to accommodate dialysis and kidney transplant therapy. Life on dialysis, especially haemodialysis, was perceived as very restrictive due to reduced dietary and fluid allowances. Many YAs experienced constant fatigue and tiredness, which affected their ability to carry out daily activities and work. Drawing on Harry’s experience, fatigue and extreme tiredness affected his functionality and performance of daily routines:

> *"… with dialysis you feel quite fatigued after the treatment and then it stops you from doing a lot of things, like going to the gym and lifting weights…then your diet is restricted as well. You can't eat whatever food you want to because you have to watch what you eat. …during the summertime when you are sweating a lot, it's easy to want to drink more fluids and you can't because you are on fluid restrictions because your kidneys don't work so that was annoying for me as well. Well, I was jealous of everyone else that was able to use the toilet and they were able to drink as much fluid as they like and eat whatever they want to. And I thought I was sort of living in a bubble maybe, so that is why it was a stressful time for me..." (Harry, M, 29 years)*

The restrictive life caused a lot of stress among other things to YAs and caused them to feel isolated.

Most of the participants felt disappointed as they realised their expectations of freedom, independence, and control were different from what was actually experienced, which is illustrated by Zoe's experience:

> *"I mean it [dialysis] really sucks, to be honest. … where already I was like I've made a terrible mistake, why have I done this [sobbing], …when I started dialysis I only did it for a few nights a week because I was like I don't want to do this, it has affected my life and I don't like it... because I was so unhappy like what I'd done, like what had happened I was so resentful that I now needed this machine to keep me alive…all the emotions of it." (Zoe, F, 25 years)*

Many YAs in this study experienced decisional regrets for either accepting recommended choices or the decisions which resulted in grief and resentment.

In contrast, gaining a better understanding of the need for dialysis enabled YAs like Ella to develop ways to manage their life and feel in control:

> *"I just felt a lot more in control… I was going there but it was more of my choice that I was doing it and I needed to go [looking elated]. I understood why I needed to go there and that I felt like there were days that …I wouldn't go there, or I wouldn't want to go, and I knew that if I didn't go, I would feel really poorly, and I didn't want that. …like once I understood that okay if going for me is better for me, that's when I started." (Ella, F, 24 years)*

Waiting for and being in receipt of a kidney transplant was associated with a lot of uncertainties and new fears. In addition to new routines such as new medication routines and the management of it, they lived in fear of rejection of the new kidney, and risks of infections due to low body immunity. For example, Ella experienced new fears compared to when she was on dialysis:

> *"I think with having transplantation comes with all new fears. It is a whole different ball game to having dialysis. You have different fears when you dialysing and different fears after your transplantation. …the biggest change for me is taking the medications and making sure I take it on time. So, it impacted me a lot because I'm very forgetful…" (Ella, F, 24 years)*

Receiving a kidney transplant also brought changes to their body image. All these changes and challenges contributed to YAs' experiences of psychological stress.

Reflective Box 04th March 2021

This reflection was written following my interview with the participants and during the analysis of the data. I was surprised about the profound lack of awareness and knowledge about the practicalities involved and the performance of therapies for example PD therapy looking at it through my professional lens. Although some YAs, for example, Zoe and Charlie had time gaps where adequate knowledge development could have occurred or facilitated to develop their understanding of the dialysis process and how to live and manage their life, this was lacking. Their expectation was different from what was experienced.

As a professional insider and a researcher, I was wondering what could have gone wrong that prevented YAs from receiving the needed knowledge that could help them to adapt to their experience of the new normal. I realised that it did not matter how many times a YA receive information about the options, it appears the information received was not accessible to YAs for them to develop their knowledge and understanding to enhance their experience of receiving dialysis and kidney transplant which was necessary to avoid YAs making decisions under ignorance.

I noticed that similar stories were told among the participants which made me believe that the lack of understanding of the practicalities and the preparation *for choice may be a systemic problem across some kidney care centres. It was important that patients had access to their peers to gain experiential knowledge of the therapies and to see how dialysis therapy was performed. I questioned how these important aspects of the practicalities of the options could have been missed by some HCPs. I concluded that it was important to share YAs' experiences with the kidney healthcare professionals and make their voices heard as this could initiate discussions about solutions to meet their needs.*

This section has highlighted the experiences of receiving dialysis and kidney transplant treatment and how YAs struggled to fit dialysis around their lives and adjust due to the disruptions to their lifestyle. The lack of preparation, information about the practicalities of the options and the lack of understanding resulted in profound experiences of physical, psychosocial, and mental implications on YAs' lives (see section 4.8.1), which made them feel different at times. The experience of feeling different will be presented next.

4.7.2. Subtheme 4.2 The experience of feeling different

The experience of feeling different is how YAs felt as they compared themselves with their healthy age-related peers and friends, which affected YAs' engagement with the decision-making process. Many participants had the belief they were different and did not want people to know about their illness, and therefore kept it to themselves:

> *"I [long silence] guess I [long silence] always felt erm [long silence] a bit, erm a bit different like erm I wasn't normal. Yeah, I just wasn't. I didn't fit in with everyone else… I was worried I won't be ever able to live a normal*

> *life, I won't be able to go out with my friends on Friday night… …but now I know that I can do that. …I can do things that normal people can do who don't need a transplant can do." (Jess, F, 22 years)*

The limitations of what YAs could not do contributed to the feeling of being different. For example, Linda felt she could not go out in the evening for drinks or have sleepovers due to the dialysis and dietary changes which made her feel different:

> *"…I just felt like…if my friends were out during the evening, I couldn't stay with them very long. …I kind of like to drink while I was with them, but it was like I couldn't do what my peers were doing. I felt I had to be different, I was different. …the area that I was living in and working in was like a very busy like and fun area and like I used to enjoy all of it. …I couldn't participate in all these kinds of things during and before living out there and then it was hard to like have a relationship with people. …because I wouldn't be able to go to their houses and things like overnight for anything and so I had to be in my own house. … it just made it difficult, and I didn't feel okay because I was just nineteen …having a huge like bottles and bottles of pills everywhere…" (Linda, F, 28 years)*

YAs felt they could no longer participate in social activities as they did in their past because of the new lifestyle on dialysis and various medications they had to take regularly.

Other YAs like Joe kept the diagnosis and treatment to themselves because of the fear of being treated differently by his friends:

> *"I never told my friends about it. I felt like if I tell them, they might feel like you are a bit different so because of that I just never told them. I kept it to myself yeah." (Joe, M, 18 years)*

The experience of having ESKD made some YAs feel different as suggested by Ella's experience:

> *"[silence] So I didn't feel like a normal person at that time. I didn't feel like a normal girl. I didn't feel like I should be doing this [PD therapy] at my age and stuff [teary voice and looking very sad]. …I guess, I just had good support around me and just got on with what I had to do." (Ella, F, 24 years)*

Some YAs felt they looked smaller in stature compared to their healthy age-related friends and siblings, which affected how they were sometimes treated. For example, Mina struggled to fit in especially among the older CKD community because she looked small:

> *"… [long silence] you go in [dialysis unit] and people are like oh what are you doing here?... but even back then I looked younger, … shouldn't you be in the children's ward? And am like no I'm twenty, I think I was 24 or 25 at the time..." (Mina, F, 29 years)*

The dialysis access and body scars from dialysis access surgery and kidney transplantation also contributed to the perception of feeling different therefore some YAs tried to avoid having it in the first place or found ways to hide them.

These scars affected their self-confidence as they became self-conscious as suggested by Ella’s experience:

> *“…I asked other renal patients and she used to wear these covers on her arm over her fistula and they were made up of this special material and that was able to help me in stuff like that because I was really self-conscious about things like that. I’m really young after all…” (Ella, F, 24 years)*

Some YAs felt stigmatisation of people with a chronic disease by society worsened the perception of their feeling different and preferred to keep to themselves. For example, Charlie withdrew from people in the beginning due to his belief in societal perceptions about people with chronic illness:

> *“I was a little bit more exclusive and then I didn’t go out much, to begin with, while I got used to it. I think I was a little bit self-conscious to have a line. So yeah, it took a little bit of time to get used to it… The physical presence of having a PD catheter is not very nice. Because you know you can see it through t-shirts and things like that so there was that. Erm and there was also erm I think like the stigma around people who have got medical conditions, and I think erm [pause] that I wanted to keep it to myself that I had something serious like kidney disease.” (Charlie, M, 26 years)*

However, feeling accepted by friends, entering meaningful relationships, and achieving goals helped change YAs' self-perceptions and improved their self-image, esteem, and confidence:

> *"…I met somebody while I was at university, erm my girlfriend now, who I'm actually living with. So, I think meeting somebody like that and having her accept me was a big step, because I thought oh you know this shouldn't be an issue at all. But also, I think because as I've started to be like getting good grades and things like that, I was making in my academic achievement, it made me realise that this does not have to be anything to hold you back at all. …So, that made me a bit confident in myself and I think it's just grown and grown really since I started my master's degree." (Charlie, M, 26 years)*

Feeling different related to YAs feeling unattractive to partners due to altered body image because of tubes coming out of areas of their body and keeping PD fluid in their peritoneum. Drawing on Rita's experience, she felt unattractive because of the dialysis fluid in her peritoneum:

> *"…the fluid tummy… I hate it…PD, those two litres of fluid just fills me up and I look pregnant again. I look pregnant again about seven months pregnant again. …it's uncomfortable…so every evening I will be just feeling full and fat quite frankly, unattractive…" (Rita, F, 30 years)*

Rita felt it made her look pregnant again, fat, and look different, which made her insecure.

YAs felt they did not fit in with everybody else because they could not do what their age-related healthy peers and friends did and could not understand why, which affected their engagement with the decision-making process. YAs became self-conscious and their self-esteem and confidence were also affected. However, being able to achieve what their peers had achieved and feeling accepted by other people changed their self-perception.

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As I analysed the transcripts, it became clear that YAs struggled with their self-perception and image because of the way they felt and looked in their own eyes. This feeling made them believe that was how other people outside their world of experience saw them and thought about them, and that affected their psychological well-being. This perception also contributed to YAs having low self-esteem and not feeling confident to talk about diagnosis or therapy and excluding themselves from socialising with their peers. This perception was linked to the lack of understanding of what YAs were experiencing at the time and what it meant for them. However, their perception changed when YAs realised that people accepted them without any reservations and started achieving their dreams. I wished they had the truth about themselves earlier as it could have avoided some of the psychological traumas it brought to their life.

The experiences of receiving dialysis and kidney transplantation and feeling different resulted in YAs searching for the meaning of the new normal experience, which is next presented.

4.7.3. Subtheme 4.3 Searching for the meaning of the new normal experience

The search for the meaning of the new normal experience demonstrates how YAs articulated the meaning of living with kidney disease. Most YAs could not understand why they developed kidney disease whilst many YAs were filled with fear of the unknown. It was only later that many YAs began to reflect on their experiences to make sense of it. Drawing on Zoe's experience, she could not understand what was happening to her as she faced dialysis decision-making and access surgery:

> *"I don't understand what is happening kind of thing [very tearful]. Erm like I said it was just kind of one of those things because it's just been it, everyone was kind of like well it has to happen and if you don't do it you die. That was literally you know that's the kind of thing with all the information I had really. I knew I had to have a catheter in, and I knew I had to start dialysis a few weeks later. So, as I said I didn't really necessary process it. I just kind of went with the flow…" (Zoe, F, 25 years)*

The search for meaning involved self-questioning by YAs of either what had been lost or had to give up and the adaptation to their lifestyle. Like most YAs, Zoe on reflection of her decision-making experiences and initiating dialysis treatment, felt her actions were driven by adrenaline rather than careful assessment and understanding of the situation:

> *"…it was all just must have been, I was on adrenaline. It was like oh, go, go, go kind of thing. So, I think that is why I reacted may be badly after [laughing with a teary voice] the catheter and after everything had calmed*

> *down. Because I was like what is going on [expression of the shock she experienced] with PD catheter insertion. I don't understand what is happening kind of thing [looking very tearful]". (Zoe, F, 25 years)*

YAs felt the whirl of events drove their actions to avoid unpleasant consequences like death, as many questioned their decisions after the calmness of events which resulted in psychological and emotional effects.

YAs felt it was easy for HCPs to tell them to dialyse for long hours because they do not understand how the treatment affects their lives as individuals, as suggested by Zoe's experience:

> *"…it's easy to say oh go on the machine eight hours every night and it's like fine. But I think they underestimate the impact that it has psychologically and mentally and physically on your life as a whole, I guess is a big change." (Zoe, F, 25 years)*

Experiencing dialysis and kidney transplantation required significant adjustments. Many YAs could not understand why they should go through the harshness of dialysis treatment or undergo major surgery due to kidney transplantation and felt life had been unfair to them as they tried to understand the meaning of all these experiences, which is illustrated by Rita's experience:

> *"…I guess when something like that happens [informed that kidney donors [parents] are not suitable to donate a kidney to her] and you get told that it's your antibodies [Rita has antibodies against her donors therefore direct donation cannot occur], it's just like another thing. You see that is what I*

> *thought. Again, like is that kind of things [unforeseen problems that occur because of ESKD].* Can it not just go smoothly please? *I've already got kidney disease, I'm already on dialysis so could it not just go smoothly? That would be great that kind of thing, that would be great. That's what it feels like. Erm, it definitely let you feel down whenever anything happens because I try to really stay positive on a day-to-day basis." (Rita, F, 30 years)*

Like Rita, most YAs self-questioned themselves about the occurrences of unpleasant situations living with the disease and receiving dialysis or kidney transplant therapy. Rita's only hope to stay off dialysis was to receive a living donor kidney transplant because she did not want to be listed for deceased kidney donation therefore questioned "Can it not just go smoothly please?" This conveyed her struggle to understand why unpleasant situations kept happening to her life and the weariness and the enormity of the situation. The phrase "that would be great…" the response to her questions illustrates the desire for a better outcome during the transplant workup process as she tried to make sense of the situation.

Although most YAs hoped for the best, they reported that each time they faced challenging situations, as illustrated by Rita's experience "whenever I hit a bump on the road [encounters problems or challenges]", this initiated the quest for the meaning of it as they questioned themselves, illustrated by:

> *"…why me, … Like what did I do to deserve this kind of thing." (Rita, F, 30 years)*

This was because YAs could not understand what they did to deserve such experiences in their life and felt life had been unfair to them illustrated by Mina's experience:

> *"…at times I felt it was a little bit unfair what's happened to me." (Mina, F, 29 years)*

The lack of meaning of their situation impacted YAs psychologically. YAs found consolation that their situation was better compared to other people with long-term conditions and were grateful to be receiving dialysis and kidney transplant therapy to stay alive.

The experience of the new normal life made YAs feel different and they searched for the meaning of their experiences to help YAs understand the issues that happened to them during the trajectory of kidney disease and therapy decision-making. The search for meaning informs the research question of how YAs experienced decision-making. It was important for YAs to understand why they had ESKD and had to experience a replacement therapy as this helped them accept the prognosis and their long-term dependence on RRT. Gaining an understanding of their experiences helped YAs to bargain their losses, fit the therapy into their lifestyle and develop new adaptive styles that allowed them to regain some control, independence, and freedom. At the same time, YAs became aware of the impact of the decisions made and how their choice experiences impacted their well-being. Next discussed is the impact of decision-making and choice on well-being.

4.8. Theme 5 The impact of decision-making and choice on well-being

This theme is about the impact of the decision-making process and the impact of the experience of choice on YAs' well-being, which is important to the research question. YAs' decision-making experiences highlighted the different degree to which they were negatively impacted, which is an important finding. This theme has three subthemes: the psychosocial effect of decision-making and choice; keeping sane and not going crazy; and enhancing my decision-making. Next discussed is the psychosocial effect of decision-making and choice.

4.8.1. Subtheme 5.1 The psychosocial effect of decision-making and choice

This subtheme is about the effect of receiving a diagnosis/prognosis, the decision-making process, and the experience of choice on YAs' psychosocial well-being. The receipt of diagnosis and prognosis and facing dialysis decision-making and experiencing dialysis and kidney transplant therapy impacted significantly on YAs. The subtheme also highlights how some YAs suppressed their emotions, felt socially isolated, experienced self-blame, the effect of the harshness of therapy and the impact on their family.

Most YAs however felt they were unable to process their feelings due to the whirl of events occurring when they received a diagnosis and/or prognosis of ESKD and were informed of the need for dialysis and/or kidney transplant therapy. Some YAs became either devoid of emotions or suppressed them due to shock and the lack of understanding, as suggested by Linda's experience:

> *"…I kind of never felt that bad, …I didn't know what it was really and so it was just kind of confusing why I've got it… I didn't really feel upset about it until later on. …I think I kind of just push them [emotions] down at that time. I didn't address them until later on." (Linda, F, 28 years)*

The lack of understanding of the ESKD diagnosis resulted in one YA distancing himself from his family, illustrated by Steve's experience:

> *"…I wasn't very close with my family at the time because I moved out and was all by myself when I found out that I was sick. So, I kind of kept myself absent from them. I don't know why maybe it is just the way I was feeling at that time. I never really discussed it with them at that time. I just kind of told them oh I'm just scared to do it that's all." (Steve, M, 21 years)*

The lack of understanding and lack of answers to why they developed ESKD made some YAs and parents experience self-blame and guilt for having ESKD. Drawing on Mina's experience, her mother blamed herself for the cause of Mina's kidney failure, which psychologically affected both of them:

> *"…for my mum, she thought that she did something wrong. She kept blaming herself. …I'd wished I'd done something sooner. …she felt it was her fault even though it's not her fault." (Mina, F, 29 years)*

YAs, like Mina, felt helpless as they watched the struggles of their parents who wished they could turn things around for their children. The feeling of self-blame and guilt links back to the lack of understanding of the cause of the kidney disease and the need for dialysis and kidney transplant.

Likewise, other YAs were emotionally and psychologically impacted due to the harshness of dialysis therapy and the challenges of kidney transplant surgery and management. Drawing on Steve's experience, he developed severe mental health problems (post-traumatic stress disorder) as a result and never coped with haemodialysis. Although he changed to PD, due to depression, he became non-adherent in performing PD exchanges:

> *"…it [PD] didn't go very well because at the time I was obviously very depressed and stuff and feeling quite low, tired whatever, so sometimes I just wouldn't do my dialysis you know just because I wasn't up to doing it at the time. I was just too low [feeling depressed]. But I wasn't really taking care of myself, it's really hard to go on. …at that time, I kind of felt there wasn't any life at all. I think I wasn't getting any better and I was convinced in my head that I was going to die soon." (Steve, M, 21 years)*

Steve felt there was no life at all and was going to die soon, therefore, was non-adherent to performing PD therapy; a similar expression was conveyed by other YAs.

Many YAs grieved for the multiple losses and uncertainty of their future as they relived their experiences. Mixed emotions of sadness, anger, disappointment, and frustration were displayed as they shared their experiences during the interviews. Anger and frustrations were sometimes taken out on spouses and parents, and this often affected their relationships. Drawing on Rita's experience, she sometimes displaced her anger on her husband, especially following dialysis, which started to affect her marriage:

> *"…I was horrible [to husband] when I came back from haemo, …and I was really quite grumpy and ratty and whenever I come back from that [haemodialysis]. I was exhausted and erm it made us argue a lot. Like it was so hard because he had to watch me go through all of this. It was all just as new to him as it was new to me. …our relationship was really tested, it really was. Like the first four months, I remember just thinking oh my God I don't know if we are going to survive this. Like it was all too much. It was very emotional, …my God it was just stress, like constant stress all the time." (Rita, F, 30 years)*

Concerns about pain during dialysis and transplant surgery also negatively affected YAs. Drawing on Linda's experience, she expressed feeling nervous about the transplant surgery:

> *"…whether it [kidney transplant surgery] was gonna hurt. …I was more nervous about the pain from it and then like it's very invasive. So, it's like a lot of you, kind of you lose some of your body self-autonomy going into it." (Linda, F, 28 years)*

Concerns of anticipated pain and the invasiveness of the transplant surgery and their inability to be in control of their own body also impacted some YAs.

YAs who considered and received a kidney transplant felt guilty about putting a family member at risk because of kidney donation. For example, Steve experienced guilt for receiving a kidney from his dad:

> *"…you will feel guilty if you take an organ from your parents. It's a natural thing because you are putting them at risk and even so, I have noticed that my dad is not as healthy as before he had the transplant [operation]. He [dad] always tells me not to feel guilty, but I still do about it. I also feel guilt." (Steve, M, 21 years)*

YAs were negatively affected by the perceived uncertainties about the future and underachievement in key areas of their milestones in life as they compared themselves with their peers. The perceived loss of standard in life which related to their experience of life thrown off track affected their well-being. Drawing on Aaron's experience, he became negatively impacted as he could not attain his desired career, family, and social heights like some of his peers:

> *"I just thought to myself, the standard of life you know but there is a lot of psychological impacts. You're not hitting you know… quite a lot of massive percentage of my life I think I've been hitting at 60 or 70%. …if you've got the potential to be 100% or maybe more, especially in a career like acting where the industry is…competitive and you know I can't really, … it's difficult yeah. …" (Aaron, M, 29 years)*

Although YAs like Aaron felt they had the potential to achieve greater academic, family, and social standards, they felt limited by the impact of the disease and therapy regimens.

Feeling socially isolated and missing out on social experiences negatively impacted on YAs' emotions. For example, Fred felt physically restricted and socially isolated as he could not do what he previously loved to do:

> *"I just thought I was feeling isolated …I was locked in my room 24/7, I was in my room. I wasn't going out. I didn't want to speak to no one. I occasionally spoke to my mum through the phone. ...Everything has been taken from me…" (Fred, M, 24 years)*

YAs felt their families, especially their parents also struggled psychologically although they stayed strong for them which in turn affected YAs. Drawing on Rita's experience, she felt her family struggled psychologically:

> *"…I think they [family] were also struggling in themselves. Like it must have been so difficult for them to see me go through it all and I think it still is, but erm they were just strong. They just helped me and supported me and yeah, they've been solid, …but it must have been so difficult for them I can imagine. …it was so hard for him [husband] as well… Like I saw him crying just once since all this started…It might have been so hard for him, …he handles it very well, I think. I don't know what he is like at home behind these closed doors." (Rita, F, 30 years)*

Drawing on Nally's experience, where a perfectly matched living donor kidney transplantation failed shortly after surgery, she felt she and her donor [father] were psychologically affected:

> *“…obviously with what happened with my dad and stuff, it was horrendous, it was a terrible process. …because my dad was in a worse place than I. Because of what happened and then he had to witness the next two years, me spending two years of my life in the hospital feeling really, really, sick and feeling that guilt that it was his fault. But obviously it wasn’t, it was one in a million chance. Like I think people underestimate it because they [parents] have to watch you go through and you go through and you deal with it because it is you, but for everybody else on the outside it’s just…traumatic.” (Nally, F, 23 years)*

Many YAs felt they and their families experienced a lot of emotional problems. As a result, YAs felt socially isolated or imposed self-isolation and many lacked psychological support and struggled to cope.

YAs believed the impact of the disease, decision-making and therapy on their life was underestimated by the kidney professionals, as suggested by Zoe’s experience:

> *“…I think they [kidney professionals] underestimate the impact that it has psychologically and mentally and physically on your life as a whole. I guess it’s a big change.” (Zoe, F, 25 years)*

This is because most YAs felt less psychologically supported at the time. The lack of psychosocial support was still an ongoing issue for some YAs. Decision-making and the experience of choice negatively affected YAs as some suppressed their emotions, became socially isolated, and experienced self-blame and guilt. The harshness of the therapy also negatively impacted on YAs and their families, but they lacked the appropriate psychosocial support and struggled to cope. The next subtheme presented is keeping sane and not going crazy.

4.8.2. Subtheme 5.2 Keeping sane and not going crazy

This subtheme is about how YAs coped with the psychological impact of the disease and the coping strategies used. YAs employed different coping strategies like online gaming and positivity to enable them to cope with their experiences. For example, Harry said:

> *“I just kept myself entertained by playing video games a lot online at the time. I think that is how it kept me sane to maintain…not going crazy at the time. …counsellors were options as such but for me as I mentioned before I just kept myself entertained by playing video games a lot and now, I don’t play video games a lot because I’m not going through that emotional toll anymore yeah. So, video games were like a joy for me for to stop may be trying to end my life at the time. So, yeah that is how I got through.” (Harry, M, 29 years).*

Harry, like many YAs, were determined to maintain their sanity and tried to find alternative ways to manage their situation. Many YAs later found counselling support from kidney charities. The benefits of counselling are suggested by Ben and Zoe’s experiences. Ben said: *“100% yeah, that [counselling], really helped me” (Ben, M, 25 years)*. Receiving counselling support enabled Zoe to cope better and to feel confident to share her story with other people as illustrated by her experience:

> *"Luckily as I said since I had the counselling, I can talk about it better now. Whilst before I could not talk about it without crying. I'm a lot better now." (Zoe, F, 25 years)*

Coping strategies such as positive thinking, denial, comparing themselves with other people, and looking at things differently, were used by some YAs to cope with their situation. Others, like Charlie, felt staying positive helped them cope without going into depression:

> *"I would like to think I dealt with it relatively well. …I think I stayed erm relatively positive compared to how some people have dealt with it." (Charlie, M, 26 years)*

Despite this Charlie later sought counselling support. Likewise, Mina used her work and friends as a positive distraction:

> *"I think it was work, friends, I think work has always been a big thing for me because it's a positive distraction. I'd rather focus on my work problems like things going on at work than to focus on my kidney health… So, when I went to work all day, I wasn't thinking about the dialysis, I wasn't thinking about my bad health. …for me is always having other things to do erm were positive distractions for me." (Mina, F, 29 years)*

YAs had psychological support from family and friends. Drawing on Steve's experiences, he felt his partner and friends supported him at the time:

> *"…the things that helped me cope was my best friends. They just come around all the time, sat with me during the dialysis, and whatever. My*

> *girlfriend as well, she helped me at the time. Family and stuff that's all that got me through. Just friends and family being there for me." (Steve, M, 21 years)*

The support received by family, partners, and friends were echoed by other YAs. For example, Dave felt that openly sharing his mental struggles with his family and friends helped him cope:

> *"…if I'm struggling mentally or emotionally, feeling down, or feeling crap then I just tell somebody. I talk to mum and dad about it, and they do the same to us. I'm glad to have an open family and I do the same with my mates. So, I think that has helped me massively in the long run." (Dave, M, 28 years)*

In contrast, Jess coped by talking to healthy age-related peers where she can talk about other things rather than her medical problem:

> *"…I just spoke about it. I spoke about it with my family, erm and friends, and yeah, I'm quite good, I'm quite steady, I deal with unexpected things quite well. I mean I am able to cope, I have a coping mechanism so yeah. Erm to be honest speaking to people was my main thing. Because I find if I'm all by myself and I become occlude and don't socialise or anything, then I really struggle. I find it better to go out and when I'm talking to people. And I find, erm I feel like am normal but is really horrible to say, but I don't feel like I've kidney transplant, that's my coping mechanism. Being around people who…haven't had a kidney transplant where I can just be myself and don't have to constantly have to talk about kidney*

> *transplant or having a medical problem. Just being able to talk about other things I think that is my coping mechanism." (Jess, F, 22 years)*

Some YAs appraised their values and learned not to take things for granted as expressed by Rita:

> *"…I've always taken things for granted, taken things for granted but I will never ever take things for granted again. Never again not after this experience, because this experience is still ongoing. But since it all started, I definitely appreciate things a lot more." (Rita, F, 30 years)*

Support from teachers and lecturers enabled some YAs to cope with the academic workload. Drawing on Sharon's experience, she worked with teachers to develop a plan to support her education:

> *"…the school did a few things, erm the made sure that I needed the time for the things that I need. …because they knew that I wouldn't be able to sit most of my exams they then pulled me out of those lessons, and I had more time to focus on the lessons that I'd missed in the days that I was in the hospital." (Sharon, F, 22 years)*

Faith in God was also another coping strategy. Drawing on Ben's experience, his faith in God kept him going:

> *"…I believe in God erm and that is what helped me through it… I wasn't alone, so I just kept the faith and kept going." (Ben, M, 25 years)*

The lack of psychosocial support experienced by YAs caused them to adapt ways to deal with their psychological burden. Positive distractions, denial, being around friends, and talking to people were coping strategies used by YAs. Family and friends also provided YAs support. YAs felt offering early psychosocial support would have made them cope better.

4.8.3. Subtheme 5.3 Enhancing my decision-making

This subtheme is about what YAs felt could have been done by HCPs to enhance their decision-making and experiences of choice, which is important to this research. The subtheme focuses on the improvement of the delivery of options information, more individualisation, being told the truth about therapy options and being informed about how to live with and manage ESKD and receiving dialysis and kidney transplant. The subtheme is also about the need for psychological support, experiential knowledge of the practicalities of options and peer support.

Some YAs believed that how communication of the information about diagnosis and prognosis was delivered heightened their fears could be improved. Drawing on Mina’s experience, she felt the way the news of having kidney failure was delivered could have been better:

> *“…how they broke the news first …oh by the way you’ve got kidney failure. …I just felt like the way they broke the news that wasn’t the best… I knew something was wrong, the way they erm people were reacting with me. …the way things were broken to erm the news was told, could have been a little bit better.” (Mina, F, 29 years).*

Some YAs felt they were all categorised into one group as YAs, but their needs differed. YAs felt they should be treated as individuals with unique preferences and not perceived as part of the numbers during decision-making or the commencement of choice to enable their unique needs to be accommodated. Drawing on Mina's experiences, she said:

> *"I think not all young adults are the same, yes, we are this same age bracket, but everyone's experiences can be different. …some of us need more independence but some of us don't want that. …I don't think we are all the same. I think as long as we are given options and information to make, erm we can make our own decisions not everybody though. But I think is just giving us the information and letting us know what the options are, erm I think that is what is important. Erm and treating us like not children so to speak which sometimes I felt…" (Mina, F, 29 years)*

For example, YAs grouped themselves as career and work-driven or those who due to other co-morbidities are unable to work. YAs in this study all categorised themselves as pursuing careers and working who felt their needs were different and healthcare professionals should work with them to understand their decision-making and dialysis needs and make room to accommodate those needs. They wanted to be provided balanced and quality information about the treatment options to enable them to make informed or shared decisions but realise not all YAs may prefer that.

Most YAs felt their concerns were not listened to when raised and wanted to be taken seriously (see section 4.6.1). YAs preferred to be told the truth about each option and the impact of their choice on their life and well-being than for it to be hidden from them. Drawing on Ella’s experience, she felt disappointed when she realised she was not told everything she needed to know following kidney transplantation:

> *“…I do want people to know that it is not all plain sailing. It won’t just be you know; you had a transplant, and you will feel better straight away, there are a lot of ups and downs. Erm and there a few things that they may not inform you about. In terms of like your health, like erm even my scar… there are little things like that that can make your life unbearable. But honestly …I was a bit in shock when I felt that they’ve told me about everything I needed to know. Erm but I just realise that I had to try and find things out on my own.” (Ella, F, 24 years)*

YAs wanted to have been provided information on how to manage their life living with dialysis or a kidney transplant when they were considering their options.

For example, Ella went on to say that although the HCPs informed her that the kidney transplant would make her better, she was not informed how to live with it:

> *“It was more like okay we will do the transplant that’s it, get you better, get out kind of thing. It wasn’t like say okay here; this is how it goes. I don’t think they are aware of all the changes that actually happens. Like even in your own personal life as well, there is a lot of changes you need to make… …So, in terms of working and stuff, how you are going to be out of work afterwards, in terms of like recovery…, The fact that you know you have no immune system, you gonna have to really look after yourself and not being around infection and stuff like that...” (Ella, F, 24 years)*

Psychological support was suggested to be an integral part of receiving diagnosis/prognosis, decision-making, and receiving dialysis and kidney transplant:

> *"…I believe every patient that has been diagnosed with kidney failure, I believe that they [YAs] should get the right support and counselling is first to understand what you're going through". (Ben, M, 25 years)*

Incorporating psychological support as part of receiving diagnosis, facing decision-making, and experiencing choice could help YAs understand their experiences and cope better.

Other YAs felt their family, especially their donors, should be offered psychological support as they struggled to care for them, as suggested by Nally's experience:

> *"…I think if you were to speak to him, …he would want more support like afterward because my dad was in a worse place than I…" (Nally, F, 23 years)*

Nally felt that her dad [her donor] was psychologically impacted after the failed transplant, and then having to watch her go through severe complications which threatened her life.

