Adolescents' Embodied Experience of Living with Chronic Kidney Disease

A thesis presented to Dublin City University for the Degree of Doctor of Philosophy (PhD)

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February 2020

Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Date: 5-2-2020

Acknowledgements

Undertaking this PhD, although challenging at times, has been a remarkable and rewarding experience. There are a number of people that I am eternally grateful to who have contributed enormously to ensuring that this project came to its realisation. First and foremost, I am very grateful to my supervisors; Dr Briege Casey and Professor Veronica Lambert for their time and support and for challenging me over the years and helping me to develop professionally and academically. Thank you for listening, encouraging and consoling me in my darkest hours and for giving me the strength and encouragement to '*never give up'*. I also want to thank all my work colleagues who were a constant source of support and reassurance throughout this journey.

Sincere thanks to the Nephrology team in Children's Health Ireland at Temple Street, particularly Dr Atif Awan for his invaluable contribution in making this research study a reality. I am most grateful to the CNS and haemodialysis nurses in the dialysis unit, without whom recruitment for this study would not have been possible. I am so grateful for your patience, support and knowledge during data collection.

I am blessed with an amazing circle of friends who have listened, supported, fed, consoled and encouraged me throughout. To Mary and Sara, my longstanding colleagues, friends and sources of inspiration. To Cathy, Susan and all the Galway Girls who have understood the times when I needed to be PhD focused and incommunicado for stretches of time, as well as the times I needed to be dragged for a night out. To Deirdre and Teresa for always being available to come for long walks with me to keep me sane. I am truly grateful to you all.

To my wonderful husband Malcolm who has been by my side throughout my PhD journey, a special word of thanks for your love, unwavering belief, constant support and encouragement not only in my academic pursuits, but in everything I do. To my beautiful children, Killian and Caoimhe, thank you for sustaining me during the hard times. Thank you for reminding me that sometimes you just need to stop and play. Their capacity to make me realise what's truly important in life and to see the beauty in all situations is second to none. I am so blessed to have such a supportive and loving family.

Research with children and young people cannot be undertaken without the active support of their parents. I sincerely thank the parents of the research participants for trusting me and for your continuous support for this research over the past few years. I know you made some sacrifices to enable your child’s continuous involvement. Thank you for inviting me into your homes and for all the cups of tea during the 18 months of data collection.

Finally, and in the spirit that the last shall be first, I wholeheartedly and very sincerely thank the five inspiring young people who took part in this study and gave so generously of their time. Their stories made this study possible. I am extremely thankful that you granted me the privilege of getting to know you and learn from you. It truly has been a humbling experience. I am confident your contribution will make a difference to children and young people in the future. This study is dedicated to you.

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List of Abbreviations

BM: Body Mapping.

CHI: Children's Health Ireland.

CKD: Chronic Kidney Disease.

ESRD: End Stage Renal Disease.

GFR: Glomerular filtration rate

DCYA: Department of Children and Youth Affairs.

HCPs: Health Care professionals.

HD: Haemodialysis.

HSE: Health Service Executive

OPD: Outpatients Department.

PD: Peritoneal Dialysis.

RRT: Renal replacement therapies.

TULSA: Child and Family Agency Ireland.

WHO: World Health Organisation.

Glossary of Terms

Adolescence: a transitional phase of growth and development between childhood and adulthood.

Adolescent: any person between ages 9 and 18.

Bilateral kidney dysplasia: is a condition in which the internal structures of both of a fetus' kidneys do not develop normally while in the womb.

Chronic Kidney Disease: is an umbrella term used to describe a range of conditions that result in the gradual loss of kidney function.

Dialysis: is used to provide an artificial replacement for lost kidney function (renal replacement therapy) due to kidney failure.

End-Stage-Renal Disease: End stage renal disease (ESRD) is the last stage (stage five) of chronic kidney disease (CKD). This means kidneys are only functioning at 9 to 15 percent of their normal capacity

Glomerular filtration rate: is the measure of the kidneys' ability to filter blood and is widely accepted as the best overall measure of kidney function

Haemodialysis: Haemodialysis is a method of removing waste products and extra fluid, which build up in the blood when the kidneys are no longer able to function properly. To accomplish haemodialysis it is necessary to have easy access to the blood vessels. Treatment is required up to three times a week.

Nephrotic Syndrome: is a kidney disorder that causes the body to excrete too much protein in urine.

Peritoneal dialysis: Peritoneal dialysis (PD) is a treatment that uses the lining of the abdomen and a cleaning solution called dialysate to clean the blood. Dialysate absorbs waste and fluid from the blood, using the peritoneum as a filter.

Permcath Device: is a flexible silicone catheter that provides central venous access for haemodialysis treatment.

Pre-emptive Transplant: Pre-emptive kidney transplant refers to transplantation that is performed before initiation of maintenance dialysis.

Renal Replacement Therapy: Renal replacement therapy (RRT) is therapy that replaces the normal blood-filtering function of the kidneys examples include dialysis and kidney transplantation.

Renal Dysplasia: is a condition in which the internal structures of one or both of a fetus' kidneys do not develop normally while in the womb.

Title: Adolescents’ Embodied Experiences of Living with Chronic Kidney Disease

Abstract

Introduction: Chronic Kidney Disease (CKD) is an enduring and debilitating condition which can have significant physical, psychological and social consequences for anyone experiencing this disease. Navigating CKD in adolescence is particularly challenging; young people are simultaneously inhabiting bodies that are transforming through pubertal processes as well as trying to manage bodies that have been greatly changed by both disease and medical technologies. Inevitably, managing these processes of unpredictable body alteration has a profound influence on how adolescents experience, perceive and use their bodies in the world. However, there is limited research that examines the embodied experiences and perspectives of adolescents living with CKD. The aim of this study is to explore adolescents’ embodied experiences of living with chronic kidney disease

Methods: This study employs a narrative inquiry research design incorporating arts-based methodology. Data were gathered using visual body maps (i.e. life-size human body images) and unstructured interviews. Five adolescents (10-17 years) living with CKD participated in the study, which took place over a period of 18 months in both hospital and home settings. The visual and oral narratives of the adolescents were analysed using Riesman's (2008) approach to narrative analysis.

Findings: The findings reveal that adolescents experience many bodily changes in living with CKD including disfigurement, scarring, leaking bodily fluids and delays in puberty. The bodily changes negatively affect the adolescents’ perceptions of their bodies and create heightened awareness of their fragile and ill bodies. Adolescents also present a positive attitude and spirit of perseverance in order to endure their illness. A nuanced finding is a disrupted sense of embodied self and identity arising from adolescents’ encounters with medical treatments and technology. The findings also reveal adolescents’ experiences of invisibility and exclusion from medical encounters. Adolescents highlight the need for HCPs to acknowledge them as knowledgeable agents in their illness trajectory.

Conclusions: Adolescent participants articulated rich visual and oral narratives regarding their experiences of living with CKD in their bodies at a time of anticipated pubertal change. Embodied experiences are meaningful, and expression of body knowledge by patients provides valuable insights for healthcare practitioners. From a clinical perspective, a multifaceted and holistic adolescent-centred psychosocial care approach is needed to support adolescents living with CKD.

Position Statement

> *'As I watch my own son navigate between hospital appointments, hospital admissions, surgeries (of which he has had many) and his daily medical routines I wonder what lies ahead for him. How will he manage this lifelong condition, as he gets older? He puts on a brave face but every now and then he asks, 'why me?' I wonder what new insights might be gained from hearing from young people like my son who must live with their condition day in and day out. What goes on inside their heads? Perhaps learning from those who are living with kidney disease might teach me and others something new'.*
>
> *(Reflective diary, September 3rd, 2014)*

I have approached this study, as a children's nurse, academic, and as a mother of an adolescent with an underlying congenital nephrology-urology condition. The conceptualisation of this project has stemmed from the challenges that I have witnessed my own son encounter on his journey of living with chronic illness. As a mother, I had some insight to the culture of renal wards and procedures and this position provided me with unique insights and experiences. I was also interested in the subject matter as I had previous experience working as a children's nurse on a renal ward and I also currently teach renal conditions to undergraduate nurses. My personal and academic sense of curiosity about the topic of CKD led me to engage with the literature, in which I was drawn to the adolescents struggles of dealing with CKD during a critical period of development and I was particularly struck by the limited research focus on adolescents embodied experiences of living with CKD.

I consciously thought about and continually reflected on the potentially positive and negative aspects of researching a topic close to personal experience. For instance, the researcher is likely to be more aware of the multiple aspects of a subject, is more likely to be attuned to the experience of the participant and may be seen by the participant as someone who understands their position. At the same time, there could be a danger of making assumptions that another's experience is similar to one's own, or of seeking out reflections which mirror one's own, leading to over identification with the participant. As a parent I entered this project with some understanding of the complexities of living with CKD. I understood the anxieties and concerns I experienced as a parent but I was also very aware that a parent's view is often different from an adolescent perspective and so my research spawned from my own personal interest in understanding more about the lives of those directly affected by CKD. True to the nature of qualitative research, I feel that it is important to take into account my own history and biases, and the ways in which these may have influenced the conceptualisation and findings of the current study. Given my own experience as a mother and as a nurse academic, I believe it is important for me to be reflexive about my own experiences. Throughout the thesis I refer to my own experiences and thoughts, thus making explicit my own position and experience as a mother of a child with a chronic nephrology-urology condition.

Chapter 1: Introduction

1.0 Introduction

Chronic kidney disease (CKD) is a significant illness that can have serious physical, psychological and social implications for adolescents and their families (Clavé *et al.,* 2019). Experiencing this disease during adolescence can cause feelings of confusion, frustration and isolation as the young person is simultaneously contending with a changing pubescent body and a body that is being changed through disease and medical intervention (de Souza and de Lione Melo, 2018). While research that addresses how these conflations and restrictions affect physical and social functioning has been undertaken (Nicholas *et al.,* 2011; Ferris *et al.*, 2016), specific issues pertaining to embodiment and bodily experiences have received little attention. This thesis presents the embodied experiences of five adolescents living with chronic kidney disease. In the context of this study, embodied experience refers to how adolescents' experience CKD in and through their bodies. An understanding and appreciation of embodied experience is highly relevant as it can determine how young people cope with CKD in daily life. In this introductory chapter, I will provide contextual information pertaining to CKD, including information on its prevalence and classification. In addition, I will discuss the consequences of living with CKD and the treatment options available, and provide an outline of nephrology care service provision for children in Ireland. I conclude with an outline of the thesis structure.

1.1 Definition of CKD

CKD, which encompasses a wide range of diseases, is a life-threatening condition, requiring a lifetime of treatment. CKD refers to a state of irreversible kidney damage over time (Kelly, 2016). The illness trajectory for adolescents with CKD is complex as it affects multiple systems and requires continuous and coordinated medical attention. The diagnosis of CKD impacts on every aspect of an adolescent's life. The demands of the treatment regimens are arduous, and the burden of care is high (Clavé *et al.*, 2019).

1.2 Prevalence of CKD

The number of people with CKD continues to increase worldwide. Adolescents constitute less than 5% of the end-stage kidney disease population and their 10-year survival ranges from 70 to 85% (Saran *et al.,* 2015; Ferris *et al.,* 2016). Globally the prevalence of CKD in children including adolescents is reported to be approximately 18.5- 58.3 cases per million children (Harambat *et al.,* 2012). In 2018, the number of children/adolescents in Ireland with end-stage renal failure was 80 with 16 requiring dialysis and 64 requiring a kidney transplant (National Renal Statistics office, 2018). Hence, the overall population of adolescents with CKD is arguably small in Ireland. Notwithstanding this, the number of cases of CKD is expected to increase by between 5% and 10% in Ireland (Kane, 2017). In addition, the mortality rate for adolescents with CKD is 30 times higher than their healthy peers (Ferris *et al.*, 2016).

1.3 Classification of CKD

Chronic kidney disease is identified by the presence of kidney damage and level of kidney function for a time period of longer than three months (Inker *et al.*, 2014). CKD is staged by severity from one to five, with stages four and five being indicative of severely decreased kidney function and end-stage renal disease (ESRD) which means kidneys are only functioning at 10%–15% of their normal capacity (Samuel *et al*, 2010). Kidneys that function properly are critical for maintaining overall good health and development. When kidney function is this low, waste or excess fluid from the blood cannot be excreted and renal replacement therapy (RRT) is necessary (National Kidney Foundation, 2012). There is currently no cure for CKD, and without RRT people with stage five CKD will inevitably die (Llewellyn *et al.*, 2014).

1.4 Bio-psychosocial effects of CKD

CKD adversely affects the physical health of adolescents with a broad range of physical symptoms, some serious in terms of medical outcomes, and all serious in terms of their potential negative effect on body functioning and bodily well-being (Kelly, 2016). The symptoms of CKD progressively develops as fluids, waste, and other substances are not excreted from the body as they should be. This imbalance may not be noticed in the early stages of the disease, but, as levels rise over the course of months and years, the excessive accumulation of water and waste starts to affect multiple organs, including the heart, lungs, brain, and the kidneys themselves (National Kidney Foundation, 2012). Adolescents can also experience significant symptoms that are either directly or indirectly associated with the condition, which include tiredness, thirst, numbness, pain, and muscle cramping (Ku and Kwok, 2019). Physical changes in body image are typically due to external changes in skin, body weight, medication side effects, and renal replacement access devices (Sánchez *et al.,* 2019). In addition, CKD interrupts the normal course of adolescent development and places high demands on the adolescent as a result (Nicholas *et al.,* 2018). For instance, adolescents with CKD experience growth failure, such as short stature and delayed sexual development, as a result of the disease process. They must contend with bodies that have been greatly changed by disease and medical intervention whilst simultaneously navigating the emotional and developmental challenges of puberty.

Not surprisingly, the findings of some studies (Tong *et al.,* 2013; de Souza and de Lione Melo, 2018; Kalfoss *et al.,* 2019) suggest that experiencing CKD during adolescence can be physically, socially and psychologically challenging. Children and adolescents with CKD have considerably lower health-related quality of life compared to their healthy peers in four important domains including physical, school, emotional, and social (Gerson *et al.,*2010; El Shafei *et al.,* 2018). The change from being in a state of health to experiencing a long-term illness can cause depression and anxiety, as can the continuous burden of physical symptoms, fear of dialysis, uncertainty about disease outcome, and negative experiences with the healthcare system (Öyekçin *et al.,* 2012; Romos *et al.,* 2015). The emotional impact of CKD reported by adolescents in the literature includes denial, anger, sadness, fearfulness, helplessness and frustration (Abrahão *et al.,* 2010; Tong *et al.,* 2013). CKD in adolescence has also been noted to affect self-esteem and autonomy (Assadi, 2013). The ensuing feelings of body inadequacy and disempowerment may result in social withdrawal and a tendency to vent frustrations through resistive behaviours (Ramos *et al.,* 2015; Bailey *et al.,* 2018). Moreover, adolescents with CKD are at risk for underperforming academically, struggling socially, and experiencing adjustment difficulties and psychological stress (Kelly, 2016). Adolescents must also face multiples challenges associated with frequent hospitalisations, painful medical procedures and an array of treatments (Clavé *et al.,* 2019).

1.5 Treatment of CKD

CKD is a deteriorating condition without cure. The goal of CKD treatment is threefold: to treat the underlying cause; to slow the progression of kidney damage; and to minimise any harm the disease can cause to the other organs (Rêgo *et al.*, 2019). CKD requires a complex therapeutic regimen, which includes renal dialysis, accompanied by a strict regimen of medication, diet and fluid control (Lins *et al.*, 2018), and kidney transplantation. This medical and surgical management has restrictive implications for adolescent bio-psychosocial functioning. Dialysis necessitates a form of intermittent medical and technological dependence in which the body is regulated and governed by a machine. For example, in peritoneal dialysis (PD) the body undergoes daily treatment (usually at night for 10-12 hours) in which a PD machine removes excess water and waste products from the abdomen via a PD catheter (Baillie *et al.*, 2012). It is the preferred option because it is performed at home and is thought to foster greater daytime independence; less family disruption and offers better quality of life than haemodialysis (Baillie *et al.* 2012; Park *et al*. 2012). However, Chua, Bradley and Warady (2010) report high rates of non-adherence to home-based dialysis.

In haemodialysis (HD), a machine governs the body three-four times a week with each session lasting three to four hours (Zitzelsberger *et al.*, 2014). This hospital-based treatment requires direct access to blood vessels, through a central line, known as a permcath, which is surgically embedded under the skin (Beigi *et al.*, 2014). Children and adolescents on HD experience a loss of identity, bodily integrity, self-esteem and freedom (Tong *et al.*, 2013; Tjaden *et al.*, 2012). Young patients describe the injustice of the dietary and lifestyle restrictions and feel that they are trapped by the dialysis machine (Waters, 2008). Furthermore, dialysis treatment schedules are burdensome and invasive and interfere with school attendance and participation in peer-related activities, thereby compromising opportunities for attaining academic and psychosocial potential (Neul *et al.*, 2012). Nevertheless, the disruptive cycle of dialysis treatment is necessary to sustain life while the young person waits for a kidney transplant, which can take one to two years (Canadian Institute for Health Information, 2011).

Since the 1990s, the gold standard of treatment for CKD is transplantation. Kidney transplantation increases survival rates, reduces symptoms, improves overall physical and psychosocial health and enhances quality of life by eliminating the time burden of dialysis treatments (Nicholas *et al.,* 2011; Tong *et al.,* 2013). However, some studies report that adolescents feel disappointed due to unmet expectations of improved health following transplant (Olausson *et al.,* 2006; Walker *et al.,* 2019). Dependence on medications post-transplant and visible side effects reinforce a sick identity. This sick identity conflicts with adolescent's priorities of peer acceptance and having a normal appearance and independence (Öyekçin *et al.,* 2012; Lewis and Arber, 2015). Although kidney transplantation offers freedom from dialysis, it is not a permanent treatment. The average lifetime for a kidney transplant is approximately 6 years and many CKD sufferers will either return to dialysis or require repeat transplantation (Perl *et al.,* 2011). It is important to reiterate that CKD is a progressive and incurable disease. Dialysis and transplantation are treatments for the disease; they do not offer a cure.

1.6 Service provision and policy context

CKD is a global health problem (de Souza and de Lione Melo, 2018). It has been described as the most neglected chronic disease despite the efforts of organisations such as the International Society of Nephrology (ISN) and the International Federation of Kidney Foundations, to inform the general public and policy makers about the importance and ramifications of kidney disease particularly in childhood (Luyckx, Tonelli, and Stanifer, 2018). In Ireland, adolescents with CKD are treated in one of two tertiary paediatric nephrology centres. However, there is only one haemodialysis unit dedicated to treating children and adolescents in Ireland. The Irish National Clinical Programme for Paediatrics and Neonatology (2016) offers a model of care that identifies the importance of providing high quality care to children and adolescents. This model specifically includes a detailed model of care for paediatric nephrology. This model of care aims to improve both life expectancy and quality of life for children and adolescents with renal disease by providing optimal specialised care, and specifically to provide for the physical, psychosocial and emotional needs of the adolescent and their family. Furthermore, this national model of care highlights the need for research that includes children and adolescents in order to advance our understanding of CKD. This present study is in keeping with the objectives of the Irish National Clinical Programme for Paediatrics and Neonatology (2016) model of care which emphasises the importance of understanding how CKD is experienced by those affected.

1.7 Rationale for study

Being ill is an embodied experience - it is felt in the whole body. The symptoms of CKD along with strict treatment regimes can alter how a person sees his or her body (Kierans, 2000). During illness the relationship between the body and the world is challenged and a person's existence can be questioned and disturbed (Thomas, 2005). In order to provide holistic care, healthcare professionals need to having a better understanding of how adolescents' embodied experiences might be altered in illness and disease. The embodied perspective is one which conceptualises the person as a whole, both mind and body. However, most healthcare research focusing on adolescents with CKD use biomedical or psychosocial models of illness (Zitzelsberger *et al.,* 2014). A considerable amount of this research has focused on determining adolescents' physiological responses to CKD, psychosocial adaptation and coping (Water, 2008; Nicholas *et al.,* 2011), and quality of life in the short and long term (Clavé *et al.,* 2019; Francis *et al.*, 2019). However, few qualitative studies have explored the somatic and embodied dimensions of living with CKD. El Refaie (2019) calls for a movement to bring bodies back into health care stressing the importance of viewing people as 'embodied' persons as oppose to people who 'have bodies' challenging us to re-connect the object body with the lived body. In other words, what is needed is an emphasis on humans as 'embodied' rather than humans who 'have bodies' (Draper, 2014). This present study explores how adolescents experience CKD in and through their bodies, which can help others understand CKD outside of its medical context and provide understandings into the personal implications such an illness can have on the adolescent body. Specifically, this study explores the ways in which adolescent participants experience CKD in relation to 1) the physical functioning and sensations of their bodies, 2) the impact of CKD on adolescents' sense of self and embodied identity and 3) adolescents' experience of medical treatment and relationships with health care professionals in the context of CKD. This research is underpinned by the theory of embodiment as developed by Merleau-Ponty (1964) to guide inquiry and understanding regarding this specific area of bodily experience. Visual (body mapping) and oral narrative research methodology is used in this study to access and illuminate these often unvoiced and nuanced experiences of CKD among a cohort of five adolescents. The following section provides an overview of the thesis structure.

1.8 Thesis Structure

This thesis comprises 12 Chapters. This chapter provided an introduction to the thesis. It contextualised CKD and outlined the structure of the thesis. In *Chapter 2*, I outline the philosophy of embodiment, the theoretical perspective that underpins this thesis. *Chapter 3* provides a critical review of the existing qualitative literature relating to children and adolescents' experience of living with CKD. The methodology employed in this study is discussed in C*hapter 4.* This chapter is divided into three sections. The first section focuses on the conceptual, methodological and epistemological considerations in using narrative inquiry. This section provides a detailed outline of, and the rationale for, the chosen methodology. Section two provides a description of the research process. In section three, the analytic process used to analyse data is presented. *Chapters 5 to 9* present the individual narratives of the five study participants. Each chapter presents adolescents' visual representation of their bodies (body maps), which are interpreted alongside oral narratives about their bodies and illness. *Chapter 10* provides a cross-case analysis of the five participants narratives. A critical discussion of the participants' narratives and cross-case findings is provided in C*hapter 11*. In *Chapter 12*, the concluding chapter, I outline the study's unique contribution; highlight strengths and limitations of this study and present the practical implications of the findings.

Chapter 2: Embodiment: A Theoretical Perspective

2.0 Introduction

In this chapter, I present embodiment as a theoretical perspective, which is informed by the work of philosopher Merleau-Ponty (1962) alongside other philosophical perspectives concerning the body; for example, the work of Foucault (1963); and Leder (1990). The concept of embodiment provides a novel perspective on how people experience the world through their bodies. This theoretical perspective offers a different way of conceptualising the experiences of adolescents living with CKD. In the proceeding sections, I present key tenets of embodiment that are relevant to this study.

2.1 The Concept of Embodiment

The body plays a central role in shaping our experience of the world as acknowledged by Nettleton and Watson (1998, p.1).

> *'If one thing is certain, it is that we all have a body. Everything we do with our bodies – when we think, speak, listen, eat, sleep, walk, relax, work and play we 'use' our bodies'.*

The body is defined as the '*physical frame or structure of a human being', viewed 'as an organic entity'* (Amirtham, 2011, p.18). As Draper (2014) posits, we conduct our daily business in and through our bodies. The body sustains life and it is central to our social lives and relationships as it is the medium for individuals to display things that matter to one's self and other people (Radley, 1994). Our bodies therefore are not just physical entities or vessels but are the vehicles for our sense of self (Higgins, 2018). In not acknowledging the importance of the body, we risk disregarding the basis of human experience and knowledge (Sharma, 2011). However, the view that the body is of central importance to human life and experience has not always been accepted, and is widely debated among philosophers and scholars (Wilde, 2003).

Cartesian dualism, which views the body and the mind as ontologically distinct entities, has dominated scientific and philosophical views of the body for over 300 years (Mehta, 2011).

Rene Descartes, philosopher, scientist, and mathematician (1596-1650), proposed that the body was comprised of two parts. Mohammed (2012) reports that Descartes' view of the person is twofold, consisting of a non-physical substance, or the cognitive machinery a person possesses, and a physical substance, which is the mechanical machinery that is the body. According to dualism, the body is an object and bodily events are explainable by physical, mechanical formula. Descartes viewed the physical body as an appendage with limited control or cognitive ability (Urban, 2018). This idea encouraged philosophers and scientists to see the mind and body as being disconnected. According to Connolly (2013), the difficulty with this objectification of the body is that it is exactly the body and our subjective experience of it that unites us to the world and our lived experiences.

In the 20th century, a non-dualistic concept of the body began to emerge. The French phenomenologist Maurice Merleau-Ponty (1908-1961), is known for his original and influential work on the philosophy of embodiment and is one of the key philosophers who emphasised the imperative role played by the body in relation to existence. He suggests that the body is the central locus of all life, all knowledge and thus of all science and philosophy. In his manuscript *Phenomenology of Perception***,** Merleau-Ponty (1945) offers an alternative way of thinking about and knowing human beings through the concept of embodiment. In a critique of the scientific and philosophical traditions of Western culture, Merleau-Ponty proposes an alternative philosophy that challenges any subject-object division. Merleau-Ponty (1962, p.83) defines embodiment as '*how we live in and experience the world through our bodies'*. A central proposition of his philosophy is that no part of the human body can be separated from the rest of the body and all parts of the body are integral to the human being. He explicitly rejects Cartesian mind-body dualism and is critical of reductionist perspectives that reduce the person to their body or biology or, alternatively, to their mind. He conceptualises the person as a whole, both mind and body. Merleau-Ponty developed his ideas further in *The Visible and the Invisible* where he continues to define the body as the fundamental basis of human existence and rejects any form of dualism (Merleau-Ponty, 1968). Bringing this back to this current study, an embodied perspective provides a way of conceptualising adolescent experience in a manner that does not interpret that experience through Cartesian spectacles. In the following sections, several core tenants underpinning Merleau-Ponty's embodiment theory are presented including body-subject; being-in-the-world; embodied knowledge and embodied self.

2.1.1 Body-subject

Merleau-Ponty, addressing the issue from the perspective of his philosophy of embodiment, introduces the idea of a *'body-subject'*. Merleau-Ponty (1962) proposes that one's body is synonymous with existence, asserting that we do not 'have' bodies, but we 'are' our bodies as body/subjects. He illustrates that the body cannot be viewed solely as an object, or material entity of the world. Sakalys (2006) describes the object body as the physical body, the inert object that can be perceived and observed; it is the body as *'it'*. Conversely the subject body is well-defined as the phenomenological body, meaning the lived body, the body as 'me' (Sakalys, 2006). The concept of embodiment amalgamates the object/subject differences and collectively views the two ways of being, representing a more integrated view of the body (Sakalys, 2006). According to Merleau-Ponty (1962), the body is objective and subjective at the same time. The relationship with the lived body is subjective and existential (Merleau-Ponty, 1962). Under normal circumstances the world is perceived as we perceive it through our bodies: we exist in the world through our bodies; from this perspective the body cannot be reduced to a mere object.

Our experience of the world is 'grounded' in our bodies, which implies that there are certain ways in which we can experience the world and there are ways in which we cannot (Merleau-Ponty, 1962). Merleau-Ponty's (1962) argument is that we do not acknowledge sufficiently how our experiences of our bodies shape and determine our experiences of the world. He proposes that a subject that is 'in-the-world' is necessarily embodied –you have to exist in some form to exist at all (Merleau-Ponty, 1962). We are not only 'in-the-world' in our bodies-as-objects, our subjectivity also influences the world we experience. Furthermore, the body-subject signifies the inseparability of the person and one's sense of self from the physical body. The body, therefore, is understood as being the foundation for self, rather than a mere substrate (Woźniak, 2018). In medicine, the body is often treated as an 'object', reducing the body to its disease or condition (Mehta, 2011). According to Thomas (2005), Merleau-Ponty rejects the dehumanising and objectifying stance of materialistic philosophies and reminds us of the sacredness of the body asserting that if we view the body as sacred, '*it (is) impossible for us to treat a face or a body… like a thing. They are sacred entities'* (Merleau-Ponty, 1962, p. 167). Thus, for Merleau-Ponty the body-subject is purposeful and makes meaning in the world. This is also relevant for Merleau-Ponty's unique understanding of 'being-in-the-world', which is pertinent to his embodiment philosophy.

2.1.2 Being-in-the-world

> *'The body is our general medium for having a world. Sometimes it is restricted to the actions necessary for the conservation of life, and accordingly it posits around us a biological world; at other times, elaborating upon these primary actions and moving from their literal to a figurative meaning, it manifests through them a core of new significance: this is true of motor habits [sic] such as dancing. Sometimes, finally, the meaning aimed at cannot be achieved by the body's natural means; it must then build itself an instrument, and it projects thereby around itself a cultural world'.*
>
> *(Merleau-Ponty, 1962, p.146)*

The body is central to one's understanding' of the world and Merleau-Ponty (1962) posits that it is through our bodies that we reach out into the world and involve ourselves in meaningful activities. Being a body renders the world intelligible to us. Merleau-Ponty (1962 p.17) claims that '*the world is not what I think but what I live through'*. He uses the metaphorical expression, '*(our) body is in the world as the heart is in the organism*', to explain how our experience of the world is grounded in our bodies (Merleau-Ponty, 1962, p.246). Experience can only be understood and reflected upon within the context of where understanding and reflecting occur in the first place; the world. Therefore, embodied existence takes place within the contextual world that each person is born into and lives. This world is shaped by culture, society, history, and personal relationships and it must be interpreted to be understood. As embodied beings, we know the world through shared understandings, making the world a social and intersubjective experience. Embodiment allows people to engage with and come to know their worlds and it also enables individuals to symbolise their worlds and relate to each other through body performance (Radley, 2005).