Likewise, Zoe echoed the need to be given information to illuminate their understanding of how the choice will make them feel:

> *“So, I wish I had more information about what this means and how this makes things happen. Erm but also yeah, the kind of mental, psychological, and counselling support before, during, and after. So, then it wasn’t just me doing it by myself and kind of facing it alone.” (Zoe, F, 25 years)*

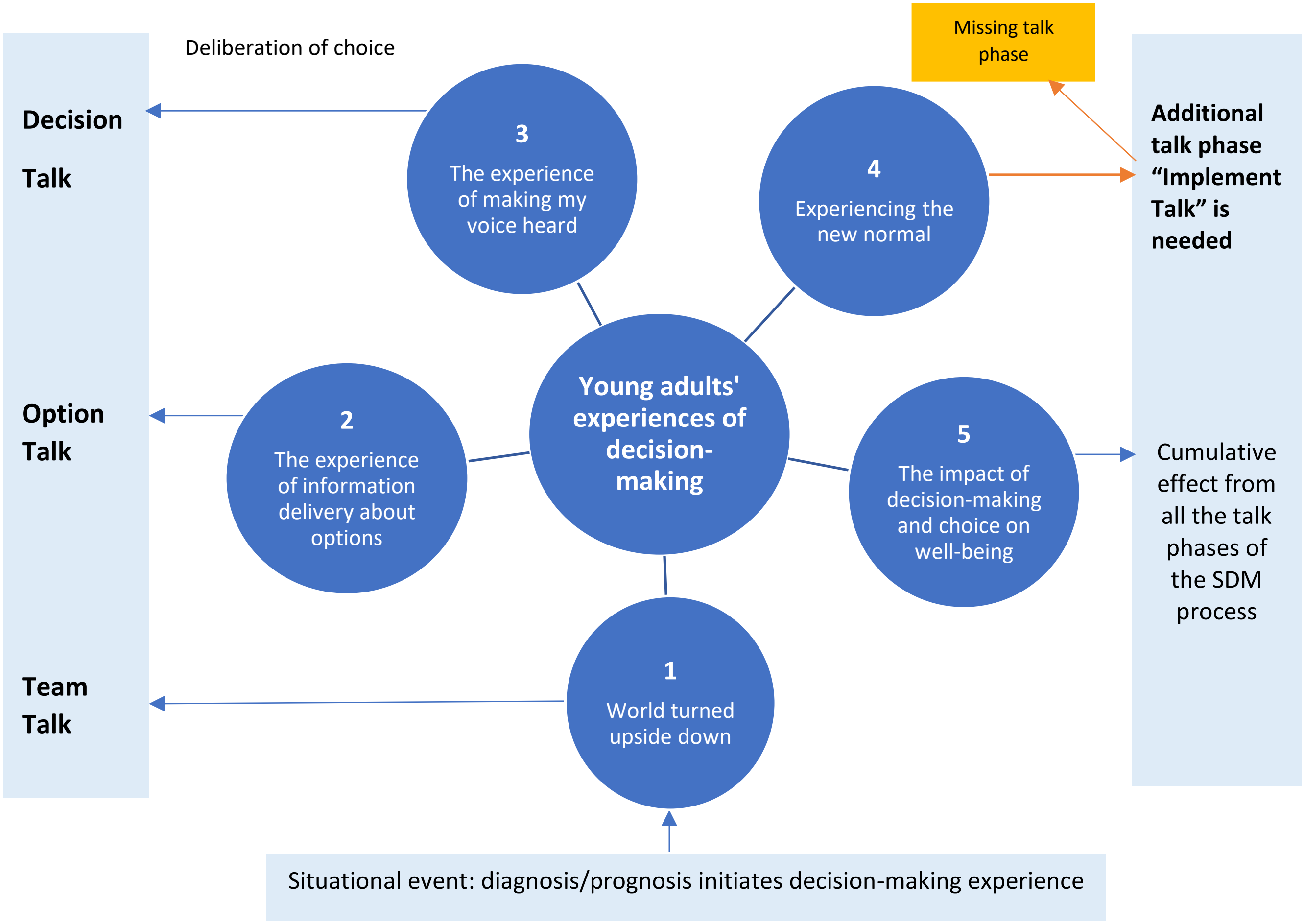
Provision of access to first-hand information from peers for practical and experiential knowledge was considered vital during the decision-making encounter of YAs. YAs believed this should be part of the option discussions as kidney professionals lacked this experiential knowledge because they have not faced dialysis decisions or experienced dialysis. Drawing on Harry’s experience, he felt lonely on dialysis as all the people around him were much older than him:

> *“…linking you with other patients that are around your age who are going through the same thing. Because at the time I was on my own for a long time. I was surrounded by people who were pensioners or middle age, and I can’t relate to them. So, it was quite a lonely experience. …so, all the time you feel isolated in everything.” (Harry, M, 29 years)*

YAs felt communication around diagnosis/prognosis, options information, and therapy discussions could be improved, and they needed to be told the truth to enhance their experience. YAs need more individualisation and to be informed and supported about how to live with ESKD and manage their life whilst receiving replacement therapy. Incorporating psychosocial support as an integral part of the decision-making process and experiencing choice would offer the appropriate support and enhance YAs’ coping abilities. Provision of access to peers with experiential knowledge, and being informed of the practicalities of each option, would enhance YAs’ decision-making experience.

For YAs the decision-making experience is dynamic and continuous and does not just end with making choice decisions. Instead, it continues with the preparation for access surgery, the transplant listing process, and the transition from their carefree life to starting the therapy (implementing the choice). Figure 4.2 conceptualises YAs’ experiences of therapy decision-making in a diagram which highlights a missing talk phase (gap) in the three-talk model of SDM. Figure 4.2 shows how YAs experienced decision-making following receipt of a diagnosis/prognosis and gained the awareness of the need for RRT where their world turned upside down (Theme 1) beginning the team talk phase. This was followed by the experience of information delivery about options (Theme 2), the option talk phase; the experience of making my voice heard (Theme 3), the decision talk phase; experiencing the new normal (Theme 4), and the impact of decision-making and choice on well-being (Theme 5), reflecting the cumulative impact of the talk phases.

Figure 4. 2 Diagrammatic representation of young adults’ experiences of dialysis and kidney transplant decision-making



4.9. Summary of chapter

The findings chapter highlighted the collective shared and individual experiences of YAs' decision-making and experience of choice. YAs felt their world turned upside down when they experienced a change in their self-identity and their life was thrown off track when they became aware of the need for dialysis and kidney transplant. The experience of suboptimal information delivery and lack of understanding of the disease and options made them experience inadequate health information and affected their health literacy. YAs struggled to make their voice heard, which affected their engagement and involvement in dialysis and kidney transplant decision-making and resulted in inequalities in decision-making.

Decisional roles and involvement levels were dynamic and evolved as YAs became more informed. The experiences of the new normal made YAs experience multiple losses, felt different and searched for the meaning of the new normal. The poor experiences of the new normal were associated with a lack of preparation to transition from their carefree life to long-term dependence on therapy, the lack of awareness of the practicalities of dialysis vascular access discussions, and decisions to be made for its preparation. The lack of psychosocial support increased already heightened fears and anxieties as YAs struggled to cope. The findings have highlighted that YAs have unmet informational and decisional needs. The next chapter will discuss the findings with existing literature and the three-talk model of SDM and proposes a new talk phase (implement talk) to address the limitation identified in Figure 4.2.

Chapter 5 Discussion

5.1. Introduction

This study set out to explore YAs' with ESKD, lived experiences of making dialysis and/or kidney transplant decisions, to understand the meaning of their experiences and the effects of decision-making and choice on their well-being. The study achieved what it set out to do as the findings provide an understanding of how YAs engaged with and made therapy decisions. It identified YAs' preferences for decision-making and factors that influenced their choice selection. Decision-making and experience of choice affected YAs' psychosocial and mental well-being and they struggled to cope due to the lack of psychosocial support. The findings also highlight the views of YAs on what could have been done differently to enhance their experiences of decision-making and receiving dialysis and kidney transplant therapy.

Facing dialysis and kidney transplant decisions was perceived as bad news (Jackson, 2014) as it made YAs' world turn upside down as they experienced a change in their self-identity and felt their life was thrown off track. This study findings highlight the experiences of inadequate health education concerning therapy options which contributed to their low health literacy, affected YAs' ability to effectively participate in therapy decision-making, and affected their psychosocial and mental well-being.

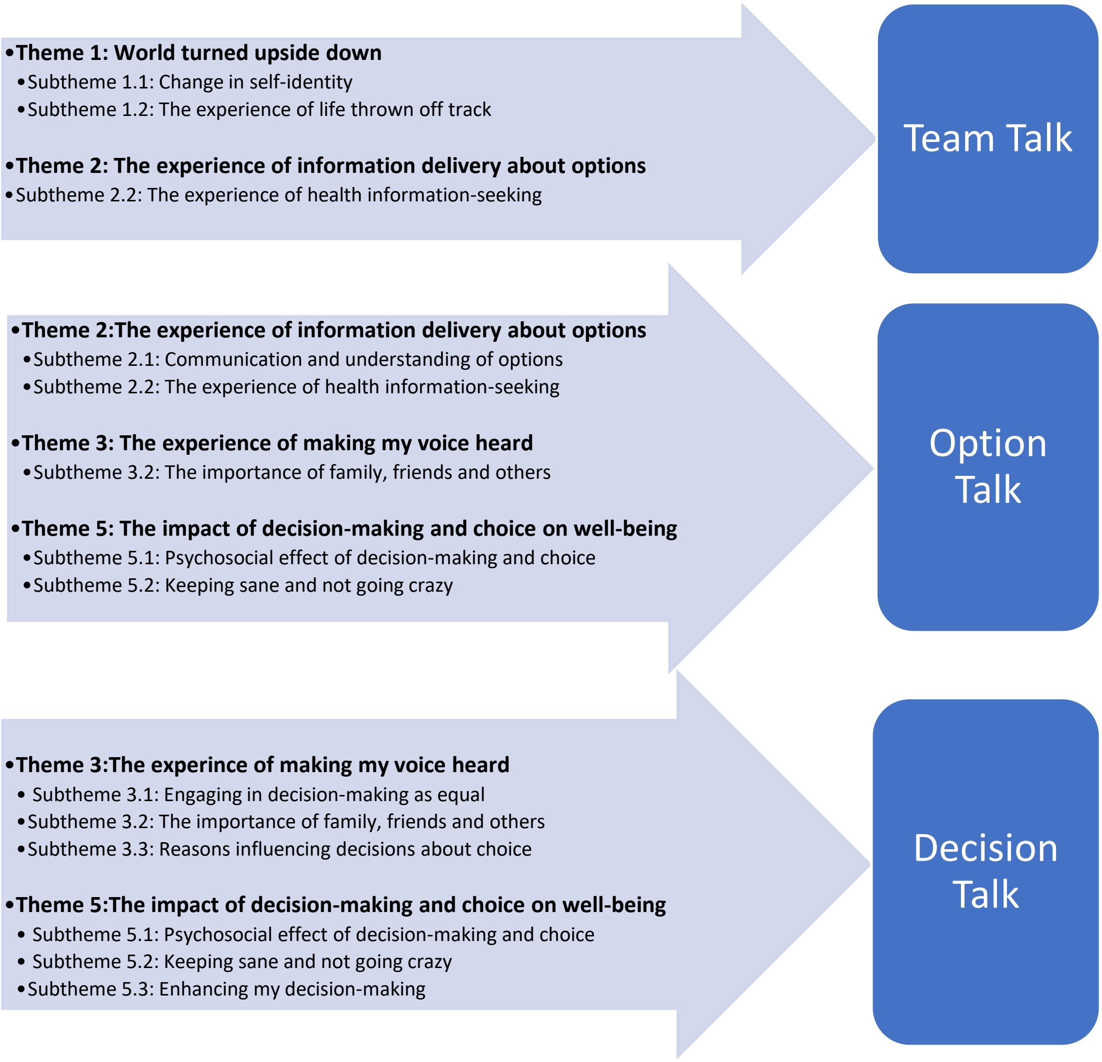
The findings of YAs' dialysis and kidney transplant decision-making experiences presented in chapter four are discussed alongside the literature reviewed in chapter two and other studies related to the findings. The integrative literature review enabled this study to identify the gap in knowledge regarding less literature with a specific focus on YAs' lived experiences of treatment decision-making (Ofori-Ansah *et al*., 2022). This study is among one of the first studies with a specific focus on YAs' with ESKD lived experiences of dialysis and kidney transplant decision-making. The integrative review highlighted a knowledge gap about the lack of focus on the psychological impact of decision-making and support provision. This study addresses the knowledge gap of the effects of therapy decision-making on YAs' well-being and the support received. The findings of this study illuminates what the integrative review highlighted regarding the unmet informational and decisional needs of YAs (Ofori-Ansah *et al*., 2022).

The discussions also highlight the relationship of YAs' experiences in relation to Heidegger's hermeneutic phenomenological principles presented in chapter three (see section 3.5.2). The five themes from the findings were conceptualised into a diagrammatic presentation (Figure 4.2) to visualise YAs' experiences of dialysis and kidney transplant decision-making with the three-talk model of SDM and further explored (Figure 5.1) to guide the discussions in this chapter. The findings in chapter 4 are discussed in relation to the three-talk model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017), to examine how the themes align with it. Finally, the chapter will discuss a proposed new talk phase: "Implement talk" and end with a summary. The discussion begins by aligning the findings to the three-talk model of SDM.

5.2. Findings aligned to the three-talk model of SDM

The themes of the findings are aligned to the three-talk model of shared decision-making to see how they fit in figure 5.1 as the model is recommended by the NICE SDM guideline (NICE, 2021b) for use in healthcare decision-making.

Figure 5. 1 Aligning findings (themes) to three-talk model of shared decision-making



- **Theme 1: World turned upside down**
  - Subtheme 1.1: Change in self-identity
  - Subtheme 1.2: The experience of life thrown off track
- **Theme 2: The experience of information delivery about options**
- Subtheme 2.2: The experience of health information-seeking

- **Theme 2:The experience of information delivery about options**
  - Subtheme 2.1: Communication and understanding of options
  - Subtheme 2.2: The experience of health information-seeking
- **Theme 3: The experience of making my voice heard**
  - Subtheme 3.2: The importance of family, friends and others
- **Theme 5: The impact of decision-making and choice on well-being**
  - Subtheme 5.1: Psychosocial effect of decision-making and choice
  - Subtheme 5.2: Keeping sane and not going crazy

- **Theme 3:The experince of making my voice heard**
  - Subtheme 3.1: Engaging in decision-making as equal
  - Subtheme 3.2: The importance of family, friends and others
  - Subtheme 3.3: Reasons influencing decisions about choice
- **Theme 5:The impact of decision-making and choice on well-being**
  - Subtheme 5.1: Psychosocial effect of decision-making and choice
  - Subtheme 5.2: Keeping sane and not going crazy
  - Subtheme 5.3: Enhancing my decision-making

The experiences of YAs' decision-making process reflect an overlap of some of the talk phases as it is not a linear process but interrelated. Although themes 1-3, and 5 could be aligned with the three-talk model of SDM, theme 4 the experience of the new normal cannot be aligned. The experience of the new normal is about the implementation of the chosen therapy, which includes the practicalities regarding the preparation and commencement of RRT and reflects some limitations with the three-talk model of SDM. The alignment of the findings to the three-talk model (Figure 5.1) suggests the need for another talk phase that will focus on discussions about the implementation of choice (see Figure 5.2, p.347). The suggested new talk phase called ‘implement talk’ is proposed and further explored in section 5.10. Each theme will be discussed in relation to the three-talk model of SDM supported by relevant literature.

5.3. Team talk-Theme 1 World turned upside down

The two key messages that arose from the first theme, world turned upside down; change in self-identity and the experience of life thrown off track, are discussed with existing literature. The team talk phase of the three-talk model of SDM is where the patient is made aware that choices exist, identifies the patient’s goals, and these goals are explored in relation to their health problem and supported (Elwyn *et al*., 2017). An assumption is made that the decision-maker understands the health problem for which a treatment decision needs to be considered. YAs in this study traced the beginning of their decision-making experiences to the time when they first received a diagnosis and/or prognosis of CKD/ESKD (see Figures 4.2 and 5.1). This was the first time YAs initially became aware of the need for dialysis and/or kidney transplant therapy where they also experienced a change in their self-identity and felt their life had been thrown off track and their world turned upside down. During the team talk phase, HCPs must acknowledge the implications of the information delivered to YAs because of the permanent life-changing situation they face, which requires a long-term dependence on RRT.

5.3.1. Subtheme 1.1 Change of self-identity

This section will discuss the change of self-identity experienced by YAs in this study in relation to thrownness of disease, having a sick identity and the effect of change in self-identity. The sudden occurrence of kidney disease can be likened to being thrown into situated events where YAs had no control or power over them but are compelled to accept what life had thrown at them, which can be related to Heidegger's hermeneutic principle of thrownness (Heidegger, 1962). Heidegger (1962) asserts that as human beings, we are thrown into a world of events or experiences where we do not have control over the events, which he referred to as thrownness. Spinelli (2005) also echoes Heidegger's perspective that human beings are always situated in a set of events that they may not have control of, such as experienced by YAs in this study. Elwyn *et al*. (2012) assert that psychosocial and emotional factors could influence the deliberation space during the SDM process and should be managed through effective patient-HCP dialogue. For YAs in this study, the team talk phase (Elwyn *et al*., 2017) was perceived as a sensitive and very emotive time.

The receipt of a diagnosis and/or prognosis of CKD/ESKD and awareness of the need for dialysis and/or kidney transplant therapy was perceived by participants as a change in self-identity (Figure 5.1). Change of self-identity is discussed in relation to having a sick identity, experiencing multiple losses, discrepancies in values and beliefs and aligned with the three talk-model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017). Self-identity is the way a person feels about themselves or within society and is the foundation of what makes a person who they are

(Abrahamse, 2019; Carter and Marony, 2021). In addition, this caused a change in YAs' perceptions about themselves (having a sick identity) as they tried to integrate ESKD into their life. The change in self-identity was twofold: having a long-term chronic condition and future long-term dependence on dialysis and kidney transplant. For many, this meant taking on a sick identity. Aligning their experience to the team talk phase, although the model (Elwyn *et al*., 2017), encourages the exploration of a person’s reaction to the option information, it was limited in acknowledging the change in self-identity of the individual and exploring the understanding of the health problem before the choice is offered.

Having a sick identity changes a person’s self-identity, as experienced by YAs in this study, and has been reported by other studies (Castro *et al*., 2012; Tong *et al*., 2013). Others have used expressions such as illness perceptions and illness identity to describe a change in identity (Bulck *et al*., 2019; Jayanti *et al*., 2016; Muscat *et al*., 2021; Oris *et al*., 2018; Suganthi *et al*., 2020). Identity is a dimension of illness perception, which is how a person thinks about their health problems and behaves (Leventhal *et al*.,1984), as experienced by YAs in this study. For example, physical weakness and loss of energy experienced by YAs interfered with their ability to function and perform the daily tasks as they had done in their past healthy selves, thus changing their self-perception and self-identity. Suganthi *et al*. (2020) reported a negative correlation between the identity dimension of illness perception and treatment adherence among people with end-stage renal disease. People who experience severe changes in self-identity that has negative outcome, struggle to accept who they have become (Knippenberg *et al*., 2002 cited in Carter and Marony, 2021), as did YAs in this study.

Tong *et al*. (2013) highlighted that AYAs with advanced CKD felt they had a sick identity which affected the performance of physical activities as they perceived themselves as less healthy and energetic compared with healthy siblings and peers. YAs with cancer felt the disease affected their identity, illness perception and their emotional perception (Castro *et al*., 2012). Also, most females compared with men believed that cancer had more negative consequences (Castro *et al*., 2012). However, in this study, there was no difference in the perception of change in self-identity and emotions between males and females, in contrast with what YAs with cancer reported. Although a change of self-identity is experienced in both situations, YAs with ESKD do not experience remission in the progression of the illness or therapy compared with YAs with cancer. Bulck *et al*. (2019) highlighted that having a heart condition posed major changes to YAs due to strict medication regimens, treatment, and lifestyles, resulting in a perceived change in self-identity. Similar effects have been reported amongst YAs with asthma (Sligo *et al*., 2019).

YAs living with a long-term condition (LTC) perceived their identity as ill or abnormal compared with their former self due to the negative effect on their sense of self and identity (Wilson and Stock, 2019). YAs with systematic lupus erythematosus (SLE) experienced marred identity due to the changes to their body (skin rash, loss of mobility, weight gain, and loss of hair) and experienced a change of their self-perception as young healthy individuals to being sick and incapacitated (Tunnicliffe *et al*., 2016). Charmaz (1995) asserts that the presence of a chronic illness undermines the unity between the body and the self which forces an identity change in the person. The presence of ESKD, the awareness of the need for future therapy, the anticipation of it, and facing therapy decision-making brought disturbances to YAs' coherent sense of self, as they tried to understand what it meant for their self-identity and everyday life (Tong *et al*., 2013; Bailey *et al*., 2018). The lack of time to come to terms with diagnosis/prognosis can overshadow the SDM discussions (Joseph-Williams *et al*., 2014a). Therefore, the person who is faced with a chronic illness must understand what that means to their identity as this enables them to integrate the illness into their sense of self and form an illness identity (Leventhal *et al*., 1999).

Thus, the change in self-identity experienced by YAs in this study is common among YAs living with other LTCs. Oris *et al*. (2016) reported different dimensions of illness identity among YAs with type 1 diabetes which affected their behaviour towards management of their diabetes and treatment. Illness identity is the extent to which a chronic illness is integrated into a person's identity (Bulck *et al*., 2019; Oris *et al*., 2016) and has four dimensions (see section 5.6.1). The perception of an illness is interlinked with illness identity and relates to a change in a person's self-identity (Oris *et al*., 2016). The finding of a change in illness perception and illness identity is similar to the findings of this study which reiterates the loss of the former self from an active and healthy person to a weak person because of the LTC. Participants in Ho *et al*.'s (2021) study expressed their inability to participate in daily activities due to changes in their body which forced them to accept the need for dialysis. Although the study does not use the term change in identity it highlights the change in performance. Therefore, it is important that during the team talk phase the HCP explores YAs' understanding of diagnosis/prognosis (the problem that has been identified) and their well-being before making them aware of the available options and offering choices.

The way CKD/ESKD was perceived and thought about by YAs in this study is important because how a person thinks about illness can affect their treatment-seeking behaviour, adherence to treatment, how they self-care and their quality of life (Bulck *et al*., 2019; Mosley *et al*., 2016). Suganthi *et al*. (2020) reported a negative correlation between the identity dimension of illness perception and treatment adherence among people with end-stage renal disease. Muscat *et al*. (2021) reported that illness perception among CKD patients did not differ across participants' age groups, level of education and occupation status. Compared to this study there was no difference among participants. Appropriate actions taken to improve their knowledge and understanding of health problems would promote better engagement with decision-making.

It was important that HCPs explore these discrepancies experienced by YAs during the team talk phase of the SDM model (Elwyn *et al*., 2017), but the model was limited in exploring YAs understanding of the health problem, and how it may affect YAs life goals and future. The three-talk model (Elwyn *et al*., 2012; Elwyn *et al*., 2017) assumes the individual already understands the health problem as it begins with offering a choice, and other SDM models: the Interprofessional shared decision-making model [IP-SDM] (Légaré *et al*., 2011) and the SHARE Approach (Agency for Healthcare Research and Quality, 2018), take a similar approach. In contrast, the informed decision-making approach in the paediatric setting explores the health problem before discussing the treatment options (Best start by Health Nexus, 2019). However, in this study, most YAs' goals were not explored in relation to their health problem during team talk.

Awareness of choice brings fear, anxiety, and deep grief as experienced by participants in Ho *et al*.'s (2021) study. Reports of shock, fear, and disbelief at the receipt of diagnosis/prognosis and treatment have been highlighted among AYAs with asthma and cancer disease (Hart *et al*., 2020; Pyke-Grimm, 2019; Sligo *et al*., 2019). The experience of fear and anxiety could be aligned with Heidegger's notion of angst, which is the feeling of deep anxiety or dread experienced in an authentic or inauthentic way of being (Spinelli, 2005). Heidegger (1962) asserted that when people experience things that life throws at them such as illness, it brings about deep emotions of anxiety and fear, as experienced by YAs in my study. A person's understanding of their present situation always has a bearing on their past and projection of their future (Langdridge, 2007).

YAs in this study understood their decision-making experiences in relation to their past healthy life, their present weak self, and the projection of their future life of receiving dialysis and kidney transplant. Jackson (2014, p. 8) asserts that a person with chronic illness can be likened to "walking down a dividing line between the past and the future". YAs in this study could see everything that the chronic illness (ESKD) and RRT will take away from them or force them to relinquish (self-identity, good health, and future) (Jackson, 2014), as highlighted in other studies too (Tong *et al*., 2013; Mitchell, 2014). People with heart conditions who successfully integrated their disease into their life were able to accept the change in self-identity (Bulck *et al.*, 2019). The lack of understanding of diagnosis/prognosis and change in self-identity can create a barrier to active engagement in therapy decision-making or cause therapy decisions to be made under ignorance (Hart *et al*., 2020) but having an understanding of diagnosis/prognosis informs treatment decision-making (Mack *et al*., 2018). Although the team talk (Elwyn *et al*., 2012) initiates the process of SDM, the person's understanding of the health problem should first be explored to develop a good foundation before the choice is offered.

5.3.2. Subtheme 1.2 The experience of life thrown off track

YAs in my study were at a pivotal progression in their developmental stages of young adulthood when diagnosis/prognosis of CKD/ESKD was received, which resulted in immediate and potential future changes to the course of their life making them experience a life thrown off track. The experience of chronic illness throwing YAs' life off track has been reported by other studies (Bailey *et al*., 2018; Murray *et al*., 2014; Tong *et al*., 2013). YAs living with ESKD reported thwarted dreams and ambitions due to lost opportunities, and moderation of their dreams in education, employment, and intimate relationships (Bailey *et al*., 2018), which supports the findings in this study. Murray *et al*. (2014) highlighted that YAs with ESKD were negatively affected in academic achievement and employment while Tong *et al*. (2013) reported a perceived inability to achieve and perform as they struggled with the uncertainty of their future. Facing decisions about RRT was difficult due to its effect on future and lifestyle and older participants were reluctant to change their lifestyles more than they wanted (Ho *et al*., 2021).

This study's findings highlight that YAs experienced disruptions to their education, work, future career and underperformed, as highlighted by other studies (Bailey *et al*., 2018; Murray *et al*., 2014; Park *et al*., 2014; Levine *et al.*, 2018; Sligo *et al*., 2019). Previous studies highlight worse outcomes experienced by YAs with CKD/ESKD compared with their healthy age-related peers (Hamilton *et al*., 2017; Hamilton *et al*., 2018b; Ferris *et al*., 2015; Tong *et al*., 2013). Hamilton *et al*. (2017) identified that YAs receiving an RRT were likely to be unemployed, live at home and unlikely to be married or have a partner. In this study, most YAs were staying at home, some were employed and in relationships, although some initially believed they were less likely to find partners. Compared with those with other long-term chronic illnesses there were fewer young adults with CKD in employment (Murray *et al*., 2014). Young people with asthma and cancer felt the presence of illness or treatment altered their life trajectory as some had to delay education, retake aspects of their course or change their plans as they could not be achieved (Sligo *et al*., 2019). Priorities such as education, job security, building a romantic relationship and family life highlighted by YAs in this study have been reported by other studies (Bailey *et al*., 2018; Ferris *et al*., 2015; Hamilton *et al*., 2018b; Murray *et al*., 2014; Park *et al*., 2014).

Focusing only on the choice options and neglecting the social and future aspects of the matter to YAs, results in conflict due to the lack of self-actualization, which is achieving one’s full potential. Ryan and Deci (2017) argue that people have an inherent desire to achieve competence, to self-actualise and achieve satisfaction in life, and so did the YAs in this study. Despite these inherent desires, YAs in this study felt limited in their ability to achieve academic heights, develop social skills, and gain high-end employment like their peers due to the disease and therapy. Those who were already employed lived in constant fear of losing their job because of the disease and the therapy regimen and in one situation a job was lost. Murray *et al*. (2014) reported that YAs experienced fewer achievements in their developmental milestones in education and employment compared to their age-related healthy peers. Bailey *et al*. (2018) also highlighted disruptions in education and underachievement in YAs.

YAs in this study lived in uncertainty of their future, which made it difficult for them to plan as they were in limbo, not knowing what would happen next. Bailey *et al*. (2018) and Tong *et al*. (2013) also reported the experience of uncertainty and liminality. Ho *et al*. (2021) found older adults perceived dialysis choice as choosing between death and life which was reported by YAs in this study. Facing dialysis decisions was associated with uncertainty about the future (Walker *et al*., 2017). This study also highlighted the perceptions of the potential difficulty of being accepted for intimate relationships or having marriage partners, which were also reported by other studies (Bailey *et al*., 2018; Hamilton *et al*., 2018b; Kim and Choi, 2016). Offering choice in the team talk phase can be disconcerting (Elwyn *et al*., 2017) and should be explored in relation to how it affects YAs' life as it can go unnoticed and hinder effective engagement with the information delivered. The findings from this study have shown the experiences and struggles of YAs and it is important to incorporate these areas identified in the team talk discussions.

5.4. Option Talk-Theme 2 The experience of information delivery about options

This section discusses the communication and understanding of options and the experience of health information-seeking (see Figure 5.1) in relation to the option talk phase of SDM (Elwyn *et al*., 2012). The discussion of communication and understanding of options information will explore health education and health literacy, risk communication of options, decisional support tools, quality and balanced information and information processing styles. The experience of health information discussions will focus on readiness to learn and peer learning.

5.4.1. Subtheme 2.1 Communication and understanding of options

This section focuses on health education and health literacy, risk communication of options, decisional support tools, quality and balanced information and information processing styles. YAs had mixed experiences of communication and understanding of options ranging from suboptimal to optimal levels. Educating people about their disease and available options relates to their health education and health literacy (Levine *et al*., 2018). Health literacy is the ability of individuals to gain access to, understand, and use information in ways to promote and maintain good health for themselves, their families, and communities and make decisions (Roberts, 2015). Health literacy about options enhances the awareness of the right to choose, access to quality information, the use of and understanding of the information (Department of Health and Social Care and Public Health England, 2021; Roberts, 2015). On the contrary, low health literacy affects the ability to utilise health information, holds a greater risk of managing a long-term condition (Berkman *et al*., 2011), and has poorer outcomes (WHO, 2013).

Rowlands *et al*. (2015) found that 42% of the working-age adult population in England were unable to use everyday health information. People with long-term conditions including kidney disease were more likely to experience limited health literacy (Public Health England and UCL Institute of Health Equity, 2015). Levine *et al*. (2018) highlighted that although YAs with CKD/ESKD face complex medication and therapy regimens, one in three AYAs experienced low health literacy, and about 23% of adults also experienced low health literacy. This study's findings demonstrate unmet informational needs due to the lack of and inconsistency in information delivery about therapy options, poor communication and in some situations a lack of awareness of dialysis therapy reflecting suboptimal health education and low health literacy. Mack *et al*. (2018) highlighted that some of the AYAs with cancer felt uninformed about treatment options while Zebrack *et al*. (2013) reported unmet informational needs about cancer, infertility, exercise, diet, and nutrition information among AYAs. Loiselle *et al*.'s (2016) study highlighted participants wanted to be told the whole truth without holding back any information as this would enable them to make an informed decision, however others lacked the readiness for it or rejected the information due to their fear of dialysis. Similarly, YAs in my study wanted to be told the whole truth but unlike Loiselle *et al*. (2016) study, none of them rejected the information.

Lower health literacy exists among patients with CKD relating to how healthcare providers support and appraise health information (Dinh *et al*., 2021). Dinh *et al*. (2021) concluded that people with CKD had difficulties in various health literacy domains relating to the communication and appraisal of information which supports my findings on suboptimal communication, access to, understanding and utilisation of information. In a particular situation in this study, an individual expressed wanting information to be explained to her like a five-year-old while others expressed fear, confusion and feeling out of the loop. Irrespective of how long YAs had lived with CKD they could not consistently use the information to improve their health knowledge. This reflects inequity in information sharing due to the inability of HCPs to explain the options information in a way that is simple and easy to understand. Ineffective health education and low health literacy affects health outcomes (Berkman *et al*., 2011) but improved literacy results in better health outcomes and reduces health inequalities (Dobson *et al*., 2015).

The use of risk communication, which is a two-way exchange of information and opinions about risk leading to the improvement of the understanding of options and better decision-making, is an integral aspect of the deliberations of options (Naik *et al*., 2012). Risk communication of options when personalised, especially in preference-sensitive decisions such as RRT decision-making, can promote health education and improve health literacy, but this is dependent on the HCPs' communication skills (Edwards *et al*., 2013; Elwyn *et al*., 2012; Naik *et al*., 2012). Edwards *et al*. (2013) highlighted that the use of personalised risk communication increased participants' knowledge and the ability to make informed choices compared to those who received generalised risk information. For patients to make trade-offs, they must first understand the risks and benefits of each option (Fagerlin *et al*., 2011), which supports the findings of this study as YAs wanted information on both risks and benefits. The use of risk communication strategies such as the use of plain language, pictorial graphs and absolute risk have been found beneficial (Fagerlin *et al*., 2011).

Information sharing during the decision-making encounter should be a two-way exchange and not unidirectional (Charles *et al*.,1999; Makoul and Clayman, 2006; Joseph-William *et al*., 2017) in the option talk phase. However, YAs in this study had mixed experiences of information sharing as most of the communication was more unidirectional than two-way in their first engagement with decision-making. YAs received inconsistent support to develop the cognitive and social skills necessary to improve their knowledge and health literacy (Sorensen *et al*., 2012). Halpern-Felsher and Cauffman (2001) assert that competent informed health decisions can only occur if the decision-maker understands the purpose of the treatment, the procedures involved, possible risks, alternative options, and likely outcomes.

Dobson *et al*. (2015) claims that knowledge, skills and experience are needed to enable people to understand health-related information as better communication has been shown to improve patient experience, clinical outcomes, and patient satisfaction (Joseph *et al*., 2020). Although the option talk phase (Elwyn *et al*., 2012) supports the deliberation of choice, which is a process of considering the pros and cons of available options, assessing their implications, and considering the future and emotions, in this study, less deliberation occurred. Deliberations about the options with YAs are vital as this encourages two-way information sharing and enhances understanding of therapy decisions, the potential risks of each therapy, and its implications for their life. Elwyn *et al.* (2014) argue that HCPs should offer patients adequate time to consider their options following the option talk discussions, before supporting them to form preferences during the decision talk phase.

The use of decision support tools, such as patient decision aids (PDAs), which are usually in a verbal, written, computer-based or video format, motivational interviewing and decision coaching to support information delivery, and the deliberation of options, is highlighted in SDM literature (Elwyn *et al*., 2012; Jull *et* *al*., 2021; Stacey *et al*., 2017b; Winterbottom *et al*., 2020b). However, patients are less aware of the term decision aid or decision support tool but refer to them as information that helped them to understand the disease or inform them of available options (Winterbottom *et al*., 2012). Similarly, YAs in this study did not use the term patient decision aid but referred to them as information materials about options. The use of decision aids for people facing treatment or screening decisions has been found to have a positive effect on patient-clinician communication (Nossair and Thornburg, 2018; Stacey *et al*., 2017b).

The use of PDAs increased participants' knowledge, the accuracy of risk perceptions, congruency between informed values and care choice compared to usual care (Nossair and Thornburg, 2018; Stacey *et al*., 2017b). Decision aids were also found to decrease indecision about personal values, decisional conflicts relating to feeling uninformed, and passive involvement during the decision-making process compared to usual care (Stacey *et al*., 2017b). Jull *et al*. (2021) evaluated the use of decision coaching compared with usual care and reported uncertainty of improved outcomes such as preparing people for decision-making, decision self-confidence, knowledge, decisional regret, feeling uninformed, and anxiety due to low certainty of evidence. In this study, the participants did not mention the use of decisional coaching or motivational interviewing.

Situational contexts, framing of information, and its delivery affected the ability of YAs in this study to gain knowledge and understand available options and that limited their ability to self-determine their choice. Hart *et al.* (2020) highlighted

AYAs received information while unwell on admission, still in shock, or during routine consultations and this affected their ability to focus or engage with the information as they felt unprepared to receive the information, echoing Morton *et al*.'s (2010a) study. Perceived fear of emotionally uncomfortable content about options also contributed to the disengagement and the inability to develop informed preferences (Hart *et al*., 2020; Mitchell, 2014), which is supported by the findings of this study. Støme *et al*. (2021) highlighted that people with CKD wanted to protect themselves from too much information by actively limiting information input or becoming passive receivers, avoiding information, or not actively seeking information. However, in this study, YAs actively sought information rather than protecting themselves from the information.

The need for balanced discussion about dialysis options has been reported (Griva *et al*., 2013; Martin and Muller, 2021), which supports this study's findings. Thomas *et al*. (2016) reported that older patients felt the quality of information could have been better. Zee *et al*. (2018) highlighted participants wanted more information than was received, while Song *et al*. (2013) highlighted that almost 70% of patients reported that information on the burden and risk of dialysis were not provided. Makkar *et al*. (2019) highlighted that half of their participants received conflicting information, which was unhelpful. Studies have reported the receipt of selective information about options (Hart *et al*., 2020; Morton *et al*., 2010a).

Others have highlighted the perceived power gap and control of information as a barrier to relationship building and trust (Devitt *et al*., 2017; Frosch *et al*., 2012;

Walker *et al*., 2017). Similarly, in this study, YAs felt HCPs controlled the information and decided the information that YAs should receive. The option talk phase of the three-talk model of SDM suggests that HCPs should confer agency in providing information, but this is dependent on a good HCP-patient relationship (Elwyn *et al*., 2012). This finding suggests the need for HCPs to take prompt action to address these concerns in the option talk phase.

YAs must be supported to develop knowledge and an understanding that is reflective of their cognitive level because good cognitive abilities influence good decision-making skills (Jackson *et al*., 2016). Information processing styles have been shown to have a considerable effect on the quality of decision-making (Ayal *et al*., 2012; Rosou *et al*., 2013). Shaham *et al*. (2006) highlighted that the presence of individual differences in cognitive heuristic strategies may determine whether stress will modify judgemental processes or not. Ayal *et al*. (2012) highlighted that the weight a person assigns to rational decision-making is highly dependent on the level of their deliberative thinking style as this increases the vigilance of the deliberative system to adjust their intuitive anchor.

Rosou *et al*. (2013) highlighted that when an individual's thinking mode and characteristics of the decision task are compatible, it results in a higher quality choice or decision-making. YAs in this study used both intuitive and analytic information processing styles during the deliberation of options information and the selection of their preferred choice. Individual differences among decision-makers have been reported to affect choice behaviours (Lauriola *et al*., 2014; Soane and Nicholson, 2008). For example, the individual differences among

AYAs have been shown to affect their risk perception (Williams and Noyes, 2007), risk seeking (Burnett *et al*., 2010; Paulsen *et al*., 2011) and avoidance behaviours (Shaham *et al*., 2006). Understanding these differences can enhance how HCPs support YAs to develop their knowledge and gain understanding.

International and national guideline recommendations on the management of CKD and ESKD support the provision of personalised and well-balanced education on available treatment options (Bagnis *et al*., 2015; KDIGO, 2013; NICE, 2021a; NICE, 2021b). Understanding of options can empower and give greater control over health decisions and actions affecting a person's health (NICE, 2019; Sanderson *et al*., 2019). Targeted information delivery appropriate to YAs' literacy level and information that is easy to assimilate could enable a better understanding of available options during option talk as recommended by the guidelines (Covic *et al*., 2010). However, poor information disempowers people and limits meaningful decision-making (Walker *et al*., 2016; Walker *et al*., 2017), which supports this study's findings.

5.4.2. Subtheme 2.2 The experience of health information-seeking

The experience of health information-seeking revealed a desire to explore social media and turn to peers for support. This section discusses how the lack of information and lack of understanding of options information led to the exploration of alternate sources for information to improve health literacy. The discussion will focus on readiness to learn and peer learning. Narva *et al*. (2016) highlighted that readiness to learn is important in developing knowledge of CKD health information. The health information-seeking behaviour of YAs in this study reflected the need for information and the readiness of YAs to learn about the disease, the therapy options, and the use of various information resources. Most YAs in this study searched for information on the internet and social media platforms like Facebook, Instagram, etc to develop their knowledge and understanding about kidney disease and choice options. This health information-seeking by YAs in this study resulted from the lack of information and the need for information. Støme *et al*. (2021) explored health literacy among people with CKD and reported variation in behaviour of health information seekers. Health information-seeking was used by YAs with cancer to improve their knowledge through information acquired from diverse sources (Pyke-Grimm, 2018).

Peer learning is recognised as important in developing a patient's knowledge and improving decision-making and self-management (Liaghat, 2017; NHS England, 2021a). NHS England (2021a) recommends peer support for all patients as it has been found to be beneficial to patients. Although HCPs provided information about options there was a belief among YAs in this study that due to their lack of experiential knowledge of choice, they could not relate to their situational experiences or provide real-life accounts of choice experiences. Therefore, providing access to peers with experiential information as part of the team and option-talk phases of the three-talk model of SDM is important to provide the experiential knowledge.

Loiselle *et al*. (2016) reported that participants with CKD expressed hearing the experience of peers helped them consider their options, which supports this study's finding as YAs gained a better understanding and knowledge about their kidney condition and therapy options speaking to peers. Peers were used as a source of information who also supported their peers to feel heard and understood (Wood, 2014). People with motor neuron disease valued the advice of peers regarding how to manage aspects of their disease, home adaptations and claiming benefits (Locock and Brown, 2010). Locock and Brown’s (2010) study supports the findings of this study as YAs valued the advice of peers on managing aspects of the disease and how to receive financial support. They also gained awareness of their right to choose, be involved in decisions, and developed self-efficacy to advocate for themselves. SDM is about understanding what matters most to patients, and peer support mattered to YAs, therefore, clinicians must provide access to peers, instead of YAs looking for it, as experienced by YAs in this study. Despite the value of HCPs' involvement, patients wanted to hear and meet people with dialysis experiences (Griva *et al*., 2013).

Participants in this study felt hearing peers’ experiences made them feel they were in the same situation as their peers understood what they were about to experience, which prepared them for what was to come. Morton *et al*. (2010a) reported the experiences of peers motivated patients to develop self-efficacy and advocate for themselves. Through information-seeking, YAs felt comfortable to ask practical questions which they were either afraid to ask or lacked the confidence to do so, improved their decisional self-efficacy, and felt confident to engage in deliberations about options and informed preferences of their choices. The option talk phase (Elwyn *et al*., 2012) requires in depth education and collaborative deliberation of all options to explore the pros and cons of each. The collaborative deliberation process requires HCP’s judgment on the quantity of information provided to the patient (Elwyn *et al*., 2012). This can give rise to situations where either information is lacking or less information is given or more is provided but lacks depth (Cassidey *et al*., 2018; Devitt *et al*., 2017; Epstein *et al*., 2010; Hart *et al*., 2020). Suboptimal communication and education of health information about options continues to be a challenge in healthcare, including kidney care (Hart *et al*., 2019; Joseph-Williams *et al*., 2017). Healthcare provider and patient factors have contributed to the health education and health literacy problem during SDM but many of these factors can be addressed (Joseph-Williams *et al*., 2014a; Pel-Little *et al*., 2021).

5.5. Decision Talk-Theme 3 The experience of making my voice heard

SDM is about supporting people to consider what matters most to them, their values and beliefs, to form preferences and make decisions that fit their situation or lifestyle, which occurs in the option and decision talk phase of the three-talk model of SDM (Elwyn *et al*., 2012; NICE, 2021b). The findings from this study highlighted that despite YAs' experiences of multiple decision-making contexts at different time points of their journey, their voices were not always heard in decision-making. Although evidence-based guidelines (Bagnis *et al*., 2015; NICE, 2021a; KDIGO, 2013) for managing people with CKD recommend that patients are supported to participate in their care and health decisions, this was not consistently experienced by the participants in this study. The discussion will focus on three areas: engaging in decision-making as equal; the importance of family, friends, and others; and reasons influencing decisions about choice.

5.5.1. Subtheme 3.1 Engaging in decision-making as an equal

This part of the discussion explores YAs’ experiences of engaging in decision-making as an equal in relation to being talked to as an adult and not as a child. Equal partnership and valuing different expertise, preference elicitation, awareness of and the lack of choice, decisional role preferences, level of participation and perception about decision-making, will also be discussed. Many of the YAs in this study lacked awareness of the decision-making process and the term SDM. They also did not know what to expect during their engagement in SDM, although one of the characteristics of SDM is information exchange (Elwyn *et al*., 2012; Entwistle and Watt, 2012).

The findings of this study indicate that not all YAs experienced equal partnership during engagement in SDM due to the power dynamics of HCPs over YAs in the decision-making encounter. Equal partnership in the SDM context is very vital as it recognises that both HCP and the decision-maker “bring different but equally important forms of expertise to the decision-making process” (Coulter and Collins, 2011, p.2). HCPs share their expertise of diagnosis, prognosis, cause of disease, treatment options, and outcomes while patients share their experience of illness, social circumstances, values, preferences, and attitudes towards risks (Coulter and Collins, 2011; NICE, 2021b). The lack of recognition of patients’ expertise by HCPs during the SDM encounter makes the decision context unequal which most YAs in this study mostly experienced especially in their first decision-making encounter. Partnership during SDM has been emphasised by adolescents as a vital component of preference sharing (Weaver *et al*., 2015).

A systematic review highlighted that not being listened to or concerns not respected hindered engagement in SDM, however, when HCPs listened to and respected the individual's concerns, this created a sense of partnership (Joseph-Williams *et al*., 2014a). This supports the findings of this study as YAs who felt listened to and heard expressed a sense of equal partnership. Makkar *et al*.'s (2019) study highlighted that over half of the participants felt the doctors talked in front of them as if they were not present. Similarly, being talked to or made to feel like a child or the use of phrases like 'you teenagers' or 'young people' and being told what to do instead of being reasoned with them during discussions about choice, did not encourage equal partnership in this study. Although international and national policies have also been put in place to enable equal participation in therapy decisions and care (NICE, 2018; KDIGO, 2013), YAs were unable to consistently do so.

The decision talk phase encourages the elicitation of preferences to explore what matters most to the decision-maker (Elwyn *et al*., 2012; Elwyn *et al*., 2014), but this was inconsistent in this study. Only a small number of YAs in this study experienced preference elicitation based on their established relationships and trust, while others could not share what mattered most to them with HCPs. Savelberg *et al.* (2020) highlighted that the elicitation of preferences and decision talk was lacking in their observational study, which hindered participants' engagement in discussions and supports this study's findings. An interventional study on the choice of dialysis modality highlighted that the participants experienced preference elicitation and were able to reach high quality dialysis choice decisions following the intervention (Finderup *et al*., 2020). Their findings reflect an ideal SDM context, where a patient's knowledge and preferences are considered alongside the clinician's expertise, to reach a mutual decision based on the best available evidence (Coulter and Collins, 2011).

YAs had the belief that clinicians have a notion of one-size-fits-all which introduced rigidity in option discussions as less emphasis was given to what mattered most to them. A recent conference by KDIGO in 2019 has highlighted the need for nephrology professionals to move away from the notion of one-size-fits-all when considering modality choice, dialysis initiation, access, and prescription of dialysis treatment (Chan *et al*., 2019). Clinicians were encouraged at the conference to use an individualised approach and to consider the patient's goals and preferences (Chan *et al*., 2019). Engagement in decision-making should occur promptly as reports of feeling unprepared or in some situations being rushed to make decisions about choice, despite the time gaps between initial diagnosis and the start of therapy, are of concern.

YAs were unaware that choice existed and were not offered choices in some of their decision-making encounters, although they later gained awareness that choice exists through their information seeking and advocated for themselves in subsequent decisions. The finding of lack of awareness of choice in this study has been reported in other studies (Dahlerus *et al*., 2016; Harwood and Clark, 2013; Morton *et al*., 2010a; Song *et al.*, 2013). Dahlerus *et al*. (2016) highlighted a third of older patients on dialysis felt the choice was not theirs, while Morton *et al.* (2010a) and Verberne *et al*. (2019) highlighted a lack of choice among older adults. Song *et al*. (2013) found that one-third of participants felt the decision to start dialysis had already been made by their clinicians. Mack *et al.* (2019) echoes this study's finding as in their study they reported that AYAs with cancer were likely to report that their oncologist told them the treatment they will receive instead of offering them a choice. Older patients with ESKD reported that choice was suggested to them (Harwood and Clark, 2013), which supports the finding of choice being sometimes suggested to YAs by HCPs. If choice is lacking, then people would not be empowered to participate, therefore, their voices would not be heard during the decision talk phase (Elwyn *et al*., 2012).

Evidence suggests that patients want to be involved in decisions about their treatment and care but are not always able to do so (Coulter, 2010; Joseph-Williams *et al*., 2014a; Martin and Muller, 2021). Joseph-Williams *et al*. (2017) highlighted that some HCPs believe that patients do not want to be involved in decision-making. Although this is possible in certain situations, Joseph-Williams *et al*. (2017) argued that the case may be that patients feel unable to, rather than not willing to do so. However, involvement should be consistent with an individual's preference and appropriate to the specific decision (Dy and Purnell, 2012). In this study, YAs preferred autonomous decisions compared with passive interactions. Active involvement in decision-making and being recognised as the main decision-maker who could make autonomous or shared decisions, was desired, and this is reported in other studies too (Dahlerus *et al*., 2016; Devitt *et al*., 2017; Hart *et al*., 2020; Kim and Choi, 2016).

Mack *et al*. (2019) reported that 58% of AYAs with cancer preferred to share decisions with their oncologists, and 22% preferred their oncologists to hold primary responsibility for decision-making, however, 20% preferred to hold the primary responsibility. The authors identified that not all AYAs held their preferred roles; for example, 22% held more passive roles than desired (Mack *et al*., 2019). The reported low preference for holding primary responsibility for decision-making, might have been due to the perceived complexity of the cancer treatment, and a lack of decisional self-efficacy (Mack *et al*., 2019). In contrast, most YAs in this study preferred to hold the primary responsibility for decision-making instead of their HCPs, although some also preferred to share decisions with their HCPs. This study also identified that not all YAs held their preferred roles, as most of them assumed passive roles during their first decision-making experience. Unguru (2011) also reported that not all AYAs participated at the preferred level during decision-making.

Although YAs are expected to participate in therapy decision-making, the complex decision-making abilities, development of skills, responsibilities, and independence necessary during adult life continue to develop in young adulthood (Halpern-Felsher *et al*., 2016). Despite this ongoing development, Halpern-Felsher *et al*. (2016) argue that some YAs can make competent choices, while others may need help to achieve their goal. Although YAs in this study were able to assert their role in decision-making, they were hindered when they lacked decisional self-efficacy. Failure to recognise YAs' decisional needs as a decision-maker resulted in disengagement and dissatisfaction in the decision context (Kim and Choi, 2016).

Thus, making a decision to select therapy was perceived as a life-changing event, or as a big decision that caused fear and anxiety because of the implications for their future, has been reported by other studies (Hart *et al*., 2019; Mitchell, 2014; Pecanac *et al*., 2020; Pyke-Grimm *et al*., 2020). People who faced treatment decision-making about major surgery and life support perceived them as very difficult decisions. AYAs with other long-term conditions (like cancer, asthma, and degenerative diseases) (Mitchell, 2014; Pyke-Grimm *et al*., 2020) categorised their decisions as either small, big, difficult, or major decisions, depending on the perceived impact they will have on their life. RRT decision-making was perceived as choosing between life and death by YAs, which is supported by other studies (Harwood and Clark, 2013; Ho *et al*., 2021). Harwood and Clark (2013) reported seven out of the sixteen papers reviewed highlighted that dialysis decisions were considered as choosing between receiving life-saving dialysis therapy or dying. Ho *et al*. (2021) also highlighted that dialysis was a choice between a life-saving measure or facing death. YAs in this study needed time to appraise the information received and make trade-offs before reaching a choice during the decision talk phase (Elwyn *et al*., 2012).

The decision conflict scale has been used in multiple decisions, among different populations and clinical contexts and has shown effectiveness in identifying decision conflicts among people facing treatment decisions (Garvelink *et al*., 2019). Goh *et al*. (2021) reported moderate decisional conflict among pre-dialysis CKD patients. Chen *et al.* (2018) reported that experience of decisional conflict was significantly associated with pre-dialysis education, dialysis knowledge, decisional self-efficacy, family support, age, and professional support. The decisional self-efficacy, pre-dialysis education, dialysis knowledge and professional support were predictors of decisional conflict (Chen *et al*., 2018), which supports this study’s findings. The participants in this study were younger compared to Chen *et al*.'s (2018) study, so increasing age was not an issue, rather, decisional self-efficacy, pre-dialysis education, dialysis knowledge and professional support contributed to the decisional conflict. However, an increase in knowledge and understanding in addition to professional support improved their decision self-efficacy and reduced decisional conflicts (Chen *et al.*, 2018). High decisional conflict was identified among decision-makers who were ill or making decisions for themselves and was associated with care planning and implementing decisions in primary care and geriatric settings (Garvelink *et al*., 2019).

Understanding YAs' decisional needs can promote effective involvement and timely treatment decisions made. The perceived power imbalances and dominance by HCPs which affected how YAs behaved in the decision context are highlighted by other studies (Joseph-Williams *et al*., 2014b; Walker *et al.*, 2016). Joseph-Williams *et al*. (2014b) identified that power imbalances hindered participation in SDM while Walker *et al*. (2016) highlighted the lack of decisional power. The decision talk supports preference elicitation as a way to move people to form preferences and reach decisions (Elwyn *et al*., 2012) but the evidence suggests mixed experiences of how it occurs in practice (Finderup *et al*., 2020; Savelberg *et al*., 2020).

5.5.2. Subtheme 3.2 The importance of family, friends, and others

My study also found the supportive role of family, friends, and others in the decision-making context and the reasons influencing YAs' decision-making, which aligns with the decision talk phase (Elwyn *et al.*, 2012; Elwyn *et al.*, 2017) (see Figures 5.1 and 5.2). The discussion here opens up a focus on the interrelations with others, the supportive roles of family, the decisional context and family dynamics and peer support. Heidegger (1962) asserts that our being-in-the-world is interrelated with others and the things in our world because we are always connected to our environment, culture, religion, and significant others. Likewise, in this study, YAs' decision-making was related to their interpersonal relationships with their family, HCPs, peers, and friends who they perceived as important in their life and had a mutual dependence. These findings support those from previous studies (Elwyn *et al*., 2012; Hart *et al*., 2020; Mack *et al*., 2019). Depending on the type of decision to be made and its complexity, people turn to significant others who form part of their socio-cultural context for support (Cassidy *et al.*, 2018), and so did YAs in this study. Therefore, consideration must be given to the interpersonal relations of other people with whom YAs have mutual dependencies during the decision-making process as they play supportive roles during the decision-making (Elwyn *et al*., 2014; Lamore *et al*., 2017; Walker and Ross, 2014). Walker and Ross (2014) have highlighted the need for clear guidance on the influence of relational autonomy in complex decision-making as it can be challenging sometimes.

Family played supportive roles in different ways as they had been with YAs throughout the journey of the disease and therapy decision-making. YAs discussed their options with them and incorporated their suggestions in their final RRT decision. Participants in this study felt their families were accommodated by HCPs as they were able to participate in receiving diagnosis/prognosis and therapy discussions. The supportive roles of family in decision-making and care have been highlighted (de Rosenroll *et al*., 2013; Hart *et al*., 2020; Walker *et al*., 2016). Family, children of patients and partners were seen as being there for participants, providing advocacy, learning together, sharing opinions, and communicating preferences and treatment feasibility (de Rosenroll *et al*., 2013). Family played significant roles in pre-emptive kidney transplantation decision-making (Calestani *et al*., 2012). A systematic review highlighted family were a source of social support as they provided emotional, informational and self-esteem support as well as acting as intermediaries between patients and HCPs (Lamore *et al*., 2017). These studies support the findings of this study, regarding the supportive roles played by family, partners, and friends to YAs, such as kidney donations, and supporting the performance of home therapies.

AYAs were grateful to be given a second chance and felt indebted to their donors and wanted to give something back (Kim and Choi, 2016) which supports the findings of this study. Chen *et al.* (2018) reported a moderate level of emotional support from family (31.07 [SD 29.21]), which was negatively associated with decisional conflict (r = -.477, p < .001). More PD (78%) than in-centre HD (70%) participants reported some involvement of spouses/partners and a low to moderate (32-60%) involvement of other family and friends (Zee *et al*., 2018). Ho *et al*. (2021) reported the fear of dependence on family in managing daily life, which supports this study's findings regarding emotional support and long-term dependence on family and partners. Culture also played a role in the way family influenced the decision-making process (Ho *et al*., 2021; Lamore *et al*., 2017; Devitt *et al*., 2017; Walker *et al*., 2017; Walker *et al*., 2016).

However, in some situations, family were perceived as having a stronger influence over the treatment decisions than people wanted (Al-Bahri *et al.*, 2019; Ho *et al*., 2021; Kim and Choi, 2016). Kim and Choi (2016) reported AYAs felt controlled by their parents who had donated a kidney to them, while Devitt *et al*. (2017) highlighted participants did not want to be indebted to donors for the same reasons. In this study, the YAs had similar concerns. Despite these supportive roles of family, Harwood and Clark’s (2013) study highlighted participants were mindful of how their dialysis choice would affect their family, in half of the studies in their review. Similarly, YAs in this study considered the impact their choice would have on their family.

The decision context also brought strains on family dynamics and relationships, especially during considerations for kidney donation where parents or family members wanted to donate but were unsuitable or YAs were reluctant to accept donations. In a rare situation, a post-kidney donation problem brought unpleasant regret and family conflicts. Refusal to accept donations due to potential concerns that donors may use it to control recipients later, or donors might come to harm, have also been reported (Devitt *et al*., 2017; Hanson *et al*., 2018; Ralph *et al.*, 2017); this study’s findings support these previous studies. Donation-related conflicts marked by guilt, disappointment, anger, rivalry, and abandonment have also been highlighted in the donor-recipient dyad's relationship (Hanson *et al*., 2018; Ralph *et al.*, 2017), while Holscher *et al*. (2018) reported regret among some kidney donors.

This study also highlighted the value of HCPs in decision-making as YAs with established relationships trusted and had faith in them to act in their best interest; similar findings were reported in other studies (Chen *et al*., 2018; Kim and Choi 2016; Devitt *et al*., 2017). Chen *et al*. (2018) found a higher level of informational and appraisal support from HCPs while Zee *et al*. (2018) reported variations in the supportive roles of HCPs among in-centre HD and PD patients. These studies support this study's findings, as YAs described distinctive roles different HCPs played, such as developing interest in their personal and social life and acting as a counsellor in difficult situations, although not all YAs had such established relationships. However, studies have also highlighted less supportive behaviours of HCPs such as being less empathetic (Devitt *et al*., 2017; Walker *et al*., 2017), and not being open to them about their condition (Hart *et al*., 2020).

YAs valued the experiential knowledge of peers as it enabled them to understand the practical aspect of choice, because clinicians could not provide that perspective; this finding is highlighted by other studies too (Griva *et al*., 2013; Taylor *et al*., 2016a; Trasolini *et al*., 2021). Peer support enabled people to develop their knowledge about their disease and treatment options, feel confident and feel supported socially and emotionally (McCarron, 2014; Nesta and National Voices, 2015; Keck *et al*., 2018), as experienced by YAs in this study. This study's findings support Gidugu *et al*.'s (2015) study, which identified that individual peer support was valued as it provided practical, social, and emotional support to people. Through peer support, some YAs in this study formed lasting relationships among those in receipt of a kidney transplant who were considered as a second family.

Evidence suggests the benefits of peer support outweigh the negative effects (Griva *et al*., 2013; Taylor *et al*., 2016a; Trasolini *et al.*, 2021) and this is gaining international recognition (Strafford *et al*., 2019), therefore HCPs should facilitate such support as it is important to YAs. However, despite the benefits of peer support, most YAs in this study lacked access. Taylor *et al*. (2016a) assert that the lack of understanding of peer support by both patients and HCPs hinders its referral and uptake in kidney care. Lack of staff time, guidelines, and information on how to optimise peer support, competing priorities, low referrals, and limited patient volunteers, have contributed to its adoption in kidney care (Trasolini *et al*., 2021; Wood *et al*., 2021).

The decision talk phase of the three-talk model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017) recognises the importance of supporting the elicitation of preferences and supporting the decision-maker to decide what is best for them and make their voice heard. The discussion has highlighted the mixed experiences of the elicitation of preferences, and it is vital that HCPs take more interest in understanding what matters to YAs during the decision talk phase of the three-talk model (Elwyn *et al*., 2012).

5.5.3. Subtheme 3.3 Reasons influencing decisions about choice

This section critically explores the reasons that influenced YAs' decisions about choice. The findings of this study suggest that personal, social, and other reasons influenced the choice of one option over another which has been highlighted by other studies (Harwood and Clark, 2013; Dahlerus *et al*., 2016; Joseph-William *et al.*, 2014b; Robinski *et al*., 2016). The section will focus on the cognitive process of choice consideration, the personal, and social reasons that influenced decision-making.

Hastie and Dawes (2001) claims that people have a set of cognitive skills that influence or constrain the way they make decisions to select choices and to determine whether the choice is logical or ideal. The cognitive processes involved in decision-making and judgement cannot be seen (Ayal *et al*., 2012) but can affect the quality of the final decision made (Bekker, 2009). In this study, YAs made rational decisions as they weighed up their options by considering the pros and cons of each option, made trade-offs, and formed preferences about what mattered most to them before concluding their decisions, following their knowledge development. People do not always make rational decisions (Divekar *et al*., 2012) but have the tendency of making decisions based on intuition or the rule of thumb (Lauriola *et al*., 2014; Soane and Nicholson, 2008). Similarly, in this study YAs were influenced by their intuition and rule of thumb. Other YAs have used logic to weigh their options and select the choice that was perceived to maximise their gains or limit perceived losses (Ayal *et al*., 2012), which may affect the quality of the final decision made (Bekker, 2009). Clinicians need to facilitate the deliberation of choice and elicit YAs' goals to understand their decisional needs.

Personal reasons such as the desire for normalcy, freedom, independence, control, body image, family life and personal preferences influenced decisions about choice. The choice of PD therapy over HD was motivated by perceived independence, freedom, and fewer body image issues. Dahlerus *et al.* (2016)

reported maintaining some normality, independence, continuing daily activities, and the convenience of doing dialysis at home as some of the reasons for the home therapy choice. The choice of PD was influenced by the desire for independence (Robinski *et al*., 2016). Needle *et al.* (2020) highlighted that consideration for family, quality of life, and the awareness of self, influenced decision-making. A review highlighted that YAs reported body image issues due to surgical interventions associated with dialysis access or kidney transplantation (Bailey *et al*., 2018). These studies support this study's findings.

Sadeghian *et al*. (2016) compared the experience of body image disturbance among HD and transplant patients and reported that kidney transplant participants experienced low body image disturbance compared to HD participants. Those who were single experienced higher body image disturbance compared with those who were married. The body image disturbance was also found to be higher in females compared to males (Sadeghian *et al*., 2016). Age correlated significantly with body image as older participants experienced low body image. In this study, both male and female YAs had concerns about body image issues, and these influenced the choice of RRT. Lewis and Arber (2015) reported that YAs with ESKD experienced body image issues due to the changing of therapies and categorised their body as transplant body (obese) or dialysis body (underweight) which made their social and parenting relationships difficult.

Although YAs in this study described how they looked on dialysis and following kidney transplantation, they did not categorise it, as reported by Lewis and Arber (2015). Tong *et al.* (2013) reported that YAs experienced impaired body image due to scars or tubes protruding out of their body, which was raised by YAs in this study. Perceptions from family members with previous experience of dialysis or kidney transplantation, or friends also influenced the type of choice. Walker *et al*. (2016) reported that family members with previous home dialysis experience influenced the selection of home dialysis choice.

Social reasons such as work-life balance, the ability to socialise, education, ability to travel, family life, and the perceived burden of therapy on the family influenced YAs' decisions about choice. Other reasons such as performance of therapy, safety and quality of life were also considered. Dahlerus *et al.* (2016) reported that spending time with other people, the ability to work, and quality of life influenced choice decisions while Robinski *et al*. (2016) highlighted that enhanced quality of life, the opportunity to work or study and lower physical strain as some of the reasons. This study's findings support those from Dahlerus *et al*.'s (2016) and Robinski *et al*.'s (2016) studies. Maintaining community involvement, family functions, cultural, and church activities influenced home therapy choice (Walker *et al*., 2016).

Various factors influenced YAs' decision-making as they deliberated on their options in relation to what mattered to them during the option and decision talk phase. HCPs should elicit YAs' preferences and values in order to support them to form an informed preference during the decision talk phase of the three-talk model of SDM (Elwyn *et al*., 2017). Deliberation of choice and active elicitation of what matters most to YAs must be encouraged as this enhances the understanding of options in relation to what matters to YAs.

5.6. Theme 4 Experiencing the new normal

The three-talk model of SDM assumes that the decision-making process ends once an agreed therapy choice is reached. As discussed in section 5.2, experiencing the new normal could not be aligned with the three-talk model of SDM (see Figure 5.1) as the SDM process ended with the selection of the therapy. However, the findings from this study highlight that YAs' decision-making experiences did not end with the selection of a choice but the preparation and implementation of the selected therapy. YAs wanted discussions to be held regarding the preparation and the implementation of their chosen therapy, which made many feel abandoned once the choice was agreed. A review of the three-talk model of SDM is needed as the model is limited in discussing the preparation and implementation of the choice selected. This suggests the need for the recognition that the SDM process goes beyond choosing a therapy but includes the preparation and implementation of the chosen therapy.

Therefore, consideration of an additional talk phase (implement talk) is required to address the preparation and implementation of chosen therapy which is explored further in this chapter (see sections 5.8-5.10). Likewise, most models of SDM do not include discussions about planning and implementation of choice. For example, the SHARE approach is a five-step process for SDM that ends with the evaluation of the decision made to monitor the extent to which the treatment decision is implemented (The Agency for Healthcare Research and Quality, 2018). It also revisits the decision to determine if other decisions need to be made (The Agency for Healthcare Research and Quality, 2018). However, it does not include discussions about the preparation and implementation of the treatment.

The Informed Medical Decisions Foundation SDM model is a six-step approach to SDM which ends with assisting decision-making but nothing about the implementation of the decision made (The Informed Medical Decisions Foundation, 2012).

The Interprofessional Shared Decision-Making Model (IP-SDM) focuses on three different levels; (i) the individual, (ii) the healthcare teams within an organisation that collaborates with the patient to enable SDM to occur and broader policies and social contexts, and (iii) the factors from the healthcare system that influence the SDM process in the care setting (Légaré *et al*., 2011). The IP-SDM model at the individual level uses a six-step process, which includes arranging the necessary steps for its implementation and supporting them for better health outcomes in relation to the choice made (Légaré *et al*., 2011). Although IP-SDM includes the arrangement for the implementation of choice, it does not involve the patient as it is focused on the evaluation of outcome. The three-talk model of SDM is the most referenced in literature and recommended by NICE (2021b) and therefore was used in this study rather than other models like the IP-SDM model.

The findings of this study highlighted a range of experiences of the new normal and the adaptations and adjustments made by YAs as they tried to accommodate RRT. This section will focus on the experience of receiving dialysis and kidney transplant, the experience of feeling different and searching for the meaning of the new normal experience. The experience of receiving dialysis and kidney transplant will now be discussed.

5.6.1. Subtheme 4.1 The experience of receiving dialysis and kidney transplant

This subtheme could not be aligned to the three-talk model of SDM (Elwyn *et al.*, 2017) as it relates to the implementation of the agreed choice as shown in Figures 5.1 and 5.2 (see sections 5.2 and 5.8). This is because the three-talk model ends with the agreement of a choice (Elwyn *et al.*, 2012; Elwyn *et al.*, 2017), however, for YAs in this study, the decision-making process did not end with the selection or agreement of a choice but continued with their preparation and receipt of the agreed choice, which relates to the implementation of choice. It was important that YAs felt prepared and supported to make the transition from their previous life to living with a chronic disease and experiencing dialysis and kidney transplantation (NICE, 2018). This is an important finding and needs to be acknowledged by HCPs. This section will focus on transitioning from carefree life to dependence on RRT, vascular access preparation and transplant listing, the reality of therapy experienced, and decisional regrets.

It is important that YAs feel prepared and supported to make the transition from their previous life to living with a chronic disease and experiencing RRT. The lack of patient preparedness is associated with high morbidity and low survival (Forster *et al*., 2018). It is vital that YAs are educated about how the therapy might affect them and how to live with the therapy. Chen *et al.* (2018) reported uncertainty about implementing the dialysis decisions made but this was not found in this study. Suboptimal initiation of dialysis is common among people with ESKD whether referred early or late (Hughes *et al*., 2013; Mendelssohn *et al*., 2011). People with >1-year of advanced kidney care experienced suboptimal initiation of dialysis (Mendelssohn *et al*., 2011). Despite international (Bagnis *et al*., 2015; KDIGO, 2013) and national guideline recommendations (NICE, 2018) that dialysis access must be created at least six months before dialysis is initiated, as it requires time and preparation for the creation of the vascular access, and for it to be ready for use, there are still gaps in practice.

This study's finding of the lack of discussions about the practicalities of experiencing choice, such as dialysis vascular access decisions and preparation and the transplant listing workup process, are highlighted in the literature (Calestani *et al*., 2014; Griva *et al*., 2019; Hart *et al*., 2019; Mendelssohn *et al*., 2011). Provider factors such as poor education and late access referral (Lopez-Vargas *et al*., 2011; Hughes *et al*., 2013) and patient factors, such as lack of readiness to receive dialysis education, avoidance, and reluctance to discuss them (Casey *et al*., 2014; Donca *et al*., 2012), have been highlighted.

Griva *et al*. (2019) argues that timely dialysis vascular access creation (fistula and graft for haemodialysis and Tenchkoff catheter for PD dialysis) can enhance the smooth transition to dialysis, but the initiation of dialysis remains suboptimal, as experienced by YAs in this study. Vascular access for dialysis therapy is more than just a surgical intervention as it becomes part of the individual and a lifeline for their survival (Taylor *et al*., 2016), therefore, discussions, decisions, and preparation for it should occur. The success of dialysis depends on a functioning vascular access (Santoro *et al*., 2014), but its acceptance continues to be a challenge due to a lack of understanding, poor acceptance, and associated complications (Polkinghorne, 2013).

The suboptimal information and lack of choice regarding the type of vascular access affected timely vascular access creation among YAs in this study. The creation of vascular access for haemodialysis and PD therapy was reported to be associated with the imminent start of dialysis in a systematic review, which also heightened emotions, as it was a constant reminder of the change in self-identity, body image and lifestyle (Casey *et al*., 2014). Vascular access education and access preferences do not form part of option discussions and tend to receive less focus during the decision-making process, as experienced by YAs in this study.