According to Merleau- Ponty (1962) our being-in-the-world is entirely dependent upon having a body that is actively and intentionally engaged in seeing, touching, feeling and moving about in the world. '*Our relationship with the world is holistic in that we are part of the world and co-exist with it: both constituting and constituted'* (Merleau-Ponty, 1962, p. 453). A person's engagement in the world permits them to become 'at home' or habituated in their own bodies and within their environments (Moya, 2014). Merleau-Pontys (1962) perception of the world is also based on trust and collaborative relations with others. He suggests that people to make sense of the world through dialoguing and interacting with others. In applying this idea to this study, the body is seen as the vehicle through which adolescents experience and understand their worlds in the context of living with CKD. More specifically this element of embodiment offers insight into how adolescents' engagement and involvement in the world may be affected because of their illness. Being anchored in the world allows for a specific kind of understanding about our bodies to emerge in the form of embodied knowledge.

2.1.3 Embodied Knowledge

Embodied knowledge is a type of knowledge where the body knows how to act with regard to the world (Tanaka, 2013). For Merleau-Ponty, all knowledge is embodied, and it is created in the unity between subjects and objects that results directly from having a body (Merleau-Ponty, 1962). It is what a person does without trying to do or what people know before trying to know. He uses the term 'habituation' to refer to bodily learning, for it essentially involves developing a habit, that is, an action that happens automatically (Merleau-Ponty, 1962 p. 166). He suggests that we develop habitual bodily relationships with the world, and it is through our habitual ways of relating to the world that we develop embodied ways of knowing (Merleau-Ponty, 1962). A simple and general example is driving a car. Most of us know how to drive a car, and we can do it without any thought. There is no need to articulate the steps required to start or stop a car. The knowledge of how to drive a car is just lived by the hands and legs or by the body. The knowledge is embedded in one's body. The knowing-subject here is the body itself, not the mind. Or more precisely, the knowing subject is the embodied-mind (Tanaka, 2011). Merleau-Ponty also refers to it as 'knowledge bred of familiarity'. This tenet of Merleau-Ponty's philosophy is critical for understanding how participants in this study come to experience and learn about their changing bodies in living with CKD.

2.1.4 Embodied Self

Our bodies are the medium through which we understand and experience the world (Merleau-Ponty, 1962) and any modifications to the body that disrupts its integrity can affect a persons' sense of self and identity. Merleau-Ponty believed the physical body to be an important part of what makes up the subjective self. Rather than perceiving the mind and body as separate, Merleau-Ponty (1962) argued that they are interconnected. Together the mind and body contribute to our sense of self. The body is, therefore, significant in the creation and portrayal of meaning and identity, which is relevant to the objectives of this study; to explore adolescents' perception of CKD in relation to their sense of self and identity. In the context of this study, '*embodied self'* refers to how one experiences one's sense of self in and through one's body. *Embodied identity* refers to who we are as a result of our interactions with the world around us with and through our bodies.

2.2 Embodiment in Illness

Illness is inherently associated with the body (Ní Mhaille, 2009). In illness, the relationship between body and world is disturbed and a person's existence is shaken (Carel, 2014). Indeed, some researchers have endeavoured to account for the corporeal constraints of the body and the nature of the human experience of illness in a social and material world and calls for the incorporation of the body into the investigation of chronic illness are gaining voice (Mehta, 2011; Ghane and Sweeny, 2012). These calls for the incorporation of embodiment into the investigation of chronic illness are reinforced by theoretical discussions about the inter-relationships between embodiment and the experience of illness. The body can be taken for granted until it is challenged by illness (Draper, 2014). The body during illness is different from what the sick person has come to expect and a person's taken-for-granted assumptions about self and world are consequently derailed (Ní Mhaile, 2009). The body that ceases to function in expected ways creates uncertainty and transgresses social norms and protocols (Ní Mhaile, 2009). Illness signifies itself through the body, creating stoppages in the person's life and interrupting habitual routines (Kierans, 2000). It is through the body that strong physical sensations and perceptions are expressed through hearing, seeing, feeling, and knowing (Raingruber and Kent, 2003). The body, which was previously a source of strength, becomes the adversary when illness impairs normal functioning (Wilde, 1999). The diseased body is considered a rival, a battle that must be fought, or is referred to as an 'adversarial' body (Wilde, 1999, p.32). Thus, illness is not simply a breakdown in mechanical functioning but a disordered way of being-in-the-world (Merleau-Ponty, 1962).

The ill body is first experienced as not feeling 'me' as there is disharmony within the body and with its relationship to the world (Lunvik Gtllensten *et al.*, 2010). However, when the mind-body-world relationship is challenged, the body captures our attention and forces itself into our conscious awareness. Merleau-Ponty's conception of illness as disordered being-in-the-world is similar to Leder's (1990, p 91) theory that the body appears to oscillate between presence and absences (Leder, 1990). He suggests the idea of body 'dys-appearance' in that we attend to our body when something is experienced as 'wrong', bad' or 'alien' that threatens the unified mind-body. During illness, the object body dominates with central focus on bodily functions and dysfunctions resulting in the 'subject' body being overlooked (Sakalys, 2006). During illness the human body struggles to preserve the subject body at a time when the object body dominates (Fuentes *et al.,* 2017). If the body is reduced to an object, a purely material thing, then a disruption in the mind–body harmony can occur, leaving people feeling disconnected with one's body (Leder, 1990). When a body malfunctions, the assumptions held about the body and the world are fractured. Thus, a malfunctioning body is 'dysembodied' (Leder, 1990).

Dysembodiment refers to the undermining of the corporeal basis of identity and the feeling of being disengaged from the body. Leder, (1990) contends that in illness the body becomes an alien presence in a person's life, which undermines previously held concepts of body, self and society. Illness can modify the way people look at the world via their bodies and in Western civilisation there has been a growing trend toward a disembodied state of life leading to a 'decoporealised existence' or 'absence body' (Leder 1990, pg.3). Bodily presence can be interpreted as paradoxical: while in one sense the body has an inescapable presence in our lives, it can also be characterised by absence because we do not usually experience the healthy body (Babb, 2002). The experience of the body therefore can be skewed towards periods of dysfunction that create a new awareness of the body. Leder (1990) argued that the body in dys-appearance is marked by being away and apart from the self. The body may be experienced as an alien thing. The problem with this de-subjectifying of the body is that it is exactly the body and our subjective experience of it that connects us to the world and makes it real and meaningful (Leder, 1990). This idea of bodily absences and presences is relevant for this study, which aims to understand adolescents' bodily experience of CKD.

During illness our habitual relationship with the world is severely unsettled as everyday objects become obstacles to be avoided (Moya, 2014). Similarly, when someone enters the medical system the body becomes a biological object to be examined, explained and treated (Fuentes *et al.,* 2017). It is interesting to examine this phenomenon in light of the French philosopher, Michel Foucault. A portion of his work focuses on the disciplining power of institutions like medicine. Foucault (1963) coined the term ‘bio power’ to refer to the ways in which power manifests itself in the form of daily practices and routines and asserts that bodies are socially constructed, controlled and managed through regulatory policies and discursive practices (van Amsterdam *et al.,* 2017). For Foucault (1963) the body is a product of power relationships, which constitute ‘the clinical gaze’, and this aspect of his work is relevant to discourses of embodiment. He suggests that the way in which we perceive and speak about the body and medical matters is the product of wider historical conditions and power relations within society. Foucault (1963) developed the idea of the gaze to conceptualise how cultural factors manipulate the production, regulation and representation of bodies, which is relevant to the objectives of this present study. Like Foucault, Lupton (2012) also observes how the body is reframed during medical examinations and argues that during such situations, the person is removed from the body and the body or parts of the body are objectified. Such objectification can alter one’s sense of embodiment.

Merleau-Ponty's concept of embodiment is particularly relevant to this study as it offers the possibility of overcoming mind-body Cartesian dualism. With the success of Cartesian medicine, physicians and nurses increasingly viewed the body as the physiological mechanical body composed of organs systems, tissues and cells (Mehta, 2011). However, such a view does not consider the profound sense of disorder, which is manifested in the experience of illness (Switankowsky, 2000). If the lived-body is understood in terms of being-in-the-world, it can reveal that illness is experienced more as breakdown of the lived world than a breakdown of the biological body (Toombs, 1988). Furthermore, an embodied perspective acknowledges the important role the body has in the recovery process. Recovery comes not ….’*by an effort of the intellect nor by an abstract decree of the will, but by a conversation of the whole body wherein the whole body re-assembles itself’* (Merleau-Ponty, 1962 p.102). Any healing process cannot begin until the range of feelings associated with an illness is experienced and expressed, and the range of feelings associated with it is brought into consciousness (Wilde, 2003). In relation to the adolescent participants of this study; puberty, chronic body changing illness and invasive medical interventions may affect the way adolescents experience their bodies. Adolescents’ embodied experience of CKD cannot be understood unless it is placed within the context of developmental tasks and transitions that happen during this time (WHO, 2007). Therefore, the application of the concept of embodiment in this study will offer a holistic approach to understanding the experience of adolescents suffering from CKD, a perspective that is currently unexplored in the field of adolescent nephrology.

2.3 Embodiment in adolescence

According to Merleau-Ponty (1962) humans, especially children and adolescents, exist in and understand the world through their own bodies. Adolescence is a critical developmental period characterised by embodied changes of both the mind and body. During this period the body is transformed; a new body, a new personality and a new sense of embodied identity emerges (Özdemir *et al.,* 2016). The onset of puberty is the most characteristic feature of adolescence (Berenbaum *et al.,* 2015). Pubescent adolescents commonly experience major embodied changes such as a rapid increase in body height and weight as well as the development of primary sex characteristics including the onset of reproductive capacity and secondary sex characteristics such as changes in body hair, voice, and sweat glands (Okyay and Ergin, 2012). The development of secondary sex characters in boys result in growth in testes and penis, pubic, axillary and facial hair development, breaking of the voice and spermatic formation. The development of secondary sex characters in girls begins with development of breasts and continues with pubic and axillary hair development and menarche. The maturation of the reproductive system and new urges as in sexual interest is associated with rising concentrations of hormones (Sawyer *et al.,* 2018).

Developmentally, adolescence is a time of increased desire for autonomy and independence. The developmental literature indicates that the fundamental tasks of adolescence are to achieve autonomy from caregivers, increase dependence on peers, and enhance emotional skill development and regulation (Christie and Viner, 2005; Soenens *et al.,* 2017; Joshi and Shukla, 2019). From a psychosocial perspective adolescence is a time for significant growth and crisis. According to Erikson (1968) people's sense of who they are unfolds throughout their lives and during adolescence, the primary struggle is over the central question of ‘Who am I?’ Erikson considered development of a healthy body image, formation of a sexual identity and the establishment of peer relationships especially important in the process of identity construction, a topic which is highly relevant and pertinent for adolescents with CKD. However, in the context of this study, a young persons’ sense of embodied identity relates to how they experience their bodies in the world and as a result of a young person’s interactions with the world around them. Configuring an embodied identity, which is attained through a gradual separation from parents, and successful functioning in groups beyond the family such as peer group membership (Joshi and Shukla, 2019), can be challenging and difficult to achieve for adolescents with a chronic illness.

Adolescents with CKD experience the same developmental issues as other young people; however chronic illness can disrupt the normal embodied changes expected at this time (Suris *et al.*, 2004; WHO, 2007). Adolescents experience CKD through their bodies as they deal with altered embodied changes such as failure to grow and mature physiologically. Delays in sexual and emotional maturation are also experienced by adolescents with CKD. And for those who do develop sexual characteristics, these changes can be exaggerated by excessive growth of facial and body hair due to medical treatment (Lewis and Arber, 2015). Furthermore, adolescents with chronic kidney disease are living in a permanent stage of ambivalence, contradictions, and search as they contend with the realities of altered physical appearance, compromised abilities and isolating, invasive treatments while striving for independence, meaningful relationships and developing an embodied identity (Morales and Castillo, 2009). Merleau-Ponty (1962) emphasised the sacredness of the body and explained that when the relationship between body and world is disturbed (i.e., when bodily capacities is changed by illness), a person's existence is shaken. In applying this to the current study, chronic kidney disease has the potential to create an alteration in embodiment during adolescence.

2.4 Conclusion

In this chapter, I have provided an overview of Merleau-Ponty's (1962) position on embodiment, as a philosophical proposition to guide this study. The concept of embodiment provides an understanding of how people experience the world in and through our bodies. Furthermore, an embodied perspective acknowledges the unity of the mind and body. The concept of embodiment offers a unique theoretical lens to explore adolescents' bodily experiences of living with CKD. Throughout this thesis, I will revisit and explore the central tenants presented in this chapter. The proceeding chapter will present the existing literature on adolescents' experiences of living with CKD.

Chapter 3: Literature Review

3.0 Introduction

This chapter presents a review of the empirical qualitative literature on the experiences of adolescents living with CKD. This literature review was informed by Arksey and O'Malley's (2005) scoping review framework and Levac's *et al.,* (2010) advancement of this scoping review framework. This framework involves five core stages: (i) identifying the research question; (ii) identifying relevant studies; (iii) study selection; (iv) charting the data; and (v) collating, summarising and reporting the results. A scoping review framework was deemed appropriate for this study given the specific broad nature of the review (adolescents' experiences) along with the fact that scoping reviews are often used in mapping fields of study where it is difficult to visualise the range of material that might be available on a specific topic. As outlined in Chapter 2, there is limited research studies that have investigated embodiment in the context of childhood nephrology. Furthermore, scoping studies are specifically designed to identify gaps in the evidence base where no research or limited research has been conducted (Arksey and O'Malley, 2005). The next section will present the five stages of the scoping review.

3.1.1 Stage 1: Identifying the research question

In accordance with Arksey and O'Malley's (2005) recommendations, a research question and purpose should be clearly identified in order to guide the scope of the search strategy. The research question guiding this review was: *What are the bodily and embodied experiences of adolescents living with CKD*? In articulating the purpose of undertaking a scoping review, Levac et al. (2010, p.5) suggest that 'researchers consider the rationale for why they should summarise the activity in a field and the implications that this will have on research, practice, or policy'. The purpose of this scoping review is to identify relevant research within the field of nephrology relating to adolescents' experiences and to identify gaps within the literature.

3.1.2 Stage 2: Identifying Relevant Studies

This stage involved identifying the relevant databases to search and the key search terms to use. The databases chosen were specific to include nursing, medical and social science literature including CINAHL, Psycho INFO, PubMed and Psych Articles. A search of the available literature was carried out at the beginning of this project in October 2014, with further searches carried out on a quarterly basis in order to supplement the literature. The last search of the literature was carried out in January 2020. The initial keywords included broad terms such as chronic kidney disease, chronic renal failure, and renal replacement therapies. These terms yielded over 11,000 hits and so further combined specific terms were necessary to give focus to the search. Specific terms relating to the focus of this present study included keywords such as embodiment, embodied experiences, dialysis, kidney transplant, adolescents' experiences, meaning, coping and adaptation, perceptions of dialysis. Boolean operators 'or' and 'and' were used to connect and define relationships between key terms and keywords.

3.1.3 Stage 3: Study Selection

In screening the literature for this review the following inclusion/exclusion criteria were used. The inclusion criteria were:

- studies with young people under the age of 19 years;
- studies related to CKD including experiences of dialysis, transplant and embodied experiences;
- qualitative studies and mixed methods studies with a qualitative element and systematic reviews of qualitative studies on adolescent experiences of living with CKD and
- English papers.

Studies were excluded if they met the following criteria:

- studies that included both parent and adolescents' experiences where adolescents' data could not be extracted and
- exclusively studies of family and HCP's experiences of CKD, dialysis or transplant

3.1.4 Stage 4: Charting the data

This stage involved charting of the data from the studies identified The following information was extracted from each article; author, year, country of origin, design, sampling and sample size, data collection, data analysis and findings. Table 1 provides detail of the included studies.

Table 1 - Overview of Included Studies

Author, Year, Country	Aim of study	Design	Data collection methods	Sampling and sample size	Data Analysis	Findings
Rêgo *et al.*, (2019) Brazil	To understand the impact of chronic kidney disease on adolescents undergoing haemodialysis.	Qualitative, descriptive study	Semi-structured Interviews	Convenience sample. n=7 (aged 12-18 years)	Narrative analysis	*Psychosocial changes *Physiological changes. *Negative emotions associated with CKD.
de Souza and de Lione Melo (2018) Brazil	To understand adolescent's experiences with chronic renal failure.	Phenomenology	Phenomenological interviews	Purposive sampling. n=6 (aged 12-18 years)	Descriptive analysis based on the philosophical frame of Martin Heidegger	*Feeling different; *Experiencing renal insufficiency through renal replacement therapy *Seeking normality.
Walker *et al.*, (2019) New Zealand	To understand adolescents' experiences and expectations of kidney transplantation	Qualitative study	Semi-structured Interviews	Convenience n=13 (aged 7-17 years)	Thematic Analysis	*Transplant as the goal *Negative emotions *Understanding CKD and the need for knowledge support.

Author, Year, Country	Aim of study	Design	Data collection methods	Sampling and sample size	Data Analysis	Findings
Kim and Choi (2016) South Korea	To understand the experiences of Korean adolescents who have undergone a renal transplant.	Qualitative study	In-depth interviews Focus group	Convenience sample n=9 (aged 12-18 years)	Qualitative Content Analysis	*Feeling different. *Mixed feelings about transplant. *Excluded from decision making.
Ramos *et al.*, (2015) Brazil	To understand the impact of the CKD and treatment in the mental health of adolescents on haemodialysis.	Qualitative study	Semi-structured interviews Observations	Purposive sampling n=8 (aged 10-19 years).	Thematic analysis	*Lifestyle changes *Mental health struggles related to living with CKD/dialysis. *Need for humanised approach to care
Zitzelsberger *et al.*, (2014) Canada	To explore children's perspectives of the time, space and technology in a hemodialysis unit.	Ethnography	Informal interviews Observations	Purposive sampling n=11 (aged 7-17)	Thematic analysis	*Time: rituals and routines affected; *Space: confinement constraints; *Technology: affects everyday

Author, Year, Country	Aim of study	Design	Data collection methods	Sampling and sample size	Data Analysis	Findings
Tjaden *et al.*, (2012) Australia	To describe the experiences and perspectives of children and adolescents on dialysis.	Systematic review and thematic synthesis	Comprehensive literature search of primary studies	Primary qualitative studies n= 17 studies	Thematic analysis	*Schooling difficulties *Fatigue, *Difficulty concentrating, *Poor self-image *Impaired bodily integrity. *Loss of control *Feeling like a burden.
Wells *et al.*, (2012) U.K.	To explore adolescents' experiences of renal replacement therapies	Qualitative Study	Photo elicitation Interviews	Purposive sampling n=10 (aged between 13-19 years)	Thematic analysis Photographs were not analysed	*Understanding treatment; *Living in a non-functioning body; *Impact upon daily life; *Sources of support
Tong *et al.*, (2011) Australia	To explore experiences and perspectives of adolescent kidney transplant recipients following kidney transplantation.	Adapted grounded theory	In-depth interviews	Purposive sampling n=12 (age 12–19 years)	Thematic analysis	*Achieving a sense of normality *minimizing lifestyle limitations, *adapting to new identity. *changes in appearance *need for information

Author, Year, Country	Aim of study	Design	Data collection methods	Sampling and sample size	Data Analysis	Findings
Nicholas *et al.*, (2011) Canada	To describe the lived experiences of children and adolescents with End-Stage Renal Disease.	Qualitative Study	Ethnographic interviews (long-interviews)	Purposive sampling n=25 participants (aged 7- 18 years).	Long-interview analysis Method. NVivo data management and analysis software used.	* Not feeling "normal"; *ESRD knowledge
Tong *et al.*, (2009) Australia	To describe the experiences of adolescents who underwent organ transplantation:	Systematic review	Comprehensive literature search of primary studies	Primary qualitative studies n=18 studies	Thematic analysis	*Redefining identity *Family functioning *Social adjustment; *Managing medical demands, *Attitude toward the donor
Waters, (2008) U.K.	To explore the experience of long-term renal illness, from the perspectives of children and young people.	Ethnography	Observations, Interviews	Purposive n=13 (aged 5-16 years)	Thematic analysis	*Inhabiting a renal space. *Intolerable thirst, *Bodily Pressures *Unrealistic expectations *Uncertainty *Fear of surgery

Author, Year, Country	Aim of study	Design	Data collection methods	Sampling and sample size	Data Analysis	Findings
Olausson *et al.*, (2006) U.S.A	To explore the impact of transplantation on the lives of young people.	Phenomenology	In-depth interviews and drawings	Purposive sampling n=18 (age 4–18 years)	Narrative Analysis	*Disappointment and feeling cheated. *Restricted physical activity, self-conscious of appearance. *Bullying, peer rejection and loneliness. *Lack of support for re-integration into school.
Harwood and Johnson, (1999) Canada	To explore adolescents' experiences of treatment after renal transplantation	Descriptive phenomenology	Semi structured interviews	Purposive n=5 adolescents (age 15-18 years)	Giorgi's data analysis method	*Weighing risks and taking chances. *The consequences of adhering or non-adhering to treatment affects physiological, social, and psychological domains

3.1.5 Stage 5: Collating, summarizing and reporting the results

A total of 14 studies were identified; 12 qualitative studies, and two systematic reviews. Characteristics and findings of included studies are summarised in Table 1. None of the studies specifically investigated adolescents embodied experiences of living with CKD. Articles originated from U.S.A. (n=1) Canada (n=3), United Kingdom (n=2), Brazil (n=3), South Korea (n=1), New Zealand (n=2) and Australia (n=3). Most participants were recruited from paediatric dialysis units or from a paediatric renal clinic. The studies included varied in their aims. Three studies set out to describe experiences and meaning of living with end stage renal failure (Waters, 2008; Nicholas et al., 2011; de Souza and de Lione Melo, 2018); five studies describe the experiences and perspectives of children and adolescents on dialysis (Tjaden *et al.,* 2012; Wells *et al.,* 2012; Zitzelsberger *et al.,* 2014; Ramos *et al.,* 2015; Rêgo *et al.,* 2019; and six studies explored the experiences and perspectives of children/adolescent following kidney transplantation (Harwood and Johnson, 1999; Olausson *et al.,* 2006; Tong *et al.,* 2009; Tong *et al.,* 2011; Kim and Choi, 2016; Walker *et al.,* 2019).

There was variance in the description and underpinning philosophy of the studies. Three studies used phenomenology; one descriptive phenomenology (Harwood and Johnson, 1999) and two nonspecific approach to phenomenology (Olausson *et al.,* 2006; de Souza and de Lione Melo, 2019) but only one of these provided details of bracketing and reflexivity within the study. One study used adapted grounded theory (Tong *et al.,* 2011) and two used an ethnographic approach (Waters, 2008; Zitzelsberger *et al.,* 2014). Six studies gave only a broad description of using a qualitative study and details of analysis by coding and themes (Nicholas *et al.,* 2011; Wells *et al.,* 2012; Ramos *et al.,* 2015; Kim and Choi, 2016; Walker *et al.,* 2019; Rêgo *et al.,* 2019)**.** Two systematic reviews were identified. One systematic review focused on children and adolescents' experiences of haemodialysis or peritoneal dialysis (Tjaden *et al.,* 2012) while the other systematic review reported on adolescent experiences following organ transplantation (Tong *et al.,* 2009). The studies varied in terms of the age of the included participants ranging from 4 to 18 years. Age ranges in individual studies were: 12 - 18 years (Tong *et al.,* 2012; Kim and Choi, 2016; de Souza and de Lione Melo, 2018; Rêgo *et al.,* 2019); 12-19 years (Tong *et al.,* 2011); 7-17 years (Zitzelsberger *et al.,* 2014; Walker *et al.,* 2019); 10-19 years (Ramos *et al.,* 2015); 13-19 years (Wells *et al.,* 2012); 7- 18 years (Nicholas *et al.,* (2011); 5-16 years (Waters, 2008); 4-18 years (Olausson *et al.,* 2006); 15-18 years (Harwood and Johnson, 1999);

0-19 years (Tjaden *et al.,* 2012). Data collection methods varied and included individualised interviews (n= 6); interviews in combination with other data collection methods (n=6) including observations (n=3), photo elicitation (1); drawings (n=1); and focus group (n=1). Two systematic reviews generated data from n= 17 studies (Tjaden *et al*., 2012) and n=18 studies (Tong *et al.,* 2009). In congruence with the scoping review framework, no formal assessment of the methodological quality of the included studies were performed. The results of the scoping review identified a number of common themes including the following: -

- Effects of CKD on the adolescent body,
- Adolescents' experiences of dialysis and medical intervention,
- Embodied difference and identity
- Embodied Suffering,
- Interacting with Others.

The themes described from the findings of the scoping review can help to provide understanding of the multidimensional and complex experiences of adolescents living with CKD, thus, providing a focus and context for the current study. These themes will be discussed in the following sections.

3.2 Effects of CKD on the adolescent body

The literature revealed that the experience of living with CKD presented many struggles that adolescents had to cope with, and address as part of the illness experience on a day to day basis. For instance, the unpleasant physical symptoms of CKD and its treatments were repeatedly cited as prominent issues of concern for adolescents (Waters 2008; Nicholas *et al.,* 2011; Wells *et al.,* 2012; Rêgo *et al.,* 2019). Adolescents experience bodily symptoms such as pain, fatigue, nausea, dizziness, breathlessness, fatigue, and itchiness (Rêgo *et al.,* 2019). The nature, severity and frequency of physical symptoms reported by adolescents varied substantially across the studies and were related to the type of treatment received. The side-effects of both HD and PD are regarded as negative effects that made adolescents feel powerless and feeble (Wells *et al.,* 2012; Nicholas *et al.,* 2011; de Souza and de Lione Melo, 2018; Rêgo *et al.,* 2019). In a recent qualitative descriptive study, Rêgo *et al.,* (2019) investigated the impact of chronic kidney disease on adolescents in Brazil. Using semi-structured interviews with seven adolescents (aged 12 to 18 years), Rêgo *et al.,* (2019) found adolescents frequently reported the symptoms of tiredness, pain, dizziness, weakness and fatigue. Adolescent participants in this study reported that these bodily symptoms imposed considerable problems in everyday life, but these were often ignored as minor symptoms by HCP’s. These findings are supported by Wells *et al.,* (2012) study which highlighted the difficulties young people experienced in living in a body that was not working ‘properly’. Many of the young people in Wells *et al.,* (2012) study were dominated by the physical consequences of treatments, which left them unable to participate in physical activities due to loss of energy and fatigue. Tongs *et al.*, (2011) also reported that a lack of energy caused by treatment meant that adolescents felt alienated in relation to their own bodily functions, causing a feeling of something being wrong inside their bodies.

Adolescents had to manage and incorporate bodily consequences of CKD and its treatments into their everyday lives. Combating bodily symptoms was a dilemma reported by many studies reviewed (Waters, 2008; Nicholas *et al.,* 2011; Tjaden *et al.*, 2012). These findings on the challenges associated with managing symptoms were supported by Nicholas *et al.,* (2011) study which reported that, young people on haemodialysis struggled to comply with fluid restriction because of the bodily experience of thirst. This study reported that young people resorted to drinking from taps, steam irons, saucers beneath plant pots and toilet bowls, to manage their experience of thirst (Nicholas *et al.*, 2011). In an ethnographic study that took place in a UK urban paediatric dialysis unit with 13 children who received haemodialysis and peritoneal dialysis, 14 parents or caregivers and 36 staff members, Waters (2008) explored young people’s experiences of renal disease. Her methods included the observational field notes over 16 months, drawings, interviews and document analysis. A central theme of this study’s findings pertained to the work that young people engaged in to manage burdensome symptoms, which Waters (2008) referred to as ‘Illness labour’. Because of their renal conditions, participants in Waters (2008) study reported that the lived with bodies that demanded constant care and attention, such as constant thirst, tiredness pain, and they experienced various states of health and illness. Waters (2008) concluded that further research was needed to examine the embodied nature of CKD symptoms and how HCP’s can help young people to manage with these symptoms in their everyday lives.

The studies reported in this theme have revealed the debilitating symptoms that children and adolescents experience in living with CKD however what remains unknown is how bodily symptoms impact on adolescent’s experience of their bodies. Understanding the meanings that adolescents attribute to the physical sensations and symptoms is crucial as studies in this scoping review identified that symptoms are often disregarded by HCP's. Further research is required to explore the impact and severity of bodily symptoms arising from CKD and its treatments. This has implications for understanding how adolescents recognise and convey bodily signals and experiences of CKD. Thus, it is important for HCP's to understand the physical burden of CKD in order to support adolescents in managing their bodily symptoms. Future research needs to address this gap and the concept of embodiment offers a novel perspective to investigate the ways CKD and its treatments impact the body and mind.

3.3 Adolescents' experiences of dialysis and medical intervention

Several studies have elicited children and adolescents' experiences of receiving dialysis, focusing on the ramifications on the participants' bodies and lives (Waters 2008; Nicholas *et al.,* 2011; Wells *et al.,* 2012; Tjaden *et al.,* 2012; Zitzelsberger *et al.* 2014; Ramos *et al.,* 2015; de Souza and de Lione Melo, 2018; Rego *et al.,* 2019). The findings of these studies report the challenging and life- changing effects of dialysis. These studies found that the dialysis machine dominated young people's lives (Wells *et al.,* 2012; Tjaden *et al.,* 2012; Zitzelsberger *et al.* 2014; Ramos *et al.,* 2015; de Souza and de Lione Melo, 2018; Rego *et al.,* 2019). The machine was seen to be controlling the body and young people described dialysis treatment as an intense, unrelenting regimen that controlled their being (Tjaden *et al.,* 2012; Zitzelsberger *et al.* 2014; de Souza and de Lione Melo, 2018). Tjaden *et al.,* (2012) conducted a systematic review of qualitative studies that explored the experiences of children and adolescents on dialysis. A total of 17 studies, which reported the experiences of 143 children and adolescents receiving dialysis, were included. Participants receiving long-term dialysis described dialysis as an intense, unrelenting regimen that controlled their being. They expressed a sense of helplessness and perceived themselves to be manipulated and controlled by medical interventions (Tjaden *et al.,* 2012). However, some studies reported that the machine may paradoxically in many cases be seen as a lifeline with the purpose of sustaining life (Tjaden *et al.,* 2012; Zitzelsberger *et al.* 2014; de Souza and de Lione Melo, 2018). In a phenomenological study of adolescents' experiences of CKD, de Souza and de Lione Melo (2018) found that adolescents acknowledged that dialysis was vital but that it was also a prison which affected their being-in-the-world. Adolescents in this study revealed that they were thrown into a world that was not chosen by them, a world that revolved around dialysis, a situation they had no control over. Loss of control and dependency caused limits in the body and adolescents had to adjust to a new way of being-in-the world (de Souza and de Lione Melo, 2018).