However, the success of haemodialysis therapy depends on good vascular access therefore timely education and counselling on vascular access are vital (Casey *et al*., 2014). There is a need for an implement talk phase with a focus to prepare people to implement agreed choice where timely vascular access discussions, decisions, and planning can occur, which is further discussed in section 5.10. This should also include discussions of the kidney transplant listing process and tests, education on living and managing life on RRT and the smooth transitioning to initiate RRT. YAs and HCPs can develop strategies of how best to prepare them and manage their fears and concerns during the implement talk phase.

The study found discrepancies between the expectations of YAs and the reality of receiving dialysis and kidney transplant. The start of dialysis brought shock, anxieties, and fears to YAs in this study, as they felt unprepared. YAs felt the therapy and its associated limitations were harsher than expected; they feared the dialysis needles, and felt their body had been turned into a machine. These experiences contributed to the psychosocial distress of YAs, in this study. Fear of dialysis and feeling forced to accept dialysis (Ho *et al*., 2021), needle anxieties (Taylor *et al.* 2016), heightened vulnerability due to body intrusion, mechanisation of the body, and perceived time wasting (Casey *et al*., 2014), have been reported. Practical concerns such as pain, disruption to lifestyle and burdening of families have also been reported (Griva *et al*., 2019), which are supported by this study.

Although it is possible that some HCPs may not want to discuss the negative aspect of dialysis or kidney transplant surgery because it could scare patients, open and honest discussions about it may have encouraged YAs to talk about their concerns and be supported. Open communication of information in the doctor-patient relationship has the potential to improve trust and adherence to medical advice (Croker *et al*., 2013). People with ESKD receiving dialysis preferred personalised communication of information about therapy, functionality, and safety rather than a one-size-fits-all approach (Vandenberg *et al*., 2019). The discrepancies between the expected and what was experienced during receipt of dialysis and kidney transplantation led to decisional regrets after experiencing choice. Chen *et al.* (2018) reported uncertainty about implementing the dialysis decisions. Saeed *et al*. (2020) highlighted that 21% of participants reported decisional regrets following the commencement of dialysis therapy, which was more common when participants chose therapy to please HCPs or family. Gilman *et al*. (2017) reported that 7% of participants experienced regrets following the commencement of dialysis.

Patients who reported nephrologists' opinions to be crucial to their decision-making experienced more regrets than those who made decisions themselves and so were those whose family influenced their decision-making (Berkhout-Byrne *et al*., 2017). However, in this study YAs whose family influenced their decision-making did not experience regrets, rather those who either accepted suggested therapy by HCPs or had different expectations of the therapy chosen, experienced regrets. Although older age was associated with lesser regret (Berkhout-Byrne *et al*., 2017), the same cannot be said in this study, as it had a younger population. Saeed *et al*.'s (2020) study did not find any association of regret with age, sex, length of time on dialysis and dialysis modality. Decisional regret among people with other long-term conditions, such as breast cancer, rheumatoid arthritis and prostate cancer, were associated with higher decisional conflict and less satisfying decisions (Pérez *et al*., 2016). Compared with this study, YAs regretted the decision because of their experience with the therapy.

The lack of balanced information about options, understanding of the practicalities of the choices, lack of experiential knowledge from peers and lack of preparation to receive RRT, contributed to failed expectations and regrets. In extreme cases, there were resentments of decisions made and hate for therapy which led to the refusal to carry out dialysis therapy with profound consequences. Experiencing choice that brought about job loss or inability to get jobs due to dialysis, has been reported by other studies (Bailey *et al*., 2018; Hamilton *et al*., 2018b). For example, in a particular situation, a participant could not provide basic needs like food and shelter due to loss of job. Bailey *et al*. (2018), Hamilton *et al*. (2017) and Hamilton *et al*. (2018b) reported that YAs receiving an RRT were likely to be unable to work, experience employment difficulties, or have no income.

HCPs must find less distressing ways to provide YAs with the reality about dialysis and kidney transplant surgery, instead of avoiding the conversations about it. The new proposed “implement talk” (see section 5.10) could be the way forward to ensuring that YAs have timely vascular access discussions, decisions and planning of surgery and feel prepared to transition from their carefree life to long-term dependence on RRT. Efficient transition preparation could have made YAs feel more prepared and supported at the start of dialysis. The experience of receiving dialysis and kidney transplant was not aligned with the three-talk model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017) as the process ends with an agreed decision. However, this study has shown that preparation for implementing the choice is equally important as the decision itself. Secondly, other discussions and decisions occur after choice has been agreed, as highlighted in the discussions in this section. Therefore, there is a need for a distinct talk phase that can address the issues raised in this section.

5.6.2. *Subtheme 4.2 The experience of feeling different*

The findings show that the perception of YAs feeling different compared with their healthy age-related peers due to the changes experienced living with kidney disease and receiving therapy, which has been reported in other studies too (Kim and Choi 2016; Lambert and Keogh, 2014; Kerklaan *et al*., 2020; Tong *et al*., 2013; Seereiner *et al*., 2010). Charmaz (1983) asserts that the experience of illness is a social psychological process where changes occur between the inner dialogue of the ‘I’ and the ‘me’ of the person thus the feeling of being different. Adults with type 1 diabetes felt different using an insulin pump due to perceived visibility of it, which affected their body image and social acceptance despite its benefits of flexibility with eating schedules and reducing hypoglycaemia (Ritholz *et al*., 2007). In another study, the use of insulin pumps was a constant reminder of living with diabetes and the presence of a foreign object made them feel different, which resulted in stopping their usage (Seereiner *et al*., 2010). Similarly, the insulin pumps can be likened to having a vascular access (fistula or central venous catheter) or PD catheter.

The “crumbling away of previous self-image” (Charmaz,1983, p.168) experienced in chronic illness can be related to how YAs perceived themselves. The constant shifting of symptoms experienced in a YA’s body due to ESKD, dialysis or kidney transplant disrupted their physical appearance which made them look and feel different. The inability to perform daily routine tasks due to constant changes in functionality, the loss of carefree life to dependence on a dialysis machine and having another person’s kidney, firmed this belief of feeling different. Feeling trapped in a medicalised life, experiencing delayed independence due to lacking the foundation to become an independent person, and feeling unprepared for the future, as highlighted in Kerklaan *et al*.’s (2020) study, were also reported by some YAs in this study who had childhood onset of CKD. Some YAs in this study who believed they were of small stature compared to their age-related healthy peers and siblings felt it was a constant reminder that they were different, and this was reported by other studies too (Bailey *et al*., 2018; Kim and Choi, 2016; Tong *et al*., 2013).

The experiences of weakness, constant fatigue, inability to participate in active sports, eat or drink what they wanted and behave like their healthy age-related peers, brought anger and frustrations, as reported by other studies too (Tong *et al*., 2013; Kim and Choi, 2016). The constant comparison of YAs in this study with their healthy age-related peers could be likened to seeing themselves through the mirror of their healthy age-related peers' achievements which they lacked. This underachievement of goals, which also contributed to some of the emotional and psychological disturbances experienced, has been previously highlighted (Bailey *et al*., 2018; Park *et al*., 2014; Murray *et al*., 2014).

Harrington and Morgan (2016) highlighted that fear of kidney transplant graft failure affected the lives of the patients who have been transplanted. Kim and Choi (2016) reported adolescents in receipt of a kidney transplant still felt different post kidney transplantation while Tong *et al*. (2013) highlighted the feeling of abnormality and having a sick identity. Similarly, YAs in this study who went on to receive a kidney transplant still felt different compared with their healthy age-related peers because of the possible rejections or failure of the transplanted kidneys, which meant going back on dialysis. Learning new medication routines and the effects of immunosuppression medications that change their lifestyle and how they look, also made them feel different compared with their healthy age-related peers. This study also reported that understanding how to live with a kidney transplant or dialysis did not form part of the decision-making discussions, which made YAs struggle and feel abandoned by HCPs.

However, most YAs expressed it was the beginning of another new era of change, an unchartered territory that brought its challenges and they needed to be guided and supported to navigate the waters. Lambert and Keogh (2014) highlighted that young people with long-term conditions felt different because of the restrictive life and treatment regimens, which was a constant reminder of not feeling normal compared to their peers and was highlighted by YAs in this study too. Participants felt different because they had another person’s organ in them, which they had to take care of as their survival depended on it, but they lacked information about how to live with a kidney transplant. However, the quality of care and support received after kidney transplantation has a direct impact on the quality of life and longevity of the transplanted kidney (Kostro *et al*., 2016).

Charmaz (1983) asserts that chronic illness may be seen to preclude a person’s former life achievements in terms of the ability to do things. It is these accumulated losses of self-image that result in reduced self-concept over time (Charmaz,1983). Similarly, these embodied changes experienced affected their self-confidence and esteem and YAs must be educated to understand them and be supported to manage the changes and empower them to develop equally valued new identities and goals. Tong *et al*. (2013) highlighted that YAs experienced low self-worth because of their impaired body and felt inferior. Kerklaan *et al.* (2020) reported that YAs with childhood onset of CKD experienced low self-esteem, failed to keep up, felt socially inept, and felt unworthy of relationships. In this study, most YAs had similar experiences.

The YAs in this study were beginning to experience adulthood and this self-belief of feeling different hindered their integration into society and progress in life, which has been previously highlighted (Lambert and Keogh, 2014; Kerklaan *et al*., 2020). Feeling accepted by people within the social context of YAs contributed to the appraisal of this belief and the formation of a new self-image. Forward and flexible planning which involved changing goals and developing new career goals for life has been also highlighted (Lambert and Keogh, 2014; Kerklaan *et al*., 2020). Likewise, over time, as YAs improved their knowledge and understanding, they appraised their beliefs, formed new perspectives, and accepted their new self. The new proposed ‘implement’ talk can offer such space for HCPs to educate YAs about how to live with and manage life on dialysis and kidney transplant.

5.6.3. Subtheme 4.3 Searching for the meaning of the new normal experience

Human beings seek the meaning of events, therefore situations that may appear to be meaningless are perceived as disturbing, and met with strong dislike (Spinelli, 2005). Situational events like kidney failure can threaten a person’s sense of purpose, goals or values, and results in distress (Park, 2010). Meaning is the relationship between an individual and their world, and their perception of their place in that world, giving a sense of coherence to life in the face of personal upheaval and change (Fife, 1994). Park (2013) suggests that meaning-making is a quest for a favourable understanding of a situation and its implications by a person. This meaning links neatly to Heidegger’s hermeneutic phenomenological concept of meaning and meaninglessness (Spinelli, 2005).

Similarly, in this study, YAs searched for the meaning of their new normal life of experiencing dialysis and kidney transplant. Heidegger asserts that the meaning of something involves an "interpretation of that thing and to understand is to interpret" (Smith, 2019, p.3). Meaninglessness prevents people from asserting the absolute truth or correctness of one interpretation over any other (Spinelli, 2005). Therefore, people need to acknowledge the beliefs with which they have chosen to live their lives rather than ignoring them (Spinelli, 2005). YAs in this study spoke about their previous beliefs and aspirations for their life but acknowledged how facing dialysis had changed these beliefs.

The meaning-making theory proposes that "an individual's perception of the discrepancies between their appraised meaning of a particular situation and their global meanings (what they belief and desire) creates distress, which in turn gives rise to efforts to reduce the discrepancy and resultant distress" (Park, 2010, p.40). This theory is discrepancy-based and identifies two levels of meaning: situational and global meaning (Park, 2013). YAs in this study also had desires and beliefs that they have developed over time, which has sociocultural and historical influences. The presence of kidney disease affected their belief about healthy life and the understanding of how one can easily lose their health suddenly without a pre-warning. YAs needed to understand the loss of their previous healthy self and be able to accept what has happened to them to decide how they could live their life going forward.

Facing dialysis and kidney transplant decisions and experiencing the therapy brought stress to YAs due to the discrepancies between the global ("basic goals and fundamental assumptions, beliefs and expectations of the world", Park and Folkman, 1997, p.116) and situational ("interactions of a person's global beliefs, goals and the circumstances of a particular person-environment transaction", Park and Folkman, 1997, p.121) meaning of the events. YAs struggled to understand the ongoing changes in their life and how life had been unfair to them. YAs could not understand why they had to depend on a dialysis machine or another person's kidney to live. Park (2010) asserts a person experiencing distress tries to reduce the discrepancy to make sense of their situation and develop strategies to reduce the resultant distress experienced. Similarly, YAs in this study, over time with the support from important people like family, peers, and friends in their lives, were gradually able to reduce the discrepancy in these beliefs as they found diverse ways to accommodate the changes.

YAs in this study viewed their situation from different perspectives, for example, making comparisons of their situation with other people with long-term conditions believed to be in worse situations, and formed new perspectives. Hart *et al.* (2020) highlighted that YAs with cancer moved on to focus on their recovery instead of focusing on the negative. Tong *et al*. (2013) highlighted that YAs adjusted their mentality about their situation. Seeing and hearing how other YAs with long-term conditions and those with kidney failure on dialysis or who had received kidney transplants managed their situation, enabled many YAs to appraise their beliefs. Sherman *et al*. (2010) highlighted that over half of the people with breast cancer reported they found sense or benefits in their illness while others were still actively searching to derive a sense of the illness or benefits. These new perceptions and beliefs brought hope to YAs, because they realised they could also live their lives and achieve their dreams and goals irrespective of the changes the new normal brings to them.

Hope is a significant predictor of adjustment among people with ESKD (Billington *et al*., 2008). It was this search for meaning that enabled YAs to cope as they develop strategies and adapted new ways of living and self-managed the new normal life. Provision of support from counsellors is crucial in enabling this process of meaning-making and understanding of their situational events. As the experience of the new normal did not form part of the decision-making discussions, a review of the three-talk model is necessary to incorporate the proposed ‘implement talk’ to form a ‘new four-talk model’ (see section 5.10 and Figure 5.3). This would ensure that timely discussions and decisions about access preparation and the commencement of RRT occur and YAs feel supported and ready to start the therapy.

5.7. Team, option, and decision talk phases-Theme 5 The impact of decision-making and choice on well-being

The findings highlight the psychosocial effect of decision-making and choice on YAs' well-being, family, and relationships, how they cope and what could have been done to enhance their experiences. Research on the impact of SDM among YAs with ESKD is limited (Ofori-Ansah *et al*., 2022). Participation in decision-making was associated with extreme emotional, psychosocial, and mental effects on YAs. The thought of long-term dependency on a dialysis machine or kidney donation from others was difficult to hear and accept. The impact of decision-making and choice on well-being is explored in relation to the effect of the talk phases of the three-talk model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017).

5.7.1. Subtheme 5.1 The psychosocial effect of decision-making and choice

YAs' decision-making experiences were associated with physical, emotional, and psychosocial challenges. Health decisions occur in an emotional context (Elwyn *et al*., 2012; Legault, 2017). Lerner *et al*. (2015) assert that integral emotions influence decision-making that arises when faced with judgement or choice. People think about options and the possible consequences of options choice which brings a lot of emotions (Beresford and Sloper, 2008). Elwyn *et al*. (2012) assert that the SDM process is associated with psychosocial and emotional factors during the deliberative process which requires effective management. The recognition of living with a long-term condition (LTC) can bring about emotional crises and destabilisation in people's lives (Schulz and Kroencke, 2015). Deciding about dialysis and kidney transplant was considered difficult because YAs in this study associated it with choosing between life (accepting dialysis) and death, which they did not want, but felt compelled to make a choice as reported by Harwood and Clark (2013). YAs with cancer experienced a rush of emotions following diagnosis and treatment discussions (Hart *et al*., 2020).

The experience of guilt and self-blame associated with ESKD highlighted in this study has been reported in other studies too (Devitt *et al*., 2017; Lerner *et al*. 2015; Nash, 2013; Walker *et al*., 2017). Some YAs in this study felt they might have contributed to the cause of ESKD especially when the cause of the disease was unknown, which made YAs and their parents believe their lifestyle could have contributed to it. Walker *et al*. (2017) highlighted that the participants blamed themselves for their illness because of the perception they failed to make the needed life changes and felt ashamed of having ESKD requiring dialysis.

Nash (2013) reported the experience of guilt and shame among people with diabetes because they felt their lifestyle may have contributed to the occurrence of the disease. The guilt and self-blame experienced by some YAs' parents (especially mothers) is a concern as they felt responsible and wished they could turn the situation around. Although it was not their fault, their feeling of guilt and self-blame also affected YAs' emotions. This shows that YAs' psychological stress is not independent of the stress experienced by caregivers/parents because of their relationship and interdependence (Bodenmann and Falconier, 2017). The well-being of YAs' caregivers/parents mattered to YAs, therefore, their psychological needs should be considered, and support provided to them during the trajectory of the disease and when facing decision-making.

Sligo *et al*. (2019) highlighted that chronic illness had a significant effect on young people's relationships and the trajectory of their life as it disrupted what they wanted to do. Turner and Kelly (2000) asserted that the emotional and psychological effect of illness is usually overlooked, which supports the belief of YAs in this study that the psychological impact of decision-making and choice was underestimated by clinicians. Psychological distress has been reported in older CKD patients (Harrington and Morgan, 2016). Facing decisions about choice brought fear and anxiety among YAs with a LTC (Ofori-Ansah *et al*., 2022). Emotional arousal and cognitive appraisal interact to shape decision-making among people with cancer (Mazzocco *et al*., 2019). The emotional, social, psychological, and mental effects of decision-making experienced by YAs in this study affected their well-being. YAs experienced fear, anxiety, and depression when they faced treatment decision-making and at the start of treatment, as reported in other studies (Bailey *et al*., 2018; Bezerra *et al*., 2018; de Britio *et al*., 2019; Hamilton *et al*., 2018b; Loosman *et al*., 2015). Tong *et al.* (2013) reported that inferiority, insecurity, doubts about the future, feeling vulnerable, and suffering injustice, affected AYAs' mental well-being.

Bezerra *et al*. (2018) reported that older patients facing decision-making experienced anxiety, stress, and depression. Bailey *et al*. (2018) highlighted the emotional effect of living with kidney disease among YAs, while Hamilton *et al*. (2018b) reported that YAs in receipt of dialysis and kidney transplant were twice as likely to experience psychological disturbance. Emotional, social, and psychological changes form part of the illness and should not be seen as secondary (Schulz and Kroencke, 2015). Emotions are perceived as dominant drivers of every day meaningful decisions in life (Keltner *et al*., 2018). Mazzocco *et al*. (2019) asserted that emotions can act as a guide for an individual to avoid negative experiences such as guilt and regrets and increase positive experiences like happiness. Loiselle *et al*. (2016) highlighted the lack of emotional support from the kidney team following involvement in options education as they were impacted by the information. Seekles *et al*. (2018) have also highlighted unmet psychological needs among CKD patients. Therefore, assessing people’s emotional and psychological needs and providing appropriate support is vital during their engagement in decision-making.

Decision-making brought much stress to YAs and their family, and this was also reported in older CKD patients (Pereira *et al*., 2017; De Britio *et al*., 2018; Loosman *et al*., 2015). YAs struggled to accept that their life had to change forever and became angry that their survival depended on a dialysis machine or kidney transplant. Choice was associated with limitations such as dietary, and fluid restrictions, changes to body image, and the routines of therapy, which made YAs feel trapped and isolated. Hodgson *et al*. (2021) highlighted the experiences of distress among YAs with cancer and their caregivers. In this study, YAs highlighted that their parents/family shared their psychological distress from ESKD diagnosis and RRT, as previously reported by Falconier *et al*. (2017).

The findings of this study also emphasised YAs’ inner emotional journey which can be likened to the Kübler-Ross (2005) stages of grieving: denial, anger, bargaining, depression, and acceptance. It also relates to the dimensions of illness identity: engulfment, rejection, acceptance, and enrichment (Oris *et al*., 2016). The intensity of YAs’ grief was dependent on their perceived loss, limitations experienced, and the continuous adaptation required (Jackson, 2014). Charmaz (1995) asserts that chronic illness brings about adaptations, as people try to bring stability to their lives; this was also reported by YAs in this study. The YAs assessed their experiences, weighed their losses, revised their goals, and made identity trade-offs to accept the changes and losses experienced. YAs felt engulfed when faced with decision-making, experienced initial rejection, but later accepted their situation, which brought enrichment as they developed resilience.

YAs in this study experienced multiple losses such as loss of previous self, health, control, self-esteem, confidence, security and safety, employment, education, career, and uncertainty of future, as highlighted by other studies (Bailey *et al*., 2018; Murray *et al*., 2014; Tong *et al*., 2013). These losses are part of an individual's basic needs in life (Maslow, 1948) and are associated with a person's state of health. The experience of the reality and harshness of dialysis therapy and the burden of performing dialysis therapy caused resentment, hatred towards therapy, and decisional regrets. Saeed *et al*. (2020) highlighted that 21% of dialysis participants experienced decisional regrets which was found to be associated with knowledge about their disease, receipt of prognostic information, quality of life to determine future care, and family involvement in decision-making and advance care planning. YAs felt regrets when complications and near misses, which almost caused their lives, were experienced which resulted in self-blame for making those choices.

The psychological problems experienced during the trajectory of the decision-making were worsened due to the phobia of needles and blood associated with haemodialysis therapy and kidney transplant surgery. This study highlighted the mental effect of the decision-making process and during the experience of choice. In a particular situation, post-traumatic stress disorder was suffered, and this is still an ongoing problem although in receipt of a kidney transplant. Hamilton *et al*. (2018b) highlighted that YAs on RRT were twice as likely to have psychological problems. In extreme situations, some YAs in this study contemplated suicide when they faced dialysis decisions and experienced the burden of dialysis treatment and complications. In Tong *et al*.'s (2013) study, AYAs felt victimised, restricted, deprived of freedom and independence, and expressed intense hatred toward CKD and a small number also considered suicide.

Although kidney transplant was associated with normalcy and brought hope, it was also linked to new forms of fears and anxieties (de Brito *et al*., 2019; Schulz and Kroencke, 2015). In this study, concerns and fear of putting another family member at risk of major surgery, and unknowns about their donor's health post kidney donation, resulted in the rejection of kidney offers in some situations, which is reported by other studies too (Devitt *et al*., 2017; Kim and Choi, 2016). These emotional and unmet needs found in this study are reported among AYAs with cancer (Zebrack *et al*., 2013). If these emotional and psychological issues are seen as secondary, then there is the danger of YAs not receiving prompt and appropriate psychological support. However, most YAs in this study lacked the confidence to discuss their emotions and psychological feelings. There was a belief among YAs that adults within society expected them to manage such issues independently.

Guidelines for managing CKD and ESKD recommend the provision of psychological support during the decision-making process (KDIGO, 2013; NICE, 2021a). However, the suboptimal and lack of psychosocial support experienced by YAs in this study falls short of the recommended guidelines. The NHS long-term plan recognises the inequalities in mental health support experienced by young people (NHS England, 2019). The NICE Impact Mental Health Report (2019) also highlighted unmet mental health needs for young people and have put guidelines and policies in place to address some of the issues raised in this study. The psychological and mental health of YAs has now become part of an ongoing discussion of kidney care in the UK (Centre for Mental Health and Kidney Research UK, 2020). The lack of support experienced by YAs in this study during the phases of the three-talk model of SDM (Elwyn *et al*., 2012) brought psychosocial and mental issues on YAs. Elwyn *et al*. (2012) suggested these problems should be managed as they occur, however, this was not experienced by YAs in this study, despite the psychosocial assessment and provision of appropriate support being recommended (NICE, 2021b).

5.7.2. Subtheme 5.2 Keeping sane and not going crazy

This study found that YAs struggled to cope with their situational events, the burden of making a choice and accepting losses which resulted in numerous emotional and psychological effects which needed adaptation and development of coping skills and strategies. Despite these emotional, psychosocial, and mental effects, most YAs lacked psychological support, and only a small number received psychological support, which falls short of the recommended guidelines (NICE, 2021b). Among YAs who were aware that psychological support was available, they either did not know how to access the psychological support or preferred not to access it.

Coping is a dynamic process where cognitive and behavioural efforts are used to appraise and deal with situational contexts that people (YAs) encounter in life (Panjwani *et al*., 2020). People have used cognitive and behavioural strategies to manage perceived health threats (Clarke *et al*., 2016). Lie *et al*. (2018) identified that YAs (aged 28-35 years) with cancer experienced challenges receiving a diagnosis, encountering the healthcare system, living with cancer, dealing with the impact of the treatment and reactions from their social network. They reported that YAs coped by either neglecting the situation or used conducive emotional or instrumental approaches which were maladaptive coping strategies (Lie *et al*., 2018). Compared with this study, some YAs preferred not to focus on their situation but did not neglect it.

Although the SDM context is very emotive and known in the literature (Elwyn *et al*., 2012), not all clinicians may actively lookout for psychological effects, or manage them during the decision-making encounter while others may expect or believe patients would inform them if such support were needed. This is because sometimes YAs may not understand why they are experiencing those emotions or may become emotionless while going through those experiences until later. The integration of psychological support into the decision-making process could eliminate the need for YAs to ask for psychosocial support when lacking, to enable them to develop appropriate coping skills (Elwyn *et al*., 2012; NICE, 2021a; NICE, 2021b).

An interprofessional approach could be the way forward for YAs' SDM process, to include professionals such as a counsellor, youth worker and welfare officer in their decision-making pathway. This would introduce YAs to the services these professionals provide in relation to the SDM process and enable them to start building a relationship with them to normalise the use of their services. The interprofessional team must be present together during the team talk phase to enable initial familiarisation and begin building the relationship with YAs. Once rapport has been established, the individual professionals would now be in the position to see YAs and/or family separately during the option, decision and ‘implement talk’ phases. This would ensure that YAs receive psychosocial support during the decision-making process to enable them to build coping skills, identify their goals for life and replace lost ones, integrate living with dialysis and kidney transplant therapy into their life, and look forward to a better future without having to ask for these services. In this way receiving psychosocial support would be seen as part of the decision-making process and break the perceived stigma associated with receiving psychosocial support.

People who experience chronic illness go through a process of adaptation to resolve the lost unity between their bodies and self which is the source of psychological distress to enable them to cope (Charmaz, 1995). Adaptation is a way of altering life and self to accommodate the bodily losses and limitations as a way of resolving this lost unity between the body and self (Charmaz, 1995). Adaptation is multifaceted and dynamic where people can experience both negative and positive emotions as they try to adjust (Stanton and Revenson, 2011). People use various coping strategies to deal with situational events where they either try to tolerate, minimise, or master what is causing their stress (Weiten *et al*., 2016).

Lazarus and Folkman (1984) highlighted two basic types of coping strategies; problem-focused which is used to “manage or alter the problem causing the distress”; and emotion-focused which is used to “regulate the emotional response to the problem” (p.150). Problem-focused involves active coping, planning, suppression of competing activities, restraint coping (avoiding being with people) and seeking social support for instrumental reasons (Lazarus and Folkman, 1984). Emotion-focused involves seeking social support for emotional reasons, positive reinterpretation and growth, acceptance, denial and turning to religion (Lazarus and Folkman, 1984).

Gurkan *et al*. (2015) compared stress coping strategies of HD and kidney transplant participants using the coping strategies questionnaire (COPE) assessment scale (Carver *et al*., 1989). They reported higher use of problem-focused and emotion-focused coping strategies among kidney transplant participants compared to HD participants (Gurkan *et al*. 2015). Emotion-focused coping was most common among older HD and CAPD participants compared with healthy volunteers, but a significant difference was found in problem-focused coping among CAPD participants compared to the healthy volunteers (Baykan and Yargic, 2012). The use of non-functional coping strategies such as mental disengagement, focusing and venting of emotions, denial, substance use, and behavioural disengagement was also higher among participants on HD compared to kidney transplant participants (Gurkan *et al*., 2015).

Likewise, Baykan and Yargic's (2012) study reported frequent use of non-functional coping strategies among HD participants compared to CAPD participants. However, among the three groups, religion was the most frequent coping strategy used, followed by seeking instrumental social support and focusing on and venting of emotions (Baykan and Yargic, 2012). In comparison, in this study, emotion-focused coping strategy (positive thinking, looking at things differently and acceptance) were often used by YAs, rather than a problem-focused coping strategy (dealing with issues as it comes and seeking advice through counselling). In addition, non-functional coping strategies (venting of emotions, online video gaming and not thinking about it) were also used. Positive coping styles, positive reappraisal, acceptance and fighting spirit have been reported among people with spinal cord injury (Dorsett *et al*., 2017).

Thinking positively and seeking spiritual help (Yang *et al*., 2020), religion and resilience (Pham *et al*., 2020) were reported among kidney patients. However, religion and spirituality was used by small number of participants in this study. Subramanian *et al*. (2017) highlighted that people with CKD used compartmentalisation, reliance on family and faith as coping strategies, and so did YAs in this study. People with kidney failure used more physical coping compared to those with a cardiac disease while more psychological and behavioral coping was used by people with cardiac disease, compared to those with kidney failure (Yasmeen *et al*., 2015). Younger people with CKD were reported to also use a combination of emotion-focused and problem-focused coping strategies (Muhammad *et al*., 2015). Snoböhm and Heiwe (2013) highlighted that AYAs with cancer used various psychological defences in addition to meaning-based, social coping, problem-focused, and emotion-focused strategies.

Learning to cope from peers who had been through similar decision-making experiences because they felt they were in it together, and forming new attitudes and behaviours, have been reported (Nesta and National Voices, 2015). For example, talking about their experiences to other peers as a way of giving back was considered therapeutic as it helped them cope better and was used often by YAs in this study. Having these positive thoughts brought hope and strengthened YAs as they felt in control. Wilson and Stock (2019) reported YAs preferred to focus on positive thinking compared with negative thinking while Gill (2012) highlighted that feeling positive and having the kidney transplant process broken down into stages enabled patients and donors to cope with decision-making.

The use of engagement style coping, such as active confronting and reassuring thoughts, had a positive effect on YAs with cancer and their caregivers (Hodgson *et al*., 2021). In this study, some YAs used an engagement style of coping by keeping themselves busy through voluntary work, which made them feel valued and improved their self-confidence. Comparing themselves with people with long-term conditions encouraged some YAs to face their future as they considered themselves in a better position. Most YAs were determined not to allow CKD and its treatment to take things away from them and adopted ways to recover some of the things lost. This attitude enabled YAs to work with their employers, teachers, and lecturers to develop strategic plans that would enable them to carry on with their education, job, and achieve their goals. The hope of receiving a kidney transplant also enabled YAs in this study to cope while on dialysis (Yngman-Uhlin *et al*., 2016) because having hope is integral to coping (Dorsett *et al*., 2017). Societal perceptions of how an adult must behave contributed to YAs' decline in not seeking psychological support. The recent collaborative work between mental health and kidney specialities (Banks *et al*., date unknown) could be the way forward to address these inequalities in psychological support, as experienced by YAs in this study.

YAs experienced growth as they became more mature and resilient, accepted themselves and the limitations they experienced, and were motivated to do things differently. Wilson and Stock (2019) highlighted that YAs reported positive benefits, such as being motivated, maturing, resilient, empathetic, and compassionate. YAs experienced a lot of psychological burdens but lacked psychological support. Many developed adaptive coping strategies that enhanced their coping, compared with the initial emotion-focused style which was less effective. Receipt of counselling was reported as beneficial to YAs in the study, therefore, it is vital that psychological needs are assessed, and support provided.

HCPs’ clinical skills can be improved to support the emotional and psychological well-being of YAs, because this would enable HCPs to discuss YAs’ emotional needs during decision-making (Taylor *et al*., 2016b). An intervention that trained HCPs to support patients’ emotional and psychological well-being highlighted those patients felt enabled to discuss their emotional concerns (Taylor *et al*., 2016b). YAs in this study over time learnt to adapt, resolve their loss, accept the changes, and changed their perceptions about themselves as they gained knowledge and appraised their situational contexts. YAs in this study also coped by seeking psychological support.

The three talk-model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017) highlights the need to use effective dialogue to manage the emotional and psychosocial factors that influence decision-making. This is important as it will support YAs to develop adaptive coping strategies. For example, in this study, YAs compared their illness to other people with other chronic illnesses and felt they were in a better position and therefore were able to let go of their limitations and accepted the new normal. This helped them move forward with their life and some were able to continue with their education and look for jobs. They also compared themselves to their peers on dialysis or in receipt of a kidney transplant who had moved on in life to achieve careers and felt they could also do the same.

5.7.3. Subtheme 5.3 Enhancing my decision-making

The findings of this study highlight the unmet needs of YAs experiencing decision-making and choice. Some of these areas identified are overlooked yet matter to YAs. Early provision of health education on options improved the development of knowledge, understanding of illness, awareness of therapy options and decision self-efficacy (Patzer *et al*., 2012). Effective health education strategies are needed to improve YAs' knowledge of the kidney transplant listing process (United States Renal Data System, 2016). Delivering options information in small manageable chunks and checking understanding and the use of the teach-back technique have been highlighted as ways to improve people's decision-making experience (Elwyn *et al*., 2012; NICE, 2021b). Evidence has shown that competing patient and clinician priorities regarding CKD and dialysis planning were less beneficial in enhancing therapy decision-making (House *et al*., 2021).

In this study, YAs reported that less focus was given to how to live better while receiving dialysis and kidney transplantation, than preparing them to receive therapy; this lack of full information adversely affected their decision-making experience. House *et al*.'s (2021) study with older adults with advanced CKD reported similar findings. Wong *et al*. (2019) highlighted inconsistency in achieving collaborative decisions among patients and their clinicians when patients did not want to initiate dialysis; better collaborative communication has shown to improve deliberation to reach an agreed choice (Elwyn *et al*., 2014). Similarly, some YAs in this study were sometimes reluctant to start chosen therapy due to perceived fear of dialysis. Being less attuned to the power dynamics that occur in the patient-HCP communication during decision-making affects YAs' experiences of therapy decision-making (House *et al*., 2021).

The views of older adults with ESKD highlight the need for information on all the available options, better deliberations, more time, and involvement in decision-making (Verberne *et al*., 2019), which supports this study's findings. In the same study, older adults preferred information to be tailored to their individual situational needs (Verberne *et al*., 2019). Covvey *et al.* (2019) in their systematic review of barriers and facilitators to SDM for people with cancer, highlighted that poor communication of HCPs and uncertainty of treatment decisions hinder SDM while HCPs' consideration of patients' preferences, use of support systems and positive behaviours, facilitated decision-making. The use of decision support has been highlighted to enable patients to remember information to focus and think about what is important to them that they wish to discuss with HCPs (Joseph-Williams *et al*., 2014b). This could enhance the deliberation of YAs' preferences and values in relation to the preferred option.

The findings of this study highlighted that most YAs sought psychological help from diverse sources for themselves, which was considered inappropriate, by

YAs, therefore, it is vital for psychological support to be provided, as recommended by NICE (2021b). The incorporation of emotional and psychosocial support into the decision-making process as part of the conversation could remove any associated stigma with seeking psychological support. Counselling, psychological, social support and social relationships were among the needs of YAs who completed cancer treatments (Galán *et al*., 2016) and this study supports these previous findings. The provision of youth workers could help with advocacy as the benefits of youth workers outweigh the cost, because its provision can reduce some of the psychosocial burdens YAs experience and should be part of the kidney service.

5.8. How this study’s findings align with the three-talk model of SDM (Elwyn *et al*., 2017)

The three-talk model of SDM (see Figure 3.3) comprises of three talk processes: team talk, option talk, and decision talk (Elwyn *et al*., 2017); The findings when aligned to the three-talk model, identified gaps in the model (see Figure 5.2, p.347). The team talk is where the clinician introduces the choice, makes the patient aware that choice exists, and draws the patient into the decision-making context, which was explored in themes 1 and 2 of the findings (see Figure 5.2 and sections 5.3-5.3.2). The option talk is where all the available options are described, and the use of patient decision support tools or decision aids are integrated during collaborative deliberations, as discussed in themes 2 and theme 3.2 (Figure 5.2 and sections 5.4-5.4.2 and 5.5.2).

The decision talk is where the patient is supported to explore their preferences and make preference-based decisions (Elwyn *et al*., 2017) and was discussed in themes 3 and theme 5 (sections 5.5-5.5.3 and 5.7-5.7.3). The alignment of the findings of this study in Figure 5.2 highlights the various problems identified with each talk phase. It also makes the case for a new talk phase proposed as the ‘implement talk’ in Figure 5.2, to deal with issues about the implementation of therapy which relates to the discussions about the preparation and commencement of the chosen therapy. In the diagrammatic representation of YAs' experiences of decision-making (Figure 4.2), the team talk phase was initiated by the delivery of diagnosis/prognosis of kidney failure and the experiences of it were discussed in theme one where YAs’ world turned upside down (Figure 5.2 and sections 5.3-5.3.2).

The option talk followed, where information delivery on available options and deliberations occurred, as discussed in themes two and three (sections 5.4-5.4.2 and 5.5.2) and aligned (Figure 5.2) to highlight the problems identified in relation to YAs’ experiences. The decision talk occurred in theme three (sections 5.5.-5.5.3) where YAs made their voices heard as they discussed and deliberated more on options and choices. The deliberations involved multiple perspectives of important people in YAs’ social context world. The aligned theme 3 highlighted the issues identified in relation to YAs’ experiences.

Figure 5.2 Problems identified when the study findings was aligned to the three-talk model of SDM

Team Talk

- **Theme 1: World turned upside down**
  - subtheme 1.1: Change in self-identity
  - subtheme1. 2 :The experience of life thrown off track

Option Talk

- **Theme 2:The experience of information delivery about options**
  - Subtheme 2.1:Communication and understanding of options
  - Subtheme 2.2:The experience of health information-seeking
- **Theme 3: The experience of making my voice heard**
  - Subtheme 3.2 The importance of family, friends and others
- **Theme 5- The impact of decision-making and choice on well-being**
  - subtheme 5.1 Psychosocial effect of decision-making and choice
  - subtheme 5.2 Keeping sane and not going crazy
  - subtheme 5.3 Enhancing my decision-making

Decision Talk

- **Theme 3:The experince of making my voice heard**
  - subtheme 3.1: Engaging in decision-making as an equal
  - subtheme 3.2: The importance of family, friends and others
  - Subtheme 3.3: Reason influencing decisions about choice
- **Theme 5:The impact of decision-making and choice on well-being**
  - Subtheme 5.1: Psychosocial effect of decision-making and choice
  - Subtheme 5.2: Keeping sane and not going crazy
  - Subtheme 5.3 :Enhancing my decision-making

Implement Talk

Theme 4: Experiencing the new normal
Subtheme 4.1: The experience of dialysis and kidney transplant
Subtheme 4.2 : The experience of feeling different
Subtheme 4.3: Searching for meaning of the new normal

Theme 5: The impact of decision-making and chocie on well-being
- Subtheme 5.1 Psychosocial effect of decision-making and choice
- Subtheme 5.2: Keeping sane and not going crazy
- Subtheme 5.3 Enhancing my decision-making

Problems identified

Team Talk phase

Lack of preparation to receive news about diagnosis/ prognosis and support on how to manage changes to life. Poor communication of diagnosis/ prognosis and lack of understanding of disease and its progression, how it will affect their life and its management.

Lack of HCPs awareness and acknowledgement of the effect of change in self-identity and life resulting from diagnosis/ prognosis and need of replacement therapy on young adults' life.

Option Talk phase

Poor communication and ineffective health education about options on relevant decision information. Variation in content of options information, lack of information and the understanding of the options information.

Unidirectional of information exchange.

Inequalities in information delivery resulting in low health literacy. Lack of peer support to gain experiential knowledge about options and lack of psychosocial support.

Decision Talk phase

Inequalities experienced during involvement in decision-making due to the inability to engage as equal, lack of awareness of choice and lack of choice.

Lack of/minimum HCP deliberations of options and elicitation of patients' values and preferences during discussions of therapy options. Young adults' voice not often heard.

Implement Talk phase - new talk phase

Lack of discussion and information about the practicalities of options, access type and its preparation. Lack of information and understanding of kidney transplant listing work-up process and preparation towards kidney transplant surgery.

Lack of preparation towards commencement of chosen therapy and the lack of individualisation of dialysis and kidney transplant therapy. Lack of preparation of transitioning from a carefree life to life depending on dialysis and kidney transplant.

Lack of information on how to manage life on dialysis and kidney transplant therapy e.g., adaptations of lifestyle and coping and lack of psychosocial support.

Discrepancies between expectations and reality of experiencing dialysis and/or receiving a kidney transplant due to the lack of understanding of the practicalities and not being informed of true reality of associated risks and uncertainties.

Theme 4 (sections 5.6-5.6.3), which relates to the implementation of the preferred choice aligned to 'implement talk', does not exist in the current SDM model (Figure 3.1). This new 'implement talk' phase is being proposed to address the implementation needs and is aligned to theme 4 in Figure 5.2 and further explored in section 5.10. This new proposed 'implement talk' in Figure 5.2 highlights the gaps identified in the three-talk model and discussed in session 5.10 to show its incorporation in the new four-talk model of SDM (Figure 5.3). Theme 5 relates to the emotional and psychosocial issues arising from all the talk phases during the SDM process; how they were managed was discussed in sections 5.7-5.7.3.

5.9. Is the three-talk model of shared decision-making effective?

The three talk-model of SDM is effective as most of YAs' experiences of decision-making could be aligned to the model. However, the experiences of YAs show some limitations when aligned to the model (Figure 5.2) as some of YAs' experiences of choice could not be aligned with the model. Although this study could not tell what SDM model was used during the YAs' engagement with the decision-making process, the core principles of SDM could be applied. The findings suggest that SDM was not consistently experienced by YAs because they experienced inadequate and suboptimal information delivery, inequalities during involvement in discussions of choice in some of their decision-making encounters, and they lacked psychosocial support.

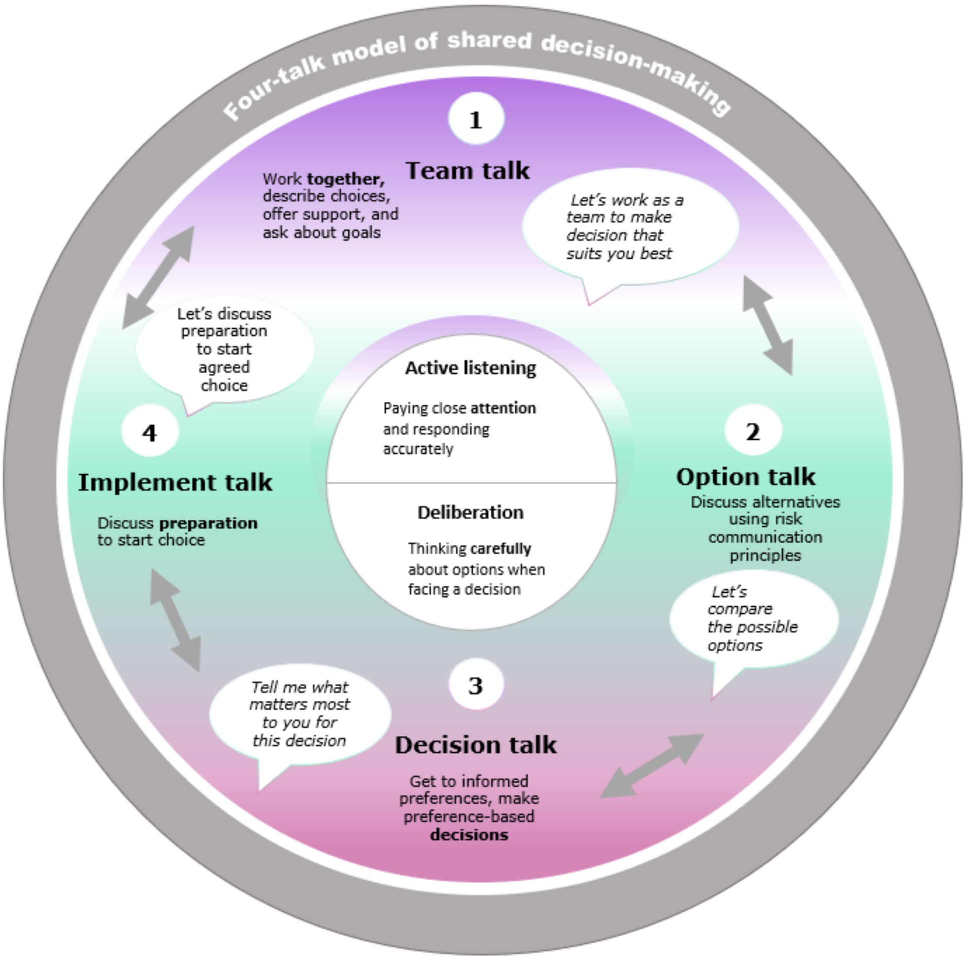
In addition, some of their experiences, such as the receipt of decision-making and the associated psychological effects, are not covered in team talk but should be the starting point of the team talk. This is because the emotions associated with the receipt of diagnosis/prognosis and lack of understanding of the disease were brought into the team talk and heightened the psychological burden experienced by YAs. Therefore, HCPs must first elicit YAs' understanding of the disease and how they are coping before discussing the awareness of choice. Elicitation of preferences was also limited in the decision talk phase in this study (Figure 5.2) and highlighted by Savelberg *et al*. (2020). The implementation and experience of choice discussed in theme four (sections 5.6-5.6.3) is not covered by the model and could not be aligned (Figures 5.1 and 5.2) but should be part of the decision-making process. Therefore, the study proposes the addition of an ‘implement talk’ phase and makes a case for a four-talk model of SDM which is next discussed.

5.10. Proposing the ‘Implement talk’ phase in the four-talk model of Shared decision-making

The thesis proposes the case for an implement talk phase in a new four-talk model of SDM (Figure 5.3). The findings of this study suggest a review of the three-talk model of SDM as the YAs’ experiences of therapy decision-making relating to the implementation of chosen therapy did not entirely align with the three-talk model of SDM. Most SDM models, such as the Informed Medical Decision Foundation model (2012), the SHARE Approach (The Agency for Healthcare Research and Quality, 2018), the Interprofessional SDM (IP-SDM) model (Légaré *et al*., 2011) and the three-talk model of SDM (Elwyn *et al*., 2017), have focused on the decision-making to select a treatment but not on the implementation of the treatment.

Although the SHARE (The Agency for Healthcare Research and Quality, 2018) and IP-SDM (Légaré *et al*., 2011) models evaluate the decisions to monitor the implementation of the treatment, they do not focus on the actual discussions of the implementation of the treatment. The existing SDM models provide a generic approach to support people with decision-making, but none of them has tailored or has a specific focus for YAs and this study makes a case for that. The study highlights that YAs' decision-making process includes the implementation of the therapy. This is because the discussions about the implementation of choice should occur before the therapy is experienced and this is conceptualised as the 'implement' talk phase in a four-talk model of SDM (Figure 5.3).

Figure 5. 3 Proposed new four-talk model of shared decision-making



As discussed in section 5.6, the three-talk model of SDM ends with the selection of therapy choice but does not acknowledge the implementation of choice as part of the decision-making process. However, YAs must be prepared and supported by relevant HCPs to implement the chosen therapy. Secondly, other decisions need to be considered, for example, the type of vascular access and its preparation, and tests for the transplant workup process (NICE, 2018). Discussions during the implement talk phase also involve preparing YAs' to transition from carefree life to living with dialysis and the provision of support during the commencement of the chosen therapy. YAs have unique decisional needs as highlighted in this study, as the decisions made about therapy have a long-term effect on their life as they continue to develop into older adults. Therefore, clear discussions about the implementation of the chosen therapy are needed, to enable them to plan for their life in relation to the preparation and commencement of the therapy.

The implementation requires discussions about the type of vascular access and decisions to be made to select a preferred vascular access for dialysis and be prepared for the vascular access surgery before the preparation to initiate dialysis therapy. Discussions about the preparation to start RRT, decisions about dialysis access type, and preparation for the access surgery, tend not to occur immediately as the implementation of the therapy is viewed as a different issue from the decision-making process. Most YAs were less informed about the practicalities involved in the implementation of the chosen therapy, less involved in the vascular access decisions and not prepared for the chosen therapy.

Time plays a crucial role in the phases of the three-talk model of SDM. The findings from this research (Theme 4) identified a series of avoidable situations that YAs experience which could be prevented if there was a clear process for the implementation phase of the SDM process. However, knowing the type of therapy choice a person prefers does not end the decision-making process as there remain certain decisions to be made in relation to implementing choice decisions (Murea *et al*., 2021; Woo and Pieters, 2021). The alignment of the findings to the three-talk model of SDM suggests the need for an additional talk phase which I have conceptualised as the 'implement talk' phase with a specific focus to address these issues highlighted (section 5.6 and Figure 5.2). The implement talk is proposed to address the implementation of choice which was not covered by the three-talk model of SDM (Elwyn *et al*., 2012; Elwyn *et al*., 2017).

To make this a reality in clinical practice a revised model, the four-talk model of SDM, has been developed (Figure 5.3) that incorporates the implementation phase, implement talk, in the decision-making process. This proposed model would be shared with the kidney care professionals, the YA kidney groups, national kidney charities, key leaders in the SDM community and other stakeholders to generate conversations about it and its adoption. Pilot research and improvement projects would be needed to trial its usage in clinical practice. This would bring to the fore the need to discuss the implementation of the chosen therapy during the SDM process, instead of viewing it as a separate issue. In kidney care, while the preparation for the implementation of choice may occur at different timing in relation to the progression of the kidney function, having these discussions and documenting the plan for it, would ensure YAs and HCPs have a clear understanding of it. It would enable YAs to feel prepared and supported to commence the therapy and plan for their life and future going forward rather than living in limbo.

5.11. Summary of chapter

This discussion brought together the findings on the decision-making experiences of YAs, encompassing world turned upside down, the experience of information delivery about options, the experience of making my voice heard, experiencing the new normal and the impact of decision-making and choice on well-being. The challenges they faced were a lack of understanding of diagnosis, suboptimal information, which was due to their low health literacy, inadequate equalities in decision-making, and lack of psychosocial support. YAs have unmet informational and decisional needs. They developed coping strategies by appraising the situation comparing themselves with other people with other long-term conditions, changing their perspective about themselves, using positivity, growing in the face of challenges, and advocating for themselves.

YAs’ experiences could be improved by making them aware that choice exists, building relationships with them, eliciting YAs' informational needs, and providing them with balanced and quality information on all options, as this will empower them to take active roles in decision-making. YAs need to be supported to form preferences and participate in decision-making as an equal. The study also proposed a new talk phase captioned ‘implement talk’ to be added to the three-talk model to become a four-talk model. Incorporation of psychosocial support in the decision-making process and throughout the trajectory of the disease starting from diagnosis would ensure YAs receive the appropriate psychosocial support.

Chapter 6 Conclusions, implications, and recommendations

6.1. Introduction

The study presented in this thesis highlights the lived experiences of dialysis and kidney transplant decision-making of young adults. This chapter concludes the thesis and will summarise the findings in relation to answering the research question and will discuss how the findings of the study made an original contribution to knowledge about shared decision-making in kidney care. The issues highlighted within the overarching five themes (Table 4.1, section 4.3) were discussed with existing literature in chapter five. In this chapter, recommendations for practice and service development and recommendations for education and future research are discussed. The strengths and limitations and dissemination of the study findings will also be presented.

6.2. Summary of the thesis, aims and objectives

This section will revisit the research question and aims addressed by this thesis, followed by a summary of the findings and how it aligns with the concepts of the three-talk model of SDM and the proposed implement talk phase to address some of the issues identified in this study. The integrative literature review highlighted little literature with a specific focus on YAs' decision-making experiences, especially those living with kidney disease (Ofori-Ansah *et al*., 2022). Therefore, the study was conducted with this group. It was important to hear participants' stories to gain an understanding and meaning of YAs' dialysis and kidney transplant decision-making experiences. The research question: how do young adults with end-stage kidney disease experience dialysis and kidney transplant decision-making? was generated to answer the gaps identified in the integrated literature review (section 2.7). The answers to the research question constituted the new knowledge generated and presented in the five overarching themes (Figure 4.2 in section 4.8.3) identified during the data analysis. Next presented is how the study contributed to current evidence and new knowledge.

6.3. How this study contributes to current evidence and new knowledge

This thesis is the first known study with a specific focus on YAs' experiences of dialysis and kidney transplant decision-making and has uncovered a significant effect of decision-making on YAs' well-being (Figure 4.2). The study contributes new knowledge to kidney care which is conceptualised in the model representation of YAs' decision-making experiences (Figure 5.1) as follows:

1. The receipt of diagnosis/prognosis and awareness of the need to decide on dialysis and kidney transplantation made YAs' world turn upside down (sections 4.4-4.4.2). This is a significant finding because YAs with kidney disease experienced a change in their self-identity and their life was thrown off track (e.g. education, career and family life) when they received the news about their diagnosis and the need to make a choice for dialysis and kidney transplant. The experience of life thrown off track identifies the need to support YAs to adjust, adapt and develop new life goals to replace lost ones. These findings provide evidence for supporting YAs to make the transition from the loss of a past healthy self to living with a long-term condition. This finding contributes knowledge to the team talk phase of the three-talk model of SDM as it highlights the need to explore an individual's

understanding of their diagnosis/prognosis in relation to the RRT decision-making before discussions about choice options are held.

2. YAs' experiences of information delivery about options identified their unmet option information needs due to the suboptimal and lack of decision-relevant information about therapy choices. This had a significant impact on YAs' knowledge development and their understanding of options and participation in decision-making (sections 4.5-4.5.2). It also highlights the impact of low health literacy (accessing, understanding, and using information) on decision-making. The finding contributes evidence to YAs' experiences of inequalities with health information. The lack of access to peers with experiential knowledge is an important finding and adds to the evidence of YAs' unmet needs. It also contributes knowledge to the option talk phase of the three-talk model of SDM as it highlights the need for HCPs to provide quality and balanced information on options.

3. The theme concerned with making my voice heard demonstrates the struggle and tensions that YAs experienced to consistently engage in decision-making as an equal, and assume their preferred decisional roles, and the importance of family, friends, and peers in making their voices heard (sections 4.6-4.6.3). These findings contribute knowledge to our understanding of how YAs make therapy decisions. The study found that the decision-making of YAs is a complex cyclical process that is multi-layered and involved significant people whom they consulted and contributed to their decision-making. Additionally, the study contributes knowledge to the self-categorisation of YAs and their unique needs, which

must be recognised. YAs categorised themselves into two main groups: career-driven individuals, who want to continue working, and those who were hindered by comorbidities and/or disabilities. The study also contributes knowledge to the decision talk phase of the three-talk model of SDM. For example, it illuminates what matters most to YAs and reinforces the importance of making their voice heard in decision-making as an equal.

4. The experiences of the new normal life (sections 4.7-4.7.3) highlight gaps in the preparation to start the agreed choice. The lack of dialysis vascular access decisions, planning, and the understanding of kidney transplant listing processes is a significant finding. The finding of the lack of preparation of YAs to transition smoothly from a carefree life to long-term dependence on dialysis and kidney transplantation is also important. The finding could not be aligned with the three-talk model of SDM and led to the newly proposed talk phase “implement talk” and the four-talk model (Figure 5.3) to address the gaps. The proposed implement talk phase and the four-talk model contribute new knowledge to YAs’ decision-making process. The finding of disappointments and decisional regrets following commencement of choice highlights differences in expectations of choice at the time decisions were made and the actual experience of choice.

5. The findings of the psychosocial impact of decision-making on YAs' well-being was underestimated by healthcare professionals. The impact of the experience of therapy on YAs' well-being reinforces other study findings, but the depth of the impact on well-being has been underestimated by

healthcare professionals. The impact of decision-making and choice on well-being (sections 4.8-4.8.3) is a significant finding because YAs were negatively impacted but lacked the psychosocial support to manage the effects on their physical, psychosocial, and mental well-being. The impact of the lack of psychosocial support on YAs during decision-making contributes new knowledge to the ongoing debate on the mental health needs of people with kidney disease.

6.4. Implications for practice and service development

The study found that there is the need for HCPs to utilise its findings and the proposed implement talk phase in addition to the three-talk model (Elwyn *et al*., 2012; Elwyn *et al*., 2017). A summary of the implications for practice is shown (Table 6.1) and conceptualised in the diagram representing YAs' experiences of dialysis and kidney transplant decision-making (Figures 5.1 and 5.2).

Table 6. 1 Summary of implications for practice

Overarching themes	Implications	Three-talk model of SDM	Topics to consider
Theme 1 World turned upside down	Communication of diagnosis to be given clearly and their understanding checked. Specific discussion between YAs and HCPs around possible change in their self-perception and self-identity. Support for developmental milestones in their education, employment, and career development. Specific measures should be established to reduce the power-dynamics and inequalities in the HCP-Patient communication. HCPs must seek to establish good relationships with YAs to build confidence and trust by showing interest in what matters to them.	Team talk	Explore their perception of diagnosis/prognosis in relation to aspirations for life. Explore diagnosis/prognosis impact on YAs' well-being and how they are managing it. For example, the use of tools to explore living with chronic illness (Ambrose *et al*., 2020), such as Patient activation measure (PAM) (Hibbard *et al*., 2004).
Theme 2 The experience of information delivery about options	Assessment of YAs' knowledge before and after receipt of options information. YAs require balanced and good quality information about choice options delivered in small manageable chunks. Standardised guidelines on the use of high quality and balanced information are recommended.	Option talk	Explore what YAs already know about options and the understanding of it. PAM questionnaire can be completed before and after discussions on options. Teach-back technique can be used to explore the understanding of information.
Theme 3 The experience of making my voice heard	HCPs to elicit YAs' preferences about their decisional roles and level of participation. Access to peers with experiential knowledge to be provided as it improves YAs'	Option/decision talk phases	Explore preferred role and offer YAs role in decision-making.

	understanding of choice options and what is to come. HCPs to support YAs to develop an informed preference about choice.		
Theme 4 Experience of the new normal	Preparation of YAs for their chosen therapy will improve their readiness to start therapy. YAs must be supported to develop new ways to adapt to the new normal. Dialysis therapy regimen should be considered to accommodate the needs of YAs (especially career driven/employment group). Home-based therapy monitoring and post-transplant care specific to YAs is needed.	Not included in original three-talk model. Implement Talk-new inclusion (Figures 5.2 and 5.3)	Explore readiness to start therapy and understanding of how therapy may affect their life. Explore dialysis vascular access and kidney transplant listing awareness and understanding. Discuss preference for the type of dialysis vascular access with YAs. Explore how YAs can be supported when receiving home-based therapy and living with a kidney transplant.
Theme 5 The impact of decision-making and choice on well-being	Specific psychosocial support for YAs is needed therefore a review of the psychosocial workforce is vital. HCPs must assess and look for signs of distress during YAs' engagement in decision-making. HCPs must reduce disparities and unequal access to psychosocial service. Psychosocial support should be incorporated with the decision-making process and not separate. Review of psychological support for YAs' care givers/family is needed.	Team, option, decision and implement talk phases	Explore and assess their psychosocial and emotional needs throughout all the talk phases. Psychosocial assessment tools can be used.

6.5. Implications for policy

The UK government demonstrated their commitment to NHS England by putting patients and the public first at the heart of NHS through an “information revolution” and “greater choice and control” to make shared decision-making the norm, using the “no decision about me without me” (Department of Health, 2010, p.3). Following this White Paper, multiple initiatives such as the NHS Choice framework (Department of Health and Social Care, 2020), the Comprehensive Model of Personalised Care (Sanderson *et al*., 2019) and NICE (2021b) guidelines on SDM have been developed. These initiatives were to ensure that people have access to accurate health information, have greater choice and control to participate in SDM (NHS England, 2021b).

This research has shown that YAs with ESKD have unmet informational and decision-making needs such as ineffective health education and low health literacy, voice not consistently heard and lack of psychosocial and mental well-being support. These findings reflect the need for greater choice and more control over kidney therapy information and implementation of dialysis and kidney transplant choice. Policy is needed to drive a culture for change in kidney practice and a commitment to the realisation of better SDM experiences in kidney care. This calls for a review of the policy regarding the SDM process for YA kidney services as Commissioners have an influence on pathway designs and quality of service (NHS England, 2021b).

The inception of the Transforming Participation in CKD Kidney (TPCKD) programme allowed the survey of kidney patients’ experiences of their kidney care to produce the Patient Reported Experience Measure (PREM) of kidney care. The PREM Report (2020) has highlighted low scores for SDM experiences over the last three years (The Renal Association and Kidney Care UK, 2021), which suggests there are issues with the provision of SDM in kidney care. The findings from this research are supported by the kidney PREM, that policy on embedding SDM in kidney care needs to be reviewed to reflect the need for culture change in kidney care practice of SDM during therapy decision-making.

This research brings a new finding which is the need for alternate ways, such as the use of technology and social media platforms, as YAs may not always want to be physically present in clinic, involvement of expert peers with experience in therapy decision-making (NHS England, 2021a) during the education of YAs, to achieve an improvement in their health education and health literacy. All these alternative ways require extra resources and a change in kidney care practice culture to enable them to happen. Therefore, there is a need for collaborative discussions between policy makers, commissioners, kidney service providers and YA kidney groups about the issues raised in this study to further explore and understand YAs' needs at a broader level and develop strategies to address YAs' information and decision-making needs.

The current three-talk model of SDM (Elwyn *et al*., 2017) ends with decision-making but does not include the implementation of the agreed therapy choice and the preparation for it. There is a need for a review of the model to reflect an implement talk phase to address the discussions about preparation to start RRT, including decisions about vascular access. The study has proposed a four-talk model of SDM that reflects the implementation talk phase (Figure 5.3) which could be adopted. The NHS England (2021b) recognises that the implementation of SDM in clinical practice will take some time, however, commitment from Policy makers and Commissioners are needed to ensure sustainable changes to the clinical practice culture in order to address YAs' needs.

This would ensure that ideal SDM can be experienced in clinical practice. The research described in this thesis highlights the need for policy shift in order to achieve better SDM outcomes. Firstly, there is a need for a policy that reflects the allocation of dedicated time, the staffing, and resources needed for the SDM process. Secondly, research is needed to explore the actual staffing levels and resources needed for an ideal SDM to occur in the clinical setting and costed. This would provide a framework for Kidney Service providers to cost their services and avoid putting more demand on limited resources which results in poor patient outcomes and experiences of the SDM process. The NHS could support funding to enable pilot projects of the proposed four-talk model in clinical practice research to explore its benefits.

YAs who are identified to have the highest relative risk of experiencing poor clinical outcomes from CKD are recognised as one of the groups who experience kidney health inequalities (Caskey and Dreyer, 2018). Evidence suggests variation in the provision of psychosocial services among different kidney care providers (Seekles *et al*., 2018), which this study has identified. The joint statement by Kidney Research UK and the Centre for Mental Health Charity (2020) and related campaigns have created some awareness of the impact of mental health among kidney patients but more needs to be done by policy makers to reduce these mental health inequalities experienced in YAs with kidney disease. Policy is needed to promote the integration of kidney care services and mental health care provision including allocation of funding for its delivery to improve YAs' psychological and mental health needs.

6.6. Recommendations for practice and service development

The findings (chapter 4) highlighted the unmet information and decision-making needs of YAs and are supported by previous studies (chapter 5). Participants shared experiences of their world turned upside down (sections 4.4-4.4.2), suboptimal health education and low health literacy of options (sections 4.5-4.5.2). They also shared their challenges of making their voices heard (sections 4.6-4.6.3), the lack of preparation for implementing choice (sections 4.7-4.7.3), the impact of decision-making and choice, and the lack of psychosocial support (sections 4.8-4.8.3). These findings highlight the need for a multi-professional approach to YAs' decision-making to address their unmet needs. Participants also shared their experiences of underachievement in education, career, employment, family life and social integration because of the negative impact of CKD and RRT. These suggest the need for multi-agency working between kidney specialists and the educational sector, social welfare, and local agencies to raise awareness of the needs of YAs with CKD/ESKD receiving RRT.

Empathetic communication is needed during the communication of options as this could reduce the negative impact of diagnosis/prognosis, information delivery and the experience of choice. Optimal health education would ensure the receipt of quality and balanced information on all therapy options that is easy to understand and appropriate to YAs’ educational levels as this improves health literacy. Assessment of psychosocial needs and provision of psychosocial support should be made available at the same time of receipt of diagnosis and prognosis, or discussions of treatment options and not be separate. Psychosocial support for carers of YAs is also needed because it has a direct impact on YAs. Establishing rapport and building effective relationships with YAs would improve trust and openness in HCP-YA encounter.

Raising awareness of YAs’ unmet needs among HCPs is important and this calls for collaborative working with YA patient groups to develop a consensus on the best way to educate them about their options. Kidney professionals should educate YAs on how each option can affect their routines of life and equip them with information to manage their life as this makes them better prepared for what is to come. Development of strategies such as teach-back and delivering information in small chunks could reduce information overload, enhance the understanding of options and promote effective engagement in decision-making and improve their outcomes.

There is a gap between the information received and the utilisation of the health information which needs to be addressed to comply with the WHO’s explanation of health literacy (Nutbeam, 1998). The use of simple words and illustrations to explain the options information that meets their literacy level would be beneficial. Measures for evaluating YAs' understanding of information should be incorporated into patient education to enable the assessment of their understanding and address the lack of it. Variations in the information content, readability, and existing biases in the presentation of information have been reported (Winterbottom *et al*., 2020a). The recent publication of a dialysis decisional aid booklet could offer the way forward to address some of these differences in the content of options information (Bekker *et al*., 2020; Winterbottom *et al*., 2020b).

Recognising that decision-making continues to the implementation of the agreed choice and evaluation of the choice experienced is vital. This would ensure preparation for smooth transitioning from a carefree life to long-term dependence on RRT and education on how to live with the therapy and manage life. Timely preparation and planning of vascular access for dialysis and referral for kidney transplant listing is vital. This would ensure that preferences for access type are elicited and the needed tests for the kidney transplant listing are done in a timely manner. HCPs should ensure YAs understand the transplant listing process and know where they are in the process.

6.7. Recommendations for education

Undergraduate education should include role play of good interpersonal and risk communication and SDM in a skills lab to develop student HCPs communication skills, the awareness of and the understanding of SDM process to equip them for clinical practice. Undergraduate education should offer students the opportunity to observe and participate in SDM during clinical placements. Postgraduate education should include SDM with patients involved in scenario development to provide practical experience of SDM. In-house education of kidney healthcare professionals on SDM training should include risk communication to promote better understanding and effective use in routine care. Kidney healthcare professionals should be educated on the development of option information leaflets, patient decisional aids as per guideline recommendations (Witteman *et al*., 2021), and decision support tools (such as motivational interviewing and decision coaching) utilisation alongside SDM.

Kidney healthcare professionals must receive training during their undergraduate and postgraduate education on communication and interpersonal relationship skills as this can improve relationship building and engagement with YAs. In-house training should include risk communication for kidney healthcare professionals in SDM to refresh their knowledge and skills. This will provide them with an understanding of YAs' needs and enable them to create an environment that is supportive of active participation and normalise the discussion. Training should also focus on the provision of compassionate care when dealing with YAs as this enables them to develop confidence and trust in kidney health professionals and the service.

6.8. Recommendations for future research

This is a retrospective study therefore observational and interventional research studies of the SDM process are needed to explore YAs' decision-making experiences using bigger sample sizes. Research is needed to explore HCPs' perspectives of supporting YAs' decision-making to understand their engagement of the SDM process. Further interventional studies are needed to explore health education of RRT options of YAs, to develop their knowledge and understanding of RRT options. Research is needed to explore strategies and techniques that support the virtual education of RRT and SDM among YAs. It is vital to explore HCPs' experiences and views of vascular access preparation of YAs and preparation of kidney transplant listing engagement, and participation in decision-making. Research is needed to explore YAs' preparation towards initiating dialysis and kidney transplant modalities. Research is needed to measure the quality of decision-making among different groups of YAs. Further interventional research is needed to explore and measure the psychological impact of decision-making during SDM. Finally, research is needed to explore the facilitators and barriers of SDM among YAs and strategies to improve outcomes. Table 6.2 summarises recommendations and implementation from the study.

Table 6.2 Summary of recommendations for practice, education and future research

Recommendations for practice	Consistent use of the SDM model e.g. Three-talk model (Elwyn *et al*., 2017) as recommended by NICE (2021b) and use of the proposed implement talk phase in the new four-talk model to address some of the issues highlighted in this study. Exploration of specific topics as detailed in the discussion chapter. Joint stakeholder and YA kidney group to explore effective strategies and techniques to support health education of options information. Create awareness among HCPs of YAs' unmet informational and decisional needs detailed in the findings and discussion chapters.
Recommendations for education	Undergraduate education to include SDM role play (in skills lab).

	Undergraduate education should offer an observation of SDM in clinical practice during clinical placements. Postgraduate education to include SDM with patients involved in scenario development. Postgraduate education to include observation and participation in SDM in clinical practice. In-house professional education of SDM skills that support RRT decisions of YAs.
Recommendations for research	Interventional studies to explore different educational techniques that promote better health education and improve YAs’ health literacy. Interventional studies to enhance coping skills and strategies during SDM among YAs. Exploration studies to explore and understand the facilitators and barriers of SDM engagement among YAs. Qualitative studies to explore and understand YAs’ and HCPs’ perspectives of SDM engagement among YAs.