The time spent on the dialysis machine has been considered in a number of studies (Waters, 2008; Zitzelsberger *et al.*, 2014). These studies revealed that adolescents repeatedly waited for their dialysis machine to be ready, waited for their bodies to be attached to a machine, waited for their dialysis to be completed, waited for their bodies to be disconnected from a machine and waited for transportation to and from the hospital. For example, Waters (2008) study of children and adolescents with CKD highlighted the time-consuming nature of living with chronic kidney disease. In this ethnographic study, children and adolescents (n=13) aged between 7 and 16 years reported the enormous time and effort that was needed to deal the multiple threats to bodily integrity that arose from dialysis. Children and adolescents were found to mourn for the time lost on dialysis and 'waiting for a kidney' (Waters, 2008, p.3110). Similarly, Zitzelsberger *et al.* (2014) illustrated the significance of time, in their ethnographic study undertaken to explore children's (aged 7 to 17 years) perspectives of the time, space and technology at of a haemodialysis unit at a Canadian paediatric haemodialysis unit. They examined children's embodied perceptions of dialysis. Having negative and positive perceptions and responses, the children held multiple and conflicting meanings about the dialysis machine. Particular to their experiences in the unit, virtually all of the participants commented that their time waiting for a treatment to end was experienced as long, wasted and taken from them due to the temporal disruptions. Because their lives were constrained by dialysis the notion of 'doing technological time' was a central theme that emerged from this study (Zitzelsberger *et al.*, 2014). The findings of this study also suggested that dialysis can affect children's sense of embodiment and concluded that further research is needed to articulate children's everyday experiences of situated embodiment, as told by them.

Studies have reported that dialysis impacted their personal spaces and environments (Waters, 2008; Wells *et al.*, 2012; Zitzelsberger *et al.*, 2014). In Wells *et al.*, (2012) study of adolescents' experiences of renal replacement therapies, participants aged between 13-17 years reported the 'hospitalized home' in which their homes had become evaded by hospital-based equipment. For these participants, life at home was particularly impacted when adolescents were having PD, due to the storage of a large amount of equipment and supplies, which always acted as a reminder of their condition. Similarly, Waters (2008, p. 3106) study also revealed the restrictions in the illness experience and established that young people with CKD lived in and grew up in what she referred to as a 'renal space'. The concept of renal space was used to portray the overall embodied experience that surrounded young people; whose lives were revolved around a ‘renal world’ (Waters, 2008, p. 3106). The ‘renal world’ referred to the contextual spaces that young people inhabited, including the haemodialysis unit, the renal home and hospital clinics. The findings of Waters (2008) illustrated that the young people experienced a challenging embodiment that included attachment to dialysis machine that limited their time and capacities to engage in other activities. These findings suggest that CKD could potentially impact on adolescent embodied experience because home had now become like hospital and there was nowhere, they could escape from their illness however further research is required to investigate this issue.

This theme on adolescents’ experience of dialysis and medical intervention has described experiences of time consumed, restricted freedom, technological dependency and dehumanisation through receiving CKD treatment such as dialysis. However, attending to the ways in which dialysis and medical treatment can lead to a modified embodiment in adolescence warrants further investigation, a perspective that is presently absent in the literature. More specifically how CKD and its medical interventions affect the boundaries between self and other in adolescent patients warrants further investigation.

3.4 Embodied difference and identity

Feeling different was a central theme in many of the studies in this literature review. Studies indicated that adolescents with CKD undergo significant changes in their appearance, with adolescents reporting problems with being physically different to peers, due to surgical interventions, medication and side effect of treatments (Hardwood and Johnson, 1999; Waters, 2008; Nicholas *et al.,* 2011; Wells *et al.,* 2012). De Souza and de Lione Melo (2018) conducted a phenomenological study in Brazil that elicited 6 adolescents’ (aged 12-18 years) perceptions of living with chronic renal failure. Open-ended interviews revealed that adolescent participants perceived ‘feeling different’ when comparing themselves to healthy peers regarding body image. Bodily difference was reported because of physical changes to their bodies caused by dialysis. Adolescents in this study reported that procedures to create a point of access for dialysis via a fistula or a catheter either on the neck, arms, chest or abdomen lead to unavoidable scarring which changed the appearance of the adolescent body. Similarly, in other qualitative studies, the presence of a dialysis catheter, short stature, and delayed sexual maturation caused by CKD and dialysis, were cited as the most disturbing physical changes which were devastating to young people's self-image (Water, 2008; Tjaden *et al.,* 2012) and increased self-consciousness (Nicholas *et al.,* 2011). Tjaden *et al.,* (2012) in their systematic review of 17 studies involving 143 children and adolescent experiences of haemodialysis or peritoneal dialysis identified that young people were concerned about being shorter and smaller because of CKD as this made them feel different to their well peers. They felt that being on dialysis distinguished them from 'normal' people, and described themselves as 'strange', or 'weird' (Tjaden *et al.,* 2012, p. 399). Because of their short stature, some older participants felt that they received differential treatment and were resentful of this. Conversely in a qualitative UK study of adolescents' experiences of renal replacement therapies, Wells *et al.* (2012) found that while younger adolescents reported body issue concerns related to dialysis catheters; older adolescents expressed a lack of concern around body changes, acknowledging the benefits of having a patent access for renal replacement therapy. In this study older adolescents reported being frustrated at the process of gaining and maintaining a viable access site and were not concerned about body image and self-esteem (Wells *et al.,* 2012). These differences may reflect the different age variation between this study and earlier studies which report on both young children's experiences combined with adolescent experiences (Nicholas *et al.,* 2011). This highlights the need for further investigation into the views and experiences of adolescents with CKD independent from younger children, whose views may differ due to developmental and age factors.

Feeling different due to bodily changes and appearance are reported to continue even after transplantation. Tong *et al.,* (2001) explored the experiences and perspectives of adolescent kidney transplant recipients following kidney transplantation. They conducted 22 in-depth, face-to-face interviews with adolescent kidney transplant recipients (aged 12–19 yr.) from five Australian paediatric transplant units. Tong *et al.,* (2011) reported that adolescents continued to have concerns and information needs regarding the effect of kidney transplantation on their physical appearance. Adolescent participants in this study reported barriers to feeling normal which included bodily issues such as weight gain from immunosuppressant drugs taken to prevent organ rejection, concerns about risk peer rejection due to bodily changes and anxiety regarding their identity post-transplant. Similarly, in a qualitative study of adolescents' experiences of renal transplant, Kim and Choi (2016) conducted interviews and focus group interviews with nine adolescents in Korea, whose ages ranged between 12 and 18 years, and who were six months or more post renal transplant. They described feeling different using terminology that suggested a sense of dehumanisation and mechanisation, such as looking ‘like a robot’ and feeling like a ‘wood block’ (Kim and Choi, 2016, p. 160). In particular, adolescents reported feeling isolated from their peers because of their appearance and were often bullied which left deep emotional scars. Many participants described finding that to some extent transplantation provided the physical normality they desired. However, others continued to experience further physical changes following transplantation (Kim and Choi, 2016). This has important implications for the way that adolescents perceive themselves after transplant.

In addition to bodily difference, adolescents’ perceived difference to healthy adolescents’ peers was also revealed through their lifestyles. A major aspect of the studies reviewed related to the way dialysis and CKD affected and disrupted normal life which further added to adolescents’ experiences of being different. Several studies reported the restricted lifestyle imposed by CKD disease and its treatments, limitations caused by medical consultations, dietary and physical restrictions and renal replacement therapies, be it haemodialysis or peritoneal dialysis. (Nicholas *et al.*, 2011; Ramos *et al.*, 2015; Kim and Choi, 2016; de Souza and de Lione Melo, 2018). These complex treatment regimens detract from time spent as a ‘healthy’ teenager; limited opportunities and interfered with socialisation and participation in peer-related activities which subsequently left adolescents feeling different from their healthy peers (Wells *et al.*, 2012; de Souza and de Lione Melo, 2018). Adolescents in these studies reported feeling tied down due to the restrictive nature of the dialysis treatment regime. They felt their lives were entirely scheduled around dialysis therapy and were subsequently unable to perform normal everyday activities. A study by Nicholas *et al.*, (2011) illustrated the social impact of CKD and dialysis therapy on the lives of 25 children and adolescents aged 7 to 18 years in Canada. The researchers employed an ethnographic approach incorporating semi-structured interviews which were subjected to content analysis. The participants indicated that the time-consuming nature of dialysis disrupted all areas of their lives which resulted in social limitations and school absenteeism. Similarly, other qualitative studies have reported that adolescents have neglected important aspects concerning other spheres of their lives, such as school activities, and experienced a sense of isolation from their well peers. Studies reported that because of their perceived difference, adolescents longed for a sense of normality and highlighted that adolescents strive for a sense of normality was more important to adolescents than following restrictive treatment regimens (Nicholas *et al.*, 2011; Wells *et al.*, 2012). Being normal was envisioned as the lives of others without this illness, and adolescents compared themselves to healthy peers as examples of normalcy. Some studies reported negative views associated with adolescent struggles for normality. For example, Tjaden *et al.,* (2012) reported that adolescents viewed their illness negatively and felt it was unfair that they had kidney disease while other adolescents led healthy lives without kidney disease. Other studies reported how adolescents refused to allow CKD or dialysis to constrain their lives and this allowed them to achieve some degree of normality in their lives (Nicholas *et al.,* 2011; Tjaden *et al.,* 2012; Wells *et al.,* 2012). These studies reported that adolescents made efforts to live as normally as possible, and exercised resilience and fortitude. A sense of identity and not being labelled as 'sick' or considered the 'odd one out' was an important issue in striving for normalcy which was reported by a number of authors (Nicholas *et al.,* 2011; Wells *et al.,* 2012).

This theme revealed how adolescents experienced embodied difference because of CKD. This raises an important question related to the potential impact CKD and its treatments may have on adolescent's sense of embodied self and identity. Identity formation is an important developmental task of adolescence as highlighted in Chapter two (see section 2.3). However, none of the studies reported in this review specifically set out to explore adolescents embodied identity in the context of CKD. Without this important contextual information, a comprehensive, in-depth understanding of the embodied experience of living with chronic kidney disease remains elusive.

3.5 Embodied suffering

This theme highlights the distressing emotional suffering associated with CKD and its treatments. Anger, sadness, anxiety, and fear seemed to be the most prevalent emotional responses experienced within this patient group (Ramos *et al.,* 2015; Rêgo *et al.,* 2019). Emotional responses occurred due to bodily changes from CKD, the continuous burden of physical symptoms, fear of dialysis, and negative experiences with the healthcare system. Studies also reported that adolescents felt uncertain about their illness trajectory and angry about the onerous and relentless treatments which they had to endure which left them physically, mentally, and emotional drained. It was also suggested that the presence of negative feelings was associated with lack of interaction with peers, and restricted activities (Rêgo *et al.,* 2019). Feelings such as fear of complications and death, the shame of what others will think of them and the difficulty in accepting the disease were expressed by adolescents (Olausson *et al.,* 2006; Waters, 2008; Ramos *et al.,* 2015). Some adolescents made references to bearing up, making the best of it, soldiering on, not complaining, and stoically accepting their situation. However, feelings of anxiety and fear re-emerged in studies focused on adolescents' experiences post-transplant (Tong *et al.,* 2011; Kim and Choi, 2016; Walker *et al.,* 2019. For example, Kim and Choi (2016) reported that adolescents feared complications associated with transplant and worried about returning to dialysis if the transplanted kidney stopped working. Adolescents in this study reported being extremely anxious and felt their heart "pounding" whenever they waited for the blood and urine test results measuring kidney function. The participants' accounts illustrated that they were concerned about their prognosis and were anxious about the possibility of future deterioration in their health. They feared returning to their pre-operative lives and felt anxious about their uncertain future. The emotional suffering associated with CKD is an important consideration in understanding the embodied perspective of CKD in particular for understanding how feelings can impact the body-mind relationship, a perspective currently lacking in the literature.

3.6 Interacting with others

Studies of adolescents' experiences of CKD frequently referred to interactions with others such as families and healthcare providers. Firstly, families are referred to in a mainly positive sense as an important source of support to them (Nicholas *et al.,* 2011; Wells *et al.,* 2012, Tjaden *et al.,* 2012, Walker *et al.,* 2019; Rêgo *et al.,* 2019). These studies found that parents supported young people both emotionally and practically, and adolescents across studies emphasized the importance of parents assisting them to undergo treatment. Parental involvement reduced anxiety around the technical demands of treatment for many young people, as well as assisting them with remembering medications and adherence to dietary restrictions. Parental presence during hospital stays also provided comfort, reassurance and encouragement (Nicholas *et al*., 2011). Participants also received care and support from their siblings. The participants relied on their parents to purchase medications, remind them to take their medications on time, and to discuss treatment decision making and prognosis with medical personnel. On the other hand, some studies also reported that CKD caused tension in adolescent– parent relationships (Nicholas *et al*., 2011; Rêgo *et al.,* 2019).

Parental support in care was deemed important by adolescents however over involvement from parents who had difficulty in relinquishing control was deemed problematic as adolescents strived to gain independence in managing their care. Gaining independence from parents who are overly protective in response to the illness is particularly challenging. Furthermore, parents were seen as overseers and enforcers of treatment and young people interpreted their parents' continued involvement as ongoing surveillance, (Nicholas *et al.,* 2011). Parents continued over-involvement in care management coupled with persistent observation and surveillance hindered the development of independence for adolescents.

In their systematic review, Tjaden *et al.,* (2012) concluded that young people with CKD reluctantly become more reliant on their parents which inevitable delayed the process of becoming an autonomous person. Adolescents with CKD revealed that they were reliant on parents to take them to haemodialysis, hospital appointments or stay at their bedside during their hospitalization. The systematic review concluded that while young people appreciated parental support, some perceived their parents to be overinvolved which left young people feeling frustrated. They felt that their parents did not trust them to monitor and manage their treatment and wanted more independence in managing their own care. Studies on adolescents' experiences of transplant, reported similar experiences with adolescents reporting conflict with their parents even when they recognized that the family support had helped them receive the transplant and adjust to postoperative management (Tong *et al.,* 2009; Kim and Choi, 2016; Walker *et al.,* 2019). In these studies, participants felt constrained by their over protective and highly anxious parents. Adolescents who received a kidney from one of their parents experienced a variety of feelings: they were grateful to the donor parent for the kidney, but still felt worried about their parents' health and even felt guilty (Tong *et al.,* 2009; Kim and Choi; 2016; Walker *et al.,* 2019). This raises important and unanswered questions about how CKD and its treatments affects adolescent's relationships and engagement with the world, issues which are fundamental to an embodiment perspective on illness.

Interactions with healthcare providers was also described briefly in some studies. Healthcare providers had both a positive and a negative influence on adolescents' experience. Adolescents undergoing hospital-based dialysis referred to the impact of staff within these units. Adolescents reported that they were dependent on the HCPs (Nicholas *et al*. 2011; Tjaden *et al.,* 2012) and being able to trust healthcare staff was valued highly (Waters, 2008; Wells *et al.,* 2012). These positive aspects depended on the attitude and appreciation on the part of HCPs. For example, Waters (2008) reported that HCPs knowledge of young people's bodies and the gruelling experiences that young people endured was fundamental to their relationships.

However, participants in Waters (2008) study acknowledged that being attached to a dialysis machine positively influenced their relationship with staff. Participants in this study reported that because they were connected to a machine three times per week for many hours, they developed a close bond with staff particularly nursing staff. Nevertheless, the attitude of HCPs was expressed negatively by adolescents in other studies (Ramos *et al.,* 2015; Rêgo *et al.,* 2019). Adolescents reported that HCPs do not pay enough attention to their experiences of living with CKD which had implications on their wellbeing. For instance, in their study of the impact of CKD on 8 adolescents undergoing dialysis, Ramos *et al.,* (2015) identified that negative interpersonal relationships with HCPs affected the mental wellbeing of adolescents. Adolescents reported that HCPs focused on the technical aspects of care and spent less time talking and attending to the adolescents needs (Ramos *et al.,* 2015). The findings from this study concluded that adolescents wanted more humanised care and interaction with HCPs. These findings have important links to embodiment as Merleau-Ponty (1962) reports the significant influence that others have on how a person experiences the world they live in. This has implications for future research. It was observed that there is a gap in terms of how interactions between adolescents and healthcare providers can be understood as embodied interactions and how these interactions may affect adolescents' experiences of their bodies and embodied selves.

3.7 Narrative types identified from the scoping review

The types of narrative told by participants can offer insights into the subjective patient view, and is a means by which links between the body, self and society are articulated (Bury, 2001). A 'narrative type' is described by Frank as 'the most general storyline that can be recognised underlying the plot and tensions of particular stories...that cultures make available' (1995, p. 75). Although the studies included in this scoping review did not specifically identify narrative types or the dominant narrative told by adolescents living with CKD, narrative typologies were evident in their accounts. Franks (1995) typologies of illness narratives (restitution; chaos; and quest) were used to identify types of narratives that were dominant within in the findings of the scoping review. These types of narratives are used by people suffering from a variety of illnesses in order to make sense of their experiences.

According to Frank the 'restitution narrative' (1995, p.77), is a narrative that focuses on a movement from health to sickness, looking to return to health in the future. This is a narrative that Frank observed as one most commonly used in the stories told by ill people, and can be viewed as helpful, reflecting a natural desire to get well and stay well. The story of modern medicine finds healing is achieved through treatment outside the body such as with surgery or through medication. Frank (1995) notes that the individual experiencing a restitution narrative subscribes to this view. The second narrative type that Frank discusses is referred to as the 'chaos narrative', a storyline which "imagines life never getting better" (1995, p. 97), In a sense, this narrative style contradicts the restitution narrative, by highlighting the pretence of control sought by medicine (Frank, 1995, p. 100). Finally, the 'quest narrative' shows how illness may be considered useful (Frank, 1995). Frank (1995, p. 117) reflects that "as the ill person gradually realises a sense of purpose, the idea that illness has been a journey emerges".

Relating these three narrative types to the findings of the scoping review, the ‘restitution narrative’ was the most dominant narrative (most common story) told in the studies reviewed. The ‘restitution narrative’ was evident whereby participants reported a categorical view of illness, sharing characteristics of a biomedical approach or institutional stories. Frank warns that the restitution narrative may also be thought of as a medicalised story, one that ‘people learn...from institutional stories’ (Frank, 1995, p. 78). Thomas-MacLean (2004) notes that institutional stories told by patients reflect Western medicine's emphasis upon diagnosis, treatment and cure, and such narratives lack the subtle nuances of the meaning of illness or personal perspective. This narrative type also leaves little room for a counter narrative to emerge. A counter story is ‘a story that is told for the purpose of resisting a socially shared narrative that purports to justify the oppression of a social group ... The socially shared story—master narrative—enters the tissue of stories that constitute the group’s identity, damaging that identity and so constricting group members’ access to the goods on offer in their society’ (Lindeman, 2015 p. 98). Counter stories repair the damage inflicted on identities and are a form of resistance, they are meant to alter oppressor’s perceptions as well as to alter perceptions of self (Lindemann, 2001). However, the lack of narrative studies in this scoping review means that counter stories remain elusive within nephrology literature. This present study addresses this gap in the literature.

3.8 Conclusion

This chapter has presented a review of the literature related to adolescents’ experiences of living with CKD. The themes described from the findings of these studies highlighted the chronic and deteriorating nature of CKD which was characterised by a complex range of bodily symptoms. Findings from the studies signified that chronic kidney disease and its treatments caused bodily changes and restricted adolescents lifestyle which made them feel different. Thus, the feeling of being different permeated the existence of adolescents with CKD. The literature emphasised striving for normalcy as an essential feature of the experience of living with CKD. Despite efforts to live a normal life, adolescents were continually reminded that their existence was dependent on medical technology and dependent on others for survival. Adolescents expressed a sense of helplessness and perceived themselves to be manipulated and controlled by medical interventions. This literature review has made clear the challenging and multidimensional nature for adolescents of living with renal disease.

A limitation worth noting is that both childrens' and adolescents' views were included in five of the fifteen studies included in the scoping review. The issues confronting adolescents are likely to be different to those of younger children. Additionally, five studies were conducted over 10 years ago. Therefore, the relevance of the findings to the current context may be questionable. Additionally, these studies provided only a descriptive account of experiences which offers an incomplete representation of the complex and bodily experience of living with CKD on the developing body. There is a dearth of research on adolescents' embodied experiences of living with CKD in nephrology literature, and there have been calls for more qualitative research aimed at developing a fuller understanding of adolescent subjective experiences of CKD and attendant care management (Waters, 2008; Zitzelsberger *et al.*, 2014; de Souza and de Lione Melo, 2018). Furthermore, despite the recognition of the value of narrative research in giving voice to participants and illuminating their experiences (Haydon *et al.*, 2018), narrative accounts of how adolescents with CKD experience, perceive or account for their bodies are not well represented in the studies reviewed in this scoping review. This present study addresses these gaps in literature and knowledge.

Chapter 4: Methodology

4.0. Introduction

This chapter presents the methodology underpinning this narrative inquiry. Initially, the study aims and objectives are outlined. The chapter is then divided into three sections. The first section provides an overview of narrative inquiry design, including the rationale for choosing this methodology. Section two outlines participant recruitment, data collection processes and ethical considerations. In section three, the data analytic process and researcher reflexivity is detailed.

4.1 Aim and Objectives of the study

The aim of this narrative inquiry was to explore adolescents' embodied experiences of living with chronic kidney disease. The objectives were to:

1) explore the experiences and perceptions of adolescents with chronic kidney disease in relation to the physical functioning and physical sensations of their bodies;
2) examine the impact of chronic kidney disease and medical treatment on adolescents' sense of self and embodied identity;
3) explore adolescents' embodied experience of medical treatment and relationships with health care professionals in the context of CKD.

4.2 Section One: Research Design

4.2.1 Introduction to Narrative

> *'Who are we but the stories we tell ourselves, about ourselves, and believe?'*
>
> *(Turow, 2005 p.90)*

Part of being human involves narrating stories to ourselves and to others (Plummer, 1995; Charon, 2006) and people provide accounts of life experiences through stories (Riessman, 2002a; Riessman, 2002b). We try to understand events and people by constructing stories to interpret and make sense of what is occurring around us (Jovchelovitch and Bauer, 2000).

Through stories, people create order, coherence, and connection between events that have occurred in their lives (Carless and Douglas, 2013). Narratives are considered the universal way by which we structure and make sense of our lives (Barusch, 2012; Andrews, Squire and Tamboukou, 2013). When people tell a story, they configure or give ‘narrative form’ to these events and experiences (Marshall and Rossman, 2011). In narratives, characters are positioned in space and time in order to make sense of what happened or what is imagined to have happened (Hinchman and Hinchman, 1997). The processes of narrative configuration in the context of illness is of particular interest to this study. According to Hyden (1997, p. 53), when a person’s life is interrupted by an illness, narrative configuration offers ‘an opportunity to knit together the split ends of time, to construct a new context’ and to fit the disruption caused by illness ‘into a temporal framework.’

4.2.2 Narrative Inquiry

Narrative inquiry is a method of research that explores stories to ascertain the meanings of the individuals' bodily and personal experiences (Bailey and Tilley, 2002). Narrative inquiry is based on the premise that individuals organise and tell stories about their lives (Riessman, 1993; Parker, 2004) and with stories; individuals make sense of their world (Jovchelovitch and Bauer, 2000). Thus, narrative inquiry refers to the study of the ways humans experience and represent the world through storied accounts (Connelly and Clandinin, 1990). People construct or configure their stories to convey a specific perspective of an event (Wang and Geale, 2015). Narrative researchers therefore are interested in what people choose to tell, how they tell it and what meaning this has for them as the actual content of the story itself.

Narrative inquiry has developed as a research methodology over the last thirty years, influenced by such disciplines as psychology (Bruner, 1986; Polkinghorne, 1988), anthropology (Ochs and Capps, 1996), socio-linguistics (Labov and Waletsky, 1967), sociology (Riessman, 1993), social action (Bell, 1988), education (Connelly and Clandinin, 1990; 2000) and medicine and illness (Frank, 1995). The field of narrative research is methodologically and theoretically diverse (Webster and Mertova, 2007). There are a wide range of understandings as to what constitutes narrative and how narratives can be analysed and represented. For example, Riessman (2008, p.155) highlights the diversity and complexity inherent in narrative research and states *‘There is no single way to do narrative research, just as there is no single definition* *of narrative'.* Definitions of narrative vary according to discipline, and may refer to extended accounts of life histories, such as in anthropology (Myerhoff *et al.*, 1992), or discrete units of discourse, such as in socio-linguistics (Labov, 1982). Labov's structural definition of narrative has resulted in a tendency to recognise narratives as only texts that appear to be well organised, with a beginning, middle and an end (De Fina and Georgakopoulou, 2008). Elaborating on Labov and Waletzky's (1967) definition, Bell (2009, p. 8) defines narrative as:

> *'a sequence of ordered events that are connected in a meaningful way for a particular audience in order to make sense of the world or people's experience in it…. This definition assumes one action is consequential for the next, that a narrative sequence is held together with a 'plot,' and that the 'plot' is organized temporally and spatially…. More than a list or chronicle, a narrative adds up to 'something…'*

In this study I took the position that not all people have the ability to provide a sense of coherence and meaning in life (Ricouer, 1984; Bruner, 1990). This is particularly so in the case of adolescent experience where the difficulties in attempting to verbalise complex experiences are well documented (Punch, 2002, Hendrick, 2008). Developmental issues in adolescence may influence processes of sense-making and articulation of stories. Adolescents may struggle with verbal forms of representation and communicate or perform complex emotions through behaviour (Özdemir *et al.*, 2016). This is often referred to as 'acting out' (Sawyer *et al.*, 2018). Furthermore, Andrews (2010) suggests that some life events (like CKD) may be so devastating that the unity between the temporal dimensions of the past, present, and future cannot be fully revitalized, stories therefore may be told in fragments with no beginning or end. Hence, in this study I defined 'story' as the act of telling, drawing and sharing of experiences that adolescents engage in as a means to recall an event or provide an experience with meaning. I considered that this would allow smaller unresolved stories to be captured that did not necessarily follow a logical beginning, middle and end (Sartwell, 2000; Bülow and Hyden, 2003). In defining narrative, I adopted Riessman's (2008) stance that 'a narrative can be the story constructed by the researcher from data which includes images or a set of images and narrative fragments from accompanying spoken or written text' (Riessman, 2008 p. 145). In the context of this present study, the word 'narrative' and 'narrative cases' then refers to the overarching narrative for each participant as analysed by the researcher which includes small stories and visual stories.

Social constructionist approaches disrupt notions of neatly ordered and boundaried configurations and representations of experience. Shlasky and Alpert (2007, p.43) contend that ‘the borders between ontology and epistemology become blurred: reality is shaped largely by the way in which we perceive it, know it, interpret it and respond to it’. Narrative research draws on the constructivist paradigm in which understanding of self and world occurs in an interpretive process that is both subjective and rooted within one’s culture (Brown, 2017). The process of narrating is fundamentally a social interaction, which means that the epistemology of meaning is created in the social realm (Crotty, 1998). The social act of narrating involves a concurrent process of engagement with self and society (Riessman, 1993) and social reality is a narrative reality that is constructed, fluid and multifaceted (Spector-Mersel, 2010). In other words, knowledge (and *all* reality) is socially constructed and discovered through researcher-researched interactions and relationships (Berger and Luckmann, 1967; Lincoln, 1990). Unlike the positivist paradigm, narrative research is approached with the view that the researchers and the phenomena studied are inseparable (Spector-Mersel, 2010 p. 216-217). A narrative researcher ‘does not *find* narratives but instead participates in their creation’ (Riessman, 2008, p.219). Narrative researchers engage in a process of co-construction and mutual reflection about the phenomena being studied.

4.2.3 Rationale for using Narrative Inquiry in this study

A large body of literature exists on the value of narrative inquiry as a way of understanding people’s first-hand accounts of their illness experiences (Andrews *et al.,* 2013; Wang and Geale, 2015; Haydon *et al.,* 2018) and the importance of incorporating these understandings into effective and sensitive care provision (Riessman, 2002a; Greenhalgh, 2016). Bell (2002) and others (Sandelowski, 1991; Frank, 2001) posit that narrative inquiry emerged in response to biomedicine’s focus on disease processes and quantitative, empirical research and consequent neglect of patient experience. Frank (2001 p. 358) is a strong proponent of the contribution of narratives in understanding illness experience, suggesting that illness stories challenge listeners to question the privileged status of biomedical formulations of disease and treatment which result in the ‘erasure of suffering from illness’.

Carless (2010) posits that narrating stories is an embodied act grounded on one’s experience of the world from the location of one’s own body. The stories we are told, and the stories we learn to tell about our bodies, are significant in relation to how we logically structure our embodied experiences and make sense of events and actions in our lives (Sparkes, 1998). Bodies cannot be separated from the conditions in which they exist (Krieger, 2005). In the context of this study, the body's story of living with CKD is accessed through spoken and visual narratives to bring experiences of embodiment to the fore revealing the innumerable ways everyday embodied experiences are constructed and interpreted by adolescents. Given that narrative research enables deeply hidden assumptions to surface through bodily exploration (Bell, 2002), it follows that the theory of embodiment (as discussed section 2.1) complements the narrative inquiry approach used in this study. Additionally, using a narrative approach helped generate stories that may help nurses and other health care providers to understand adolescents' experiences of living with CKD (Holloway and Wheeler, 2016). Moore and Hellenbeck (2010) argue that narratives can advance and enhance empathetic forms of understanding. Such narratives can in turn improve patient care by providing a more holistic perspective of the lived life (Alicea-Planas, 2016).

4.2.4 Limitations and Challenges of Narrative Inquiry

Narrative research is not without its limitations and challenges. Stories are personal as well as cultural, and the culture we live-in provides and shapes the types of story available, as well as the modes and conventions of telling. Some stories dominate within a culture**.** In the field of chronic illness bio-medical narratives of illness dominate. The emphasis on these `dominant narratives of science and medicine to explain chronic illness have overshadowed patients' experiences of their illness and bodily experiences (Hyden 1997, p. 49). If the individual's story is at odds with what dominates in a particular culture the individual may have few narrative resources for narrating individual experiences; thus an individual lives with an experience that has no narrative form. Furthermore, the story an individual tells is dependent on their 'narrative resources'. Narrative resource refers to a person's linguistic and non-linguistic ability to articulate or convey a story to an audience. A person who has no resources will find it difficult to articulate a story, similarly a person with few narrative resources will articulate a limited superficial story. Post-structuralist narrative approaches (Taylor, 2003; Lapum *et al.*, 2012) signal complexities and possibilities in meaning-making through highlighting the limits of socially constructed and habituated language in formulating and expressing interpretations of the lived world. Some experiences like traumatic and painful events such as serious illness are at times beyond words, uncertain and difficult to speak of (van der Kolk, 2014). This is a particular challenge in conducting narrative research. This has led to a range of narrative approaches that attempt to move beyond habituated language forms, for example; experimenting with language/text and alternative forms of expression (Irwin and Springay, 2008).

In the literature review there were no stories in nephrology literature about bodily experiences. One potential reason for the non-representation of bodily experiences in the literature is that the ‘story’ about CKD is predominantly a medical story where the focus is on medical treatments and regimes. As such, for the young people, there were no socially and culturally accepted ways to narrate embodied experiences, and no counter-narratives were evident in literature review; thus adolescents were silenced, living with a story that could not be told nor could not be heard. Counter-narratives provide an antidote, and challenge dominant and ‘totalitarian’ narratives that can be harmful, and life and identity limiting (Douglas, 2016). This is why - as Ken Plummer writes in Documents of life (1983) – stories and counter stories can only be told when they can be heard - stories will only be heard when there is a way to tell them and a body to hold and listen. One way to overcome some of the challenges of narrative research is to introduce an alternative method to convey stories such as the arts based method of body mapping.

4.2.5 Arts based research methods

Arts based research methods offer a particularly important and unique extension to narrative research (Casey, Proudfoot and Corbally, 2016) in that the creation of art draws on personal experience and the art produced tells stories about lived experiences. The term ‘arts-based research’ was coined by Eisner in the early 1990s and is an approach to knowledge building that combines the tenets of the creative arts in research contexts (McNiff, 2014; Leavy, 2015). Arts based research approaches are ‘sensitive and robust’ (Manning, Hemingway and Redsell, 2017 p. 69) research methods enabling expression of thoughts and experiences in forms that go beyond the verbal (Coad, 2012; Casey and Webb, 2018). Eisner (2008, p. 5) suggests that ‘knowledge or understanding is not always reducible to language … we know more than we can tell’. Furthermore, some experiences particularly complex experiences may be better understood through modes of expression other than language (Charon, 2006; Leitch, 2008; Schick Makaroff *et al.*, 2013). This is particularly so in the case of adolescent experience where the difficulties in attempting to verbalise complex experiences is documented (Punch, 2002).

Young people’s competencies and capacities are different from adult research participants (Yonas, Burke and Miller, 2013) and developmental issues may impede young people’s ability to fully articulate their experience.

Arts-based research allows access to dimensions of somatic knowledge located within the body (Carless and Douglas, 2017). A valuable aspect of arts based research is the understanding that emerges from ‘the act of doing or making art’ (Barone and Eisner, 2012, p. 48). In the process of creating, performing, and sharing a piece of art, stories are voiced and meanings created and articulated in evocative ways (Barone and Eisner 2012). Eisner (2008 p12), asserts that ‘many of the most complex and subtle forms of thinking' occur through working meaningfully on the creation of images 'whether visual choreographic, musical literary or poetic' and scrutinising them appreciatively. Efforts to involve adolescents in such innovative research process are increasing; some have employed creative arts based methods such as photo-elicitation, films, video and theatre productions to encourage dialogue about factors influencing their health and well-being (Ozer *et al.*, 2010; Jackson *et al.*, 2010; Jacquez *et al.*, 2012; Guillemin and Drew, 2012). Research has highlighted the potential of arts-based methods in the study of health and illness, particularly the ways in which participants (including children and adolescents) interpret, give meaning to and make sense of their experiences including embodied aspects of experience (Chalfen and Rich, 2007; Guillemin and Drew, 2010). Arts-based approaches have been successfully used in previous research to facilitate adolescents in ‘voicing’ their unique experiences and perceptions (Carter and Ford, 2013). In this current study the arts-based method of body mapping (BM) was used as a stimulus for adolescents to think about how their bodies had been affected by CKD as well as to create a visual narrative of their embodied experiences.

4.2.5.1 Body Mapping

Body mapping is a collection of activities that involve drawing full-sized body images, which tell the story of the body through the use of drawings, symbols, words and painting (de Jager *et al.*, 2016). The use of body mapping has traditionally been associated with psychotherapeutic objectives and outcomes and has more recently been recognised as a powerful form of research inquiry. Body maps have been used as a therapeutic tool and gained much attention when used with women living with HIV/AIDS in South Africa (Devine, 2008; MacGregor Hayley, 2009). In 2002, Jonathan Morgan, a clinical psychologist from the University of Cape Town, South

Africa, developed the Memory Box Project which was designed as a bereavement workshop to help women with HIV/AIDS to prepare for their own deaths and to leave their story behind for their children. In these workshops, facilitators discovered that women were starting to receive anti-retroviral treatment and so the focus was beginning to change with less emphasis on death and more on living with enduring disease processes (Meiring and Müller, 2010). Body Mapping grew out of the Memory Box initiative where graphic artist Jane Solomon adapted this technique using a narrative process to create body maps which reflected living with HIV/AIDS. Solomon (2002) designed and produced a comprehensive facilitator's guide to body mapping. The guide contains step-by-step guidelines for facilitators/researchers to collaboratively and sensitively support participants in creating narratively informed body maps (Solomon, 2002).

Body mapping is a creative and reflexive method for collecting visual data and is a valuable tool that encourages connection to embodied experience (de Jager *et al.,* 2016). Previous studies have reported the benefit of using body mapping as a data collection tool with adult populations in various contexts (Gastaldo *et al.*, 2012; Senior *et al.,* 2014; Ludlow, 2014; Silva-Segovia, 2016). Previous research with adolescent populations has also suggested that body mapping can lead to stronger engagement of participants in the research process and ultimately strengthen the richness and utility of data (Crivello *et al.*, 2009; Chenhall *et al.,* 2013; Davy *et al.,* 2014). As reported by de Jager *et al.,* (2016) body mapping is a useful research tool with youth participants, however this method has not been used as a research method with the adolescent population in the context of CKD. The use of body mapping in this study was an innovative method that filled a methodological gap in adolescent nephrology literature, as no previous studies have used body mapping to unearth bodily experiences of CKD. Furthermore, the use of body mapping in this study was considered a suitable method '*for gaining access to people's perceptions of their bodies'* (Cornwall, 1992, p. 1) and was a holistic method of amalgamating the mind and body (Skop, 2016).

4.2.6 Riessman's Narrative Framework

Riesman's (2008) approach to narrative theory, construction and analysis underpins the methodology of this study. Much of the focus of her work is concerned with processes of narrative analysis which will be discussed in more depth later in the chapter, however the guiding principles for the analysis work reveal a great deal regarding Riessman's approach to narrative. Riessman sees narrative as ubiquitous, citing Barthes in this regard:

> *'Narrative is present in myth, legend, fable, tale, novella, epic, history, tragedy, drama, comedy, mime, painting…stained glass windows, cinema, comics, news item, and conversation. Moreover, under this almost infinite diversity of forms, narrative is present in every age, in every place, in every society; it begins with the very history of mankind (sic) and there nowhere is nor has been a people without narrative…it is simply there, like life itself'*
>
> *(Barthes, 1982, as cited in Riessman, 2008, p. 4).*

Riessman is interested in the function of narrative in a social world; 'narratives are strategic, functional, and purposeful' (Riessman, 2008, p. 8) and serve a communicative function by informing, entertaining, persuading, predicting, and controlling. Riessman takes account of how narratives are told or performed to influence audiences. Narratives are socio-political, not just reflecting the person's life and social world but also effects on the person of living in the world and engaging with wider socio-political narratives and discourses. Thus Riessman's wide focus on 'what' is being narrated as well as 'how' and 'why' makes this approach particularly fitting to a research study that involves potentially non-traditional participant narratives in a context where bio-medical meta- narratives and discourses are privileged.

Riessman uses a typology in considering narrative and undertaking narrative analysis. This consists of four elements; thematic, structural, dialogic/performance, and visual. This approach is eclectic, encompassing and often reconciling perspectives from a wide range of narrative approaches; for example, while suggesting the more formulaic approach of Labov (1972) for analysing the structural aspects of narrative, Riessman's (2008) framework also accommodates more pluralistic approaches that come from constructionist, and post postern approaches, in particular, the notion of performativity and the recognition of visual approaches in narrative construction and analysis.

4.3 Section Two: Research Procedures

4.3.1 Sampling and Sample size

Purposive sampling was used to select adolescents who had first-hand experience of living with CKD. Purposive sampling involves explicitly selecting potential participants who are likely to generate information-rich data related to the phenomenon under investigation (Palinkas *et al.*, 2015). The sample for this study included five adolescents (aged 10-17 years) living with CKD. Riessman (2008) posits that sample frames typically remain small in narrative research because of the intricate and labour-intensive analytical procedures required in this type of research. The size depends on the phenomena under investigation and the rationale for the study. For example, a sample of four participants generated sufficient data in an in-depth study of adolescents' narratives of living with an ostomy (Garthwaite, 2008). The sample of five in this study was chosen as the stories gathered were extensive and, given the focused nature of the study, extremely detailed.

4.3.1.1 Inclusion and Exclusion Criteria

The sample eligible for inclusion in this study were adolescents:

1. aged between 10-17 years old,
2. who had a confirmed diagnosis of CKD,
3. who were physically and mentally able to participate,
4. who assented.

The age range of 10-17 years incorporates early, middle and late adolescence. This inclusion criterion responds to the literature that identifies adolescence as a particularly challenging time for young people who have to contend and live with CKD but also navigate typical adolescent biological and psychological changes (Snethen *et al.*, 2001; de Souza and de Lione, 2018; Clavé, *et al.*, 2019). Exclusion criteria were adolescents;

1. presenting with an intellectual disability or developmental delay,
2. with any additional significant medical conditions (other than CKD),
3. who did not assent despite parental consent.

Adolescents presenting with intellectual disability, developmental delay, or an additional medical condition were excluded from this study because this group of adolescents might have additional needs and concerns not directly related to CKD.

4.3.2 Recruitment process

Adolescent participants were recruited from a renal unit of a tertiary paediatric hospital in Ireland. A consultant nephrologist and a clinical nurse specialist informed potential eligible adolescents, including their parents, about the study. If adolescents (and their parents) expressed interest in the study, they were referred to me, the researcher, who was on-site in the renal ward. I then made contact with interested participants and families to discuss the study.

4.3.3 The story gathering process

Data generated in the process of narrative inquiry provided the researcher with the opportunity to observe and analyse the activities, movements and meanings of the individual participants. This process was enhanced by using different types of data (both verbal and visual) that facilitated insights and understandings that may have proven difficult to establish through reliance on a single method of data collection (Riessman, 2008). In this study, stories were gathered using unstructured interviews and body mapping as a visual narrative method. Adolescents were not obliged to take part in all data collection methods, and they could decide which elements they wanted to engage in. In this way, adolescents were in control of the way they conveyed their stories. This study took place in both a hospital and home setting. The hospital setting is a tertiary children’s hospital and data was gathered across a number of inpatient and outpatient settings including an inpatient renal ward which catered for children and adolescents requiring extensive investigations and management of diverse renal conditions; a haemodialysis day unit which is a four bedded unit adjacent to the renal ward consisting of three dialysis machines/bed spaces and one single-bedded dialysis room; and an outpatient clinic located behind the renal ward and adjacent to the haemodialysis unit which adolescents with advanced stages of CKD attended on a weekly or monthly basis. The home setting included the adolescents’ home and natural environment. In keeping with the objective of the study to follow adolescents over time and in various contexts, the location of data collection varied. Collecting narrative data took place over the course of 18 months during which both visual and verbal stories were collected at the same time, in an iterative process. I engaged in multiple interactions with the five adolescents. Appendix A provides the reader with an example of the data collection process with one adolescent spanning 18 months. The duration of data collection sessions with participants varied, lasting anything from ten minutes up to one hour and a half at a time. The aim of data collection sessions was to create a space where adolescents felt willing to share their personal stories. For the purpose of the thesis, I present data collection techniques separately, to provide the reader with contextual information on body mapping and unstructured interviews.

4.3.3.1 Narrative interviewing

While there are different kinds of data that can be used in narrative inquiry such as talking, writing or drawing, Riessman (2008) focuses on interviewing and posits that 'interviews are narrative occasions' (p.23). She argues for interviewing methods that offer participants the opportunity to tell their story in their own ways (Riessman, 2008) and in ways, which makes sense to them (Mishler, 1991). I adopted an unstructured approach to interviewing adolescents, which began by asking each adolescent to recount their stories of living with CKD. This type of interview takes the form of an informal and relaxed discussion through which both the researcher and participant 'journey together visiting topics of interest relevant to the research study' (Bessareb and Ngandu, 2010, p. 40). Structured interviews can limit or constrain open dialogue in narrative research as noted by Carless and Douglas (2013). I opted for an informal conversational style interview where interviews were not directed by pre-arranged scripts but directed by the participants. An unstructured approach to interviews afforded adolescents with a sense of ownership of topic discussions and helped to address power imbalance, an approach to interviewing advocated by both narrative and child health researchers (Riessman, 1993; Lambert *et al.* 2013). Furthermore, unstructured interviews allowed for organic stories to emerge from elements of the body maps that appeared relevant to the participant/researcher as the visual story making process unfolded.

The content of our conversations predominately centred on issues that adolescents wanted to discuss. Below are some examples of the types of information revealed by adolescents during conversational interviews for example they:

- recounted events and encounters (e.g., '*When I was still on P.D, like… my face used to swell every day' Jack 17 years*);

- communicated reactions and feelings regarding kidney disease and dialysis regimes (e.g., *'I hate that. I'm still fuming about it. I just want to go in and do my thing and go home'* Jack *17 years*);
- provided explanation of reactions and feelings (e.g., '*They like... Not lie to you, but they just promise stuff, and then it doesn't happen…then I kind of got angry' Maggie 15 years*).

Interviews were interactive. As Riessman (1993, p.55) notes 'interviews are conversations in which both participants – teller and listener/questioner – develop meaning together'. In this study, I determined that interviews were co-constructed by adolescents and me the researcher. For example, although adolescents were encouraged to tell their stories in their own way, the conversation was taking place because I had instigated it. Kvale (1996) refers to this collaborative relationship using the metaphor of the researcher as a 'traveller', journeying to distant places and bringing back stories about other people's lives. I found that reflecting upon these metaphors helped me to consolidate and clarify what I hoped to do throughout each narrative encounter, which was to go with adolescents' stories wherever they brought us. On occasions, I had to inquire more about topics that related specifically to this study. For example, '*You mentioned earlier about the time you were first told you needed dialysis treatment, would you mind telling me more about that?'.* This type of questioning helped to elaborate on issues that adolescents brought up and that I deemed to have been left underdeveloped. Riessman (2008) advocates for this type of questioning suggesting as it can expand and develop narratives. At other times, I sought clarification, understanding and interpretation of stories told. By using this approach, I was able to obtain information relating to everyday life experiences of living with CKD. As stated earlier, stories were simultaneously gathered and co-created using unstructured interviews and body maps.

4.3.3.2 The process of creating Body Maps

The arts-based method of body mapping was used in this study to assist young people to make sense of their experiences of CKD and to help them to articulate these embodied experiences through their visual narratives. Before using the body mapping technique with adolescents, I felt it was important that I as a researcher understood what the process of creating a body map entailed. Without fully experiencing the creative process itself, I felt I could not truly understand what I would be asking of study participants. For this reason, I undertook specialised training in body mapping as a research methodology with Dr Christine Lummis who has adapted Solomon's approach for use in wider health related therapeutic and research contexts (Lummis, 2013). The workshop took place over a two-day period and involved creating my own body map. This proved invaluable and gave me insight into some of the possible limitations and challenges of using this method. Following this training I made some slight wording modifications to reflect the context of this study as applied to adolescents living with CKD. An outline of body mapping activities is outlined in Table 2 and a more detailed account of each activity is provided in Appendix B.

While original works using body mapping have undertaken the process as a group activity (Solomon, 2002; Brett Maclean, 2009), for this study I engaged with adolescents in the body mapping process on an individual basis because adolescent participants were on a variety of different renal replacement regimes (i.e. dialysis) which restricted their availability to engage in group activities. Furthermore, using an individualised approach facilitated a more open discussion of issues that may be difficult for adolescents to discuss in an open forum. This individualised approach to body mapping has been used previously in research with adolescents (Davy *et al.*, 2014). The length of each of the 15 body mapping activities (see table 2) varied lasting between 30 minutes and 2 hours; these time frames reflect Solomon's recommendation in her original works (Solomon, 2002). The location and timing of body mapping activity varied throughout the study and fluctuated between the hospital and home setting depending on whether the adolescent was an inpatient or being cared for at home. Regardless of location, sufficient space was required to facilitate body mapping, as body maps can be as long as 2 meters. The body maps in this study varied in size from between 2.1 to 2.5 metres in length and 1 metre in width. In the hospital setting, I liaised with the renal play specialist regarding an appropriate environment/space in which to facilitate body mapping. I sought permission to access space in the hospital setting to conduct body mapping from the appropriate hospital personnel. In the home setting, I negotiated with the adolescent and their parents an appropriate place and time in which to conduct artwork in the home environment. Strategies to ensure privacy during individual body mapping sessions included the use of single rooms and using screen dividers in open ward areas. Other preparatory tasks included gathering and purchasing a variety of art supplies (for example, coloured paper, magazines, watercolour paints, pencils, glue, tape, scissors, pencil sharpeners, rulers, paint brushes, sponges, markers, pencil crayons, felt, tissue paper, construction paper, feathers, gloves and table clothes). I liaised with the play specialist and HCPs to ensure art supplies were safe and appropriate for adolescents with CKD as many people with renal conditions have skin sensitivities. I worked collaboratively with the adolescents as they created their body maps. In each exercise, I gave adolescents specific directives to follow which provided them with some guidance yet was flexible enough to allow them to explore their own bodies and relationships to others in a personal and safe way. In this process, each adolescent's body was traced on a sheet of paper. Thereafter a self-portrait, hand and foot prints, different colours and symbols were painted onto the body map to tell some of the stories on the 'outside' and 'inside' of their bodies. Appendix C provides an example of a completed body map. While I guided the body mapping process, adolescents had a greater degree of influence on the data created and the initial interpreting of this data via their narrative reflections on their body maps. During our conversational interviews, adolescents shared their stories regarding the images created. This is an example of iterative process of collecting visual and verbal narratives.

Table 2 - Overview of Body Mapping Activities

Body mapping exercise number	**Focus of exercise**	**Anticipated length of exercise**
1	Body tracing	30 minutes
2	Highlighting your body shape	30 minutes
3	Drawing where you come from. Drawing what you are moving towards	45 minutes
4	Personal print	45 minutes
5	Painting your support	30 minutes
6	Journey map	90 minutes
7	Body scanning: marking the power point in the body	20 minutes
8	Creating a personal symbol	45 minutes
9	Drawing a self portrait	60 minutes
10	Creating a personal slogan	30 minutes
11	Marks on the skin	40 minutes
12	Marks under the skin	40 minutes
13	Living with kidney disease	60 minutes
14	Drawing Treatments	60 minutes
15	Decorating and Finishing Body Map	120 minutes

4.3.4 Ethical Considerations

There have been calls for greater effort to be made to include vulnerable populations in research but with relevant safeguards in place (Long and Johnson, 2007). Adolescents are considered a vulnerable population (McGregor, 2015; WHO, 2018) due to their developmental stages concerning maturity and decision-making as well as the power differential between the researcher and the adolescents (Morrow, 2005). Although there is widespread debate on the vulnerable nature of this population, there is a general agreement for the need to recognise their agency and voice in research (Solomon, 2013; Graham, Powell, and Taylor, 2015). Specific ethical issues considered in this study were gaining access and ethical approval, the potential risks and benefits, obtaining informed consent/assent and protecting confidentiality and privacy (Huang *et al.,* 2014). The following sections will address the core ethical issues that were considered as an ongoing part of the research process.

4.3.4.1 Gaining access to hospital and ethical approval

Ethical approval to conduct this study was obtained from the University Ethics Committee and the Scientific and Ethics Committees of the hospital study site. Permission to access the hospital and renal unit (inpatient, outpatient and haemodialysis) was obtained from the Director of Nursing, Consultant Nephrologists and Clinical Nurse Managers respectively. Once ethical approval and access to the hospital/renal unit was obtained, I held a number of information sessions, over a 4-week period, and developed an information sheet (Appendix D) to inform staff (e.g. healthcare professionals, schoolteachers, play specialists and domestic staff) about the study and my role as researcher.

4.3.4.2 Navigating informed consent and assent

In this study, informed parental consent for adolescents to be invited to take part in the study was sought. This is in line with the Department of Children and Youth Affair guidance (Department of Children and Youth Affairs, 2012). The procedure for obtaining the informed consent and assent is outlined below.

Nominated gatekeepers in the renal department of study site informed parents of potential eligible adolescent participants about the study during renal clinic hours. If parents expressed an interest in finding out more about the study, they were referred to me. I then arranged an informal meeting to openly discuss the study in more detail. I provided information for the parent to consider further whether they would consent for their adolescent child to be invited to take part. The parent information sheet outlined the purpose/nature of the study, risks and benefits, confidentiality, privacy and child protection issues for their adolescent should the adolescent wish to take part (Appendix E). I arranged to meet with parents a week later or at their adolescent's next hospital appointment to ascertain their interest and willingness for me to approach their adolescent to invite them to participate, or not. Prior to obtaining parental written consent I verified their understanding of what their adolescent child would be asked to do in the study and encouraged them to ask questions. Subsequently, parental written consent was obtained for their adolescent's participation in the study (Appendix F).

Once parents gave their approval for their adolescent to be involved in this study, eligible adolescents were approached to ascertain their assent to participate in the study. The assent process in this study was deemed vital in helping adolescent participants understand the elements of the research project and to make a choice of whether or not to participate (Kumpunen *et al.,* 2011). Often one concern about obtaining assent is young people's ability to understand information (Department of Children and Youth Affairs, 2012) highlighting the need to present information in an accessible format relative to the cognitive abilities of the young participants (Marshall *et al.,* 2012). Consequently, I designed two versions of information leaflets (Appendix G and H) and assent forms (Appendix I and J), one for younger and one for older adolescents to reflect potential differences in developmental stages. Using accessible language, I included information on what the study involved, and the associated risks and benefits. Due to the ongoing nature of data collection over a prolonged time, after initial written assent was obtained from adolescents, verbal assent was an ongoing process that was renegotiated on an ongoing basis at every point of data collection (Crane and Broome, 2017). Adolescents were informed that should they wish to withdraw from the study at any point, they were free to do so without any negative consequences. However, no adolescent withdrew from the study.

4.3.4.3 Benefits, Risks and Burdens

A dilemma in this study was contending to the potential tensions between risks, burdens and benefits of involving adolescents undergoing continuing medical treatments in research (Daley, 2013). This study is non-therapeutic in nature therefore no direct personal benefit to the adolescent could be assured. The direct and indirect benefits of this study were outlined from the onset so that adolescents clearly knew what they could expect. For example, adolescents were informed that knowledge gained from this study would provide health care practitioners with a deeper understanding of the unique needs and embodied experience of adolescents living with CKD. Adolescents were also informed that their stories may benefit other adolescents suffering from CKD.

Bold (2012) maintains that narrative research by its nature may become more intrusive than expected, drawing on physical and emotional reserves to an extent that participants do not expect. While it was difficult to estimate at the beginning what harm might occur from engaging in informal conversations and body mapping, I was conscious that adolescents could get upset especially if questions triggered memories of distressing experiences or feelings (Murphy and Dingwall, 2001). Body mapping is noted as an emotionally intensive activity that can arouse psychological and emotional distress for both the participant and facilitator (Maina *et al.,* 2014). In this study during body mapping activities adolescents were instructed to pay attention to what was happening within their own bodies as they worked on the body maps and this process had the potential of unearthing hidden anxieties, triggering painful memories and reminding participants of the fragile nature of their sick body (Subotzky, 2004). Revisiting of these events may be traumatic or therapeutic to the teller and the listener (Maina *et al.*, 2014). In this study body mapping activities were divided into 15 sessions with varied time frames for completion and adolescents were given sufficient time and space to reflect on and deal with issues that emerged during the process. I also continually ‘checked in’ with adolescents to see how they were mentally, emotionally, and physically handling the process (Hartman *et al.,* 2011). In the event of an adolescent being distressed the following protocol was followed

(i) being aware and open to adolescents’ emotions, validate them and make them feel that they were in a safe environment where these could be expressed

(ii) discontinuing recording devices and halting body mapping activities followed by asking adolescents if they would like to continue or not.

(iii) support services were available in the hospital via a clinical psychologist should any adolescents become upset or anxious during data collection.

Although the narratives often contained recounts of painful experiences, none of the adolescents required psychologist input or counselling. Listening and responding to adolescents' narratives (both verbal and visual) was at times emotional, for me as a researcher. To manage the risk of researcher fatigue/burden, I engaged in self-care techniques such as maintaining reflective field notes, availing of supervisory support and debriefing, (Gastaldo *et al.,* 2012) and family and friend support (Dickson-Swift *et al.,* 2009).

Another ethical risk considered in this study was the potential level of burden it might impose on the lives of adolescents (Kennan, 2016). I was conscious of the risk of over-burden this study could impose by asking adolescents to engage in research activities, and this is reflected in an exact from my reflective diary below;

> *'I'm sitting there in someone's home –I've interrupted Emily's home life, the nerve of me! - I don't want to impose on this family. Even though I've gotten to know them quite well, they are very busy. Emily attends hospital 4 days a week and today is her day off from dialysis. I am conscious that this is her time away from hospital, away from her illness and here I am asking her to share with me personal stories about her kidney disease. I do not want to burden her and as I sit there I begin to realise what I am asking of these young people. Doing research and fitting research into the busy lives of young people is no easy matter, practically or ethically'.*
>
> *(Reflective diary, February 25th, 2015).*

It was important for me to minimise the burden on participants. To address this issue of over burden I had to be flexible in order to fit research into the busy lives of the participants. The location, nature and frequency of contact varied depending on the individual contexts and wishes of adolescents and their families.

4.3.4.4 Protecting the Adolescents' Rights to Privacy

Three core issues relating to protecting adolescents' rights to privacy were addressed in this study (i) child protection safeguarding procedures, (ii) protecting and maintaining anonymity and (iii) confidentiality issues specific to using body mapping.

4.3.4.4. 1 Child protection safeguarding procedures

This study was carried out in accordance with Children First, National Guidance for the Protection and Welfare of Children 2017 (DCYA, 2017). A number of child protection safeguarding factors were implemented throughout this study including:

- Completion of Garda-vetting prior to data collection
- Completion of training TULSA (Child and Family Agency Ireland) Child First online module
- Development of a number of protocols for reporting Child Protection Concerns with in accordance with the Children First, National Guidance for the Protection and Welfare of Children document (DCYA, 2017) (Appendix K).

4.3.4.2. 2 Protecting and maintaining anonymity

Ensuring anonymisation of participants in narrative research is problematic. This is attributed to the fact that data collected in narrative research is so detail specific and 'saturated with identifying markers' (McLeod, 1996, p. 311) that there is a possibility of participants being identifiable (Smythe and Murray, 2000). In such cases, as Chase (1996) and Plummer (2001) both point out, research participants are made easily recognisable to those who know them when they divulge personal stories even when pseudonyms and other forms of disguise are used. The fact that this study recruited from a small specific population group (adolescents with CKD) and took place within the context of the only haemodialysis unit for children and adolescents in Ireland, anonymisation was challenging. It was (and still is) feasible that the adolescents and their stories might be identifiable to their parents or to hospital staff who read the final thesis or publications that arise from this study. Recognising the limitations involved in protecting the anonymity of participants, all adolescents and their parents were made aware of the difficulties involved and I informed them of the strategies I had in place to limit the risks. For example, while some HCPs were aware of the identities of adolescents (because some data collection took place on open wards), no individual information was shared with them. Each adolescent was given a pseudonym in order to protect their identity. All identifying details were removed from raw data and data transcripts with access to any identifying codes accessible only to me. All data were stored on a password protected computer accessible only to me. Any personal information (i.e. body maps/consent forms) relating to adolescents was stored in a locked filing cabinet in my office and will remain there for a period of 5 years or until publication of the study at which point computer files will be deleted and paper records shredded.

4.3.4.4.3 Confidentiality issues specific to using body mapping

The final challenge of maintaining confidentially in this study emerged from using body mapping. Often adolescents where attached to their dialysis machines while drawing on their body maps. This invariably meant that some clinical staff knew who was taking part in the study; an unavoidable situation when conducting research within a clinical setting. When negotiating access and during information sessions held with health professionals, I stressed the importance of respecting adolescents' confidentiality. I took measures to ensure privacy during individual body mapping sessions by using single rooms where available and using screen dividers in open ward areas. Although some health care staff may have witnessed body maps being created from a distance as they approached or attended to the medical needs of the adolescent, body maps were folded and removed from sight. Care and attention were given to ensuring that no personal information featured on any of the body maps produced in this study. This was difficult at times given that there were certain activities in the body mapping process in which potential identifiable information could translate onto the map, for example creating a self-portrait. Some adolescents were very good at drawing which put their own identity at risk. In these situations, I reminded adolescents of anonymity and asked them to think of creative ways to do their self-portraits. During other body mapping exercises, for example 'painting your support', some adolescents wanted to name family members and friends that supported them throughout their illness. I asked adolescents to refrain from using real names, real pictures or including exact names of family members or friends and instead I recommended alternatives such as using symbols or nicknames. Like interview data, body maps were stored in a safe place with restricted access and digitalised versions were stored in a password-protected and encrypted computer accessible only by me. Adolescents and their parents were made aware of and assented/consented to the use of images from body maps in the final thesis and wider dissemination activities (i.e. conference presentations, publications).