6.9. Strengths and limitations of the study

6.9.1. Strengths

The strength of the study is the phenomenological approach used to explore the experiences of YAs, supported by my previous knowledge and through the professional lens in kidney disease care. The use of a reflexive diary (section

3.22) to identify how I influenced the interpretation of the data and the decisions about themes, contributed transparency to the conduct of the study. The social media recruitment method allowed the study to capture perspectives of YAs across regions in the UK. These perspectives provided an insight into YAs' decision-making experiences which were consistent across different kidney services. Robust measures (chapter 3) were put in place to ensure the accuracy, trustworthiness, and authenticity of the documentation of the research process. This ensured the recruitment process was ethically conducted too.

Appropriate methods were used to collect data and a detailed analysis was performed. Ensuring sensitivity to context and returning transcripts to participants to confirm the content of information also added to the transparency and confirmability of the data. The study involved eighteen participants therefore the findings are considered transferrable to similar contexts of YAs with long-term conditions (Creswell, 2013; Lewis *et al*., 2014). The PPI strengthened the study as YAs helped firm the research question, contributed to the reviewing of the study poster to meet the targeted population and supported the recruitment process.

6.9.2. Limitations

The onset of the SARS-CoV-2 (COVID-19) (WHO, 2020) pandemic affected the progress of the study. Recruitment via social media was undertaken but this had some limitations. YAs wanted to find more information about the researcher which was evident from the analytic report from Twitter as the researcher's profile was viewed several times. The process of getting to know the researcher's background and deciding whether they could trust the researcher with their information possibly affected the response to the study invitation. Recruitment via social media was slow and required reliance on YAs with ESKD (influencers on social media) to advertise and promote the study on their social media platforms. This was managed by including the researcher's picture on the poster advert of the study and being open to YAs through establishing rapport with YAs who expressed their interest in the study. This resulted in building trust between myself and the participants. The use of virtual interviewing limits the ability to capture all non-verbal communications of significance to their experience. Cautious probing may have occurred where extreme emotions were expressed by participants as the researcher and participants were physically miles apart.

6.10. Dissemination of findings

The findings of the study have been submitted for publication in a peer-reviewed journal and presented at conferences. The integrative literature review was submitted and accepted for publication in the Journal of Renal Care (an international peer-reviewed journal) in 2021. The study methods and findings have been disseminated at National (Doctoral Conference June 2018- July 2020; UK Kidney Week June 2019) and International Conference (49th European Dialysis Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) International Conference in September 2021), as mentioned under impact pathways.

Future dissemination

Future dissemination includes working with the YA kidney group to develop a virtual online peer learning that would support their health education needs about options information to equip and enhance decisional self-efficacy and their engagement in decisions about their care. The findings will be published in professional and peer-reviewed journals such as the Journal of Renal Care, Qualitative Research, and BMJ Nephrology, following completion. The plan is to disseminate the study findings to UK Kidney Association and national Kidney Patient Associations.

Further plans include the following journal articles entitled:

i) "World turned upside down: young adults' lived experiences of dialysis and kidney transplant decision-making". The study has shown that gaining awareness of the need for RRT following receipt of ESKD diagnosis or prognosis changed YAs' self-identity and threw their life off track.

ii) "*it's hard to hear*": the psychological impact of decision-making on young adults' well-being. This study showed the impact decision-making had on YAs and how they coped.

6.11. Reflexive summary

The use of reflexivity in the study allowed me to explore my role and position as an insider yet an outsider and examine how I influenced the research process and my actions of the social world I investigated (Palaganas *et al*., 2017) (section

3.22). Although I knew about the benefits of being reflexive, I was less aware of the different types and how it was applied in research (Finlay, 2002b). My journey with YAs during my exploration of their experiences of decision-making as a professional insider challenged my perspectives as I gained new insights into YAs' decision-making experiences and formed new perspectives. Insider-outsider perspectives can be explored in three concepts: power, the context of knowledge and the role of the researcher (Rabe, 2003).

There are benefits of an insider-outsider position in the research context (Saidin and Yaacob, 2016) but there are also some draw backs (Berger, 2013). I had a passion to research YAs with ESKD experiences of dialysis and kidney transplant decision-making and had pre-existing knowledge of the research context. My insider position, as a person with the context of knowledge of ESKD and its management, enhanced the depth of my understanding of the participants' experiences which would not have been accessible to an outsider (researcher) position. While my insider position gave me access to potential participants, however, none of the participants recruited were known to me or were from my local kidney unit.

Being a professional insider made YAs feel more confident and willing to share their experiences with me as they trusted in my ability to make their voice heard. Despite this, there were observed occasions where participants left things unsaid expecting me to know what they intended to say or withheld certain information they felt less comfortable to share with me. This affirms Berger (2013) assertion that participants may be more confident and willing to share information with an insider researcher but may also leave things unsaid expecting the researcher to know.

At the same time, my outsider position allowed me to examine my role as a researcher, my relationship with participants, how I influenced the research context and the actions taken through reflexivity (Day, 2012). My position as an outsider enabled me to probe deeper, listen carefully, analyse and interpret participants' lived experiences to make sense of them in a non-biased way and maintained neutrality. Bridges (2017) argues that outsider researchers are able to ask questions to illuminate their understanding. The researcher's position in relation to the subject researched is as important as examining the philosophical perspectives of subjectivity and objectivity. Davis (2020) asserts that researchers come to terms with their own research philosophy during the deliberation about the choice of a research approach for their study which resonates with me.

Throughout this study I have demonstrated how my philosophical stance resonated with the research approach, the methods and the analytic process used to generate knowledge. Being reflexive enabled an in-depth examination of my researcher role in the construction of the new knowledge in this thesis. It reaffirmed Davis's (2020) assertions of the importance of reflexivity in research as it is a way of recognising the researcher's voice and position throughout the thesis. My role as an insider but an outsider was reflected in the concept of power dynamics in the researcher-participant relationship (Råheim *et al*., 2016), regarding what the participants chose to share with me and how to present their stories (Rabe, 2003).

As an insider researcher, I understood the sensitivity and emotive nature of the topic, was able to ask meaningful questions, interpret non-verbal clues during the interviews and have presented a truthful account of YAs' experiences. Bridges (2017) asserts that the prime responsibility of a qualitative researcher is to seek an honest and truth-like understanding of an enquiry as far as it is possible which I had done in this thesis. Interpreting the data has made me more aware of the complexities of YAs' decision-making experiences of selecting a dialysis and kidney transplant therapy and have gained further knowledge about YAs' experiences of living with CKD/ESKD. Through reflexivity, I became more aware of YAs emotions as they relived their experiences and took prompt action to put my participants first. I gained more insight into the depth of psychosocial burden experienced by YAs and their families from prognosis to receiving therapy and how this affected their lives.

I gained a worth of experiences through the stages of the research process, from the inception to the completion of the study. Although I was aware that facing RRT decisions affected people, I was less aware that it changed their self-identity and threw their life off track. I have learnt more about myself and the stories that my participants shared with me which is of great value to both of us. Through my research journey, I have gained an understanding of how YAs with ESKD experience dialysis and kidney transplant decision-making and its impact on their well-being.

PPI was beneficial to the study process as YAs continuous feedback on documents ensured the participant information, consent forms, and recruitment poster attracted the target population. Listening to the expert views of the YAs with kidney disease user group, the inclusion criteria were amended which enhanced the recruiting process because it broadened the sample population of potential participants, therefore making the study more accessible for YAs with ESKD who met the study criteria. The contribution of some of the YA kidney group members with social media influence, for example, on Twitter and Facebook, enhanced the continuous advertising of the study to the target population.

Including the views of some PPI members in a poster presented at a conference (UK Kidney Week, 2019) made them feel valued, to have been part of the research process. The involvement of members of the PPI group in future dissemination of findings to different audiences would ensure YAs' voices are heard. For example, they would be able to contribute to the writing of a lay summary for the study and participate in discussions with the kidney care community about how to implement the recommendations from the study to address YAs therapy decision-making.

6.12. Conclusion

The research question aimed to explore how young adults diagnosed with end-stage kidney disease experienced dialysis and kidney transplant decision-making and to investigate the effects of decision-making. YAs struggled to engage with the decision-making process as they lacked the awareness that choice existed, adequate information to understand their options, and participate in decision-making as an equal to make their voices heard. YAs wanted active participation and to be recognised as the decision-maker who can make autonomous decisions. They weighed their options and considered what mattered most to them, such as their ability to maintain normalcy, continue education and jobs, socialise, and have a certain future and made decisions.

The study found that YAs lacked the quality and balanced information they needed to make decisions about their options. They were not prepared on how to live with and manage the disease and therapy choices. Therefore, they need education and support in managing the disease and their chosen therapy. YAs lacked preparation to transition to their chosen therapy and therefore wanted to be prepared and supported to make the transition. Aligning YAs' decision-making experiences to the three-talk model, the study found the model did not address the transition to initiating therapy choice. Therefore, the implement talk phase was proposed to address this issue and incorporated into the three-talk model to develop a four-talk model of shared decision-making (Figure 5.3).

This revised version of the model would ensure that discussions and preparation for smooth transitioning from a carefree life to a long-term dependence on dialysis and kidney transplant occur. It would also ensure the planning and preparation for dialysis vascular access and the kidney transplant listing tests are organised in a timely manner and YAs feel ready to experience therapy and are supported through the process. This would also allow ownership of the decisions made. The experience of decision-making and choice affected YAs' physical, psychosocial, and mental well-being but this impact was underestimated. YAs experienced a lack of psychosocial support which made them struggle to cope. YAs need psychosocial support during the receipt of diagnosis/prognosis, receiving health education about therapy options and receiving choice to enable them to cope.

The study has made original contributions to knowledge by identifying YAs' experiences of a change in self-identity and life thrown off track upon receipt of diagnosis and the need for dialysis and kidney transplant. The study also found decision-making had a psychosocial impact on YAs' well-being and newly proposes an implement talk phase in the four-talk model of SDM. I desire to advocate for YAs with CKD and give them a voice by sharing their experiences of therapy decision-making with kidney professionals. I hope that this work will provide a focus on YAs' needs and add to the ongoing drive to improve health literacy, change attitudes towards mental health, and improve psychosocial support for people with kidney disease. Together the findings call for collaborative working with YAs to improve their service provision.

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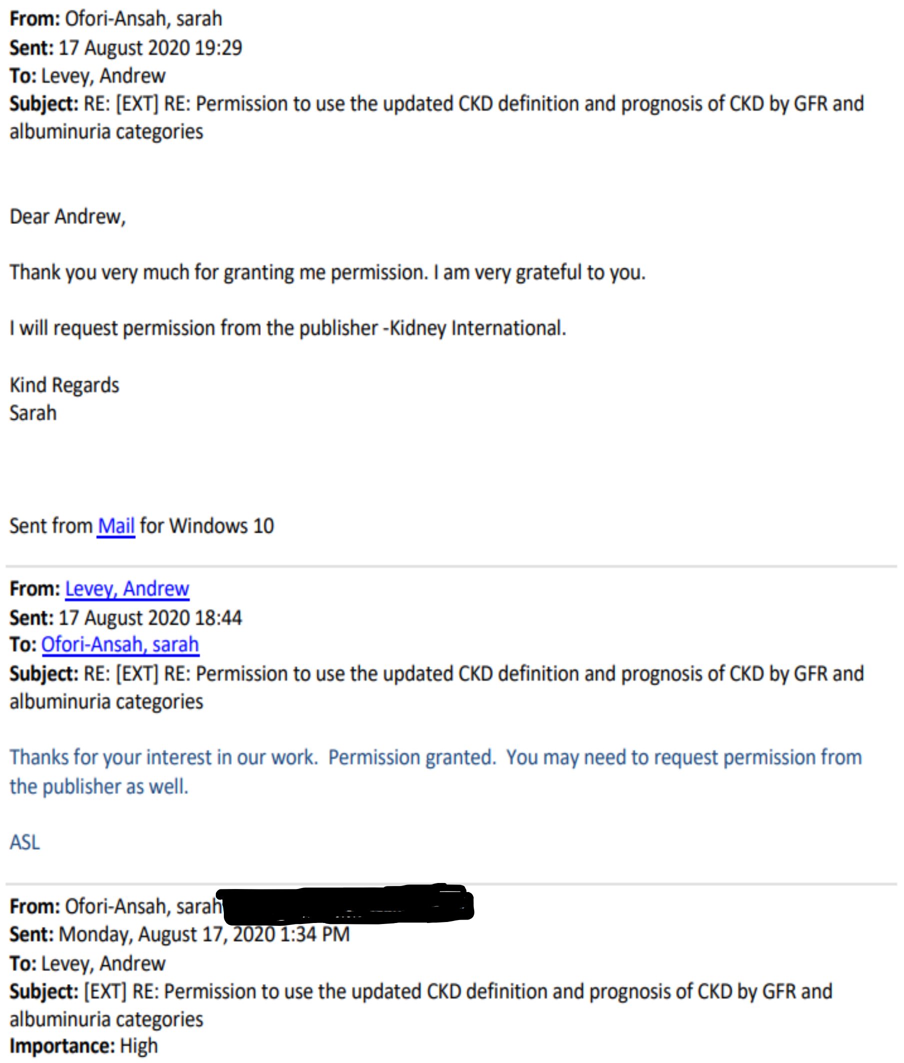
Appendices

Appendix 1 Permission granted by author to use eGFR and Albuminuria categories



From: Ofori-Ansah, sarah
Sent: 17 August 2020 19:29
To: Levey, Andrew
Subject: RE: [EXT] RE: Permission to use the updated CKD definition and prognosis of CKD by GFR and albuminuria categories

Dear Andrew,

Thank you very much for granting me permission. I am very grateful to you.

I will request permission from the publisher -Kidney International.

Kind Regards
Sarah

Sent from Mail for Windows 10

From: Levey, Andrew
Sent: 17 August 2020 18:44
To: Ofori-Ansah, sarah
Subject: RE: [EXT] RE: Permission to use the updated CKD definition and prognosis of CKD by GFR and albuminuria categories

Thanks for your interest in our work. Permission granted. You may need to request permission from the publisher as well.

ASL

From: Ofori-Ansah, sarah [redacted]
Sent: Monday, August 17, 2020 1:34 PM
To: Levey, Andrew
Subject: [EXT] RE: Permission to use the updated CKD definition and prognosis of CKD by GFR and albuminuria categories
Importance: High

Appendix 2 Permission from publisher

Nomenclature for kidney function and disease: report of a Kidney Disease: Improving Global Outcomes (KDIGO) Consensus Conference

Author:
Andrew S. Levey, Kai-Uwe Eckardt, Nijsje M. Dorman, Stacy L. Christiansen, Ewout J. Hoorn, Julie R. Ingelfinger, Lesley A. Inker, Adeera Levin, Rajnish Mehrotra, Paul M. Palevsky, Mark A. Perazella, Allison Tong, Susan J. Allison, Detlef Bockenhauer et al.

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Appendix 3 Explanation of different types of renal replacement therapies

Haemodialysis: This is the process of removal toxins, excess fluid and other waste product harmful to the body of a person with ESKD through a dialysis machine.

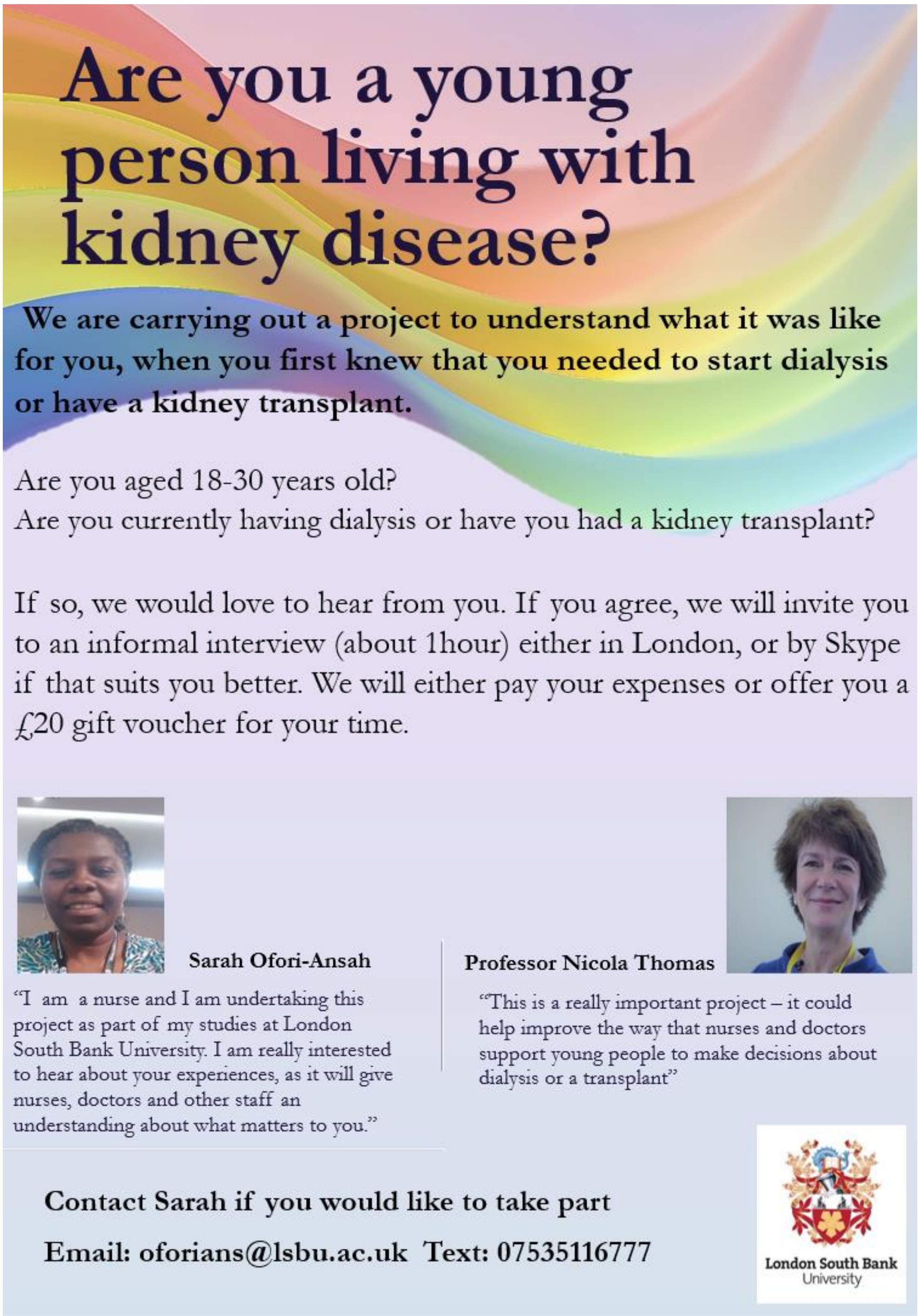
Home haemodialysis: This is a haemodialysis therapy that is performed by the person with ESKD at home.

Peritoneal dialysis: This is the removal of removal toxins, excess fluid and other waste product harmful to the body of a person with ESKD through fluid exchanges. It involves a minor surgical process to insert a catheter into the person's peritoneum which is the used to drain a dialysis fluid in and out of the peritoneum during dialysis. The fluid is left to dwell in the peritoneum for four to eight hours for dialysis to occur after which it is drained out and another dialysis fluid drained in. PD dialysis can be done manually or using an automated peritoneal dialysis machine.

Fistula Access: A surgical process where a small incision is made in the wrist or arm to join a vein and an artery together and used for haemodialysis. It takes four to six weeks for a fistula access to mature and be ready for use.

Kidney transplantation: This is the surgical removal of a kidney from a donor and transplanted into a recipient (a person with ESKD).

Appendix 4 Poster Advert



Are you a young person living with kidney disease?

We are carrying out a project to understand what it was like for you, when you first knew that you needed to start dialysis or have a kidney transplant.

Are you aged 18-30 years old?
Are you currently having dialysis or have you had a kidney transplant?

If so, we would love to hear from you. If you agree, we will invite you to an informal interview (about 1hour) either in London, or by Skype if that suits you better. We will either pay your expenses or offer you a £20 gift voucher for your time.

Sarah Ofori-Ansah

“I am a nurse and I am undertaking this project as part of my studies at London South Bank University. I am really interested to hear about your experiences, as it will give nurses, doctors and other staff an understanding about what matters to you.”

Professor Nicola Thomas

“This is a really important project – it could help improve the way that nurses and doctors support young people to make decisions about dialysis or a transplant”

Contact Sarah if you would like to take part

Email: oforians@lsbu.ac.uk Text: 07535116777

London South Bank
University

Appendix 5 Participant information sheet

London South Bank University

EST 1892

PARTICIPANT INFORMATION SHEET

Research Title: Young adults' experiences of dialysis or kidney transplant decision making.

You are being invited to take part in a research study. This study is about young adults' experiences of making a dialysis or kidney transplant decision. Kindly take a few minutes to read the information provided about the study below.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to conduct research to explore young adults' experiences of making a dialysis or kidney transplant decision to raise awareness and improve the process. I am undertaking the study as part of my PhD (research degree) at London South Bank University.

WHAT IS THE AIM OF THIS STUDY?

The aim is to find out what happened when you had to make a dialysis or a kidney transplant decision and the impact of the decision on your well-being.

WHY HAVE I BEEN CHOSEN?

You have been chosen because you are a young person diagnosed with end-stage kidney disease for more than three months, either on dialysis or have had a kidney transplant and aged between 18 to 30 years.

DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. However, once you have undertaken the interview, the data (words you have spoken) can only be withdrawn up to the point of data analysis (usually around 2 weeks after the interview has taken place) as the data will be anonymised at this stage and your data will not be able to be identified. If you wish to withdraw you may simply contact the researcher and state that you are withdrawing.

WHAT WILL HAPPEN TO ME IF I CHOOSE TO TAKE PART?

Once I have received your phone number or email information, I will contact you to arrange an interview date, time and a suitable place, preferably at the London South Bank University Doctoral Academy or by Skye if that suits you better. This University is near the Elephant and Castle tube station and Waterloo main line station. I will ask you questions about your experiences for up to a maximum of one hour. If you agree, our conversation will be recorded using a voice recorder, and then I will type up the interview at a later date.

WHAT ARE THE POSSIBLE DISADVANTAGE AND RISKS OF TAKING PART?

There are no anticipated disadvantages or risks should you decide to take part in the study. However, should discussing your past experiences of dialysis or kidney transplant choice selection during the interview make you feel upset, then the interview will be stopped to give you time to recover. Interviews will be restarted following recovery if you choose to continue. If you prefer not to continue, the interview will be stopped completely. You will be asked if you have a friend or family member you would like to talk to should you become upset while sharing your experiences with me. If need be, I will also have the name of a counsellor or advocate who you could be in contact with if need be.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There may be no direct individual benefits from taking part in the study. However, sharing your experiences may be therapeutic to you. You will either be reimbursed for your travelling expenses or offer you a £20 gift card for your time. The results of the study will be shared with Healthcare professionals and other patients to help to improve our understanding of young people's experiences of dialysis and kidney transplant choice selection. The information will be used to develop our pre-dialysis services for young people.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

All the information collected about you and other participants will be kept strictly confidential (subject to legal limitations). Data generated by the study will be retained in accordance with the University's Code of Practice. Digital recordings and records will be stored on a password protected computer accessible only by the research team. Non-anonymised data (personal data) will be stored for as long as it is needed in compliance with the General Data Protection Regulations. All personal data will be kept for a period of 5 years after the completion of the project or until the end of the project and then destroyed. No information regarding your participation in the study will be shared outside the research team. In the write up of the study all data will be completely anonymised. No names or any identifiable information will be included.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

You will be given a summary of the results if this is what you prefer. Results of the study will be shared with the renal community with the aim to initiate discussions on how to improve young adults' engagement and experiences of the kidney failure choice selection process and care. It will allow Healthcare professionals to understand what matters to young adults' and identify the support needed by young adults to reduce the impact of choice selection and improve their well-being. The results will be submitted as my thesis for a PhD at London South Bank University, presented at conferences and published in a journal.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

The study is organised by Sarah. O. Ansah in conjunction with patients who are part of the steering group. Professor Nicola Thomas, Dr Janice Jones and Dr Michelle Evans are my supervisors in the London South Bank University Doctoral Academy. The study is funded by the School of Health and Social Care, London South Bank University Doctoral Academy.

WHO HAS REVIEWED THE STUDY?

The research study has been reviewed by London South Bank University Health and Social Care Research Ethics Panel (ethics number: ETH1920-0022).

CONTACT FOR FURTHER INFORMATION: If you need further information about the study please contact Sarah .O. Ansah on 07535116777 or email me at **oforians@lsbu.ac.uk.**

You can also contact my main supervisor if you have concerns about the way in which the study has been carried out; Professor Nicola Thomas on 02078158045 or email nicola.thomas@lsbu.ac.uk

If you have any concerns regarding the study, please contact Dr Adéle Stewart-Lord (Chair HSCSEP) on adele.stewart-lord@lsbu.ac.uk

Date: Researcher signature:

Thank you for taking time to read the information sheet.

Appendix 6 Participant Consent Form

London South Bank University
EST 1892

Research Project Consent Form

Full title of Project: Young adults experiences of dialysis or kidney transplant decision making

Name: Sarah Ofori-Ansah

Researcher Position: PhD Student

Contact details of Researcher: email: oforians@lsbu.ac.uk telephone: 07535116777

Taking part	**Please initial in each box**
I confirm that I have read and understood the information sheet and/or the researcher has explained the above study. I have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without providing a reason.	
I agree to take part in the above study.	
I agree to keep all discussions confidential.	

Use of my information	**Please initial in each box**
I understand my personal details such as phone number and address will not be revealed to people outside the project.	
I understand that my data/words may be quoted in publications, reports, posters, web pages, and other research outputs.	
I agree to the interview being audio recorded.	
I agree to the use of anonymised quotes in publications.	

Name of Participant Date Signature

Name of Researcher Date Signature

Appendix 7 Interview schedule

INTERVIEW SCHEDULE

1. What were your experiences when your doctor or nurse first discussed with you that you needed to make a decision about a dialysis or transplant choice?

2. What were your experiences of the information that was available to you that helped you make a decision about dialysis or transplant choice?

3. What were your experiences of the impact of the decision-making process to select a choice on you and your family?

4. What improvement would you like to see in the decision-making process?

Prompts

1a) At that time, how much did you know about your condition and how it might progress?

1b) What were your feelings at the time? and how did your family feel?

2a) What impact did the information you were given have on you, your family and your lifestyle?

2b) What resources were available to you and your family that helped you cope during that time? Films, internet, charities, other patients etc.

3a) Since you made the decision on your option, what has happened since

3b) How have you and your family been since you made the decision?

Thank you for your participation.

Appendix 8 University Ethics Approval letter

Dear Sarah

Application ID: ETH1819-0029

Project title: Doctoral Research Project

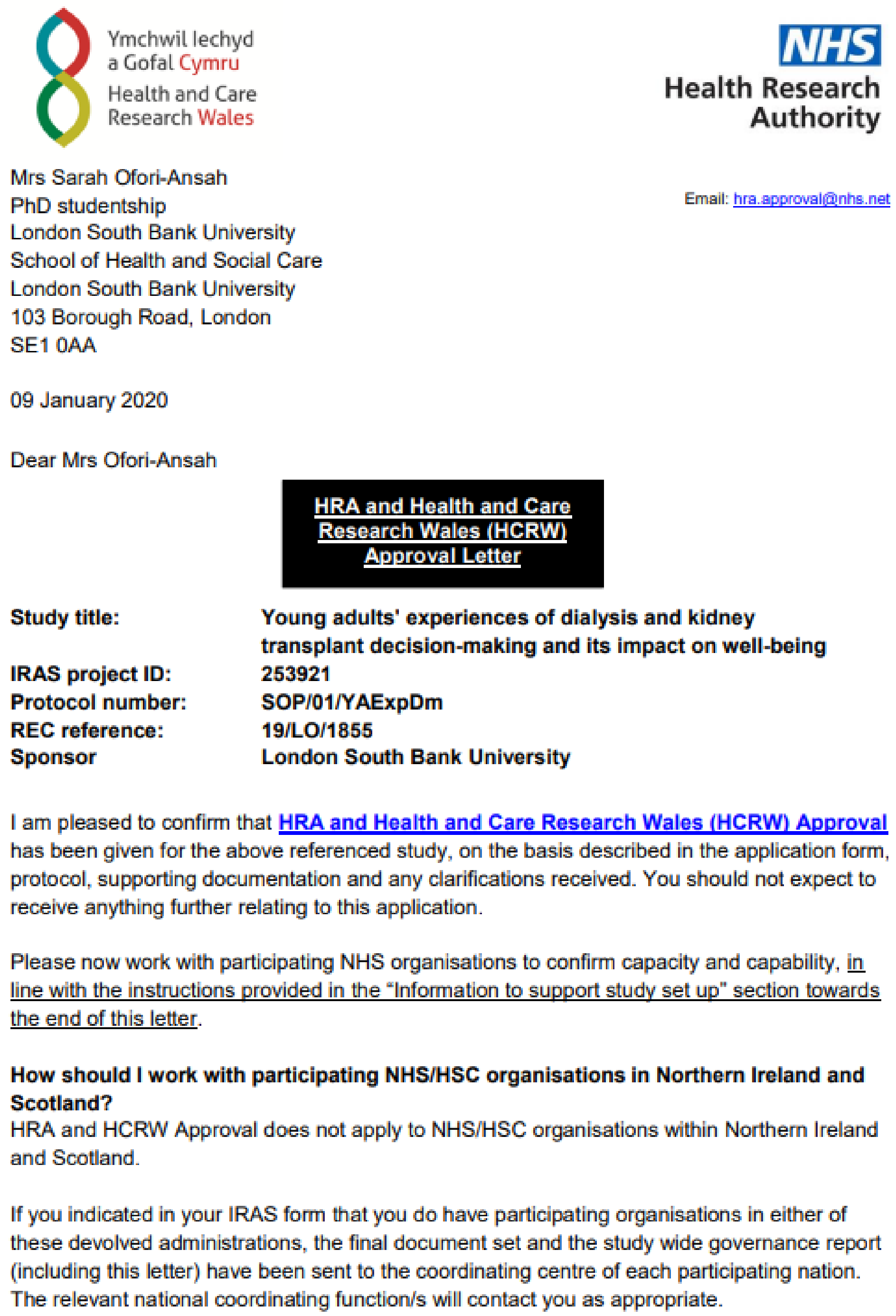
Lead researcher: Mrs Sarah Ofori-Ansah

Thank you for submitting your proposal for ethical review. I am writing to inform you that your application has been approved. Your project has received ethical approval from the date of this notification until 26th February 2023.

Yours Dr Adéle Stewart-Lord

Chair HSCSEP

Appendix 9 NHS Health Research Authority approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net

Mrs Sarah Ofori-Ansah
PhD studentship
London South Bank University
School of Health and Social Care
London South Bank University
103 Borough Road, London
SE1 0AA

09 January 2020

Dear Mrs Ofori-Ansah

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Young adults' experiences of dialysis and kidney transplant decision-making and its impact on well-being**
IRAS project ID:	**253921**
Protocol number:	**SOP/01/YAExpDm**
REC reference:	**19/LO/1855**
Sponsor	**London South Bank University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions 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.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **253921**. Please quote this on all correspondence.

Yours sincerely,
Rebecca Evans
Approval Specialist

Email: hra.approval@nhs.net
Copy to: *Professor Nicola Thomas*

Appendix 10 Demography of participants, pseudonyms, and interview duration

Pseudonym	Age in years at the time of interview	Gender (Female -F; Male -M)	Time of diagnosis	Interview time (minutes)
Zoe	25	F	Young adult	37.47
Ben	25	M	Young adult	31.2
Charlie	26	M	Young adult	60.35
Nally	23	F	Young adult	67.73
Jess	22	F	Since birth	51.41
Mina	29	F	Young adult	38.29
Ella	24	F	Childhood	42.52
Georgia	28	F	Young adult	63.19
Arron	29	M	Since birth	91.44
Dave	28	M	Since birth	77.4
Fred	24	M	Young adult	71.54
Paul	28	M	Young adult	49.3
Rita	30	F	Adolescent	43.08
Sharon	22	F	Since birth	41.4
Steve	21	M	Young adult	65.2
Harry	29	M	Young adult	41.25
Joe	18	M	Childhood	55.12
Linda	28	F	Young adult	101.21

Appendix 11 Data analysis approaches

Type of data analysis	What it is for	Reason for not using the approach
Content Analysis	The content analysis method is used to analyse the content of textual data for the presence of words, themes, or concepts to interpret and understand the meaning and existing relationships (Drew and Heritage, 2006). It uses a priori coding (identify specific themes before conducting the analysis) scheme of concepts for the dataset and follows a positivist paradigm historically (Neuendorf, 2019).	Content analysis was not chosen as the use of priori conceptual coding can lead to leaving key areas of the experience that had not been included in the priori codes. The content analysis focuses on identifying selective concepts, patterns, or practices that underline the meaning constructed during the interaction of people. However, the study wants to understand the whole experience instead of selective experiences. The analysis does not provide the individual level of meaning of the experience which is also relevant to understanding the phenomenon.
Framework Approach Analysis	Framework analysis is a systematic approach that uses a matrix format to provide a structure to code, identify and manage themes (Hackett and Strickland, 2018). It is particularly	Framework analysis was not used as it will not provide both individual and collective shared experience to fulfil the hermeneutic principles. It is more suited for pre-designed samples and priori issues such as

	beneficial for large-scale research, to analyse key themes within the dataset (Gale *et al*., 2013). Coding is either derived from the data to create a coding scheme or coding is done priori to analysis. It is not aligned to a particular epistemological or theoretical approach, therefore, can be used deductively, inductively or a combination of the two to analyse the data especially where multiple analysts perform the data analysis (Hackett and Strickland, 2018 and Gale *et al*., 2013).	organisational and integration issues that need to be dealt with in a limited time frame. Novice researchers require adequate training, skills, and guidance from more experienced researchers to enable effective use of the approach.
Narrative Analysis	Narrative analysis is a cluster of analytic frameworks concerned with the structure, content, and function of stories in oral and written communication (Demuth and Mey, 2015). It is concerned with understanding how and why people talk about their story of experience to understand the social	Narrative analysis was not used as its focus is to understand the characteristics of an individual's story (Bamberg, 2011) but not to understand and interpret the meaning of a phenomenon. Although narrative analysis is good in providing a description of personal autobiographies, the self, identity, and chronological story of people (Bamberg, 2012), it will not allow the

	interactions among groups (Lieblich *et al*., 1998).	understanding of the multiple interrelationships that occur during decision-making and how it influenced the process.
Discourse Analysis	Discourse analysis (DA) can be used to analyse text, to identify socially produced patterns, and tends to refer to a wide range of pattern-type analysis of data. It is informed by social constructionist epistemology and seeks to understand how people interact with each other. It also focuses on the use of language, its function, and its role in the creation of reality (Beedholm *et al*., 2014)	DA was not used because of its focus on social discourses within the data and not on both individual and shared levels of the context. Therefore, it will not allow the exploration of the intersubjective relationship that occurred and the interpretations of its meaning from young adults' perspectives.
Interpretative Phenomenological Analysis (IPA)	Interpretative Phenomenological Analysis framework is used to analyse and interpret the meaning of a lived experience of a phenomenon (Smith *et al.,* 2009). It uses a systematic approach to explore and understand the experience on the individual	Although the IPA framework was suitable. It was not chosen as the IPA framework is more suited for smaller sample numbers (1-10) and it seeks to understand an individual's unique experience on the individual level. It was important that the findings of

	level of a situated context (Pietkiewicz and Smith, 2014). IPA framework is informed by a specific philosophical and theoretical framework by various phenomenologists. The approach aligns with both phenomenological and hermeneutic principles to provide meaning and understanding of an experience (Smith *et al.,* 2009).	this study achieve an in-depth understanding of the experience on a shared level. It also aligns to specific theoretical frameworks which must be adhered to therefore not theoretically flexible. IPA framework was not used as the study also wanted to gain broader perspectives about participants' social interrelatedness of the decision-making experience in addition to an individual level.