4.4 Section Three: Data Analysis

4.4.1 Narrative Analysis

Narrative analysis incorporates a range of diverse approaches. Riessman (2008) argues however that this diversity is a major strength in narrative studies. She describes narrative analysis as a family of analytic approaches to texts ‘as in all families, there is conflict and disagreement among those holding different perspectives’ (Riessman 2008, p. 151). The methodological and analytic approaches, which are used within narrative research, dictate the role that the researcher will take in capturing and interpreting the participant responses (Bal, 2009). The level of analytic sensitivity in Riessman’s approach to intrapersonal and interpersonal processes was particularly well suited to the focus of this research. Riessman (2008) advocates the use of a ‘case centred’ rather than ‘category-centred’ approach. In case-centred approach, the focus is on one participant at a time to gain insight and reflect on their individual story. This approach preserves and interrogates particular instances and sequences of action in a story, such as how language is negotiated and what narrative genres are used in conversation, and other unique aspects of a given case (Riessman, 2010). By contrast, category-centered approaches generate theoretical concepts inductively across participants (Riessman, 2010). For this present study, each adolescent account of their CKD experience was analysed and presented as an individual case. Using a case-centred approach, I kept the whole story of adolescent’s experiences intact. This individualised approach was followed by a cross-case analysis, which also follows Riessman’s (2008) narrative analysis approach. The aim of the cross-case analysis was to generate insight into the similarities across the five individual cases, details of this process is described in section 4.4.7.

Narrative research provides rich, complex and nuanced data that is not necessarily easy to analyse. Riessman (2008, p. 69) in describing narrative analysis, observes that

> *‘The methods are slow and painstaking. They require attention to subtlety: nuances of speech, organisation of a response, local contexts of production, social discourses that shape what is spoken and what cannot be said.’*

Squire *et al.*, (2014) also acknowledge the complexities involved in analysing narrative, highlighting the lack of structure or rigid method for researchers to follow, running the risk that researchers may remain at the level of description rather than undertaking a more rigorous analysis. While there is no standard process or steps to analysing data, several authors have offered guidelines to assist researchers to engage with the interpretive process, all of which require a construction of data for further analysis (Denzin and Lincoln, 2005; Riessman, 2008). Riessman (2008) proposes a typology of analysis: thematic, structural, dialogic/performative and visual. However, she notes that the boundaries between these four types can sometimes be blurred and the various aspects can be combined to provide a rigorous analysis that examines the content, structure and context of narrative production. In this study, each of the elements of this typology was incorporated into the analysis.

4.4.2 Thematic analysis

Thematic narrative analysis, according to Riessman (2008), is the most widely used analytic strategy. Its focus is on the content i.e. 'what' is said. The unit of analysis is the complete narrative, which is not segmented in any way. In this study, thematic analysis was achieved through the primary focus on individual cases, establishing the coherence of narrative content in both the verbal and visual narratives. Recurrent and connected content themes were identified in each participant's verbal and visual narrative.

4.4.3 Structural analysis

Structural analysis attends to 'how' a story is told – the sequencing, specific words and metaphors. Riessman (2008, p. 81) likens this type of analysis to analysing a musical score, considering that in this process of '*how a composition is structured and what each part contributes, musicians break the score down, see what each instrument or musical phrase adds, that is, its function in overall composition*'. Here, Riessman incorporates socio-linguistic influences such as that of Labov to accomplish this detailed examination of the structure of the text. In relation to the structure of visual analysis, she is influenced by the work of Rose (2016) in examining the structure of the visual piece including colours, metaphors and placing of elements. This focus on how content is organised can generate insights beyond what is simply 'said' in a narrative. In the context of my study, structural analysis involved paying attention to the speech patterns and construction of verbal narratives. Some adolescents are more fluent verbally, while others articulate halting, partial or ‘thin’ narratives. These structural modes can inform interpretations of the adolescent sense of identity and agency. In relation to the visual narratives, structural analysis involved use of colours, space occupation on the map, juxtaposition of elements on the map, size/emphasis of various elements/images.

4.4.4 Dialogic/Performative analysis

Riessman (2008) argues that the thematic and structural approaches are the two foundations of narrative analysis, and that the dialogic and visual methodologies build on these. Dialogic/performance analysis is based on the social constructionist proposition of narrators as social actors performing according to their interpretations of self and audience. Here, Riessman is influenced by the social constructionist theory of Erving Goffman (1959). Central to Goffman's theory is the social construction of the self as it is presented to and managed for others. Goffman uses the term ‘performance’ to refer to all the activity of an individual in front of a particular set of observers, or audience. Through this performance, the individual, or actor, gives meaning to themselves, to others, and to their situation. These performances deliver impressions to others, which communicates information that confirms the identity of the actor in that situation. Similarly, in research terms performativity is viewed in a similar way. Building on Goffman’s work on performativity, Riessman developed her own performative approach to narrative analysis. According to Riessman (2008), a performative analysis, is concerned with, and directs researchers’ attention to, examining how talk among speakers is relationally and interactively produced and performed as narrative. The performative approach focuses on both content and performative aspects in the construction of narrative, for example, language, positioning of characters, audience and self (Riessman, 2008). It examines to whom a person is talking and for what purpose are they engaged in conversation (Riessman, 2008). Consideration of these socio-political forces are important in the analysis of the narratives of vulnerable young people who are often at a disadvantage in adult centred contexts. It is important to examine how these participants are positioned and how they position/perform themselves to achieve/exert agency. The core aspects that Riessman suggest are common in performative analysis include attending to context; attending to language and attending to the function of the narrative (the work of the narrative).

4.4.4.1 Attending to Context

Performance analysis focuses on the interactional and institutional context in which the narrative is produced (Atkinson, 2005). Performance analysis interrogates how talk among speakers is interactively produced and performed as narrative. This approach involves a close reading of contexts, including the influence of the researcher, setting and socio-cultural circumstances on the production and interpretation of narrative within certain situations. To guide me in analysing context I considered the following contexts as recommended by Riessman (2010);

1) The interaction between the interviewer and interviewee,
2) The local context of the narrative (where in the overall account does this particular bounded narrative appear),
3) The broader social context (what are the taken for granted assumptions of the participant, what impact does the wider world have on the assumptions of the interviewer and interviewee).

Riessman (2008) proposes, ‘meaning in the dialogic approach does not reside in a speaker’s narrative, but in the dialogue between speaker and listener(s), investigator and transcript, and text and reader’ (p. 139). The voice of the researcher and the subjectivity they bring from their own experiences are part of the analytic processes. Consequently, in this study, I acknowledged myself as an active participant in the narrative and its interpretation-a distinguishing feature of performative analysis.

4.4.4.2 Attending to Language

Riessman (2008) points out that in performance analysis language; in particular, the words and styles participants use to narrate experiences, must be scrutinised and not taken at face value. This type of analysis demands a close linguistic reading, rather than accepting the denotation of words used, and advocates questioning the structure and effects of language, the positioning of the people involved and other aspects of the narrative’s construction (Riessman, 2010). Attending to the language used by adolescents (in both textual and visual data) was an important component of analysis in this study. In analysing language, I followed Riessman’s (2010) line of questioning:

1) How is language used?

2) What does this achieve? For example, how are characters in the narrative positioned using language?
3) What do the specific words a participant uses carry on their backs from prior uses?

These questions helped me to examine the linguistic choices adolescents made and I analysed certain words, phrases, key metaphors, use of pronouns, use of direct speech, verb tenses and other linguistic choices adolescents made. I also examined the language contained in participants' visual narratives specifically examining the symbols and metaphors used to express embodied and nuanced experiences. Attending to the nuances used in language allowed me to make inferences on the effect these had on both visual and word-based text. It was also crucial that the narratives represent both the voice of the researcher and that of the participant, so as to recognise that meaning is created relationally.

4.4.4.3 Function of the narrative (the work of the narrative)

The function or as Riessman (2008) refers to it 'the work that the narrative does' refers to the purpose of the narrative. Riessman (2008) points to the construction and performance of identities in the dialogic/performance method. Individuals negotiate how they want to be known in the stories they create collaboratively with their audiences. I observed and analysed how and why adolescents' performed themselves in stories. I was drawn to Goffman's theory (1959) that suggests people perform their desirable selves in order to preserve 'face' in situations of difficulty. Riessman (2008) also suggests that participants do not simply tell a story or communicate information, they are doing something, presenting themselves and their world in some way. As Riessman (2008) suggests narratives ate purposeful, they are composed for the listener and other invisible audiences to accomplish something-to have an effect. In this, focusing on the embodied experiences of adolescents living with CKD, the meaning making function of narrative is a key element. To assist me in analysing performance with an emphasis on the work of the narrative I attended to the following questions adapted from Riessman (2010);

1) Why was the story told that way?
2) What did the story accomplish for the speaker?
3) What did the story accomplish for the audience?
4) What does the speaker accomplish by adopting a particular narrative form?

Following the dramaturgical framework performative approaches can analyse the narrative as scenes. The story is considered as well as the context, speaker, and listener. The concept of time, past and present, is important in the analysis. In dialogic/performance analysis, both thematic and structural approaches are used. The language of the narrative is scrutinised, and the face value of the language is not taken for granted. Meaning is constructed from speaker to listener. Seeing narrative as dialogically produced and performed, dialogic/performance analysis views stories as social artefacts which say as much about society/culture as it does about a person/group.

4.4.5 Visual analysis

Visual analysis focuses on how people communicate using images, either through telling a story with images or telling a story about images that tell a story (Riessman, 2008a). Riessman, 2008, p. 182) states, 'visual images are so thoroughly embedded in our worlds that not to take them seriously and not to work at making them part of analysis, is to reduce our understandings of subject worlds'. As previously discussed, image making goes beyond the limitations of linguistic narratives and can help people encounter and express nuanced and evocative experiences. This is particularly useful for young people who may be contending with verbal inarticulacy associated with adolescent development, illness trauma and medical contexts where individual narratives are colonised by homogenous, habituated perceptions of CKD. Visual analysis is closely allied to Riessman's (2008) conception of performative analysis as the production of visual images could be considered as the performance of meaning in a social context and there are similar pre-occupations; particularly the focus on the context of narrative production the performance/language of the image and the recursive/reciprocal relationship with the audience. Riessman (2008) recognises the similarities between visual analysis and word-based analysis. For example, she contends that visual analysis is created with a particular purpose or function. In word-based analysis, participants perform their preferred identity using words and story construction. Correspondingly, in images researchers must critically scrutinise participant's reasons behind image creations (*this relates to the work of the narrative),* determining how an individual's identity is performed visually, and for what purpose (Riessman, 2008). As with word-based narratives, multiple readings are always possible there is not one singular reading of an image (Riessman, 2008). Visual genres can include photography, image making/painting, and video. In her consideration of visual analysis, Riessman (2008) draws on the work of Rose (2016). Like Rose, she contends that images do not just ‘speak for themselves’ but are often co-constructed between participant and researcher, participant and audience (Riessman, 2008, p. 179).

Riessman (2008) suggests images need to be contextualised and explained and that three sites for analysis needs to be incorporated into visual narrative analysis: the story of the production of the image, the image itself and how it can be read. In this study, contextual visual analysis is achieved through making visible the conditions of image production, including the researchers own influence, soliciting participant explanations and accounts of their visual narratives; the function of the image and the intended audience and a thorough analysis of the image itself; examining what was absent from the narrated account but visible in the image and vice versa and the possible interpretations that can be made, based on content and structure.

4.4.6 Analytic Process for Narrative Cases

The practical steps to analysing the five individualised narrative case accounts are outlined in this section. In keeping with Riessman’s approach, individualised cases were analysed with a particular focus on the context, function and language. I analysed the different features in the data namely: actors (e.g. characters and their positioning in a story); settings (setting of the story performed); the enactment of dialogue between characters (reported speech); and audience response (the listener(s) who interprets the drama as it unfolds, and the interpreter in later reading(s). Table 3 outlines the procedures followed in analysing individual narrative cases.

Table 3 - Analysis process for analysing individual narrative cases

Steps	**Analytic activity (Riessman, 1993; 2008)**
1	I listened to the recorded interviews, becoming familiar with the overall content of stories and noted any significant verbal communication characteristics as participants relayed stories of their experiences; e.g. emotionality, verbal emphasis at particular phases in the stories. These notes were included in the interview transcripts (thematic/structural/performative analysis).
2	The interview recordings and field notes were transcribed, and the visual images were analysed alongside verbal data.

3	Written transcripts were read and re-read and visual images were studied closely and in relation to the accompanying participant explanations. Through this activity, I became familiar with the verbal and visual language, images, content and structure of each narrative case (thematic, structural and visual analysis).
4	I then transcribed elements of text that took narrative from and those that related to the specific images created by participants. Thus, the data was reduced to core narratives and synergised visual and textual narratives. Riessman 1993; 2008 terms this narrative reduction (thematic, structural and visual analysis).
5	I engaged in what Riessman (1993, p. 67) terms analytic induction; noting what 'jumped out' e.g. striking language, visual metaphors, narrator emphasis/performances and recorded these observations for further analysis (thematic, structural, performative and visual analysis).
6	The next step involved a deeper analysis of content and plot in the text and images. Riessman refers to this as the 'what' of the narrative. Attention was paid to language and visual content, focusing particularly on recurring or emotion-laden words and images (thematic analysis). I examined structure; how the textual/visual narrative was organised and why the narrator told the story in this way (significance of chosen language/ images, narrative style/performance). Riessman refers to this as the 'how' of the narrative (structural, performative, visual analysis).
7	Following Riessman's (2008) framework, the data were then analysed for the wider social and cultural influences evident in the narrative construction through the language and images used. This included an examination of power relationships both in the story content and in the way the narrative was configured and shared (dialogical/performative and visual analysis).
8	Findings for each of these areas; content, structure, performative and visual aspects/ contexts were combined and overall findings for each individual narrative were composed.
9	Following the analysis of the individual narrative cases; I carried out a cross case analysis (Riessman, 2008) to identify commonalities and disparities across participant narratives.

Appendix L provides an example of a transcript demonstrating analysis of context, language and function of a narrative. Body map images were analysed using the same analytic technique (see Appendix M). Stories emerging from both interviews and body maps were used to present adolescents' narrative case accounts of their illness experience. Following the individual analysis of the narratives, the narratives were compared in order to determine what they had in common; the details of this process are outlined in the following section.

4.4.7 Analytic Process for Cross Case Analysis

While analysing the narratives of adolescents produced whole accounts of their illness experience, in contrast cross case analysis produced distinctive themes that emerged across cases. Riessman's (2010) comparative approach to cross-case analysis was used. In a comparative approach, content is the exclusive focus and involves identifying common thematic elements while preserving narrative features. According to Riessman (2008), a thematic approach is useful in finding commonalities across cases. Although cross case analysis adopts a thematic approach that is common in other qualitative research studies, what differentiates it from other approaches is that it takes the individual narrative cases as its primary data for analysis (Polkinghorne, 1995); rather than returning to the original transcripts. In this study, I analysed the small stories (including verbal and visual stories) within each narrative case. The different phases of the cross case analysis are summarised in Table 4.

Table 4 - Phases of Cross Case Analysis

Phase	**Description of the process**
1. Familiarising with stories	Reading and re-reading each narrative, noting down initial ideas from each story within each narrative case.
2. Coding stories form narrative cases	Coding similar features of the stories relevant to research questions, collating data relevant to each code.
3. Developing sub-themes from the coded stories	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Generating overarching themes	Generating a thematic 'map' of the analysis.

In drawing out themes for the cross-case analysis I began by reading and re-reading the narrative cases of each adolescent. I then separated words and sentences across the narrative texts in a process of manually coding the data. I coded all the sections from each narrative case that related to embodied experiences. By identifying common patterns, I collated the codes into possible sub-themes putting together all data that were pertinent to each possible sub-theme. The analysis of narratives did not take place in a linear fashion and the process saw me going backwards and forwards between the coded stories. I generated five main overarching common themes that arose from my analysis of the individual narrative cases. I have presented the main themes and sub-themes from the cross case in Chapter 10.

4.4.8 Maintaining Quality and Rigour

To ensure quality and rigour in narrative research, issues of verisimilitude, trustworthiness and reflexivity need to be addressed (Loh, 2013). These issues are addressed in the following sections.

4.4.8.1 Issue of Verisimilitude

Verisimilitude is an important criterion with which to judge the value of narrative inquiries (Connelly and Clandinin, 2000). Verisimilitude does not establish truth-this is not what a narrative study is about (Loh, 2013). A narrative account is said to exhibit the quality of verisimilitude when it resonates with lived experiences (Schwandt, 2015). In order to establish verisimilitude, the narratives presented must honour the voices and meanings of the participants and offer the ‘truth’ of these lived experiences to readers of the study for their interpretations. Denzin and Lincoln (2005, p. 577-78) identify the ‘crisis or representation’ which refers to the challenges involved in representing fairly and meaningfully, all the voices in the research process. Denzin and Lincoln (2005) suggest a variety of strategies to support verisimilitude and representation. These include collaborative research methods, creation of multi-voiced texts and interviews were ‘co created’. I have used some of these strategies to assist in verisimilitude of this study. For example, using the arts-based method of body mapping addressed the collaborative aspect of representation as well as the empowering adolescents to become active participants in the research process. Furthermore, adolescent participants provided their rationale and explanation behind images created. These strategies helped to ensure that narratives presented in this study are representational of participant experiences as they decided which experiences to share and what images to draw to represent their experiences of CKD.

4.4.8.2 Issue of Trustworthiness

Trustworthiness is one way researchers can persuade themselves and readers that their research findings are worthy of attention (Lincoln and Guba, 1985). Trustworthiness is an iterative and reflective process that developed over the course of this research study. Lincoln and Guba (1985) suggested several techniques to address trustworthiness such as credibility. To address credibility in this study, the story gathering process involved extended engagement and interaction with adolescents over an 18-month period. During this time, I engaged in an ongoing process of validation with the adolescent participants by seeking clarification for images drawn and stories told. Furthermore, the trustworthiness technique of peer validation and audience validation, were used in this study. Through a process of peer validation, the interpretation of a study's data can be verified (Loh, 2013). To establishing trustworthiness of my interpretations of adolescent's stories, peer validation was achieved through my two academic supervisors; one who is an expert in narrative research; the other an expert in children's research. Peer validation provided an external check on the research process, as well as ensuring my interpretations and findings were clearly derived from the data. My interpretations of adolescents' narratives and the cross case analysis of narratives were sent to them and they critically interrogated my work and interpretations which helped me to think about my analysis. In addition to peer validation, I also engaged in audience validation. This involved validation from the main intended users and readers of the study (Patton, 2002). Audience is important for establishing trustworthiness because the views from those in the field, and other researchers, allow for a fuller and rounder understanding of what is happening in the field (Loh, 2013). I presented the study design and findings at national and international conferences in both the fields of nephrology and narrative research (Appendix N).

4.4.8.3 Reflexivity

To enhance the rigour of this study and to help me to consider my experiences, perceptions and responses within the research process, I engaged in reflexivity. My own personal interest contributed to and was integral to the research process. Narrative researchers are advised to carefully consider their reasons for conducting a particular study (Hickson, 2016). My interest in the topic was at once personal and intellectual. As stated in Chapter 1, my own son suffers from a nephrology-urology condition and so I came to this study with first-hand experience of some of the daily challenges faced by adolescents living with chronic illness. This unique insight meant that I needed to reflect on my own position, biases and assumptions and how these may influence this study. I kept a reflexive diary as recommended by Crepeau (1997) and Primeau (2003). This diary served as my record of what was happening throughout the study and enabled an understanding of my thought process and feelings, which ultimately influenced the research. The literature on rigour and quality in narrative inquiry increasingly acknowledges the importance of reflexivity (Clandinin *et al.,* 2012; Goldstein, 2017). Riessman (2015) describes reflexivity as taking account of the researcher's role in the production of the story and believes that the researcher is inseparable from the story produced given their engagement with the data and their interpretation of it. I used reflexivity throughout the study not only when reporting findings but also in data collection and data analyses, and writing up as discussed below.

4.4.8.3.1 Reflections upon data collection

At the outset of the study, I spent time getting to know each adolescent participant which involved hanging out with the adolescents while they received dialysis treatment or were waiting for outpatient consultations. For narrative inquiry to be effective, researchers need to be cognitively and emotionally connected with participants, as this allows researchers to enter participants' 'meaning-making' worlds with empathy and understanding (Rager, 2005). As I spent time interacting with adolescents, I developed a close and trusting rapport with them. I watched movies and TV programmes; we discussed pastimes, played cards and video games. During this time, I did not share in depth my own personal experiences with the adolescents, I did tell them that I had experience of renal illness in my family and this allowed us to identify with each other at a human level. Some were curious about this; others were not. Other than a brief mention of my own family experiences, I did not spontaneously offer further information about my son but, if asked, I replied honestly. In my reflective diary, I was able to process my own thoughts as a mother of a child with a nephrology-urology condition. I personally found it very important to write and process those thoughts, in order to examine the potential influence of my own experiences and perceptions in all the activities of the research endeavour.

In this study, adolescents gave accounts that resulted from reflection on their own lives and experiences of living with CKD. Their accounts were influenced by the way in which I collected data with them and by my presence as co-constructor. I thought about the importance of reflexivity and considered my position as the researcher. I was initially nervous about documenting my personal views and thoughts as illustrated in the extract from my reflective diary below.

> *'At the onset of this study, I felt some trepidation at the thought of reflecting on and writing my own thoughts and feelings. It seems clear now (having begun data collection), that if I am not writing down ideas and thoughts as they come to me, then those insights will be forgotten. Since I've started to write reflective field notes, I am becoming more aware of what I am seeing, as well as what is inhibiting my seeing. For example, I find at times I am distracted by the noise of the dialysis machine, but I am also distracted by my own assumptions on what it must be like to be dependent of a machine for survival, such thoughts are clouding me from seeing what is truly important from the adolescents' perspectives. However, reflecting on such instances is helping me to become more focused. By listening to their stories, I am beginning to hone in on aspects of CKD that I never thought about before. It seems now that this study is constantly on my mind'*
>
> *(Reflective diary, November 6th, 2014)*

The stance I adopted with the five adolescents in this study could best be described as standing beside: listening closely to their stories and trying to appreciate their perspectives on their life and experiences as accurately as possible; this is the position favoured by Frank (2010). I did not take the position of the expert and tried not to judge or categorise. At the end of most of the body mapping sessions or interviews, usually over a cup of tea, some adolescents asked me more about myself and my family and this acted as a useful winding down after a data collection session. I believe this also allowed adolescents to appreciate that I was genuinely interested in understanding what their experiences were and they trusted me enough to share theirs. Some of the adolescents openly told me that they had never spoken to anyone about certain aspects of this illness experience before and this highlighted to me that they felt safe and comfortable in discussing topics with me. However, this disclosure surprised me, realising that in navigating this challenging and life changing condition, these young people did not have the opportunity or support to articulate troubling aspects of their bodily experience.

4.4.8.3.2 Reflections upon data analysis

Riessman (2015) believes that research is inseparable from the particular investigator, their observations, their engagement with the data and their interpretation of it. Analysing interview data and analysing body maps was time-consuming and emotionally draining. I spent long periods on my own considering their stories and gazing at their body maps. At times, I would find tears running down my cheeks as I listened back to audio recordings of our conversations. In presenting the findings, I will refer to reflective diary entries to illustrate my thinking and perspectives and how these shaped the narrative analysis. Through this process, I was able to develop my awareness of my own biography, assumptions and personal values, and in so doing, provide a context in which my analysis and interpretation of data could be understood.

4.4.8.4.3 Reflections upon writing up

There are multiple 'voices' in this thesis: the voices of adolescent participants and my voice. Riessman (2008) asserts that this plurivocity is a normal and important feature of narrative expression. Davis and Dwyer (2017) acknowledge the challenge for narrative researchers in presenting the voice of participants and the voice of the researcher. In writing each chapter, I use the first and third person. I chose to write in the 'I' to denote my first person writing as the author. I also write in the third person as the teller of the stories of participants to portray the adolescent's experiences of CKD. First-person writing enabled me to pursue reflexivity and to give the reader insight into my own thoughts and thinking. In any case, by drawing on narrative literature which calls for relational engagement between researcher and participant (Riessman, 2010; Berry, 2016) I acknowledge that I was not an observer or neutral bystander. I made decisions and exercised choices that influenced the research process and which I openly and honestly discuss throughout the thesis. By writing the narratives using pseudonyms and third person I acknowledge that I am not a character in the stories, but I take on the task of reporting what the adolescents themselves recounted through their voices about their own experiences of CKD. Although I am the writer of their stories, every effort is made to retell their stories crafted from verbatim excerpts and visual images created by adolescents.

4.4.9 Conclusion

This chapter has outlined the aims and objectives of this study and has provided an overview of narrative inquiry. I have presented Riessman's (2008) approach to analysing narratives and completed the justification for using a narrative research methodology. An account of the process of gathering stories using unstructured interviews and body maps was described including the process of analysing individual narrative cases and cross case analysis in accordance with Riessman's approach (2008). The possible ethical considerations and challenges facing this study were also identified and discussed. Having presented the methodological foundation of this research, I concluded this chapter by discussing the process of maintaining quality and rigour. The chapters to follow (chapters 5-9) will detail the co-constructed narratives of the five adolescent participants.

Chapter 5: '*My life is less sparkly than others*': Emily's Story

5.0: Introducing Emily

This chapter presents the stories of Emily, a 12-year-old girl, who was born with renal failure. She commenced peritoneal dialysis (PD) shortly after birth as a neonate. She continued on PD until the age of three, at which point she received a donor kidney from her father. She continued to have significant medical needs following the transplant, which required frequent hospital trips. At the age of 11, her transplanted kidney started to fail. At this point in her illness trajectory, she commenced haemodialysis treatment. When I first meet Emily, her haemodialysis regime consisted of dialysis four days a week. Her journey to hospital took 3 hours each way, which was a source of frustration for her. Six months after my first meeting with Emily, she received her second transplant from her cousin, Sara. She had just turned 13 years old.

Emily is an only child and her mother always accompanies her to hospital appointments and treatments. Her stories represented different experiences including her experience of life on dialysis as well as life after transplantation. I spent many hours getting to know Emily. We had many conversations, including a discussion about her favourite TV show '*Pretty Little Liars',* and her favourite '*Harry Potter'* books. In her stories, she often made references to films and books that were popular among young teenagers. Through developing a trusting relationship and engaging in the body mapping process, Emily explored and discussed her embodied experience of renal disease. She loved art and during the 18 months we spent together, body mapping became a means of processing and expressing the visceral reality of living in a body with CKD. Figure 1 presents Emily's completed body map.

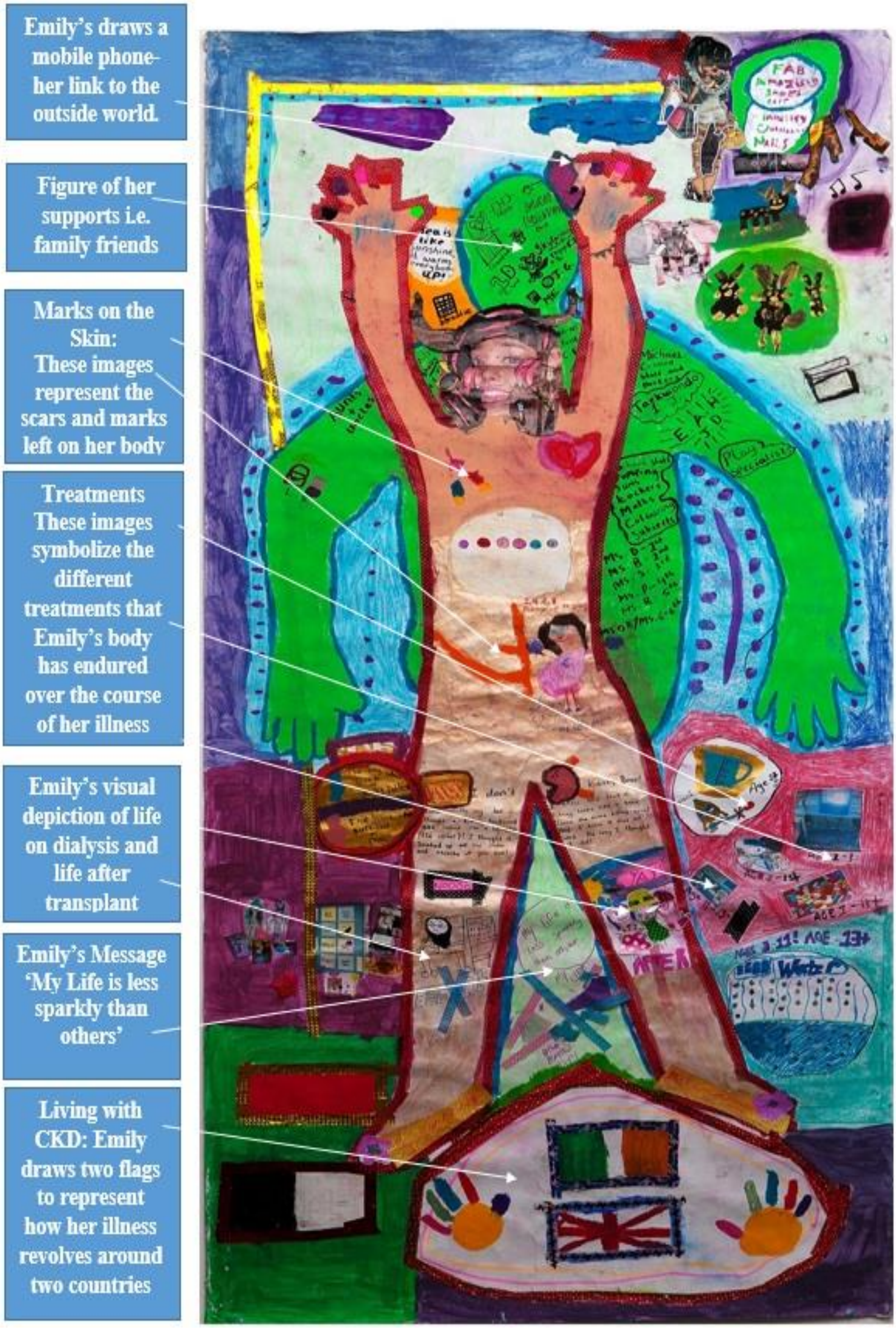


Figure 1: Emily's completed body map

5.1 Overview of Emily’s body map

During the creation of Emily’s body map, I was present and part of the construction process. Emily created different images in different locations i.e. at home and in hospital. Emily’s body map is like a gallery of her life and she visually represented key bodily events that had occurred over the course of her young life. The posture she assumed on her body map was interesting and had the power to convey a message to others. With her hands up and an unclenched open-handed posture, she adopted a taller and larger position than her real life size stature. Emily looked younger than she was and this was a significant source of frustration for her. This interpretation is further supported in her stories to follow. In drawing her support person - she drew a large green figure standing over her. While drawing this image, Emily commented that she had never thought about all the people who have helped her through her illness. She recalled how her parents, friends, teachers, healthcare staff and even the taxi drivers who brought her to and from hospital had supported her in one way or another. Prominently displayed on the inside of her body were drawings relating to kidney disease. The centre of her body displayed many scars and marks left on her body as result of CKD. Conversely, Emily drew images to represent more positive elements of her illness experience. She drew a picture of a heart on her body map, to convey where she gets her inner strength to deal with the everyday challenges of living with CKD. In creating her message to the world, Emily wrote on her body map ‘*my life is less sparkly than others’* to convey her sense of comparative life deficits. Through her body map, Emily visually conveyed the different emotions that accompanied her illness experience as demonstrated in her reflection on her body map.

> *‘THIS IS ME and there the countries I’ve been treated in so it’s kind of me going…orbiting the two countries. Ya I’m orbiting the countries because this is my life. I have had pee tubes, wound drains, hand cannulas, foot cannulas oh and neck lines and scars. I had my PD tubes. I had a replacement of those. Then I had the transplant. Then I had fluid removed from my lungs. Then I had the transplant taken out. Then I had the haemo line put in. Then I had another transplant. That felt weird and uncomfortable, like I was being sucked and pulled inside. So this is my life less sparkly than others’.*

Through this process of body mapping, critical issues surfaced relating to the embodied experience of living with CKD. In the following sections, I will draw on images from Emily's body map to augment the stories of her embodied experience of living with CKD.

5.2 Overview of Emily's Stories

Figure 2. illustrates the stories that are reflective of Emily's embodied experiences of living with CKD.

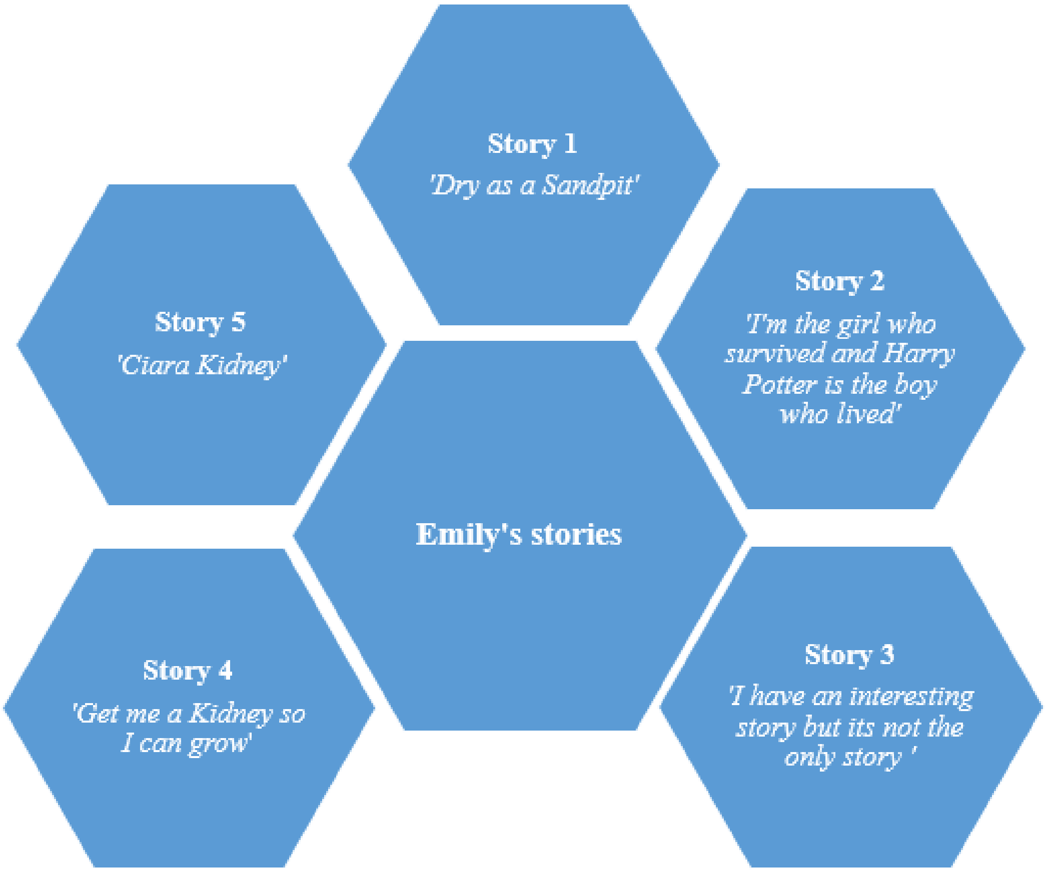


Figure 2: Overview of Emily's Stories

Emily's accounts of her illness experience revealed her sense of lack of control and agency over her ill body. Her first story is a lengthy account of the physical sensation of thirst, which she experiences on a daily basis. The occurrence of thirst forced Emily to attend to her body.

5.2.1 Story 1: *'Dry as a sandpit'*

The experience of thirst was a preoccupation that recurred frequently throughout Emily's accounts of her illness. Her fluid intake was restricted to 500mls a day while she was on dialysis treatment; this included the fluid required for cooking and for taking tablets. As a result of this restrictive regimen, Emily experienced excessive thirst:

> *E: I felt like I was dying of thirst but of course I couldn't have it [water]. I've brushed my teeth more than I have in my entire life just to get water. I've been very thirsty lately. My plan was [pause], well, I didn't plan on getting thirsty, but like my plan was if I got thirsty I could ask them and they'd up my fluid. That didn't work [laughter] so I just have to wait until the transplant arrives. The hardest bit is when I go out with somebody else and they can have WAY WAY more because they just can. They can have a refill, a refill, a refill, refill, and a refill and there am I, dry as a sandpit. It sucks!*

Emily's description of thirst was compelling. Her body was '*dying of thirst'* yet she could not give her body what it needed. She continued to communicate her frustration regarding her fluid limitations in her body map where she drew an image relating to water (Figure 3).

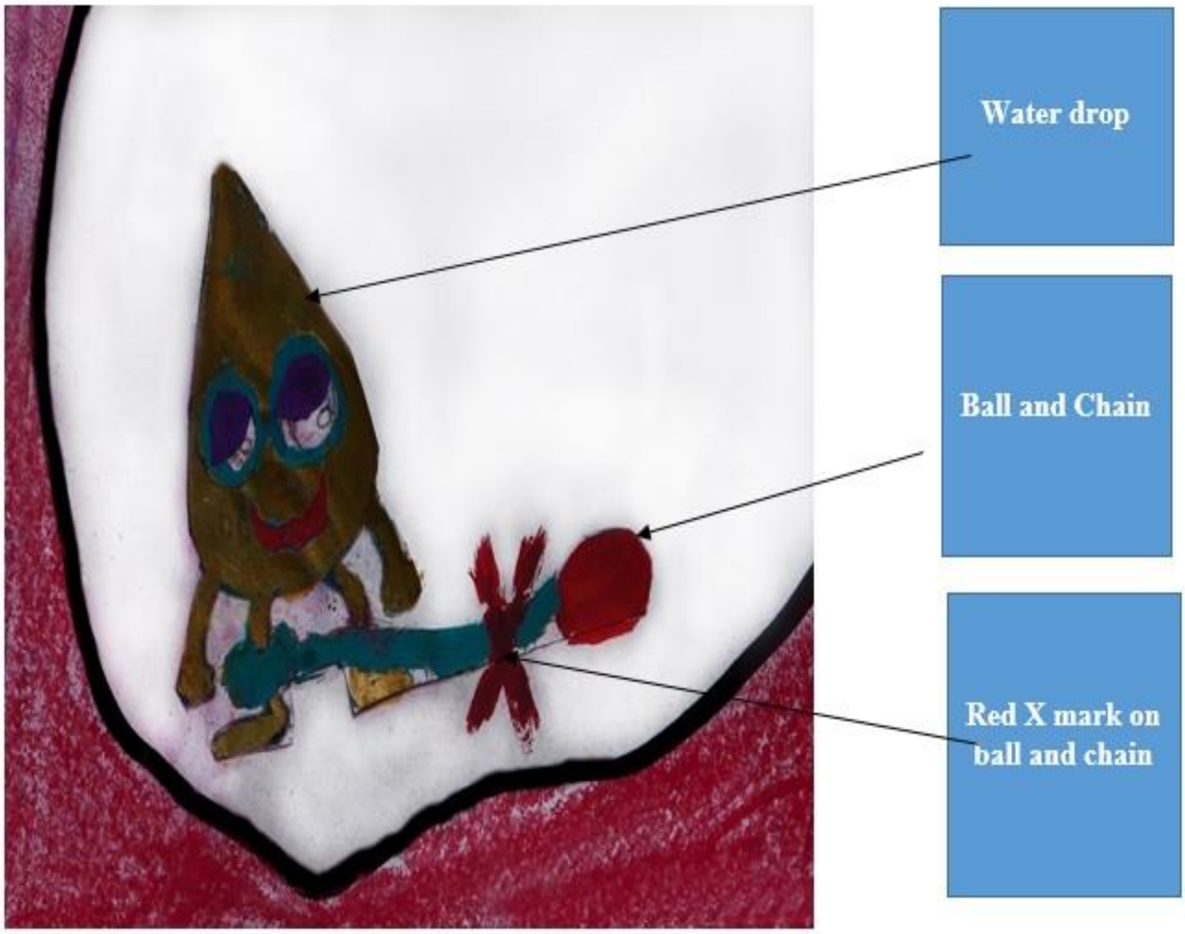


Figure 3: Emily's Image of Fluid restriction

Emily provided an explanation of her image;

E: That's my fluid restriction and wishes. I love this one [image]. I'm very proud of this one. It's limited water! It's stuck on a ball and chain. It cannot move. That's drinking! He was a sad teardrop with a ball and chain on him and I made him a happy teardrop with a ball and chain on him. The Harry Potter [films] are really funny. It's like Harry has got sort of a wonky cross, which means suffering, but there is also the sun that means happiness. And then Ron is like 'so you're gonna suffer but you're going to be happy about it'! So this is my teardrop; happy with suffering.

C: And the [red] cross is?

E: NO MORE! When will that dream come true? WHEN?

Emily introduces the metaphor of imprisonment, and a losing battle, through her visual image of an animated water drop as a prisoner that was deprived of water. Here, she is representing her perceptions of confinement and powerlessness. The water drop is smiling yet the eyes are dreary. The colours in this image are functional - she used a gold/brown colour, which further adds to the dreary look of the water drop. The description of being *‘chained’* creates a strong image of imprisonment. Yet she tried to make the water drop happy to demonstrate her willingness to accept the suffering that accompanied this mode of treatment. Interestingly, she adopts a narrative from the Harry Potter novels to symbolise her hope that happiness would emerge from suffering. It seemed to me that appropriating and adapting these storylines enabled Emily to make sense of her bodily suffering. It perhaps allowed for self-preservation in hardship. She continued to convey her battle with fluid restrictions as she explained:

> *E: Doctor [A] is convinced that I'm drinking extra fluid because the numbers don’t add up. The nurses in here aren't convinced that I'm drinking more. They know I wouldn't do that. But he said there were children before that were so desperate to get a drink that they go when their parents aren't home. They'd get water from the kitchen, in the tap, in a tall glass. But mum said to him, ‘Just because that happens sometimes, doesn't mean it has to happen every time someone's up’. I was just very angry.*
>
> *C: And do you ever feel like that, like you need an extra drink?*
>
> *E: I do, but I wouldn't get an extra drink like that. The thing is, I think I know where he's getting the extra fluid thing from - but it's not actually fluid, its food. Potatoes tip me up a lot. They make me very heavy. And it's not fluid, but they just won't listen to me. Especially lately, since he [Doctor A] had that theory that I'm drinking more. He won't listen, because he thinks it's just a cover up for my drinking more. Say I said ‘I had potatoes’ or something, he'd think that was a cover up to what I was [pause] that I was drinking more. It annoys me. I mean, I've known him for nine years. I thought we had a level of trust, a good level of trust.*
>
> *C: Did you talk to the doctor about the whole issue?*
>
> *E: No, because apparently I don't have an input on this. As I said, everything is a cover up. A cover up to say that I'm not drinking. I think they [healthcare staff] should*

> *have an annual live like me day. Where they all have to live like a child with the limited fluid, with the limited food. See how they like it: 'An annual live like me day.' You'd have to do it once every year. I think it would be hilarious, because now they know how we feel. Now they know how hard it is for us. Everything has to be measured exactly. You can't go over. You just cannot go over. It's killing me!*

The function of this story is to assist Emily in finding meaning as she attempts to put events into perspective, cope with accusations and endure the physical and emotional suffering of thirst. Performatively, she stages a dramatic representation of her victim account, which helps her to disavow an imputed identity and to re-establish a good self. The story unfolds to explain how and why false accusations were made. It specifies the central characters - Emily, the doctor, nurses and her mother - and assigns motives, moral characteristics, and responsibility for outcomes to each character. She portrays herself as a powerless victim that had no say over her body's needs. She describes her pain and bewilderment at the accusations from the doctor, with whom she believed she had a trusting relationship. In her account, Emily tries to remain positive and strongly assert her innocence and her conviction that the doctor was making false accusations against her. She attempted to convince me, her audience, that she was innocent as illustrated in the following reflective notes:

> *'As I listen to this story, I hear a need for Emily to share her side of the story. She attempts to draw me into her point of view. She appears quite angry and frustrated with the doctor. I sense her need for me to understand that she is innocent and to claim her identity as an innocent and complaint patient—an antidote to the non-compliant picture that the doctor created for her'.*
>
> *(Reflective diary, May 2015)*

In this story, Emily visually and verbally portrays a body deprived and stripped of the basic freedom of being able to drink water. There is an overall sense that CKD and its restrictive treatment regime are an intrusion on the body causing bodily suffering and a loss of body agency. She tries to remain positive and fight through her battle. Her portrayal of a suffering body, enduring within a challenging environment continues in Story 2.

5.2.2 Story 2: *'I'm the girl who survived and Harry Potter is the boy who lived'*

Emily has undergone 16 surgeries since birth, which have left many scars on her body. Her peritoneal dialysis (PD) scar, in particular, serves as a constant reminder of the trauma her body has endured. This scar signifies a key point in her life; her survival as a baby, which she represents in the image (Figure 4).

Figure 4: Emily's image of scars

In this image, her body communicates its own story through the presence of a permanent scar. This scar signals what is generally invisible to outsiders; the medical inscription of kidney disease. This scar is permanent, lasting after the therapy is complete, and it is therefore significant, as it marks her identity as a CKD 'patient'. However, in drawing this image and in using the word *'survived'*, she exerts control of how her scarred body affects her in the present. As a survivor, she has ownership over how she wants to be perceived rather than letting other people create it for her. Emily likened herself to the character of Harry Potter. She drew an image of Harry Potter's lightning bolt scar in blue and her PD scar in pink. She used a gold background and a bright red colour to encircle this image. Two statements '*The body who lived – Harry Potter'* and '*The girl who Survived-Me'*, accompany this image. Through this visual image and her identification with Harry Potter, Emily attempts to make her body trauma visible and understandable to others. She explained:

> *E: I'm starting to think maybe Harry Potter and I are related. I'm kind of the Girl Who Survived - the one who survived peritoneal dialysis [the first newborn]. So, like I'm captioned as the girl who survived, and Harry Potter is captioned as the boy who lived. So, I'm wondering; are we related? We have our scars in different places, but we still have a scar. Harry Potter's scar is on his forehead and mine is on my tummy [laughter]. Do you see my point? So I'm the girl who survived and Harry Potter is the boy who lived. And that's why I have: 'The boy who lived-Harry Potter/ The Girl who survived-ME!' And we both have very mean scars.*
>
> *C: Do the scars bother you?*
>
> *E: Not really. I just wouldn't want anyone to see them, for their sake and mine. I still try to wear teenage clothes. I would like to wear short-cropped tops but I am conscious of the type of clothes I wear. Sometimes that one does get itchy though, [points to her transplant scar on her body]. This is my zip. We call it the 'zip'. Only the surgeons have access to the key. It kind of feels like I'm sewed up on the inside, like you can feel the stitches on the inside. I fear scratching it because it opened by accident once, and I don't want it to open again. They didn't sew me up tight enough after my transplant. It was maybe a week after it. I was brought here urgently, obviously, and I was done straight away. I was just sewn back up again nice and tight.*

Emily portrays herself as a *'survivor'* which offers an interesting dynamic to this story. By connecting her story to the broader context of popular literature and film, she creates a sense of a shared story, which helps her to feel connected to other people who have been scarred and who have survived. Harry Potter's scar makes him recognisable to others, which is similar to

Emily's experience of her PD scar. She, like Harry Potter, is a survivor of a battle, hers against CKD and Harry's battle against Lord Voldemort. Their bodies are both marked because of their battles and Emily is proud of her battle scar. Her use of language is interesting; for example, the phrase '*I'm captioned'* reveals how she perceives her body is inscribed and medically marked as a result of her illness. However, this scar also signifies her survivorship and it makes her famous in the medical world, just as Harry Potter's scar made him famous in the wizardry world.

Emily refers to a more vulnerable state as she describes the loss of power over her bodily state following transplant. She uses the metaphor of a *'zip'* to describe her transplant scar as a portal of body entry, which was accessible to others i.e. medical practitioners. She views the surgeons as the people who had ultimate control and power over her body: The zip metaphor connotes a lack of boundaries and a fear of body invasion and Emily portrays her body as a site freely accessible for multiple entry and exit by medical personnel. She has become disembodied and detached from the body she had no control over. The body as object, therefore, is the body that she has, rather than the body that she is at one with. Despite itchiness and the bodily urge to scratch the scar, Emily avoids engagement with this area of her body because of past medical trauma and medical colonisation. The theme of medical colonisation is also evident in her next story.

5.2.3 Story 3: *'I have an interesting story but it's not the only story'*

A central characteristic of this story concerns the way in which Emily's identity is constructed through - and in the context of - her illness. She reflects on the colonisation of her life experiences as an interesting medical case history, which she finds frustrating.

> *E: What really annoys me is when the student doctors come in. Because it's just always a case of my story being told over and over again and people poking and prodding. I know I have an interesting story, but it's not the only story. Last summer, or the summer before, the student doctors kept coming and coming and coming and coming and coming and coming and coming. Like I know I have an interesting story but I'd rather talk about the home side of things just for a change. It's a LITTLE overwhelming at times. Because you know technically I'm up here [in hospital] more*

> *days that I am at home. I mean there could be something amazing going on in school and I'd have to go to hospital. I missed like two years of school - you could say two years, technically anyway. Technically, because when you're up here, you've no idea what they're talking about down there, because you can't text them because they're in school, and you can't hear them because they're miles and miles away.*
>
> *C: Does anyone ever ask about those things?*
>
> *E: No. It's the other side the medical side.*
>
> *C: Does the doctor talk to you about your illness?*
>
> *E: Not really. He calls Mum or Dad or whoever is with me out and they pass the news onto me. I'd like to be told what's happening but I prefer knowing what's happening, if you know what I mean. Because I would not really understand a lot of what he is saying really, but Mom and Dad could kind of translate it down to the way I'd know. I have a word for it; it's all spoken in doctorish! When I was younger they would kind of speak in English but now that I'm older they speak in doctorish and I'm still like, 'I still can't tell what you are talking about' 'I don't know everything! I haven't been a qualified doctor. You have. There is a small difference! [Laughter]. I'm just standing there thinking, 'I'm still in the room'!*

In this story, Emily performs her position as powerless. She articulates her body as an object that is monitored and observed. She is afforded little bodily privacy or choice about who can observe or disrupt her body at any given time. She is renowned for her interesting and complicated medical history and her comment '*I know I have an interesting story, but it's not the only story*' demonstrate her awareness that she is more than her illness. However, from a medical perspective, the focus of care is on the medical needs of the physical body. There is little room if any for discussions on other aspects of Emily's life. She feels disconnected from her adolescent world which results in meaningful activities being sacrificed or disrupted. This disruption inhibits Emily's engagement with her peers.

In this story, it appears evident that Emily's experience of illness incorporated certain institutionalised expectations, such as the expectation to understand medical terminology. The incomprehensible medical language used alienates and deters her from engaging in conversations about her body and her illness. She explains that in order to understand what the professionals are talking about requires interpreters; her parents. She wants to understand and know about her illness but doctors hold the medical knowledge, which puts them in the position of power. This situation further adds to her lack of agency regarding her illness and body. This common thread of loss of agency and powerlessness also emerges in her next story as she reflects on her current body size. She asserts her need for the perceived growth that a new kidney would engender.

5.2.4 Story 4: *‘Get me a kidney so that I can grow’*

For Emily the delay in her biological and pubescent development, as a result of kidney disease, is a source of much self-questioning and body vigilance. Drawing the outline of her body map renders the materiality of her body even more visible to Emily (see Figure 5).

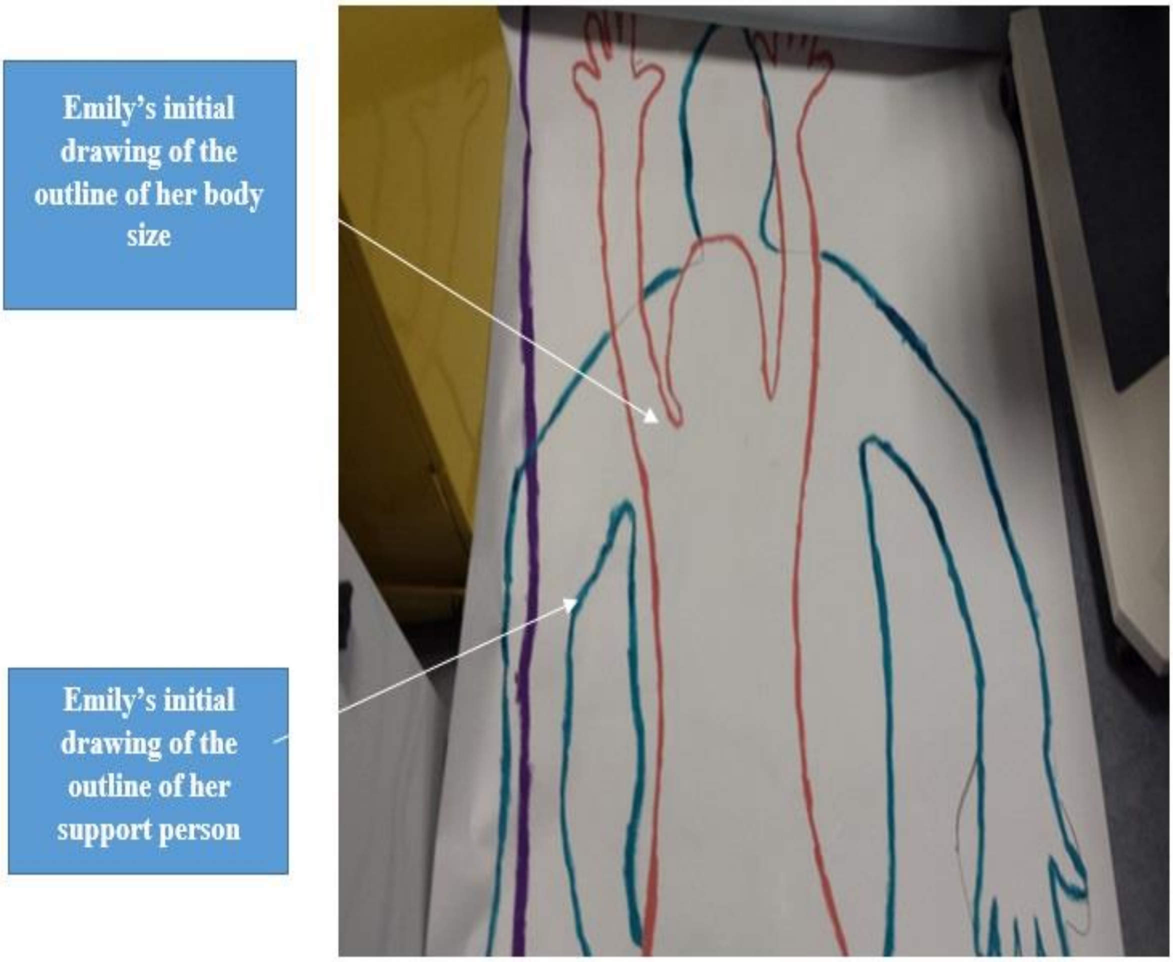


Figure 5: Emily's initial outline of her body

Emily’s commentary on her image:

> *E: I’m quite small. Well, am I really that small? I look smaller there than I do in real life. I come from a small family. [Pause.] Don’t judge me! My classmates are very tall.*
>
> *C: They are very tall.*
>
> *E: Ya. The thing is I think my body is saying now [pause], this is just my opinion, but I think it is beginning to say I’ve had enough of being underweight of the average 13 year old should be. I think I should go to what a 13 year old should be you know. So get me a kidney so that I can grow back to that! Ya and my periods haven’t started and I asked a nurse one day when I was on dialysis about it. The nurse said I was the first person who ever asked her about that and she didn’t know. I then asked another nurse and she couldn’t answer my question either. My friend Moya started her period when we were in 5th class and I’m in 1st year and I still haven’t had a period!*

In viewing her body outline she perceives her body to be short in stature. As she looks again she questions if she really is that small. Given the resilience she customarily exhibits, perhaps Emily perceives herself as bigger. Emily attempts to challenge her small stature by imagining what her body is saying, ‘*I think my body is saying now [pause], I’ve had enough of being underweight of the average 13 year old’.* Here, interestingly, she gives her body a voice and agency, compared to the many times in other contexts where her body/body needs are invisible and silenced. Her body is externalised as an ally and support when none other existed.

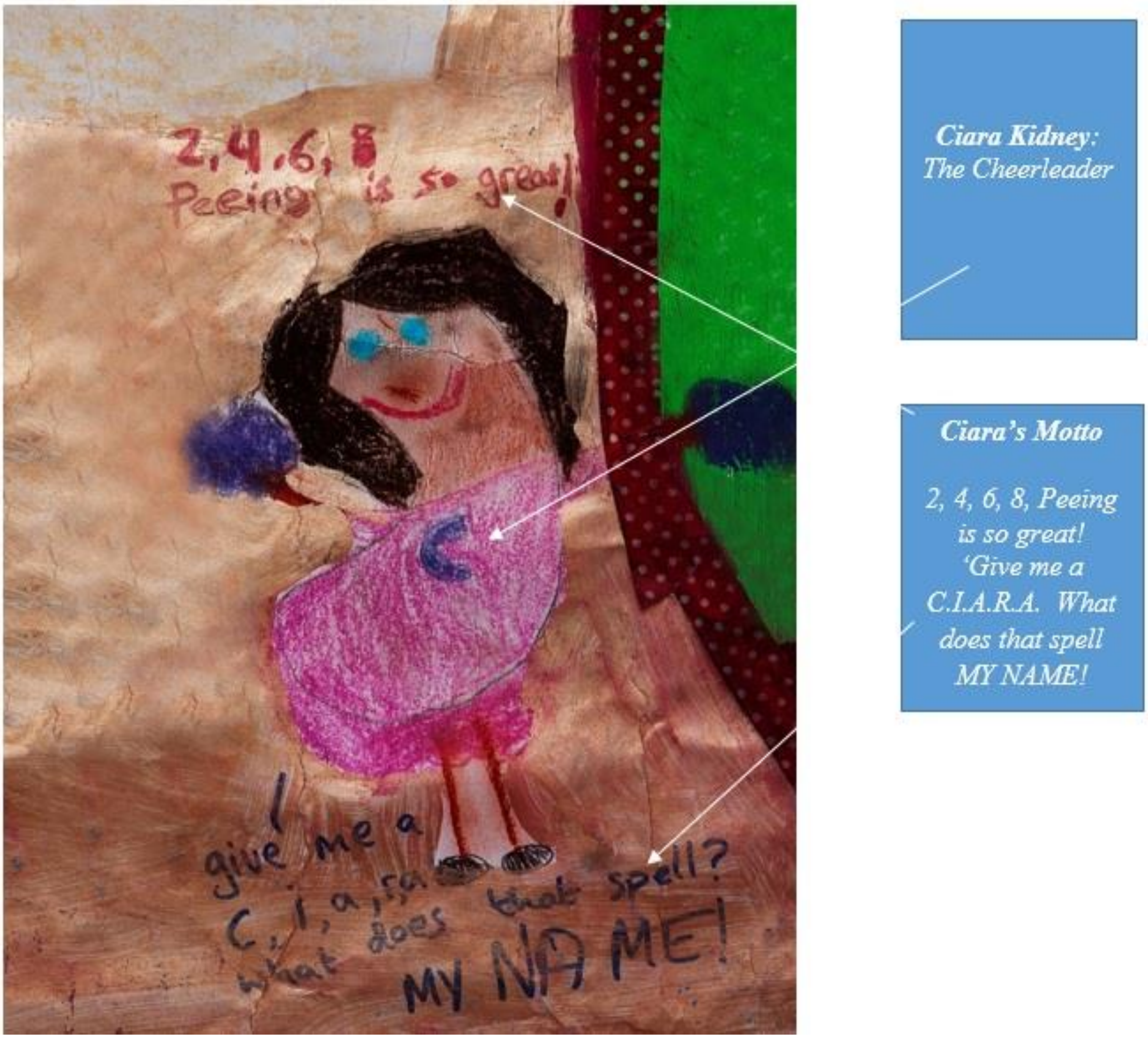
She performs a counter narrative for her body; her body is fed up of living with this debilitating disease and the impact it is having on her growing, pubescent body. This counter narrative enables her body to body communicate its need for internal growth and renewal. As well as struggling with reduced height, Emily also has to contend with a delay in sexual maturation. The onset of menstruation is a significant and symbolic milestone for young girls, representing the rites of passage from girlhood to womanhood. Emily feels she is being denied this progression in body development and body agency. This delay in pubertal growth means that she is not undergoing the sexual body changes normal for an adolescent her age, and therefore is not able to incorporate these changes into her identity as a young woman. Rather, the changes occurring in Emily's body at this time are engendered through illness and medical intervention. Her attempts to navigate these 'abnormal' and medically mediated body transformations are apparent in her next story concerning her post–transplant embodied experience.