Appendix 12 Excerpt example of phase one of data analysis: Reading and re-reading of transcript (Zoe)

Excerpt example of transcript of data analysis reflecting reading and re-reading for familiarisation of the data. Researcher observations including noting of moods and intonations etc are highlighted in yellow on the transcript.	
Transcript	**Phase one: Reading and re-reading** **Notes made during immersion and familiarisation of transcript**
R: …. tell me what your experiences were, erm at the time when your doctor or nurse first discussed with you that you needed to make a decision about a dialysis or kidney transplant choice **P: okay** **R: Can you tell me a little bit what happened?**	
P: Yeah of course. Ermmm so some background. I was diagnosed in 2013, erm when I was pregnant with my daughter. So, I was already pregnant when they did the blood test from the beginning.	Background information Pregnant with daughter when diagnosed.
Ermmm and told that I had some kind of erm well you know some kind of problems with my kidneys. I think at that point it was about stage 3 (Tone of her voice changes and observable expression and mood communicated fear, disappointment and sadness). Erm and I went on to have my daughter (smiling), but I had pre-eclampsia (facial expression changes, looking sad and down) which kind of escalated things a little bit, erm, so that was two.	Informed of some kind of problems with the kidneys and was at stage 3 of kidney disease. Developed pre-eclampsia during the time of having baby which escalated her kidney disease, the second to happened. That might have been difficult for her. Why is she saying that was two?
And then in 2014, I had a biopsy erm and they haven't been able to actually figure out why this is happened. (Voice sound a little bit teary speaking about those moments, eyes suddenly look wet. A lot of sniffing and swallowing of saliva trying to control her emotions). So, there is no disease. So, there is kind of nothing like that. (Facial expression shows a lot of sadness, stirring up to the ceiling often and deep sighs).	Underwent biopsy to determine the cause of the kidney disease but remains unknown as she says there is no disease, nothing like that.
Erm and they think I might be, I can't remember the technical term but like reflux. So erm in, so in, so after I was pregnant in 2014, we went through the kind of biopsies and treatment.	Given a possible cause, which was due to reflux which is explains. After the pregnancy in 2014 they looked at the biopsies and considered treatment options.
And I think at first the plan was to get me a transplant, before I would even have to go on dialysis, and kind of skip that all together.	Plan was to get a kidney transplant before the need for dialysis so she could skip

Erm, so at that point I must, erm I was twenty, I was 20, or 21, erm so and then erm (voice sound like she is weeping and sobbing within herself, pinching both eyes, wiping from right to the left side of eye, sniffing and swallowing saliva. Then moment of silence).	dialysis. She was in her early twenties at that time.
So, erm and then over the years I went back every kind of few months (voice continue to sound like she is weeping within whilst talking), to see how things were going. And things will kind of drop and come back up, drop, and come back up (swallowing saliva to control emotions and tears from coming). And we got nearer to the point where we had to talk about dialysis, erm but I actually had a very, very, very supportive doctor, who,	Decline of kidney function happened over the years because she said things dropped and went up and dropped. Note in my journal: reflects my concern at this point. I was becoming very concerned about her emotional state and how to intervene due to so much emotions being displayed. I am also on the edge as I am affected by her emotions but putting a strong face, thinking about what action to take as I do not want her to break down emotionally. At the same time, she is at a far distance where I cannot reach, nor really assess the situation because the interview is done virtually. I am watching her very closely and the space as to when to pause the interview and ask her if she is okay and wants to continue with the interview or stop it all together. I am holding my emotions internally but empathising with her.
P: So, I work full-time, I have a daughter, erm and I never wanted to do haemodialysis and not for any particular reason, I just didn't like the thought of the needles. (Eyes well up with tears then burst into sudden laughter but underneath the laugher was teary voice, and I am getting concern due to the emotions displayed).	Another background information about her life before the diagnosis and living with the disease. She works full time and has a daughter. She conveys her strong dislike for haemodialysis therapy, not for any reason but dislike the thought of needles, but could have a bearing on her work and family life. **Observation note**: I recall she looked very sad, tears in the eyes and trying to hold back the tears as she relived that moment. A lot of emotions pouring out as she describes her experience. I was getting concern about her emotions. At the same time, there were also sudden outburst of laughter perhaps seeing herself as being afraid of needles as grownup woman.
Erm one of my best friends, erm was on haemo at the time, erm he started on PD and then went on to haemo. Erm, he said that he was tired all the time (voice sound like she is weeping within herself, which is more pronounced, with a lot of facial and hand gesture as she talked). He did not feel worse in himself (sounded like she was going to burst into tears but still holding back) but afterwards he felt very tired.	Talks about another situation -first-hand haemodialysis experience of a close friend. He experienced tiredness after dialysis. Perceived tiredness from haemodialysis seems a concern for her.

Erm and I really didn't want the destructions to my day that I happen to go into the hospital a few times a week. (Says it with firm certainty). Erm so, I definitely wanted to do erm PD (says it with strong certainty), kind of from the beginning (holding back tears and wiping round her eyes with laughs intermittently).	Switches back to her experience and explains her reason for disliking dialysis- because it would cause disruption to her day as she must go the hospital few times a week. She talks with certainty about her preference for PD choice right at beginning when choice discussion was held.
She informed me you know and gave me all the information straight away, and I was like that seems like the obvious choice for me, my circumstances at that time. Erm, and then we spoke about doing it overnight and it just felt for both of us that was like the least disruptive version (teary voice again).	Provided all the information about the options straight away (doctor). Based on her circumstance at that time, PD choice seemed the obvious choice following receipt of the all the information. Felt doing overnight PD therapy would allow her to carry on with her life with minimal limitations.
Where I could technically kind of carry on with my life with some limitation but erm like the day to day wouldn't be ermmm centred around dialysis (teary voice deepens).	Accepts the limitation PD will come with but felt okay with it because her life will not work around the PD choice.
Erm I kind of didn't want dialysis to be the kind of my whole life and everything works around that. I wanted it to work around my life as it is now and so erm home.	She preferred the PD choice to work around her life. Does not want dialysis to take over her life but for dialysis to work around her life.
So, erm even now I think PD was kind of the best what decision for me at the time yeah (I am really getting more and more concerned about her emotional state).	Believes PD was the best choice for her. **Reflective note:** I recall my mother instinct kicked in at that time because her age is within the age range of one of my children. Wanting to just hold her and comfort her, but that was not possible as she was not physically near me. However, I am also in a dilemma (a catch 22 situation) as I must act professionally. Where do I draw the balance? I must stay professionally and have her welfare as my priority not just the interview. I continued to show empathy while I listened attentively. I reassured myself I have a psychological support backup to support her in the worst-case scenario, as I monitored the situation very closely.

Appendix 13 Excerpts from phase two of data analysis: coding of data

Coded themes	Zoe	Ben	Charlie	Nally	Ella	Georgia	Jess	Mina	Aaron	Fred	Paul	Harry	Dave	Sharon	Rita	Joe	Steve	Linda
Ability to achieve prospects	yes	Yes	yes	yes	no	yes	Yes	Yes	Yes	Yes	no	Yes	yes	yes	no	Yes	no	yes
Ability to travel	no	No	yes	yes	no	no	Yes	Yes	No	Yes	no	no	no	no	Yes	no	no	yes
Acceptance of choice	yes	Yes	yes	yes	yes	yes	Yes	Yes	Yes	Yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Access to peer experience	yes	Yes	yes	no	no	yes	Yes	Yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	yes	yes
Active	yes	Yes	yes	yes	yes	yes	Yes	Yes	Yes	Yes	yes	yes	yes	yes	yes	yes	yes	yes
Anger	yes	No	no	yes	yes	no	Yes	Yes	Yes	yes	no	Yes	no	yes	Yes	no	no	yes
Appraised values and beliefs	yes	Yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	yes	no	yes	no	Yes	Yes	yes	yes
Autonomous decision	yes	Yes	yes	yes	yes	yes	Yes	Yes	No	no	yes	yes	no	yes	Yes	no	no	no
Belongingness	no	No	yes	no	no	no	Yes	Yes	Yes	yes	no	Yes	yes	no	no	no	yes	no
Building new relationships	no	No	yes	no	no	no	Yes	no	Yes	yes	yes	no	no	no	no	no	yes	yes
Communication	yes	Yes	yes	yes	yes	yes	No	yes	No	no	no	Yes	no	no	Yes	no	no	yes
Comparation of paediatric and young adult choice experiences	no	No	no	no	yes	no	Yes	no	Yes	no	no	no	yes	no	no	no	no	no
Considered impact on education	no	Yes	yes	no	yes	yes	Yes	no	Yes	no	no	no	yes	yes	no	Yes	no	yes
Considered the burden on family	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	no	Yes	no	no	Yes	Yes	yes	no
Considered the impact of choice on life	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Coping	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Decision role/level Type of decision-made	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes
Decisional conflict	yes	Yes	yes	yes	yes	no	No	yes	Yes	yes	no	no	no	yes	Yes	Yes	yes	no
Decisional regrets	yes	No	yes	yes	yes	no	No	no	Yes	yes	no	no	no	no	Yes	no	yes	no
Decisional role	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	no	yes	no	no	no	Yes	Yes	yes	yes
Decisional self-efficacy	yes	Yes	yes	yes	yes	no	Yes	no	No	no	no	no	no	no	Yes	no	no	no
Desire to socialise	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes

Desired to know the whole truth positives and negatives	yes	Yes	yes	yes	yes	yes	Yes	yes	No	no	no	Yes	no	yes	yes	yes	yes	yes
Diagnosis and its impact	Yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Donor conflicts	No	No	no	yes	no	no	No	yes	No	no	no	no	no	no	no	no	no	no
Effect of therapy on family	Yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	yes	Yes	no	no	Yes	Yes	yes	yes
Establishing relationship	Yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	no	Yes	yes	no	Yes	no	yes	yes
Factors influencing donor to give a kidney	No	No	yes	yes	yes	no	No	yes	Yes	no	yes	no	no	no	no	no	yes	yes
Factors that influence choice decision	Yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Family understanding of diagnosis	Yes	No	no	no	no	no	No	yes	No	yes	yes	Yes	no	no	Yes	no	no	yes
Fear of being treated differently by people	Yes	No	yes	no	yes	yes	Yes	yes	No	no	no	Yes	no	no	no	Yes	yes	no
Feeling lied to by health professionals	Yes	No	no	no	yes	no	No	no	No	no	no	no	no	no	Yes	no	no	no
Flexibility with work life	Yes	Yes	no	yes	yes	no	No	yes	No	no	no	no	no	no	no	no	no	no
forced to assume passive role	No	No	no	yes	no	yes	No	no	No	yes	no	no	no	no	no	no	no	yes
Framing of choice	Yes	Yes	yes	yes	yes	yes	No	yes	No	no	yes	no	no	no	no	no	no	yes
Freedom	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Good information delivery	yes	Yes	yes	no	yes	yes	Yes	yes	Yes	no	yes	Yes	yes	yes	Yes	Yes	yes	yes
Growth in the midst of challenges	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	no	Yes	yes	no	Yes	no	yes	yes
Guilt	yes	No	yes	yes	no	yes	Yes	yes	Yes	yes	yes	Yes	no	no	Yes	no	yes	yes
How decision of choice made	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	no	yes	Yes	no	yes	Yes	Yes	yes	yes
Impact of diagnosis / choice (PD, Haemodialysis, kidney transplant) on life therapy	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Impact of choice on life and living with should be discussed during	yes	Yes	yes	yes	yes	yes	yes	yes	Yes	no	yes	yes	yes	yes	yes	yes	yes	no

decision-making discussions																		
Impact of choice on social life	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
impact of depression on choice/life	yes	Yes	yes	yes	no	no	No	no	Yes	yes	no	Yes	no	no	no	no	yes	no
Impact of diagnosis and choice on family	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Impact of dialysis therapy on academic life	yes	Yes	yes	yes	yes	yes	Yes	no	Yes	no	no	Yes	yes	yes	no	Yes	no	yes
Impact of information on participant	yes	Yes	no	yes	no	yes	No	no	No	yes	no	no	no	no	Yes	Yes	yes	yes
impact of kidney donation on family	no	No	yes	yes	yes	yes	No	yes	Yes	no	no	Yes	yes	yes	no	Yes	yes	yes
Impact of societal perceptions	no	No	yes	no	yes	no	Yes	yes	No	no	no	Yes	no	no	no	Yes	yes	yes
Independence	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	no	Yes	no	yes	yes
Information delivery	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Information seeking behaviour	yes	Yes	yes	yes	yes	yes	Yes	yes	No	no	yes	no	no	yes	Yes	Yes	yes	yes
Involvement in decision-making	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	no	yes	Yes	no	yes	Yes	Yes	yes	yes
Kidney donation and its impact	no	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
know gather as much information as you can, be knowledgeable about your condition, be knowledgeable about erm your treatment	yes	Yes	yes	no	no	no	No	yes	Yes	no	no	Yes	yes	no	no	no	no	no
Lack of psychological support to make the transition from being a carefree person to plugged into a machine person	yes	No	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes
Lack of support	yes	Yes	yes	yes	yes	yes	No	yes	No	no	yes	no	no	no	Yes	no	yes	yes
loss of confidence	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	no	Yes	no	yes	Yes	Yes	yes	no

loss of control	yes	No	yes	yes	yes	no	Yes	yes	No	yes	no	Yes	no	no	Yes	Yes	yes	yes
Normalcy	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	yes	Yes	yes	yes	Yes	Yes	yes	yes
Not fitting in	yes	No	no	yes	yes	yes	Yes	yes	Yes	yes	no	Yes	no	yes	no	Yes	yes	yes
Outcome of choice/decision-making	yes	Yes	yes	yes	yes	no	Yes	yes	No	no	no	Yes	no	yes	no	Yes	yes	yes
Participation in decision-making	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes
Passive role	yes	Yes	yes	yes	no	no	Yes	yes	Yes	no	yes	Yes	yes	yes	Yes	Yes	no	yes
Patient transport is a big thing and it's very frustrating.	yes	No	yes	no	yes	no	No	yes	Yes	no	no	no	no	no	no	no	no	no
Perception of decision-making/choice	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Perception of self	yes	Yes	yes	yes	yes	yes	Yes	no	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes
Personal situations occurring at the time decision-making	yes	Yes	yes	yes	yes	yes	Yes	yes	No	no	no	no	no	yes	Yes	no	no	yes
Physical impact of therapy on body image	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	no	yes	yes
Plug in the machine person"/machine life/life on dialysis	yes	Yes	yes	yes	yes	yes	No	yes	Yes	yes	yes	Yes	no	no	Yes	no	yes	yes
Post-transplant life	no	Yes	no	yes	yes	yes	Yes	yes	Yes	no	no	Yes	yes	yes	no	Yes	yes	yes
Preference elicitation in decision talk	yes	Yes	yes	yes	yes	no	No	no	No	no	yes	no	no	no	Yes	no	no	no
Preference for RRT	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes
Preparation for choice	yes	Yes	yes	yes	yes	no	Yes	yes	No	yes	yes	Yes	yes	yes	Yes	Yes	yes	no
Preparation to receive news	no	Yes	yes	yes	no	no	No	no	No	yes	no	no	no	no	Yes	no	no	no
Provision of access to first-hand information from peers for practical experience	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	yes	yes	yes	yes
Provision of advocate for young person should have a cracking advocate by your side, you know if you don't	yes	yes	yes	yes	yes	yes	yes	yes	no	yes	no	Yes	yes	no	Yes	Yes	yes	yes

have a strong voice personally																		
Provision of Psychological Support	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Psychological and mental support should be part of the conversation not separate thing to remove associated stigma	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	yes	yes	yes	yes	yes	yes	yes	yes
Psychological and social impact of transitioning into new adult care setting.	no	No	no	no	yes	no	Yes	no	Yes	no	no	no	no	no	no	no	no	no
Psychological effect of being diagnosed with CKD	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	yes	yes	Yes	yes	yes	no	Yes	yes	yes
Psychological effect on family	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	yes	Yes	no	yes	Yes	Yes	yes	yes
Psychological effect on kidney donor	no	No	no	yes	yes	no	No	yes	Yes	no	no	no	no	no	Yes	no	no	yes
Psychological impact	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Psychological support should form part of routine care	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	no	Yes	Yes	yes	yes
Reason for choice	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	no	Yes	yes	yes	Yes	Yes	yes	yes
Reason for trusting doctor	yes	Yes	yes	yes	no	no	Yes	no	No	no	no	no	no	no	Yes	Yes	no	no
Refusal of kidney transplant	no	No	no	yes	no	yes	No	no	No	no	no	Yes	no	no	Yes	no	yes	no
Role of employer	no	Yes	no	yes	yes	yes	No	yes	No	no	yes	no	no	no	no	no	no	yes
Role of partner	yes	Yes	yes	no	no	no	No	no	Yes	no	no	no	no	no	Yes	no	yes	no
Role of positive personality in coping	no	Yes	no	no	no	yes	No	no	No	no	no	no	no	yes	Yes	Yes	no	no
Role of religion and culture in coping & Decision-making	no	Yes	no	no	no	no	No	no	No	no	no	Yes	no	no	no	no	no	yes
Role of significant others healthcare professionals	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	no	yes	yes	Yes	Yes	yes	yes

Role of significant others -family	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Safety	yes	Yes	yes	yes	yes	yes	Yes	yes	No	no	yes	Yes	no	no	no	no	yes	yes
Searching for hope	yes	Yes	yes	yes	no	yes	Yes	no	Yes	yes	yes	Yes	no	no	Yes	no	no	yes
Searching for meaning of the new normal	yes	No	yes	no	no	yes	No	yes	Yes	yes	yes	Yes	no	no	Yes	no	no	yes
Self-blame	yes	No	yes	yes	yes	yes	No	yes	Yes	yes	yes	no	no	no	no	no	yes	yes
Self-imposed isolation	yes	No	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	no	no	Yes	yes	yes
Shared/collaborative decision	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	no	yes	Yes	no	yes	Yes	Yes	yes	yes
skills used in decision-making	yes	Yes	yes	yes	no	no	No	no	No	no	no	Yes	no	no	no	no	no	no
Suboptimal information provision	yes	No	no	yes	yes	yes	No	no	No	no	yes	no	no	no	yes	no	no	yes
Suggestions for improving the decision-making process	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	no	Yes	Yes	yes	yes
Suggestions for improving the transition process	no	No	no	no	yes	no	No	no	Yes	no	no	no	no	no	no	no	no	no
Support provided by HCPs	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
The new normal but normal"	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Time commitment to therapy	yes	Yes	yes	yes	no	no	Yes	yes	No	yes	no	no	no	no	yes	no	yes	no
Timing of information provision	yes	Yes	yes	no	no	yes	No	yes	No	no	yes	no	no	yes	Yes	Yes	no	no
Transitioned into adult care	no	No	no	no	yes	no	Yes	no	Yes	no	no	Yes	yes	no	no	no	no	no
Trust in HCPs	yes	Yes	yes	yes	yes	no	Yes	no	No	no	yes	no	yes	no	Yes	Yes	no	yes
Types of information materials given during education on options	yes	Yes	yes	yes	yes	no	No	yes	No	yes	yes	Yes	no	no	no	Yes	no	yes
Uncertain future	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	no	no	Yes	Yes	yes	yes
Underestimation of the psychological, mental, and physical impact of choice on life	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	no	Yes	Yes	Yes	Yes	Yes	Yes	no

Understanding and development of knowledge	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes
Understanding Practicalities of therapy choice	yes	Yes	yes	yes	yes	no	Yes	yes	Yes	yes	yes	Yes	no	no	Yes	no	yes	yes
Weighed alternatives	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	yes	Yes	yes	yes	Yes	Yes	yes	yes
World turned upside down	yes	Yes	yes	yes	yes	no	No	yes	Yes	yes	yes	Yes	no	no	no	Yes	yes	yes
Young adults struggle to seek psychological help when most needed.	yes	Yes	yes	yes	yes	yes	Yes	yes	Yes	no	no	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix 14 Excerpt from phase three of analysis: Examining themes for recurrent and frequency of themes

Themes	Zoe	Ben	Charlie	Nally	Ella	Georgia	Jess	Mina	Aaron	Fred	Paul	Harry	Dave	Sharon	Rita	Joe	Steve	Linda	Present in
Communication	Yes	yes	yes	yes	yes	yes	no	yes	No	No	no	Yes	no	no	Yes	no	no	yes	10 out of 18
Considered impact on education	No	yes	yes	no	yes	yes	yes	no	Yes	No	no	no	yes	yes	no	Yes	no	yes	10 out of 18
Self-blame	Yes	no	yes	yes	yes	yes	no	yes	Yes	Yes	yes	no	no	no	no	no	yes	yes	11 out of 18
Anger	Yes	no	no	yes	yes	no	yes	yes	Yes	Yes	no	Yes	no	yes	Yes	no	no	yes	11 out of 18
Searching for meaning of the new normal	Yes	no	yes	no	no	yes	no	yes	Yes	Yes	yes	Yes	no	no	Yes	no	no	yes	11 out of 18
Types of information materials given during education on options	Yes	yes	yes	yes	yes	no	no	yes	No	Yes	yes	Yes	no	no	no	Yes	no	yes	11 out of 18
Personal situations occurring at the time decision-making	Yes	yes	yes	yes	yes	yes	yes	yes	No	No	no	no	no	yes	Yes	no	no	yes	11 out of 18
Lack of support	Yes	yes	yes	yes	yes	yes	no	yes	No	No	yes	no	no	no	Yes	no	yes	yes	11 out of 18
Trust in HCPs	Yes	yes	yes	yes	yes	no	yes	no	No	No	yes	no	yes	no	Yes	Yes	no	yes	11 out of 18
Autonomous decision	Yes	yes	yes	yes	yes	yes	yes	yes	No	No	yes	yes	no	yes	Yes	no	no	no	12 out of 18
Shared/collaborative decision	Yes	yes	yes	yes	yes	no	yes	yes	Yes	No	yes	Yes	no	yes	Yes	Yes	yes	yes	12 out of 18
loss of control	Yes	no	yes	yes	yes	no	yes	yes	No	Yes	no	Yes	no	no	Yes	Yes	yes	yes	12 out of 18
Outcome of choice/decision-making	Yes	yes	yes	yes	yes	no	yes	yes	No	No	no	Yes	no	yes	no	Yes	yes	yes	12 out of 18
Decisional conflict	Yes	yes	yes	yes	yes	no	no	yes	Yes	Yes	no	no	no	yes	Yes	Yes	yes	no	12 out of 18
Safety	Yes	yes	yes	yes	yes	yes	yes	yes	No	No	yes	Yes	no	no	no	no	yes	yes	12 out of 18
Searching for hope	Yes	yes	yes	yes	no	yes	yes	no	Yes	Yes	yes	Yes	no	no	Yes	no	no	yes	12 out of 18
Guilt	Yes	no	yes	yes	no	yes	yes	yes	Yes	Yes	yes	Yes	no	no	Yes	no	yes	yes	13 out of 18
Not fitting in	Yes	no	no	yes	yes	yes	yes	yes	Yes	Yes	no	Yes	no	yes	no	Yes	yes	yes	13 out of 18
Post-transplant life	No	yes	no	yes	yes	yes	yes	yes	Yes	No	no	Yes	yes	yes	no	Yes	yes	yes	13 out of 18
Decisional role	Yes	yes	yes	yes	yes	no	yes	yes	Yes	No	yes	no	no	no	Yes	Yes	yes	yes	13 out of 18
Impact of dialysis therapy on academic life	Yes	yes	yes	yes	yes	yes	yes	no	Yes	No	no	Yes	yes	yes	no	Yes	no	yes	13 out of 18
impact of kidney donation on family	No	no	yes	yes	yes	yes	no	yes	Yes	No	no	Yes	yes	yes	no	Yes	yes	yes	13 out of 18

Passive role	Yes	yes	yes	yes	no	no	yes	yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	no	yes	14 out of 18
Self-imposed isolation	Yes	no	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	Yes	no	no	no	Yes	yes	yes	14 out of 18
Freedom	Yes	yes	yes	yes	yes	yes	yes	yes	Yes	No	no	Yes	no	yes	Yes	Yes	yes	no	14 out of 18
Plug in the machine person"/machine life/life on dialysis	Yes	yes	yes	yes	yes	yes	no	yes	Yes	Yes	yes	Yes	no	no	Yes	no	yes	yes	14 out of 18
Information seeking behaviour	Yes	yes	yes	yes	yes	yes	yes	yes	No	No	yes	no	no	yes	Yes	Yes	yes	yes	14 out of 18
Considered the burden on family	Yes	yes	yes	yes	yes	yes	yes	yes	Yes	Yes	no	Yes	no	no	Yes	Yes	yes	no	14 out of 18
Ability to achieve future prospects	Yes	yes	yes	yes	no	yes	yes	yes	Yes	Yes	no	Yes	yes	yes	no	Yes	no	yes	14 out of 18
Desired to know the whole truth positives and negatives	Yes	yes	yes	yes	yes	yes	yes	yes	No	No	no	Yes	no	yes	yes	yes	yes	yes	14 out of 18
World turned upside down	Yes	yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Access to peer experience	Yes	yes	yes	no	no	yes	yes	yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	yes	yes	15 out of 18
Involvement in decision-making	Yes	yes	yes	yes	yes	no	yes	yes	Yes	No	yes	Yes	no	yes	Yes	Yes	yes	yes	15 out of 18
How decision of choice made	Yes	yes	yes	yes	yes	no	yes	yes	Yes	No	yes	Yes	no	yes	Yes	Yes	yes	yes	15 out of 18
Preparation for choice	Yes	yes	yes	yes	yes	no	yes	yes	No	Yes	yes	Yes	yes	yes	Yes	Yes	yes	no	15 out of 18
Effect of therapy on family	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	yes	Yes	no	no	Yes	Yes	yes	yes	15 out of 18
Establishing relationship	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	no	Yes	yes	no	Yes	no	yes	yes	15 out of 18
Appraised values and beliefs	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	no	yes	no	Yes	Yes	yes	yes	15 out of 18
Growth in the midst of challenges	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	no	Yes	yes	no	Yes	no	yes	yes	15 out of 18
Underestimation of the psychological, mental, and physical impact of choice on life	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	no	Yes	Yes	Yes	Yes	Yes	Yes	no	15 out of 18
Provision of advocate for young person should have a cracking advocate by your side, you know if you don't have a strong voice personally	Yes	yes	yes	yes	yes	yes	yes	Yes	No	Yes	no	Yes	yes	no	Yes	Yes	yes	yes	15 out of 18
Psychological effect of being diagnosed with CKD	Yes	yes	yes	yes	yes	no	yes	Yes	Yes	Yes	yes	Yes	yes	yes	no	Yes	yes	yes	16 out of 18
Uncertain future	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	no	no	Yes	Yes	yes	yes	16 out of 18
Perception of self	Yes	yes	yes	yes	yes	yes	yes	No	Yes	Yes	yes	Yes	no	yes	Yes	Yes	yes	yes	16 out of 18

Good information delivery	Yes	yes	yes	no	yes	yes	yes	Yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	yes	yes	16 out of 18
Reason for choice	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	no	Yes	yes	yes	Yes	Yes	yes	yes	16 out of 18
Independence	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	yes	no	Yes	no	yes	yes	16 out of 18
Psychological effect on family	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	yes	Yes	no	yes	Yes	Yes	yes	yes	16 out of 18
Young adults struggle to seek psychological help when most needed.	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	no	Yes	Yes	Yes	Yes	Yes	Yes	Yes	16 out of 18
Impact of choice on life and living with should be discussed during decision-making discussions	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	yes	yes	yes	yes	yes	yes	yes	no	16 out of 18
Decision role/level Type of decision-made	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	no	yes	Yes	Yes	yes	yes	17 out of 18
Preference for RRT	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	no	yes	Yes	Yes	yes	yes	17 out of 18
Participation in decision-making. DECISION TALK	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	no	yes	Yes	Yes	yes	yes	17 out of 18
Weighed alternatives	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	yes	yes	17 out of 18
Normalcy	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	No	yes	Yes	yes	yes	Yes	Yes	yes	yes	17 out of 18
Desire to socialise	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	no	yes	Yes	Yes	yes	yes	17 out of 18
Kidney donation and its impact	No	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	17 out of 18
Role of significant others healthcare professionals	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	no	yes	yes	Yes	Yes	yes	yes	17 out of 18
Physical impact of therapy on body image	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	Yes	yes	Yes	yes	yes	Yes	no	yes	yes	17 out of 18
Lack of psychological support to make the transition from being a carefree person to plugged into a machine person	Yes	no	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	no	yes	Yes	Yes	yes	yes	17 out of 18
Suggestions for improving the decision-making process	yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	no	Yes	Yes	yes	yes	17 out of 18
The need for psychological and mental health support to be inbuilt into decision-making and therapy commencement	Yes	yes	yes	yes	yes	yes	yes	Yes	yes	no	yes	Yes	yes	yes	yes	yes	yes	yes	17 out of 18

Psychological and mental support should be part of the conversation not separate thing to remove associated stigma.	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	no	yes	yes	yes	yes	yes	yes	yes	yes	17 out of 18
Diagnosis and its impact	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Active	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	18 out of 18
The new normal but normal	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Perception of decision-making/choice	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Information delivery-OPTION TALK	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Understanding and development of knowledge	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Considered the impact of choice on life	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Acceptance of choice	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Factors that influence choice decision	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Freedom	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Support provided by HCPs	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Role of significant others -family	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Impact of diagnosis / choice (PD, Haemodialysis, kidney transplant) on life therapy	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Impact of diagnosis and choice on family	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Impact of choice on social life	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Psychological impact	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Provision of Psychological Support	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Psychological support should form part of routine care	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	no	Yes	Yes	yes	yes	18 out of 18
Coping	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Provision of access to first-hand information from peers for practical experience	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	yes	yes	yes	yes	18 out of 18

Understanding Practicalities of therapy choice	Yes	yes	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Yes	yes	yes	Yes	Yes	yes	yes	18 out of 18
Donor conflicts	No	no	no	yes	no	no	no	Yes	No	no	no	no	no	no	no	no	no	no	2 out of 18
Suggestions for improving the transition process	No	no	no	no	yes	no	no	No	Yes	no	no	no	no	no	no	no	no	no	2 out of 18
Feeling lied to by health professionals	yes	no	no	no	yes	no	no	No	No	no	no	no	no	no	Yes	no	no	no	3 out of 18
Psychological and social impact of transitioning into new adult care setting.	no	no	no	no	yes	no	yes	No	Yes	no	no	no	no	no	no	no	no	no	3 out of 18
Role of religion and culture in coping & Decision-making	no	yes	no	no	no	no	no	No	No	no	no	Yes	no	no	no	no	no	yes	3 out of 18
Forced to assume passive role	no	no	no	yes	no	yes	no	No	No	yes	no	no	no	no	no	no	no	yes	4 out of 18
Comparation of paediatric and young adult choice experiences	no	no	no	no	yes	no	yes	No	Yes	no	no	no	yes	no	no	no	no	no	4 out of 18
Role of positive personality in coping	no	yes	no	no	no	yes	no	No	No	no	no	no	no	yes	Yes	Yes	no	no	5 out of 18
Transitioned into adult care	no	no	no	no	yes	no	yes	No	Yes	no	no	Yes	yes	no	no	no	no	no	5 out of 18
Preparation to receive news	no	yes	yes	yes	no	no	no	No	No	yes	no	no	no	no	Yes	no	no	no	5 out of 18
Flexibility with work life	yes	yes	no	yes	yes	no	no	Yes	No	no	no	no	no	no	no	no	no	no	5 out of 18
skills used in decision-making	yes	yes	yes	yes	no	no	no	No	No	no	no	Yes	no	no	no	no	no	no	5 out of 18
Refusal of kidney transplant	no	no	no	yes	no	yes	no	No	No	no	no	Yes	no	no	Yes	no	yes	no	5 out of 18
Better Patient transport is a big thing and it's very frustrating. I know it's great but it's just not reliable.	yes	no	yes	no	yes	no	no	Yes	Yes	no	no	no	no	no	no	no	no	no	5 out of 18
Suboptimal information provision	yes	no	no	yes	yes	yes	no	No	No	no	yes	no	no	no	yes	no	no	yes	6 out of 18
Role of partner	yes	yes	yes	no	no	no	no	No	Yes	no	no	no	no	no	Yes	no	yes	no	6 out of 18
Psychological effect on kidney donor	no	no	no	yes	yes	no	no	Yes	Yes	no	no	no	no	no	Yes	no	no	yes	6 out of 18
Preference elicitation in decision talk	yes	yes	yes	yes	yes	no	no	No	No	no	yes	no	no	no	Yes	no	no	no	7 out of 18
Family understanding of diagnosis	yes	no	no	no	no	no	no	Yes	No	yes	yes	Yes	no	no	Yes	no	no	yes	7 out of 18
Decisional self-efficacy	yes	yes	yes	yes	yes	no	yes	No	No	no	no	no	no	no	Yes	no	no	no	7 out of 18