5.2.5 Story 5: *'Ciara Kidney'*

This story concerns a time three months following Emily's second transplant surgery. Transplantation, while welcomed and longed for by Emily, brought with it, its own challenges and upheavals.

> *E: I named it Ciara; I named her Ciara. I named my kidney Ciara. She came christened Ciara; she came from California christened Ciara. But I agreed with Ciara. I liked Ciara Kidney. I'm so tired today. Ciara took me out to the bathroom 5 times last night. I gave up and got up at 8.15. I tried to sleep in until 9 or something. I wanted to lie in. I mean now I am a free teenager you know, but not in Ciara's mind. I think she is used to Sara, [donor] always going for a run at like 5am over in California because that was the coolest time over there and school started at 7am. So Ciara probably still has that in her mind that we have to get up early now because Ciara/Sara got up early.*

Here, Emily is attempting to configure the history and origins of the alien body part now implanted in her body. She does this by personifying the body part and employing a unique narrative and 'foreign' history for 'Ciara'. Throughout this narrative there seems to be a power struggle as Emily tries to figure out who is in control of her body; her or Ciara. Her struggle to adapt to the new bodily function of urinating is evident. She is frustrated because while transplantation means freedom from dialysis, her body is now constrained by a new bodily change; a functioning kidney. A plausible interpretation is that by performing *'Ciara'* as a living, conscious entity separate to herself, Emily is distancing herself from the transplanted organ. She has not yet fully assimilated this new kidney into her embodied identity. The material separation of Ciara from Emily is also evident in her visual narrative (Figure 6).



Ciara Kidney:
The Cheerleader

Ciara's Motto

2, 4, 6, 8, Peeing is so great! 'Give me a C.I.A.R.A. What does that spell MY NAME!

Figure 6: Emily's image of her newly transplanted kidney

I reflected on this image and the following excerpt from my reflexive diary summarises my thoughts:

> *'I am intrigued by this image. I naively expected her to draw an image of an actual kidney to represent her transplant experience. This makes me aware of the danger of my own expectations and I refocus my attention on the purpose of this image. I sense Emily is struggling to process the changes in her body following transplant. I wonder is her visual creation of the character of Ciara helping her through the messiness and chaos that she is experiencing in her body'.*
>
> *(Reflective Diary, September 2016).*

Emily's new kidney is visually constructed as an individual person, rather than as a bodily organ. She assigns the organ a specific female gender. This female organ known as Ciara, is dressed as a young cheerleader with long dark hair, blue eyes and a beaming smile. Emily chooses vibrant colours for her image of Ciara. Dressed in a bright pink dress with the initial 'C' on it; Ciara holds a blue pom-pom in each hand. This visual representation of the kidney as a young teenage girl is symbolic of Emily's internal struggle to assimilate the new body part into her embodied identity. This interpretation is supported by her verbal account:

> *E: I imagined her a cheerleader. I decided she was going to be a cheerleader before I ever had her. And I thought, because she was a cheerleader she needs a cheer. So here is her motto (that I made up 3 hours before she was put inside me): '2, 4, 6, 8, Peeing is so great! Give me a C.I.A.R.A. What does that spell MY NAME!'*
>
> *C: So do you see Ciara?*
>
> *E: Like that. Yes. Sometimes she'll change clothes. So, when we're going out she kind of looks like I do a bit, not exactly like I do. Say we were going out playing with my cousins, I would wear these [pointing to her track suit] so Ciara would probably wear a jogging pants she brought from California. She brought her winter clothes, her summer clothes and she brought her holiday clothes for when we take her on holidays. I technically see her you know dressing and changing clothes like we do. Like all the normal functioning we do; when I'm drinking it passes down to her, she drinks. She does yoga. She's very calm. I don't do yoga but when I'm sleeping she does her yoga. Ciara never sleeps. You know they say kidneys never sleep? So she never relaxes. She does yoga or meditation but she never actually goes to sleep. Then she could be meditating and her alarm would go off: 'I have to pee.'*

Using a performative process, Emily endeavours to accommodate the presence of an alien body part. Rather than viewing the organ as a replacement part or as now part of her own body, she portrays her new kidney as a different person inside of her. She dedicates a large amount of effort and time to building a contextual identity for Ciara. Her choice of cheerleader persona is interesting, perhaps communicating the excitement and anticipation associated with receiving a functioning kidney. Ciara the cheerleader was going to bring energy and healthy functioning to her body. Following transplantation, however, Emily's embodied identity and sense of self is in jeopardy. One possible conclusion is that Ciara Kidney is a way of coping with this identity disruption and uncertainty. Here, Emily engages in 'biographical work', in terms of foreground and background: the person who she was before transplantation moves to the background as she reflects upon who she is now. She has to integrate the new kidney into her sense of self and adjust to her new reality. However, her story appears to confirm the nonlinearity and complexity of this transforming process. She is struggling to incorporate Ciara into her embodied self. Although she continues to present Ciara Kidney as a separate person, at the same time she begins to demonstrate interconnectedness with Ciara. They wear similar clothing and she suggests they are similar, yet they are not quite the same. Ciara never sleeps, she is a constant, live and functioning presence in Emily's body who asserts her own demands and needs. Perhaps her creation of Ciara gives her body a new voice, and an opportunity to explore a new identity. Emily's task is to reconfigure a body story that fits with the existential crisis she was forced to face. This transformative process is ongoing.

In summary, Emily's visual and verbal stories centre on specific events and experiences in her life with CKD. Through the telling of these experiences, she performs stories with people, characters, plots, events etc. to communicate her struggles of living with CKD. In her case, different storylines interweave with others, particularly: the disease and its symptoms; bodily suffering and body survival; and self-identity and relationships with healthcare staff. Her stories are marked by variations in style and mood, shifting, for example, from gravity and sadness to light-heartedness and humour. These stories collectively formed the basis of her narrative with many narrative threads (storylines) emerging, which built towards a wider narrative. The following section presents a summary of Emily's narrative as interpreted by me and supported by her stories.

5.3. Emily's Narrative: *Battling and Surviving CKD*

Emily ultimately battles between two core narratives; one of being colonised and the other of being a strong survivor. Like all narratives, Emily's narrative is set in a particular setting. For Emily, her narrative is set in the landscape of her body and she frequently uses the militaristic trope of the body as a battlefield. She is a survivor in the context of battles and colonisation of her body by CKD and medicine. In her stories, CKD is cast in the role of an enemy, a foreign invader of her body. Emily's body is the battlefield on and in which she fights to survive CKD, its treatments and medicine as evidenced by her use of military language used throughout her stories. Military connotations are evident in the phrases ‘*it’s killing me’*, ‘*cross’,* ‘*suffering*’, ‘*mean scars’* and *‘ball and chain’* Her body was frequently attacked, injured and colonised by CKD, treatments and unpleasant medical encounters. Her colonised body emerges in her visual creations of a *‘Water drop’, ‘Ciara Kidney’* and *‘Scars’*. In these images, she refers to her imprisoned, invaded and scarred body. A sense of powerlessness, body violation and vulnerability emerge through her stories. She is at war with the biomedical narrative that seems to dominate her life. She describes how medical understandings of the body do not acknowledge the impact of illness on the body outside its physiological impact. She asserts a counter narrative – *‘not the only story.*’ Understood from her experience, it does not make sense to her that doctors focus solely on the ill part of her being. She fights to counteract her medical identity by proclaiming there is more to her story than her illness.

However, Emily continues to battle her illness by asserting a ‘survivorship narrative’ where she self-positions herself as a ‘survivor’. The word survivor carries the connotation of being harmed by external forces i.e. her illness and CKD treatments. However, she expresses her positive attitude through her use of military metaphors, in which she demonstrates her fighting spirit, striving to endure suffering and retain her sense of self. Internalising a survivorship discourse requires Emily to position herself within a particular narrative expectation: an eventual imagined triumph over her illness. She gives examples of successful triumphs. The fact that she survived a life-threatening illness and body trauma as an infant helped establish her identity as a survivor. As a survivor, she has the opportunity to recognise the impact of CKD on her life without being a victim. She can hold on to the reality of what she has been through whilst recognising that this was in the past. Positioning herself as a survivor enables her to demonstrate her body’s strength and endurance. Her desire for body agency, power and strength is an ongoing feature of her stories. In addition to its implications of strength, the label of survivor also locates her within a larger collective category of survivors of suffering like Harry Potter. The theme of suffering, enduring and surviving is prominent in the Harry Potter storyline and her adoption of this narrative frame allowed her own suffering and survival to be processed and understood. Emily’s words of ‘*I’m the girl who survived’* suggests an empowering stance of having survived. The temporal orientation of this story was in the past, she survived as an infant, however, in the immediate urgency of the present she is still battling. She battles treatments and medical instruction. Her body is colonised by scars and wounds, and constant bodily changes are a feature of her CKD experience. Following transplantation, she continues to struggle with colonisation of her body. Her creation of ‘Ciara Kidney’ as a separate person living inside conjures the image of a body colonised by another. Her body is subject to the exclusive control of Ciara. Nevertheless, from the field of battle Emily emerges as a strong survivor, albeit one whose body is scarred and colonised. CKD continues to threaten her life even after transplantation, but Emily continues her battle for survival.

5.4 Conclusion

This chapter presented Emily’s visual and verbal stories of her illness experience and her cumulative narrative which were shaped by my own interpretation and understandings of her experience. In Chapter 10, in presenting a cross case analysis, I will refer to Emily’s narrative in identifying common themes across all cases. In Chapter 11, Emily’s narrative, as presented in this chapter, will be critically discussed through the lens of the core themes that emerged from the cross case analysis. In the following chapter, I will introduce the next participant, Lucy and present her narrative account of her experience of living with CKD.

Chapter 6: *'Organised chaos':* Lucy's Story

6.0 Introducing Lucy

This chapter presents the stories of Lucy, a 13-year-old girl with CKD. Lucy was diagnosed with bilateral kidney dysplasia, which meant that both her kidneys did not develop properly in utero. Although Lucy was born with this condition, she and her family were unaware of it until she got sick at the age of 11 years**.** A few months after being diagnosed, haemodialysis was initiated on three alternate days a week. Each dialysis session involved approximately four hours of treatment and at least 2-3 hours a day of travelling to and from hospital. This period in her life was characterised by many changes and upheavals. She was the eldest child in her family and her mother and sometimes her younger sister would accompany her to her dialysis sessions.

I spent nearly 18 months with Lucy and during that time she received a kidney transplant. Our meetings were sometimes situated in Lucy's home, and sometimes the dialysis ward. Lucy often referred to herself as a '*bit of a science nerd'* and she was keenly interested in learning about her illness and treatment regimes. Lucy was also very artistic and seemed comfortable when I suggested the idea of creating a body map. Through images, she explored her life before and after kidney transplantation and explored the disruptions it caused to her body. Figure 7 presents Lucy's completed body map.

Lucy's Message to the world

Lucy's self-portrait

Lucy's support figure

Marks under the skin: Lucy depicts kidney disease as an atom

Marks on the skin Lucy's permcath and dressing occupy a large space on her body, as does her transplant scar.

Treatments: Lucy chose to draw her dialysis machine and a urinary catheter

Living with CKD encompasses mixed emotions about her body

Symbol of where Lucy comes from.

Figure 7: Lucy's completed body map

6.1 Overview of Lucy’s body map

Lucy created her body map at different points of her illness trajectory so different images represent different experiences. Some images were created while she was receiving haemodialysis, while others were created on the sitting room floor in her home. Lucy’s body maps took months to create, which allowed her ample time to make meaning and articulate her embodied experience of living with CKD. In her first body-outline drawing, Lucy adopted an open body posture, which involved keeping the trunk of her body open and exposed. In addition to an open posture, she assumed hands on hip pose with her feet evenly apart to take a wider stance. This position helped Lucy to achieve a bigger physical presence by taking up more space on the body map. In drawing her self-portrait, Lucy created a feminine portrait of herself. She drew a smiling flower blossoming where her face should have been. To the left hand of the flower, she used a magazine cut-out of one seductive eye and voluptuous lips framed around a smile. This image is interesting; it seems to create a mysterious identity for her. Lucy drew many images on her body map relating to her kidney disease and treatments. She drew illustrations of a dialysis machine, catheter, scars and medical devices. Through her body map, Lucy also visually conveyed the diverse feelings that accompanied her illness experience. For example, the image of a question mark symbol on her right leg communicates the mixed emotions she experienced in living with CKD, emotions such as uncertainty and confusion as written on her body map. In creating her personal slogan (motto) and message to the world, Lucy used a quote from a Ronald Dahl book:

> ‘*My candle burns at both ends; It will not last the night; But ah my foes and oh my friends –it gives a lovely light’*

During challenging times, Lucy used this quote to give her strength to help her deal with her illness and everyday struggles. The process of creating a visual representation of her body allowed Lucy to look back at what she had been through and it created the space for new possibilities to emerge. Reflecting on her final body Lucy commented:

> *‘I think it looks really cool now. Nice and colourful. It was really nice to do. It’s weird to look back on it because I don't connect with some of it anymore. Obviously, I did at*

> *the time or I would not have done it, but some of it I'm looking back and going, like, that doesn't even seem like a thing that happened to me anymore'.*

This creative process helped Lucy to make sense of her bodily experiences and I will draw on particular images from her body map to illustrate her embodied experiences of living with CKD.

6.2 Overview of Lucy's Stories

I identified five stories that are representative of Lucy's embodied sensations, knowledge and ways of being in the world. Lucy's stories tell of her strive for a 'normal' adolescent body amid the chaos of an ill and invaded body. She demonstrates courage, persistence and determination to configure her experiences and live life as best she can despite her illness. These stories are illustrated in Figure 8.

Figure 8: Overview of Lucy's Stories

6.2.1 Story 1*: ‘I know what I'm doing here’*

Reflecting on her experience of haemodialysis, Lucy drew an image of her permcath device on the left upper side of her body map (Figure 9).

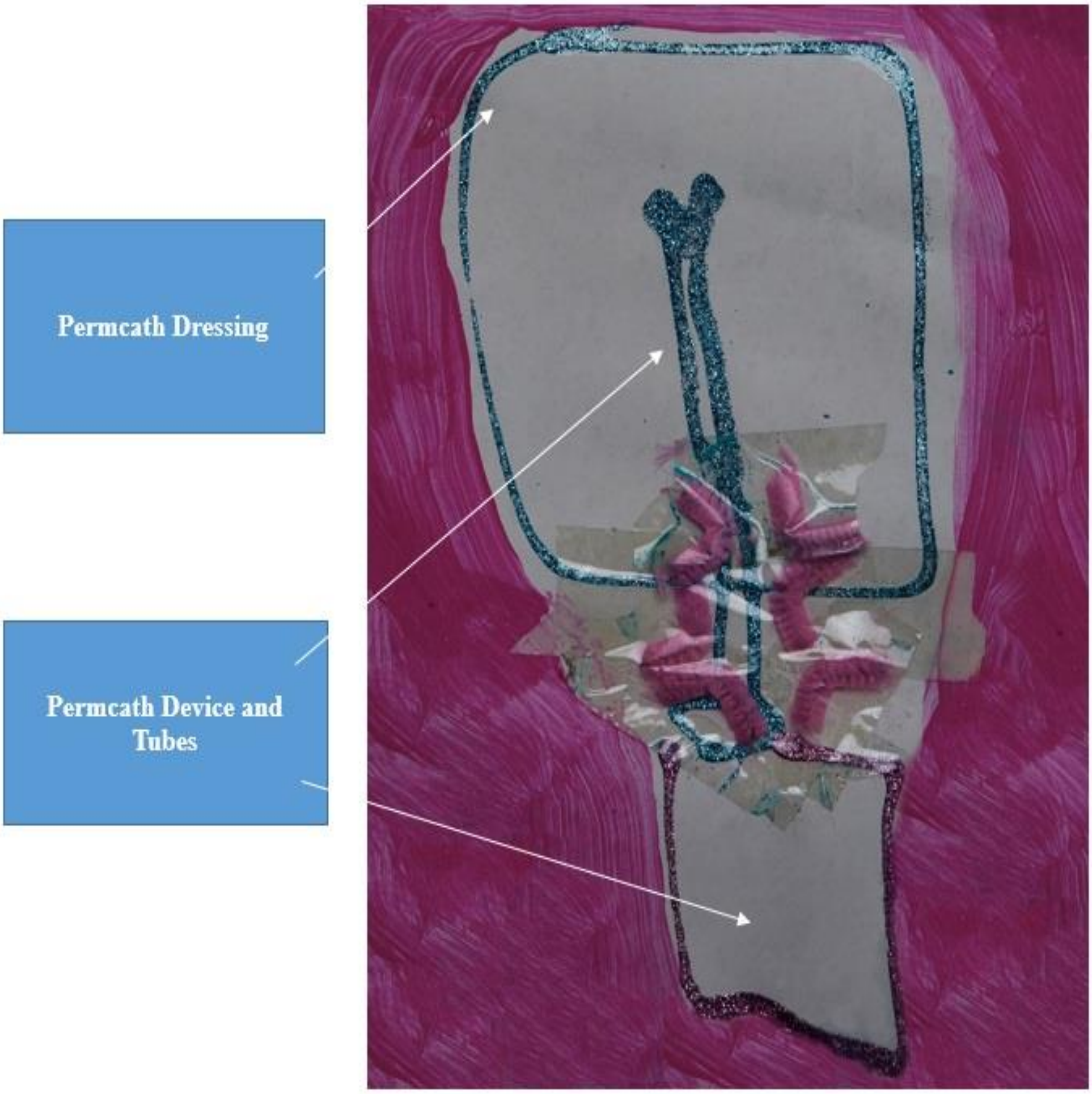


Figure 9: Lucy's image of her permcath device

There are two components to this image; one component consists of a permcath dressing, the other of a permcath device. A permcath is a long, flexible catheter that is tunnelled under the skin before it enters the neck vein. The permcath device marks the body as that of a CKD sufferer. The permcath dangles from her body and in this image, the body’s boundaries are extended as a result. Interestingly, Lucy dedicated a significant amount of time and space to drawing a large permcath dressing, rather than the actual device. At the time, I wondered why? The permcath device was her lifeline, yet she was more focused on drawing the dressing. These dressings are small and unnoticeable in reality. However, Lucy explained that for her this image represented a common dialysis experience related to dressing changes.

> *L: They (nurses) listen but they don't always. I don't know if it's just that they're used to working with little kids, but they talk straight to my Mam instead of me. And then I have to sit there and go: 'Yeah, I'll just jump into this conversation then, since you haven't asked me anything.' It's just a bit annoying because I know what I'm doing here. I know. I tend to be quite good at explaining what a symptom feels like and that kind of thing. If I just say, 'It's just not working for me' then that's all I'm saying.*

> *L: The one thing I kind of remember most is when I was on dialysis and my mum was talking on the phone while I was getting a dressing changed. Instead of asking me what way I wanted it - I can't remember what nurse - the nurse just turned and started talking at my mum to ask her what way I wanted the dressing. I was just [pause] trying to get her attention. 'You can just do it like this.' They're used to going straight to a parent. If they're just talking directly to my Mum, then I feel like they're not acknowledging that I have an opinion on this [laughter].*

At the time of telling this story Lucy was no longer on dialysis, yet this dialysis-related experience was still relevant. The challenge to her body agency is evident in this story. Lucy wants to take charge, be involved in her care and to reclaim her agency. She performs herself as a capable and strong person who had embodied knowledge. Embedded in her account are feelings of irritation and frustration, as she tries to grapple with being unacknowledged by nurses. Yet, she demonstrates resilience and attempts to get the nurse's attention. While she does not succeed, this story is an example of how Lucy tries to endure and take charge of her life, claiming and demanding agency.

6.2.2 Story 2: *‘Which pain am I looking for here?’*

In this story, Lucy reveals how kidney disease makes it difficult for her to focus on pubertal changes such as menstruation and her body is left perplexed about which pain she was experiencing:

> *L: My first period started as I went onto dialysis and that made my weight go up, down and fluctuate, and my blood pressure was bad. So it's bad enough as it is. When I went in this time and they [health professionals] asked if I had a period, and I had to say like, ‘Yeah, it ended just there, in the last couple of days’. I even struggle now because my periods aren't steady, or aren't regular [pause]. I tend to have a couple of months where there's nothing and then a period [pause]. My periods, when I have a period, are steady, but the time in between isn't, and I can never tell if it's going to start. Especially because there's nothing to tell me. I get a pain in my kidney area as opposed to an actual cramp that you would feel.*
>
> *C: So, it's hard to determine which pain is?*
>
> *L: Yeah, definitely. Which pain am I looking for here? And I have to be like, ‘Am I being told something here or am I just having a bad day’? Especially because my periods are irregular. If I get a period it's like: ‘Oh, those still exist. Hang on [pause] it’s fine, we'll just sort this out really quickly and then we'll go out to whatever.’ Because I have so much going on with [pause] medication and all that kind of thing, it's just sort of like: ‘Oh, things happening again? That's all right. We'll sort it out, and just get on with everything else.’*

Menstruation is one of the most significant pubertal transitions. However, in Lucy’s story, menstruation is processed and experienced through a medicalized frame. Her medicalised body demands much of her attention which diverts her attention from the more normal pubescent changes in her body. Menstruation signals are difficult to interpret as pain is a common everyday experience for Lucy. She engages in intense body vigilance to become attuned to which bodily organ is causing pain and demanding her attention. The presence of these co-occurring body processes are confusing and difficult to manage so it is important to Lucy that she imposes order on the processes that are within her control. This need to keep things normal, to be a capable agent, exerting embodied power and knowledge was characteristic of Lucy, as I observed at the time in my reflective notes.

> *'I am intrigued by Lucy's calm and resilient attitude. She is determined to continue normal life and activities, making adjustments as necessary, but not allowing her illness to alter her life. Much of our conversation today is devoted to other topics like her interests and her favourite activities. She is determined to tell me about the things that she can do, not about what she cannot do. She frequently refers to 'just dealing with' CKD and getting on with life'.*
>
> *(Reflective diary September 2015)*

Lucy wanted to perform her identity as that of a capable young person who can organise disorder and confusion and maintain control and agency over her body and her life. Enduring her illness and getting on with life is Lucy's way of coping with CKD. However, her ability to control body functions and experiences is challenged in Lucy's next story.

6.2.3 Story 3: *'I know I'd be able to (move) if this bloody catheter wasn't stabbing me'*

In living with CKD, Lucy experienced many sources of pain and discomfort. The greatest source of pain for Lucy was not her underlying kidney disease but rather the intrusive technology of a urinary catheter in the post-transplant period. On her body map, Lucy drew a large catheter extending from her body to represent this painful experience (Figure 10).

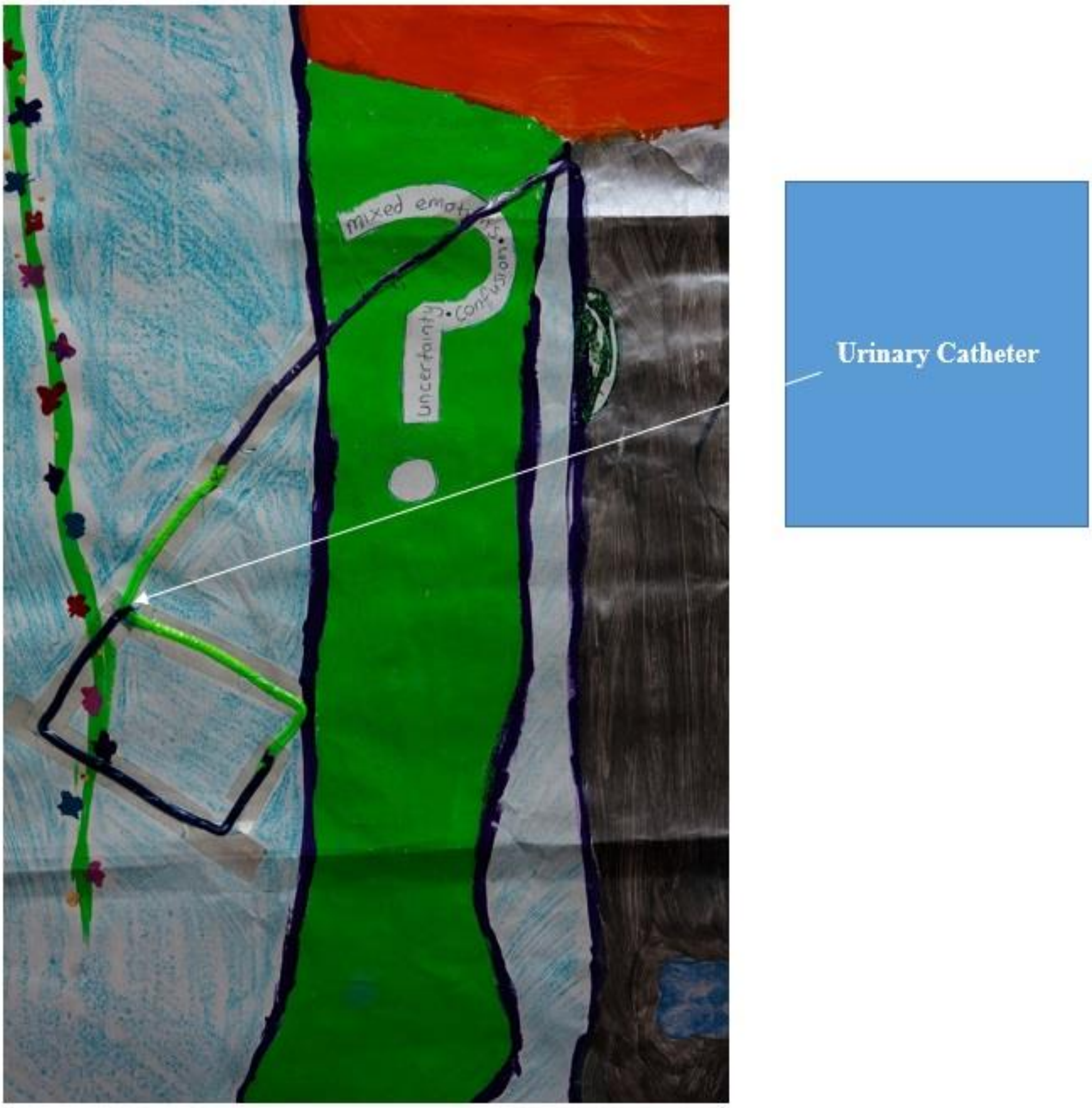


Figure 10: Lucy's image of a catheter

This image draws attention to the visceral experience of the urinary catheter within the body. The catheter was positioned in close proximity to an intimate and personal part of the body, the genital region. By drawing the catheter, Lucy makes known to the audience that her once private bodily function of urinating has become public. Additionally, the visible presence of the catheter is an outward sign of her illness to others. The vivid and evocative power of this image expresses not only Lucy's experience of sensory pain and body invasion but also the impact Lucy's illness is having on her being in the world. Her visual depiction of a catheter is further enforced and elaborated on in her verbal account of pain and body invasion.

> *L. The catheter! That's the hardest. That has to have been the worst. They always wanted you to get up and start walking and whatnot, and I was going, 'I know I'd be able to [move] if this bloody catheter wasn't stabbing me'. It was really painful; it was not fun. It just was really painful. They were like, 'We can't take the catheter out until we're sure that you're able to stand up'. But I couldn't stand up with the catheter in. I knew I'd be able to just get up and go if I didn't have it in but they were like, 'No, we have to make sure'. It was so bad because they were like, 'Alright, up and walking,' but I couldn't sit up to get out if the catheter was in. Then, once I was out they had me sit down on a chair for something like 20 minutes. It's so painful. It was fine when you're standing. It's just when you're actually sitting on the catheter, it's like stabbing you. It's really not fun. So much pain.*

In this story, Lucy recounts the pain and distress of this medical intervention. She repeatedly uses the word '*stabbing*', a word used to indicate a violent act or penetration of the body. She chooses this word and others such as *'bloody catheter'* to communicate body invasion and a body in pain. The presence of the catheter is an unpleasant and hard to ignore bodily event made more difficult by the apparently inconsistent medical guidance; she was told the catheter could be removed when she was able to stand and walk. Lucy is thrown into inconsistency and confusion regarding her bodily function. Additionally, being at the mercy of an artificial catheter means not being in control of a body process, urinating, which had been previously been under her control. Once again, Lucy tries to 'sort' this situation by engaging in body vigilance. Despite degrees of body impairment, she knows her body's strengths and limitations. She positions two types of knowledge against one another, the nurse's expert knowledge concerning the benefits of mobility and her own embodied knowledge of her body capabilities and limitations in the context of body pain and invasion. The following story reveals Lucy's responses to an even greater body invasion; that of a transplanted kidney.

6.2.4 Story 4: *'A new body part in your body'*

Lucy received a cadaver kidney after two years of haemodialysis treatment. On her body map, she drew a large surgical scar on the left side of her abdomen (Figure 11). This was the site of her renal graft implantation.