Ability to travel	no	no	yes	yes	no	no	yes	Yes	No	yes	no	no	no	no	Yes	no	no	yes	7 out of 18
Role of employer	no	yes	no	yes	yes	yes	no	Yes	No	no	yes	no	no	no	no	no	no	yes	7 out of 18
Reason for trusting doctor	yes	yes	yes	yes	no	no	yes	No	No	no	no	no	no	no	Yes	Yes	no	no	7 out of 18
Building new relationships	no	no	yes	no	no	no	yes	No	Yes	yes	yes	no	no	no	no	no	yes	yes	7 out of 18
know gather as much information as you can, be knowledgeable about your condition, be knowledgeable about erm your treatment	yes	yes	yes	no	no	no	no	Yes	Yes	no	no	Yes	yes	no	no	no	no	no	7 out of 18
Decisional regrets	yes	no	yes	yes	yes	no	no	No	Yes	yes	no	no	no	no	Yes	no	yes	no	8 out of 18
Factors influencing donor to give a kidney	no	no	yes	yes	yes	no	no	Yes	Yes	no	yes	no	no	no	no	no	yes	yes	8 out of 18
Impact of societal perceptions	no	no	yes	no	yes	no	yes	Yes	No	no	no	Yes	no	no	no	Yes	yes	yes	8 out of 18
impact of depression on choice/life	yes	yes	yes	yes	no	no	no	No	Yes	yes	no	Yes	no	no	no	no	yes	no	8 out of 18
Belongingness	no	no	yes	no	no	no	yes	Yes	Yes	yes	no	Yes	yes	no	no	no	yes	no	8 out of 18
Framing of choice	yes	yes	yes	yes	yes	yes	no	Yes	No	no	yes	no	no	no	no	no	no	yes	9 out of 18
Impact of information on participant	yes	yes	no	yes	no	yes	no	No	No	yes	no	no	no	no	Yes	Yes	yes	yes	9 out of 18
Timing of information provision	yes	yes	yes	no	no	yes	no	Yes	No	no	yes	no	no	yes	Yes	Yes	no	no	9 out of 18
Time commitment to therapy	yes	yes	yes	yes	no	no	yes	Yes	No	yes	no	no	no	no	yes	no	yes	no	9 out of 18
Fear of being treated differently by people	yes	no	yes	no	yes	yes	yes	Yes	No	no	No	Yes	no	no	no	Yes	yes	no	9 out of 18

Appendix 15 Excerpt of the development of candidate (Main and sub) themes

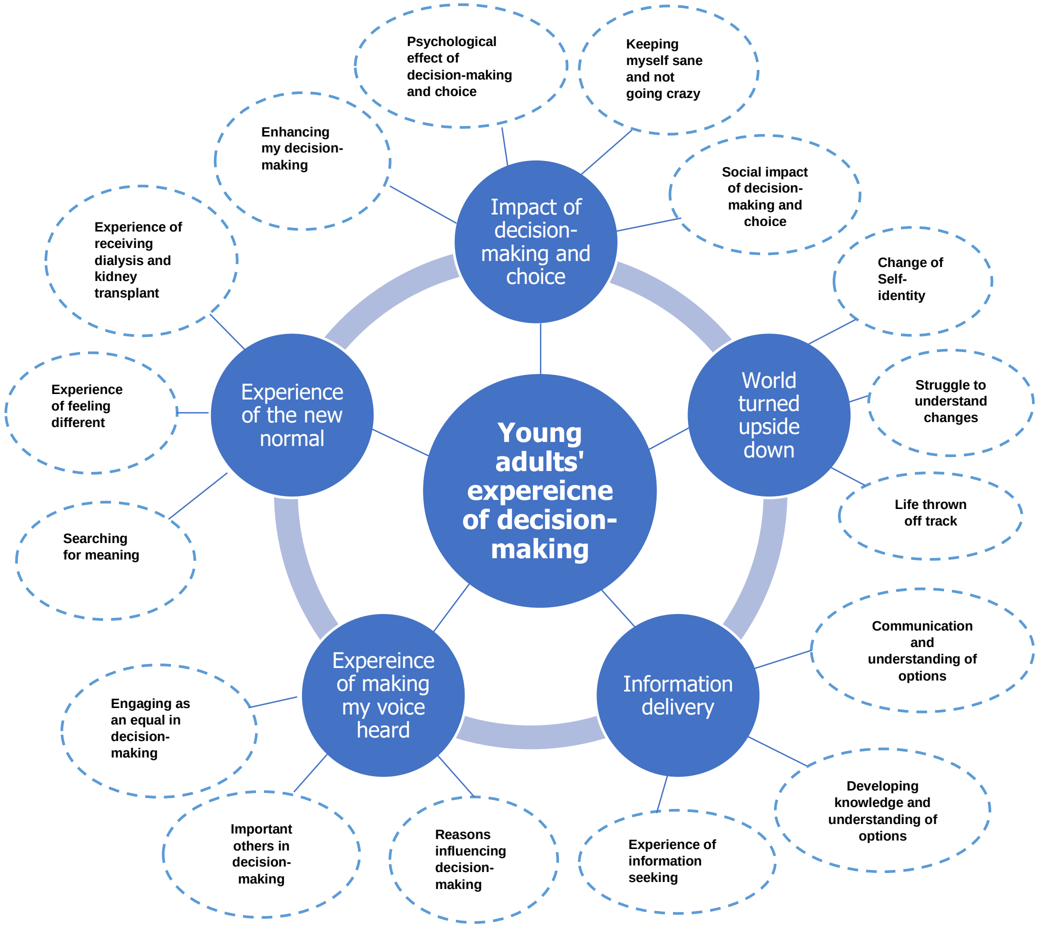
Phase 4 of thematic analysis: Development of themes	
Themes	
World turned upside down ***Change of self-identity*** Diagnosis, understanding and impact Communication of information on diagnosis/prognosis Understanding of diagnosis and prognosis Psychological effect of being diagnosed with CKD **The experience of life thrown off track** Impact of diagnosis/prognosis on immediate life Effect of diagnosis/prognosis on future Perceived multiple losses Uncertain future	**The experience of information delivery about options** ***Communication and understanding of options*** Information delivery Knowledge and understanding of options Lack of Peer support Framing of choice Impact of information on participant Timing of information provision Types of information materials given during education on options and content ***The experience of information-seeking*** Information seeking behaviour (doing own research to know more) *Perception of decision-making/choice* Searching for peer support Lack of information Lack of Peer support
The experience of making my voice heard ***Engaging in decision-making as an equal*** Involvement in decision-making Decisional role (preferred and actual, perception of choice, preference of choice), Autonomous decision and shared/collaborative Weighing alternatives Considered what matters to them, Decisional conflicts Acceptance of choice Decision role/level Type of decision made (active, passive, and shared roles) *Personal situations occurring at the time decision-making* Outcome of choice/decision-making Decisional conflict	**Experiencing the new normal** ***Experience of receiving dialysis and kidney transplant*** Preparation for choice The new normal Adjusting into new normal loss of control Physical impact (body image, chronic fatigue and tiredness) Social impact [self-imposed isolation, societal perceptions], academic, employment, family; decisional regrets) Preparation for choice Plug in the machine person"/machine life/life on dialysis loss of control Decisional conflict *Post-transplant life* *Anger* *Self-blame*

The importance of family, friends, and significant others Kidney donation Supportive role of significant others in decision-making (family, partner, friends, employers, academic teachers) Establishing relationship (with clinicians, peers) Trust in HCPs ***Reasons influencing decisions about choice*** Factors that influenced decision-making (safety, social and family life, ability to work, independence, control and freedom, survival, future, quality of life) Freedom *Normalcy* *Desire to socialise* *Considered the impact of choice on life, education, employment, career)* *Independence* *Considered the burden on family* *Ability to achieve future prospects* *Time commitment to therapy* *Safety*	***The experience of feeling different*** Plug in the machine person"/machine life/life on dialysis *Self-blame* *Anger* *Fear of being treated differently by people* Not fitting in Physical limitation The perceived self (blame, guilt, loss [health, freedom, confidences, self], anger) ***Searching for meaning of the new normal experience*** Lack of understanding of new normal Lack of understanding of self and changes in life Young adults struggle to seek psychological help when most needed. Uncertain future Perception of self Decisional conflict Searching for hope
Impact of decision-making and choice on well-being ***Enhancing my decision-making*** Provision of psychological and mental support (Should form part of decision-making process) Address issues with underestimation of the psychological, mental, and physical impact of choice on life by staff attitudes Provision of advocate for young person Impact of choice on life and living with should be discussed during decision-making discussions Provision of access to first-hand information from peers for practical experience Underestimation of the actual psychological and mental support impact Provision of psychological and	***The psychosocial effect of decision-making and choice*** Lack of Psychosocial support Social impact of choice on life Lack of psychological support to make the transition from being a carefree person to plugged into a machine person Impact on mental health and well-being Kidney donation and its impact *Psychological effect on family* Underestimation of the psychological, mental, and physical impact of choice on life *Physical impact of therapy on body image* *impact of kidney donation on family* *Impact of dialysis therapy on academic life, career and life* ***Keeping myself sane and not going crazy***

mental support (Should form part of decision-making process) Transitioning into new change	Coping strategies of coping [positivity, religion, belongingness] Appraised values and changed beliefs, Growth in the midst of challenges Peer support *Appraised values and beliefs*

Appendix 16 Phase four of analysis: Mapping of thematic code patterns

Appendix 17 Phase five of analysis: Refinement and renaming of themes



Appendix 18 Publication

Decision-making experiences of young adults with long-term conditions

Abstract

Background: Young adults with long-term conditions can struggle to accept their diagnosis and can become overwhelmed with managing their condition. Sub-optimal transfer from paediatric to adult services with a resultant disengagement with the service, can result in less involvement in care and decision-making. Shared decision-making can improve involvement in health decisions and increase satisfaction with treatment/therapy and care.

Objectives: An integrative literature review was conducted to explore and understand young adults' experiences of decision-making in healthcare.

Design: An integrative literature review.

Data sources: CINAHL, EMCARE, PsycINFO, HMIC, EMBASE, Web of Science, PubMed, MEDLINE, EBSCOHOST and COCHRANE databases were searched for relevant literature published between January1999 to January 2020.

Findings: Thirteen primary research papers met the inclusion criteria. Four main themes were identified: (1) Information delivery and communication; (2) Participation in decision-making; (3) Social factors influencing decision-making; and (4) Emotional impact of decision-making.

Conclusions: Young adults with long-term conditions have specific decision-making needs which can impact on their emotional health. Research with a specific focus on young adults' experiences of decision-making in healthcare is needed.

Keyword list: Chronic kidney disease, decision-making, long-term conditions, renal replacement therapy, young adults

Introduction

Decision-making is complex and multifaceted. It is a central part of everyday activity that people undertake consciously or unconsciously, to manage and coordinate their actions (Peterson, 2009). Shared decision-making (SDM) and enabling of choice have become pinnacles in personalised healthcare and are positively promoted within Healthcare settings in the UK (NHS England, 2018; National Institute for Health and Care Excellence (NICE), 2016a). Although there are varied definitions of SDM, one commonly agreed definition is that SDM occurs where health professionals collaborate with patients and/or carers to deliberate and agree on a treatment/therapy choice (Charles et al.1997; Elwyn et al. 2012). In this model both the patient and the health professional share decision-relevant information, deliberate on a choice, agree, and then implement the choice (Charles et al. 1997). The drive for patients' involvement in care decisions led to the development of international (Härter et al. 2011) and national guidelines (NICE 2016a); where *"no decision about me without me"* has often become the norm in the UK (Department of Health, 2012). Evidence suggests that SDM can promote patient satisfaction and improve health outcomes (Care Commission, 2017; Joseph-Williams et al. 2017).

Young adults with long-term conditions such as chronic kidney disease (CKD), often struggle to accept their diagnosis and can become overwhelmed with the burden of managing their condition and coping with the complex decisions they have to make during the trajectory of the illness (Bailey et al. 2018; Krischock et al. 2016). As a result, they can experience worse outcomes because of disruptions in their education and employment (Murray et al. 2014), growth development and building of relationships (Kaufman et al. 2010), depression (Kogon et al. 2013), and low quality of life (Gerson et al. 2010) compared with an age-related healthy population (Neinstein and Irwin 2013; Park et al. 2014).

The worsening of health outcomes is common around the time of transitioning from paediatric to adult services and for the first three years after transition (Ferris et al*.* 2016; Foster, 2015; Samuel et al. 2014). At this time, young people can often experiment and take risks but can also acquire skills to manage more complex tasks and become more independent (Kaufman et al. 2010; Murray et al. 2014). These studies and others have led to the development of transition guidelines to support adolescents and young adults (AYAs) to improve their knowledge and understanding of their long-term condition and enable participation in decision-making (NICE, 2016b).

Despite the above recommendations and policies (NICE, 2016b) for AYAs involvement in decision-making and better transitioning, not all AYAs are able to participate in decisions about treatment/therapy (Care Quality Commission, 2017). Although young adults (YAs) in receipt of dialysis and kidney transplant appear to have worse outcomes compared with adolescents, and older adults with the disease (Bailey et al. 2018; Hamilton et al. 2018) there is little understanding of their decision-making experiences. The aim of this integrative literature review was to explore young adults' experiences of making a treatment/therapy decision to provide a comprehensive body of evidence.

Method

An integrative literature review method (Whittemore and Knafl, 2005) was applied as a framework to synthesise knowledge from primary research studies to understand the decision-making experiences of YAs. The integrative literature review used a structured process to identify the relevant body of literature to explore the research question and offers a strong scientific body of evidence and holistic understanding of the topic or question (Whittemore and Knafl, 2005). Primary research studies in the review investigated or explored the views or experiences of YAs making diagnostic or therapeutic choices. It was necessary to use an approach that would allow the integration of different methodological approaches which can be critiqued and synthesised in an integrated way to generate new ideas, perspectives and knowledge on the topic reviewed (Torraco, 2005).

Search Strategy

A comprehensive search strategy was used to undertake searches across ten databases (CINAHL, EMCARE, PsycINFO, HMIC, EMBASE, Web of Science, PubMed, MEDLINE, EBSCOHOST and COCHRANE) for primary articles published from January 1999 to January 2020. An initial search for papers exploring the experiences of YAs with a kidney condition retrieved a small number of papers therefore, the inclusion criteria were broadened to include other long-term conditions. A combination of key words and terms (Table 1) to ensure relevant articles were identified were used for the search. Table 1 is provided as supplementary material. The title and abstract for all citations were screened for articles that met the inclusion criteria and duplicates removed. The reference list of relevant studies was screened for additional relevant papers. The retrieved articles were further screened using the inclusion and exclusion criteria detailed in the study selection. In this review the term treatment decision is used for studies on other long-term conditions (such as cancer, asthma, diabetes, cystic fibrosis, and sickle cell) and the term therapy decision is used for studies on kidney disease. This paper presents the findings of an integrative literature synthesis to understand young adults' experiences of decision-making in healthcare.

Study selection

There is no consensus for the age range for young adulthood, so an age range of 16-30 years (inclusive) was used for this review, as this is accepted globally (United Nations Convention, 1990; European Union Agency for Fundamental Rights, 2017). This integrative review therefore included studies of YAs with long-term conditions, aged 16-30 years old, and explored views, experiences, or aspects of treatment/therapy decision-making. Studies that included other age groups <16 to >30 years were also eligible, but only where it was clear which data related to ages 16-30 years. Authors of studies published less than five years ago were contacted to clarify the actual numbers of YAs in the studies if they were not stated. All included studies were published in English. The Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flow chart is shown in Figure 1.

Insert Figure 1 PRISMA Flow chart here

Data extraction and quality appraisal

Data extracted from primary studies (Table 2) included aims, design, sample characteristics, variables measured, data collection methods, data analysis, findings/results, and limitations. Table 2 is available as supplementary material. The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework (Tong et al. 2007) was used. Data were initially extracted from one study using a line-by-line approach and coded into different categories of themes (Table 3) to create a coding framework.

Table 3 removed

The remaining twelve articles were then coded into the framework to create a matrix for each of the classification and new codes identified during the process added to the list. The coded data were grouped into clustering of codes, patterns or themes, the relationships across the data was noted setting the scene for comparation and interpretation of the data. The codes were then grouped according to patterns based on the commonalities, differences, and shared properties to form concepts to show the relationship between patterns and themes to provide clarity of the emerging themes to form higher clusters and enhanced a holistic interpretation (Whittemore and Knafl, 2005). The final themes were grounded in the data to confirm accuracy, credibility and confirmability of the themes and allowed the themes to be verified from the primary data sources.

Results

The thirteen studies (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al. 2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016*;* Weaver et al. 2015; Zee et al. 2018); nine qualitative and four quantitative studies, met the inclusion criteria. The studies were in three categories of long-term conditions: cancer (4), degenerative and other chronic illness (2) and kidney diseases (7) and conducted in seven countries (Australia (n=1), Europe (involved multiple sites n=36 countries including UK), UK (n=3), Ireland (n=1), New Zealand (n=1), South Korea (n=1), Taiwan (n=1), and USA (n=4). Studies reported 19-32 of the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist (Tong et al. 2007). The quality of the qualitative studies ranged between 7-10 for the Critical Appraisal Skills Programme (CASP) qualitative checklist (2018) and 7-12 of the Centre for Evidence Based Management (CEBM) checklist for survey studies (2014) with an overall quality range of moderate to strong quality (Table 2). The four main themes identified were: (1) information delivery and communication; (2) participation in decision-making; (3) social factors influencing decision-making; and (4) emotional impact of decision-making. See Figure 2

Insert Figure 2 Final themes here

Participants quotes reported in primary studies (Table 4) used to illustrate the themes are provided as supplementary material.

Information delivery and communication

The delivery and communication of treatment/ therapy information varied across studies and was considered as integral to the understanding of diagnosis and available treatment/therapy options, participating in decisions and also managing the long-term condition (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Kim and Choi, 2016; Mark et al. 2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016; Weaver et al. 2015; Zee et al. 2018). Verbal and written information were the main source of communicating information and was often provided by a health professional (Calestani et al. 2014; Coyne and Gallagher, 2011; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015), although perceived sometimes as biased (Coyne and Gallagher, 2011; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018). The situational context, timing of information, the content and how information was communicated enhanced or hindered YAs ability to absorb and understand the information received (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Mark et al. 2019; Pyke-Grimm et al. 2018).

The quantity and quality of information varied; where more was received, sometimes less was desired (Calestani et al. 2014; Mitchell, 2014; Walker et al. 2016) and vice versa (Calestani et al. 2014; Pyke-Grimm et al. 2018). Providing too much information over a short period caused fear, confusion, and lacked depth (Calestani et al. 2014; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016). Preference for slower and just enough information to gain understanding of treatment/therapy and make right decisions was highlighted (Calestani et al. 2014; Coyne and Gallagher, 2011; Mitchell, 2014; Pyke-Grimm et al. 2018). Explaining information in a way perceived to enhance easy understanding was associated with positive information experiences and satisfaction with communication (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Mark et al. 2019; Mitchell, 2014; Walker et al. 2016; Zee et al. 2018). Two sub-themes encompassing knowledge and understanding of information and information seeking as subthemes is now discussed.

Knowledge and understanding of information

Studies highlighted experiences of limited knowledge, which was due to the lack of information, difficult engagement and understanding of treatment/therapy options (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016; Weaver et al. 2015). When information was perceived to be communicated very quickly, or the content found to be too complex or technical with medical jargons this hindered YAs understanding of treatment/therapy options (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015). Patients receiving in-centre haemodialysis therapy felt less informed (Chen et al. 2018; Devitt et al. 2017; Zee et al. 2018) compared with those on peritoneal dialysis (Zee et al. 2018). Culturally appropriate information and communication were considered enabling to engage people from indigenous background (Chen et al. 2018; Devitt et al. 2017; Zee et al. 2018). These participants felt either uninformed or lacked understanding of aspects of information received such as the practicalities of dialysis therapy and kidney transplant option (Chen et al. 2018; Devitt et al. 2017; Weaver et al. 2015). Lack of awareness of the kidney transplant listing process for example eligibility, the implications of receiving a kidney transplant and whether or not they were listed on the national transplant register were reported (Calestani et al. 2014; Coyne and Gallagher, 2011; Walker et al. 2016). Health professionals were sometimes perceived to use their power to restrict access to information (Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Mitchell, 2014; Walker et al. 2016). The lack of information and understanding was associated with the inability to participate in treatment/therapy decision-making (Calestani et al. 2014; Chen et al. 2018; Devitt et al. 2017; Hart et al. 2020; Pyke-Grimm et al. 2018; Walker et al. 2016).

Information seeking

The desire to conduct one's own research on treatment/therapy options such as searching the internet or using alternate information sources like family opinions were highlighted (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016). YAs appeared to improve their knowledge on the options and the practicalities involved through their information seeking, which in turn enhanced their understanding and involvement in decision-making. YAs with kidney failure (Calestani et al. 2014; Walker et al. 2016; Zee et al. 2018) and degenerative conditions (Mitchell, 2014) found talking to peers beneficial in enabling their understanding of treatment/therapy options and the practicalities involved compared with YAs in cancer studies (Coyne and Gallagher, 2011; Pyke-Grimm et al. 2018). The receipt of valuable information and understanding of options was associated with satisfaction of therapy choice (Chen et al. 2018; Mitchell, 2014; Walker et al. 2016; Weaver et al. 2015; Zee et al. 2018).

Participation in decision-making

Although many participants in all the studies felt involved in the decision-making, their preference of decision type, decisional role and level of involvement varied across studies. Three sub-themes encompassing perceptions about choice, decision-making preferences and roles of significant others is now discussed.

Perception of choice

The perception of choice varied across studies; not all YAs felt choice was offered (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al. 2020; Mark et al. 2019; Mitchell, 2014; Weaver et al. 2015) and others lacked choice or were not involved in decision-making (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al. 2020; Kim and Choi, 2016; Mark et al. 2019; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016; Zee et al. 2018). Choice was framed as supporting or inhibiting independence and/or autonomy (Coyne and Gallagher, 2011; Mitchell, 2014). Reports of choice already decided before conversations on options were held was highlighted (Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020). Limited interaction time between healthcare professionals and patients resulted in a lack of depth during choice discussions (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020). Decisional conflict and decisional regrets following commencement of therapy were highlighted (Chen et al. 2018; Mark et al.

2019; Zee et al. 2018). The degree of decisional conflict was associated with age, the level of education, work status and education of therapy but not with gender or marital status (Chen et al. 2018; Mark et al. 2019). Dialysis knowledge, decisional self-efficacy, family, and clinician support were predictors of decisional conflict while uncertainty of implementing a dialysis choice was associated with higher decisional conflict score (Chen et al. 2018).

Decision-making preferences

Preference for decision-making, roles and level of involvement varied across the studies. Decision-making was perceived to have lesser or greater consequences depending on the threat to life and categorised into small or minor, intermediate, big, or major or life threatening in relation to its outcome, impact on life and future (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al. 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015). Passive, shared/collaborative or active decision-making preferences were highlighted (Coyne and Gallagher, 2011; Hart et al. 2020; Mark et al. 2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Weaver et al. 2015). However, not all were able to participate in their preferred level and role (5-7,9). Decision-making preferences and roles were dynamic as preference for involvement changed overtime (Calestani et al. 2014; Hart et al. 2020; Mitchell, 2014; Pyke-Grimm et al. 2018).

Role of significant others in decision-making

Studies reported parents/family, partners, peers, and health professionals played supportive roles in decision-making and were valued, although on some occasions their involvement were considered inhibiting (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Kim and Choi, 2016; Mark et al. 2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016; Weaver et al. 2015; Zee et al. 2018). However, not all YAs wanted parental involvement in decision-making (Coyne and Gallagher, 2011; Hart et al. 2020; Mitchell, 2014; Pyke-Grimm et al. 2018). Trusting the source of information and building relationships with health professionals provided some degree of certainty or assurance especially where outcome was uncertain or carried serious risks and consequences (Calestani et al. 2014; Chen et al. 2018; Hart et al. 2020; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015). Health professionals perceived to be trustworthy were able to help participants with a limited support network to overcome the vulnerability associated with performing home dialysis therapy (Walker et al. 2016). Positive support enhanced their coping with treatment/ therapy (Coyne and Gallagher, 2011; Hart et al. 2020; Pyke-Grimm et al. 2018; Weaver et al. 2015).

Social factors influencing decision-making

A desire for normality, ability to work, independence, and quality of life influenced treatment/therapy decision-making (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Kim and Choi, 2016; Mark et al. 2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015). Perceived independence, invasiveness of procedure and its impact on life influenced decision-making of medical devices needed to sustain life (Mitchell, 2014). Therapy was rejected when the risk outweighed the benefits (Mitchell, 2014). Some participants preferred to keep their social life rather than having a therapy that prevented them from socialising. Family and friends influenced dialysis choice (Walker et al. 2016) and living donor kidney transplant decisions (Calestani et al. 2014; Devitt et al. 2017; Kim and Choi, 2016). Normalcy in life and avoidance of constraints of dialysis therapy drove the desire for a kidney transplant (Calestani et al. 2014; Devitt et al. 2017). Participants from indigenous backgrounds negotiated cultural and social beliefs for community leaders and family to accept kidney donation as it was considered a taboo and associated with bad omen (Devitt et al. 2017; Walker et al. 2016). Health professionals influenced dialysis modality decision based on their advice and framing of discussions (Calestani et al. 2014; Walker et al. 2016; Zee et al. 2018).

Emotional impact of decision-making

Emotional impact of decision-making was not directly explored except for one study reporting assessment of baseline psychological level of participants in addition to other areas (Mark et al. 2019). Reports of shock, fear, anxiety, distress, and mixed feelings following receipt of a cancer diagnosis due to the fear of possible death were highlighted (Coyne and Gallagher, 2011; Hart et al*.* 2020; Pyke-Grimm et al. 2018). Fear and lack of understanding hindered the ability to engage with treatment/therapy options when information was perceived to have the potential to cause emotional distress (Coyne and Gallagher, 2011; Hart et al*.* 2020). Others struggled to build lasting relationship due to their perceived self-image (Coyne and Gallagher, 2011; Kim and Choi, 2016; Mitchell, 2014). Cultural and religious beliefs and fear of kidney donor outcome due to beliefs of donor risk affected the ability to discuss kidney transplant donation with family members (Calestani et al. 2014; Devitt et al. 2017). Concerns of not wanting to be perceived as a “spoiler” or “taker” of another person’s life (Devitt et al. 2017; p 6) should the donor come to harm or suffer problems later in life or be indebted or controlled by their kidney donors for the rest of their life were highlighted; therefore, these participants opted for deceased kidney donation (Calestani et al. 2014; Devitt et al. 2017).

Discussion

YAs in the selected studies were diagnosed with different long-term conditions, yet all faced life-saving decisions despite their different situational and social context for the treatment/therapy decision-making. The focus of this discussion is to compare young adults’ experiences with older adults in relation to the themes identified: information delivery and communication; participation in decision-making; social factors influencing decision-making and emotional impact of decision-making.

Information delivery and communication

Information delivery and communication was a pivotal part of receiving/understanding the diagnosis, prognosis, and treatment/therapy. Despite this, suboptimal information delivery and understanding was highlighted across studies. Participation in decision-making was dependant on YAs’ understanding the need for decision-making, the type of decision and the roles they preferred to play. The framing of treatment/therapy information, the content, timing of delivery, the situational contexts and how information is communicated influenced YAs ability to absorb, make sense of, gain understanding and be able to participate in the decision-making. The integrative review highlights the unmet decisional needs of YAs and the lack of understanding of how elements in the decision context affects the emotions of YAs.

YAs health literacy contributes to the understanding of their illness, its progression, available treatment/therapy options and decisions they need to make during the journey of the disease (Levine et al. 2018; Morsa et al. 2018). YAs tend to be provided with information without a consideration of their literacy level which may have contributed to their dissatisfaction of information delivery and communication in the decision-making context. YAs' literacy levels should be assessed prior to or during information delivery so that information is provided at the appropriate literacy level, which in turn can enhance their understanding. Assessing the knowledge and understanding of YAs prior to, during and post treatment/therapy education could highlight their information needs and enable health professionals to reinforce their understanding of treatment/therapy options. Provision of simple and non-technical information less of medical jargon was perceived as enabling the understanding of choice and the practicalities involved. Coulter and Collins (2011) argue that patients who are less informed about available treatment/therapy options are less involved in health decisions and become dissatisfied.

Participation in decision-making

Reports of lack of choice, feeling rushed, and lack of understanding in decision-making have been highlighted by other studies among older patients (Dahlerus et al. 2016; Morton et al. 2010a; Morton et al., 2010b; Robinski et al. 2016; Song et al., 2013). In Dahlerus et al's (2016) study, one third of the participants perceived that they lacked choice. The complexity of the treatment/therapy decision-making process can bring some degree of emotional stress which relates to the concerns YAs may have about what matters to them. The decision-making context was perceived by YAs as choosing between lifesaving treatment/therapy verses death or giving up autonomy or independence of areas of their life and reported among older people with the disease (Harwood and Clark, 2013; Morton et al. 2010a; Tong et al. 2013).

YAs are still developing their autonomy and independence, and some may not feel confident to make decisions (Davies et al. 2015) therefore, the elicitation of their decisional preferences and roles are vital. Providing YAs support to feel more in control and independent to make an informed or shared decision could enhance their self-esteem and self-actualization which is a basic element of human need (Maslow, 1943). A person can make competent informed health decision only if that person understands the purpose of the treatment/therapy, the procedures involved, the possible risks, alternative options and likely outcomes (Halpern-Felsher and Cauffman, 2001).

Social factors influencing decision-making

YAs decision-making does not always involve two people nor is it linear but can be a triad, cyclical, multi-relational and/or contextual depending on the situational and social context (Umeh, 2009). The type of decisional task, situational context, relationship and trust with health professionals, family, impact of therapy on life (short and long term) and quality of life influenced YAs involvement in decision-making. These factors highlighted in this integrative review are echoed by other studies (Dahlerus et al. 2016; Harwood and Clark, 2013; Morton et al. 2010b; Murray et al. 2009). Although studies (Calestani et al. 2014; Chen et al. 2018; Hart et al. 2020; Pyke-Grimm et al. 2018; Walker et al. 2016; Weaver et al. 2015) in this review highlighted that YAs trusted their parents and health professionals to look after their best interest based on their experience and expertise due to the uncertainty of choice, they were unable to determine whether YAs were willing to take higher risk and this reflects a notion of trust.

The notion of trust is when a person tends to rely on others when there is uncertainty about choice (Zinn, 2015). Harrington and Morgan, (2016) asserts that having a notion of trust does not always mean that people are willing to take higher risk. YAs who experienced uncertainty about choice relied on parents and/or health professionals support and collaborated with them to conclude their decisions. Trust in health professionals was associated with the quality of information delivery and communication on treatment/therapy options and influenced acceptance and recommendations about a choice. However, where aspects of information were found lacking following decision-making and commencement of treatment/therapy it resulted in a feeling of betrayal.

Cultural and religious beliefs can influence autonomy (Halpern-Felsher et al. 2016). Cultural and religious beliefs negatively influenced acceptance of dialysis and kidney transplant choice as it did not always encourage decisional autonomy among people from indigenous population (Devitt et al. 2017; Walker et al. 2016) and has been highlighted by Jones and Cornwall, (2018) and Sheu et al. (2012). The informational needs of YAs, their perception of the decisional context and how it impacts on the personal, social and psychological well-being are different compared with older people who have the same disease. Without understanding what matters most to YAs, alongside their informational and decisional needs, health professionals are likely to get it wrong.

Emotional impact of decision-making

The thought of choosing between lifesaving treatment/therapy or death can bring emotional and mental distress for YAs during decision-making. However, the studies (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al. 2020; Mack et al. 2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al. 2014; Walker et al. 2016; Weaver et al. 2015; Zee et al. 2018) in this review focused on the decision itself and less consideration were given to how the decision-making is perceived by YAs and the impact of these perceptions on the decisional context, the practicalities involved and the performance of the treatment/therapy. The anticipation of significant changes that the treatment/therapy choice will bring into YAs life adds to already heightened fears. Compared to the emotional stress experienced during decision- making by older adults' (Joseph-Williams et al. 2014; 2017), YAs may be different because they are yet to have a future. The personal, material, and subjective losses that could occur when a person is faced with decision-making also has the potential to lower self-esteem and can affect the person's ability to make a good or bad decision.

Although older people's decision-making needs are well documented (Dahlerus et al. 2016; Harwood and Clark, 2013; Morton et al. 2010a; Robinski et al. 2016), the same cannot be said of YAs. Less attention is given to the issues that mattered most to YAs in the decisional context and is less understood how the decision-making impacts on their personal, social, and psychological well-being.

Strength and weaknesses

The strength of this integrative review lies in the ability to combine studies with different methodological approaches that have explored the decision-making experiences of young adults with kidney disease and other long-term conditions. As the majority of the studies were retrospective and relied on participants' ability to recall experiences, it is subject to recall bias. Selection biased could have resulted to an unbalanced representation of age groups, as most studies had either more adolescents and/or older adults compared with young adults. The findings cannot be generalised but are transferable to similar situations.

Implications for practice

YAs have unmet information and decision-making needs that are vital to develop their knowledge and understanding that could enhance their ability to participate in therapy decision-making. Assessing and evaluating YAs informational needs could highlight their knowledge gap. The provision of simple information with less medical jargon is vital to improve YAs understanding and to reduce the emotional burdens experienced during their interactions (Jackson, 2014). Good clinician-patient interpersonal relationships can act as a safe zone for YAs to feel confident to share what matters most to them.

YAs' decision-making is complex with many different facets intertwined with personal, emotional, and cultural sensitivities which must be navigated. Planned preparation of YAs is important in ensuring that they are ready to receive information and be supported to participate in decision-making. YAs have unmet decisional needs such as sub-optimal communication, knowledge and understanding the decision-making process, the practicalities involved in performing treatment/therapy and psychological support. Eliciting feedback from YAs and/or their family to ascertain their understanding of information can improve clinician's awareness of their knowledge and understanding and address any knowledge gap. Empathetic communication and timely preparation of YAs and parents/family prior to receiving therapy information and offering psychosocial support could promote absorption of information and engagement with the decision-making process.

Conclusion

YAs with kidney disease and other long-term conditions have specific decision-making needs which can impact on their emotional health. This integrative review found that YAs experience suboptimal information delivery and communication on the available therapy options and lacked understanding of the practicalities involved with the treatment/therapy. The lack of consideration of YAs' situational and personal circumstances, appropriate timing of information delivery hindered their development of knowledge, understanding and involvement in decision-making. The desire for independence, the ability to work, normalcy and trust in health professionals also influenced YAs' decision. How the decisional context affects YAs' emotional health is less understood which must be elicited to address their unmet decision-making needs. There is less literature on YAs' experiences on decision-making therefore research with a specific focus on YAs' experiences of health decision-making is needed.