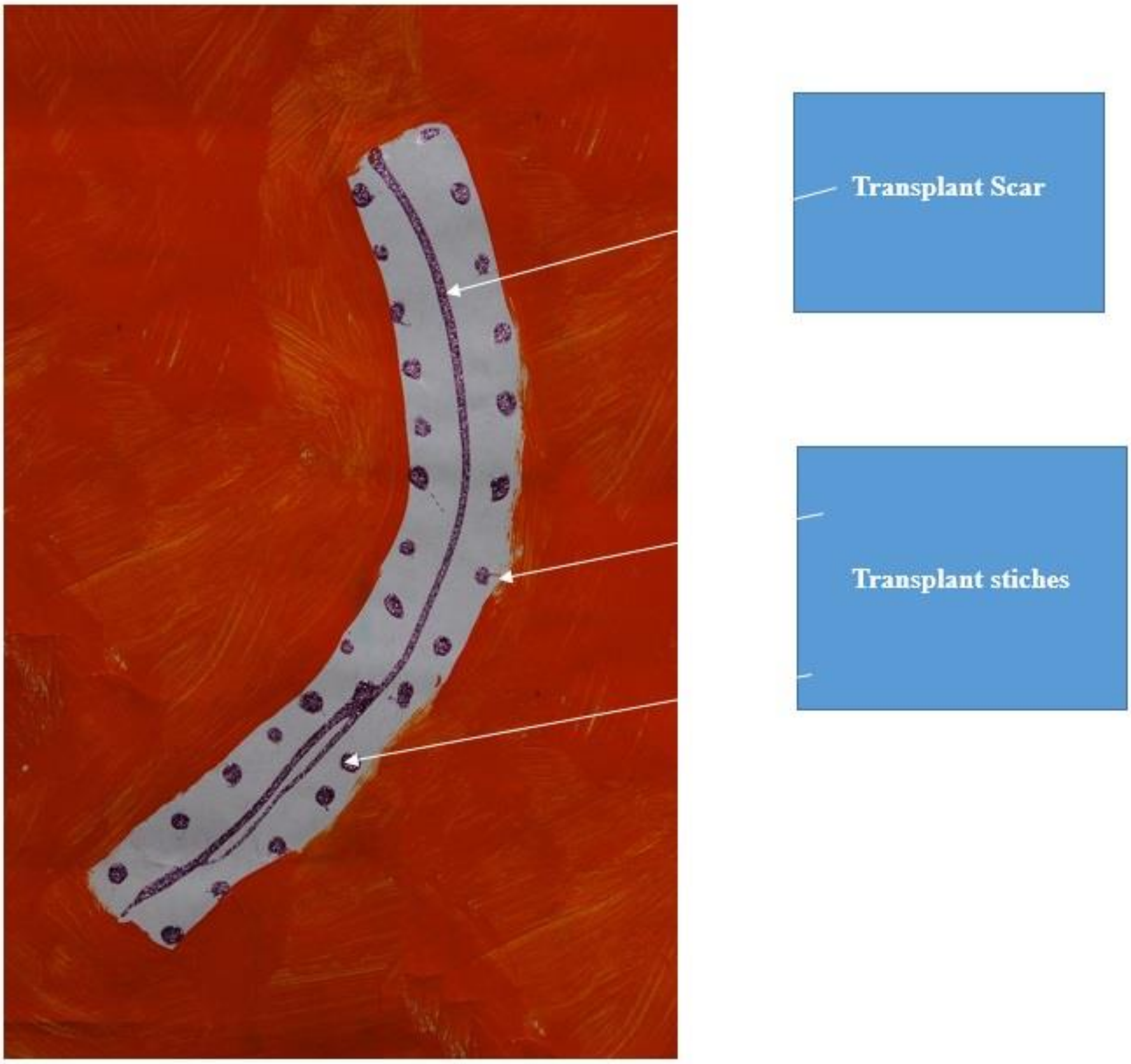


Figure 11: Lucy's image of her transplant scar

The scar constituted a major change in her body. She used the colour purple to highlight and accentuate the scar. Lucy’s experience of renal transplantation was a complicated experience in which she experienced both positive and negative emotions as she revealed in the following excerpt:

> *L: I'm just really chilled. Even when I went down for my transplant, they were like, ‘You must have the lowest blood pressure of anyone about to have a transplant, ever’. I was just chilled. It was funny because they were going, ‘Alright, you'll be fine,’ and I was like, ‘Yeah, I know’. It wasn't a big thing but then I was like, ‘So, I might actually die, but don't worry, I probably won't’ [laughter]. It doesn't seem like a serious topic.*

> *It is a serious topic; I know that it's a serious topic. But it just doesn't seem like one to me. It doesn't even get in the way of other things. It's just there and I have to work around it. But then after transplant I was really bloated because obviously there was a new body part in my body. It's a new weight. It's a new body part. It's hard to get used to, but it's fine now. It just feels like something under the skin, like a little bit of a bulge there. It's big. It's like where the scar is, so it's all the way down that way. It still feels a bit weird because I feel uneven [pause] because I have a body part that's bigger than what mine would have actually been. This is an actual kidney, whereas mine would have been [pause] I had two kidneys, but they were literally like that size [demonstrates small size through gesture]. Non-existent, yeah. [Laughter.]*
>
> *So it's weird to get used to. Not in a noticeable way but just when I'm like thinking about it, like I have this extra weight on one side. It's weird! Right after transplant it was really weird and I didn't feel comfortable with it or anything. For a while I refused to stand up without holding onto it because I felt like it was falling out, weirdly, because I wasn't used to the weight of it, like it felt heavy. Even after I knew it was all good and I was like wandering round the ward so that I could try and fall asleep, I was still walking around like this and then I was going, 'No, wait, I don't need to hold on to this,' and I'd hold onto it again.*

Transplantation brings existential disruptions to Lucy's body and sense of self. After transplant Lucy can feel the tangible presence of a new body part. Its presence disturbs her relationship with her body and threatens her embodied identity. She describes how her body came into corporeal and sensual contact with a newly transplanted kidney. The organ can be felt underneath the surgical scar. It bulges through the skin. She experiences new bodily sensations that are detected underneath the skin; the transplanted organ announces its presence, weight, and fullness. She is aware that the transplanted kidney is not in proportion to her own original kidneys and the transplanted organ occupies a larger space in her body as represented in her image of a large scar. She perceives her body to be *'uneven'* because of this disparity. Lucy's sense of feeling *'uneven'* connotes a deep visceral awareness of this new body part that has suddenly appeared inside her body. This unevenness, although not noticeable to others, challenges Lucy's need for body steadiness and order.

Lucy’s body is undergoing significant changes and alterations, which causes a lack of body stability. She consciously thinks about the presence of the new kidney and she feels extra weight on one side of her body. We do not consciously think about how an internal organ feels or weighs until it is suddenly brought to consciousness through the experience of transplantation. In feeling the weight of the kidney, she is bringing awareness into her body. She is noticing how it feels to have a kidney in her body from an internal, embodied perspective rather than from the outside looking in. Her vulnerable body is in need of constant surveillance and she engages in the bodily performance of touching and holding to safeguard the kidney. Lucy continues to describe the experience of a new body as feeling weird and not belonging to her. The kidney is not an original part of her body- it is foreign. At this point she struggles between regarding the kidney as part of ‘me’ and ‘not me’.

> *L: And every now and then I’d be like, ‘Oh yes, this is like someone else’s kidney’ or ‘I have a dead person's kidney in me’. Then I was like, ‘Um ... that's weird’. [Laughter.] It's weird but [pause] it's like, 'Oh my god, I have this person's kidney'. [Laughter.] It's like it's not [pause] yeah, it's still a kidney. It's still someone else's kidney. It's not yours. Well, technically it is now, but now it just feels like another organ. You know, your everyday organ.*

She is slow to acknowledge the kidney as truly hers as she has not yet totally assimilated the kidney into her body. Whilst she is thankful for getting a kidney she is still very much aware that she has ‘*a dead person’s kidney’*. Although she makes light of the situation, there is still a hint of the horror that is evoked in this young girl by the situation. Living in a body that is being kept alive by the body part of a dead person is a surreal experience. She attempts to minimise the experience by using humour and laughter, yet she is still conscious of the seriousness of the situation. Nevertheless, she perseveres in trying to make sense of and order these strange occurrences a common thread running through her overall narrative and which is evident in Lucy’s final story.

6.2.5 Story 5: *‘Organised Chaos’*

Lucy tried to make sense of her embodied existence in a world of CKD. She conveyed her experience through the visual metaphor of an atom on her body (Figure 12).

Figure 12: Lucy's image of an atom

This visual metaphor demonstrates her attempts to make sense of and explain a potentially indescribable phenomenon: *the world of kidney disease*. The abstract object of an atom to represent kidney disease is an interesting way for her to anchor her body to a world of CKD. The spiral patterns of colours of various sizes in the circle represent different emotions and mental states. She continued to explain the ever changing nature of kidney disease through metaphors, and displayed an enduring desire to keep her body and her life ‘sorted’ and normal in the context of CKD.

> *L: I'm going to draw an atom. I decided I just wanted it to be in a circle because of the black hole theory. It's kind of just draw a black hole [laughter]. Like that's it, that's all it is. Because it's just a nothing and just because [kidney disease] has an everything and a nothing [laughter]. And circles are everything. Circles are the beginning of life [laughter]. And because the kidneys, my kidneys at least, were non-existent. Everything is non-existent when there's a black hole around, right? There is a lot of scribbling, because I decided scribbling was appropriate for this. Because scribbling symbolises madness, and you've just got to go with the madness, you know. Because*

> *when it comes to kidney transplants and kidney diseases, you just don't know what the hell's going on, even when you get an answer. There is just something going on in there, and its kind of ridiculous, and it doesn't make any sense whatsoever [laughter]. It’s [pause] organised chaos.*
>
> *C: So that's what kidney disease is like?*
>
> *L: Ya. It makes sense to me. ‘Organised chaos.’ It's still the circle - but it's got a mess inside it. Well, you know, you have all this stuff obviously. Yeah, the scars, and the marks and whatever. It obviously makes you see things differently, but [pause] just in a different way. So, you know, it changes your perception of things. I don't see hospitals as sad, dreary places. Because it's like a community in there, there's all these other people. Even though most of them are younger than me, I still feel like, 'Yeah, this is a cool little place that I can be,' [laughter]. I almost forgot about it [after transplant], because I was going, 'Oh my God, remember that madness, and that simple organised chaos that it was'? Now, it's just like [pause] chaos, except not so organised. It's no longer this closed little bubble of the hospital, versus this [pause] not so much madness, but structure of real life [laughter]. I just don't know any more [pause and laughter] you have to reorganise the chaos!*

Living with CKD involved learning to live with constant changes and adjustments. Lucy makes use of the scientific metaphor ‘*black hole’* to represent her embodied experience of living with CKD. The black hole is the perfect metaphor for Lucy to explain kidney disease. A black hole is not visible, just as kidney disease is not visible to the naked eye. The gravity of a black hole is so strong that nothing could escape it, and Lucy cannot escape her illness. In a mystical sense the black hole may be her way of explaining the inescapable nature of CKD and its unfathomable power. In this way, the strength and power of the black hole becomes a metaphor for the strength required to get through this chronic illness.

Lucy creatively elaborates and extends her story of the chaotic nature of CKD through the metaphor ‘*Organsied Chaos’*. The underlying message is that CKD is predictable only in its unpredictability. In most other contexts, the notion of organised chaos would carry negative connotations, typically signifying someone's confused state. Yet, here the organised chaos clearly stands for some positive effects rather than something undesirable. Amid the organised chaos, Lucy feels at home in hospital. This suggests that the organised chaos of hospital life and dialysis allows her to have a sense of predictability and institutionalised care even if this seemed nonsensical and disempowering at times. It also anchors her to a world where other children are going through similar experiences. This '*Organised Chaos'* becomes less organised after transplant and hospital discharge; Lucy now has to reorganise the chaos in her wider life world. This is a much more daunting prospect for Lucy.

In summary, Lucy's stories centre on the ways CKD encroach on every facet of her life. She was continually reminded of her illness through the everyday symptoms that caused much pain and discomfort. Medical technologies and treatment constrained and invaded her body. Lucy's narrative illustrates episodes of confusion, ambiguity and chaos which threaten her sense of a predictable ordered body. However, there is also a counter narrative in which she asserts her embodied knowledge and intentions to 'sort' and organise the body processes that are under her control; in other words, to understand and claim agency over her body. The following section presents Lucy's overall narrative; a narrative of organising chaos.

6.3 Lucy's Narrative: *Organising chaos*

Lucy's narrative reveals the tensions between trying to preserve a 'normal' adolescent body which she has control over and the chaos of an ill and invaded body. Lucy communicated the complexities of living with CKD and her stories allowed for a rich narrative to emerge in which she attempted to give CKD the role of a minor character, but often a very deadly one, that threatened to destroy the more positive aspects of her life. Lucy gave narrative accounts of adversity in which she struggled with the physical consequences of her illness, an illness which interfered with puberty and caused bodily discomfort and pain. In living with CKD, Lucy's well-being was threatened, a situation that was out of her control. Medical devices and treatments continually invaded her body, which affected her sense of self and well-being. However, in her narrative, Lucy also demonstrated her resilience despite adversity. The disruptions brought about by CKD were often well managed by Lucy as she attempted to organise her body in the context of CKD. In her stories she endeavoured to 'normalise' her illness through the performance of self as a resilient and stoic being. She asserted her bodily strength, endurance and emotional control in dealing with CKD. Lucy's narrative revealed important aspects of her self-understanding, her own mentality and positive thinking. Lucy's embodied knowledge of her illness stood out in these narratives. Lucy paid attention to her body and held valuable embodied knowledge regarding her body and illness. She wanted be an active agent in her illness trajectory despite her attempts often being curtailed by HCPs. Lucy's embodied knowledge was overlooked and the potential benefits of this untapped resource as a tool for managing her illness was ignored. However, Lucy persisted and she decided what to allow CKD to mean in her life. She accepted the changes in her body and tried to move forward. Throughout her narrative, she shifted between the voice of a tolerant sufferer—working to '*just deal with it'* and keeping CKD from interfering with her life - to the voice of a vigilant sufferer working to recognise symptoms and careful monitor her body. Her perseverance stood out very clearly and her attitude often included: '*We'll sort it out, and just get on with everything else.'* Even in life-threatening situations, she downplayed the severity of her situation: '*It doesn't seem like a serious topic'; 'So, I might actually die but don't worry, I probably won't'.* Therefore, instead of dwelling on the problems of CKD, she seized the present and showed how resourceful she could be by engaging in body vigilance despite degrees of impairment. This act of vigilance demanded she remain constantly aware of the limitations and changes to her body caused by her illness and subsequent treatments. Lucy continually compensated for her ill body, allowed for its unruliness and vulnerability and paid attention to her body's limitations. By remaining stoical and sustaining an attitude of resilient self-presentation throughout her narrative, it was possible for Lucy to manage and cope with CKD. She did not allow her illness to determine how she expressed herself.

6.4 Conclusion

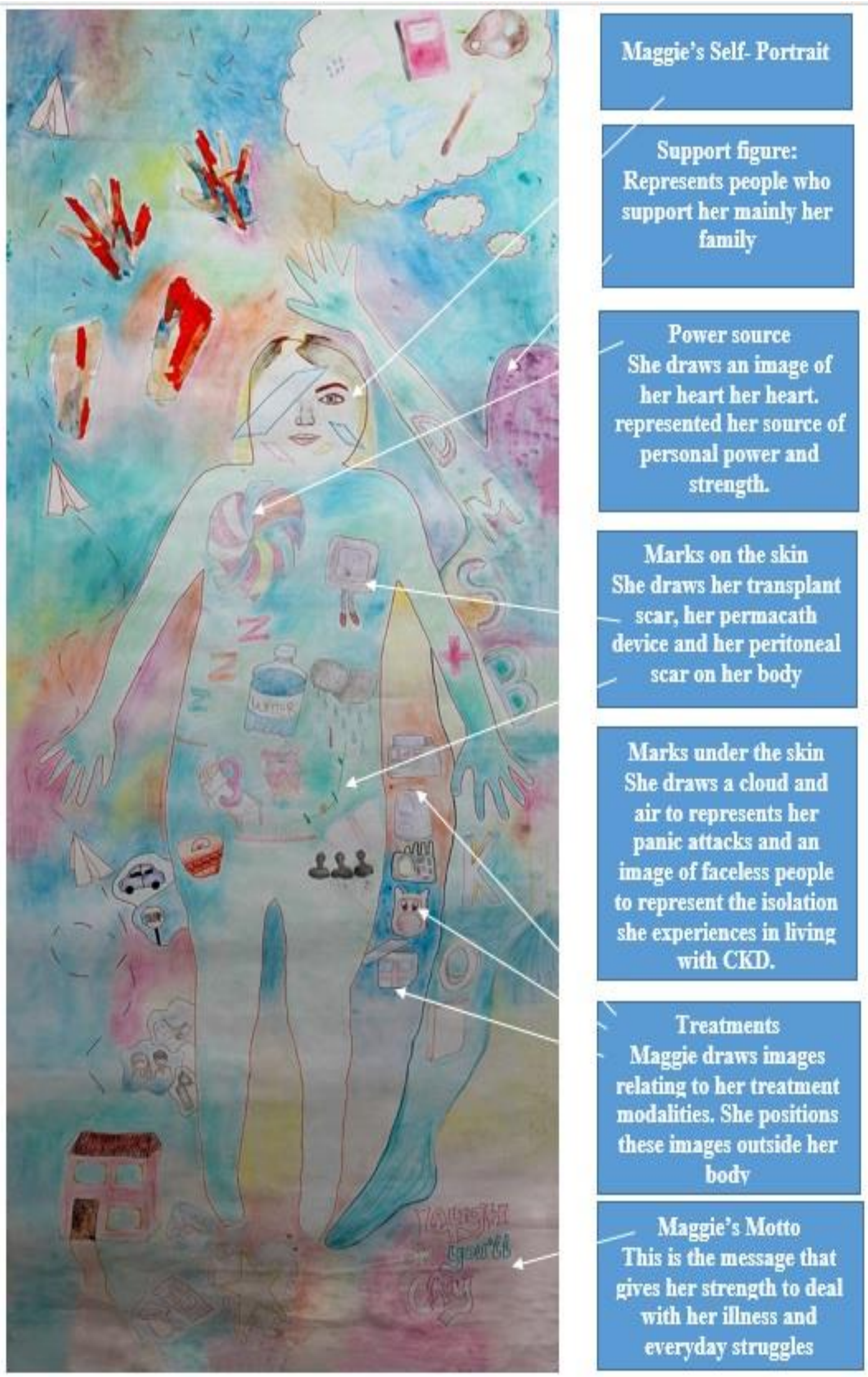
This chapter presented Lucy's narrative of her illness experience, which emerged from her visual and verbal stories. Her narrative illustrated how CKD can cause bodily suffering and pain. She described moments and periods of being overwhelmed and distressed in living with CKD. However, Lucy also described the great effort, willpower and strength required to counteract negative feelings in an attempt to regain emotional control over her illness. Her stories will be revisited in the cross case analysis chapter and subsequent discussion chapter. The next chapter introduces Maggie and her experience of living with CKD.

Chapter 7: '*Laugh or you'll cry*': Maggie's Story

7.0 Introducing Maggie

This chapter presents the stories of Maggie, a 15-year-old girl with CKD. At the age of three, she was diagnosed with CKD and was treated with medications. As her kidney disease progressed, her need for a pre-emptive transplant became evident. A pre-emptive transplant meant she underwent a transplant before needing to start dialysis. She was placed on the transplant list despite her dad agreeing to donate his kidney. While on the transplant list, a cadaver kidney became available and she did not receive her father's kidney as expected. This was a challenging time for Maggie as her body rejected the cadaver kidney within hours of transplantation. Following rejection, peritoneal dialysis was commenced. After a year of PD, she became very ill; at that point, haemodialysis was initiated. She received dialysis four times a week until the age of 14, at which time she received her second transplant. On this occasion the donor was her father and transplant surgery was a success.

Maggie had one older sister and a younger brother. Her mother or father accompanied her to hospital appointments. However, at my time of meeting Maggie, her need for hospital based treatments were minimal so our meetings predominately took place in the family sitting room of her home. Maggie was a very shy young girl so the safety and privacy of this cosy setting helped her to feel relaxed and comfortable. She loved art, which was her favourite subject in school. Maggie welcomed the opportunity to engage in the creative process of body mapping and she shared her experiences of her illness as she simultaneously created her body map. Image 13 provides an outline of her completed body map.



Maggie's Self- Portrait

Support figure: Represents people who support her mainly her family

Power source
She draws an image of her heart her heart. represented her source of personal power and strength.

Marks on the skin
She draws her transplant scar, her permacath device and her peritoneal scar on her body

Marks under the skin
She draws a cloud and air to represents her panic attacks and an image of faceless people to represent the isolation she experiences in living with CKD.

Treatments
Maggie draws images relating to her treatment modalities. She positions these images outside her body

Maggie's Motto
This is the message that gives her strength to deal with her illness and everyday struggles

Figure 13: Maggie's completed body map

7.1. Overview of Maggie’s Body Map

Maggie created her body map over many months on a table in her sitting room. She spent a great deal of time reflecting and thinking about each body mapping activity. In drawing her body outline Maggie depicted an open body posture and she positioned her support person to her left hand side. Family members featured as her main sources of support throughout her illness. In Maggie’s body map there are no visual references to a kidney or anything that portrays her kidney disease. Yet the image of Maggie’s permcath line or medical lifeline marks her as a renal patient. Her body map is dominated by images relating to key events in her illness trajectory.

Maggie was very careful about the images she placed inside and outside of her body. She positioned images of medical technology and treatments outside of her body. The inside of her body map is dominated by images representing events that have left a lasting mark on her body and body’s memory. These images indicate her psychological state and mood at that time, for example; images of dark clouds, rain, faceless people and her use of one eye on her self-portrait. However, positive emotions and experiences also feature on Maggie’s body map. In her personal message to the world, she drew in large bubble writing ‘*Laugh or you’ll cry’,* and positioned this image at the base of her body map. With this image Maggie decided to present her positive self who chose to ‘*laugh*’ rather than ‘*cry*’ about her life with CKD. Body mapping enabled Maggie to activate memories held in her body and in doing so helped her connect with different events that would have otherwise been overlooked or forgotten:

> *‘It's good to - not re-live, but - remember what happened, all the events that I was drawing on it [body map], and then remembering what happened and stuff that I probably would have forgotten about. I didn't really forget it. It kind of just got blurred into one. So by drawing it [body map] I was able to separate events and stuff.’*

In this way, body mapping offered Maggie a way to access information and facilitated a deeper and more personal reflection of her illness experience.

7. 2 Overview of Maggie’s Stories

The five stories illustrated in Figure 14 represent Maggie’s narrations of her embodied experience of living with CKD as identified in the systematic process of analysis. Throughout her stories Maggie portrayed the destructive effects of CKD and its treatments on her body.

Figure 14: Overview of Maggie's stories

7.2.1 Story 1: *‘I didn’t want it. I wasn’t sick’*

This story recounts Maggie’s need for a pre-emptive kidney transplant, which arrived earlier than she expected. Receiving a transplant caused a major disruption in Maggie’s life and consequently affected her sense of a well identity.

> *M: I was well before it [pause]the first one [transplant], in 2011. Yeah, like I wasn't on anything, or anything. They put me on the list. I thought it would take years to get one [a kidney], but I got offered it 4 weeks later. I was at home. I was in my bedroom and it was really early in the morning and we were all in our rooms. We were all awake and I was playing with my toy when I heard my mam's phone ring. Then I heard her voice go all proper, so I just figured it was a nurse. Then I stopped listening, and then she came in and told me. I don't remember what happened next. I just remember getting into the car and going. Mam said that I cried. I remember saying in the hospital that I didn't want it.*
>
> *C: So you remember not wanting it?*
>
> *M: Ya because I wasn't on dialysis and I wasn't sick. I wasn't like [pause], it's like I didn't need it at that point really, but like I did, but not really. Ya I thought I was fine. I was still going to school every day and stuff. It lasted 8 hours. Yeah, they said that my body knew that it was [pause] a 'foreign object'. Yeah, and my body sent out loads to attack, loads of antibodies to attack it.*

At the beginning of this story, Maggie positions herself as a healthy person in the absence of medical treatment. Her experience of transplant challenged her former assumptions about a healthy self. She was taken by surprise when a viable donor became available just weeks after she was placed on the transplant list. Her initial reaction was one of shock and apprehension. She did not need or want the kidney. However, looking back on this experience she now realises that her body needed the kidney. This retrospective awareness serves to help her make sense of this disruptive event in her life. Maggie makes it known that her body subsequently attacked the '*foreign object'* rejecting the unwanted kidney within eight hours of surgery. This whole event represented a major disruption in her life, causing a tension between her old way of life and her former perception of a healthy self. She was suddenly transported into a new way of life, which was unfamiliar and dominated by the need for medical treatment. In the following story, she portrays a series of upsetting, frightening and painful experiences which entailed, among other things, bodily and functional losses as a consequence of peritoneal dialysis (PD).

7.2.2 Story 2: ‘My lungs filled up with water’

Following her kidney rejection, Maggie started PD immediately. For Maggie, this form of home dialysis required 10 hours of treatment every night. In the following story, she recalls the physical and emotional disruptions she endured as a consequence of PD treatment. She reflects:

> *M: It was a big, rectangular white machine on a dresser, it had two big bags of water on top and another bag of water hanging on the wall down. And then it had a big bag of water on the floor that filled up overnight. When you attach it to the machine, there's water in the bags on top of the machine. That [water] comes out of the tube and goes into your stomach. And it stays there for like 40 minutes. Then it drains out, back to the same tube, but goes to the bag on the floor. And that happens 10 times over the night.*
>
> *C: What was that like?*
>
> *M: It was really sore at first. The first time, you get huge pains in your shoulders and legs, and I'd have to put warm water to stop the pain. Because to get the water out it has to suck the water out, so it'd be really sore. Yeah, and my legs and stomach! It was just because of all the water, what it was doing. I wasn't used to it. Yeah, but then it became grand. I got used to it.*
> *C: So you got used to it?*
>
> *M: I didn’t have a choice. I used to go to bed at 9 o'clock, because you had to get connected to it. You’d kind of be annoyed because you had to go to bed early. If you wanted to be on time for school, you had to go to bed at 9. Then, if the machine ran over you’d be waiting for it to end. If the alarms went off at night, it wasted time. Then it kind of got a bit bad because [pause] the machine wasn't working that well. It kind of kept messing up and stuff. It was annoying. Yeah, it made you more healthy, but it didn't make you feel better. It made your blood test levels good, but it didn't make you good. Just too many side effects.*
>
> *C: What kind of side effects?*

> *M: When I was 12 I got really sick from it and stuff. For a year they just thought I was gaining weight and being healthy, but then I wasn't. Cause I was taking on loads of water into my lungs, and by the end of it I couldn't breathe. They thought I had a stomach bug, so they put me on loads of fluids. I was getting more fluids in but I already had too much fluid, so it was really dangerous. All like my lungs filled up with water and then the left side of my heart got really stiff from the … it was putting strain on the heart. It made the whole left side really stiff and weak. Dialysis kept putting pressure on it. It's been coping under the water for a year so without knowing. [Pause.] The water everywhere in your legs, my arms and then my heart just got real weak from coping with the water like trying to work. I hated it by the end, because it stopped working so it got annoying. It stopped working after a while so I didn't have a choice [about going on haemodialysis]. Just got to keep going on dialysis. Just waiting.*

This story reveals the unexpected repercussion of dialysis on Maggie's whole body. The fact that Maggie dedicates such a large amount of her account to narrating the disruptive nature of this treatment suggests she considers it important. In telling this story, Maggie relives and performs the powerful embodied experiences of the bodily suffering she endured while on dialysis. She begins by portraying herself as a passive agent in the presence of the dominant machine, which controls her body. The ongoing cycles of PD cause temporal disruptions as she is physically confined and constrained by the PD machine. She positions herself as a person with limited agency or choice over this treatment. She reluctantly adjusts to the presence of the PD machine and she notes that when the machine is working well it receded from her perceptible awareness as she becomes habituated to it '*it became grand, I got used to it'.*

Maggie asserts her own embodied knowledge of dialysis, which contrasts with medical knowledge. From a medical perspective, the dialysis machine makes her *'blood test levels good';* however, the focus here is on numbers and tests to determine if Maggie's body is healthy and does not conceptualise her body as a whole, living system. This tension between medical intervention which claims to make things better yet results in further deterioration is a feature of Maggie's narrative. Her first transplant is rejected by her body and in this story she describes how the PD machine malfunctioned, causing her considerable pain and distress as a result. The dialysis machine, which had receded into the background is now positioned in the foreground.

Because of the machine dysfunction, Maggie pays closer attention to its harmful impact on her body. Maggie describes excess water indiscriminately invading her body organs (lungs/heart) and her body extremities. Water gushes inside her lungs, causing an inward pressing and suffocation-like symptoms; the sensation of drowning is palpable in her account. With her lungs submerged in water, she struggles to breathe. Her body fights for every bit of air. Her lack of agency surfaces again at the end of the narrative, where she states '*I didn't have a choice'*. She must continue to endure dialysis until transplantation. As she states: '*Just got to keep going on dialysis. Just, waiting.'* In her visual image below, Maggie returns to this experience through her illustration of a water bottle (Figure 15).

Figure 15: Maggie's image of a water bottle

Her image of a water bottle, centred in the core of her body, is one of the largest images on Maggie's body map. Water is essential for life. Maggie's body cannot live without water, yet excess water had become a source of threat to her body. Water permeates her illness experiences. Through this image, she employs a creative way to visually narrate the dominant presence of water in her experiences of living with CKD, including her sense of being drowned and overwhelmed by water. This story evoked a strong empathic, embodied response within me at the time and I reflected on this experience in my field notes.

> *'Maggie recounts this story with a matter of urgency. As I listen, I experience the unfolding events with her, reliving this event and identifying with her. I empathetically insert myself into re-experiencing her dialysis experiences. I imagine her room filled with dialysis equipment. Her body filling up with water. Her struggling to breathe. It is difficult to bear witness to her tale of bodily suffering without feeling empathy. Was this her intention? Perhaps I represented someone who would listen and understand. I recall Maggie frequently asking me about my personal experience as a nurse. I wondered did this help her to voice this experience'*
>
> *(Reflective field notes, September 2016)*

It is also worth noting that at the time of telling this story, Maggie was no longer on PD treatment. Yet she was able to vividly describe PD, which testifies to the lasting impact the experience had on her. She implies that the breakdown of the PD machine, in particular, was a key event in her life, and the cause of additional bodily suffering. Of all the participants, Maggie appeared most attuned to the embodied experience of CKD at a deep, visceral level. This is also evident in the following story.

7.2.3 Story 3: *'Chronic tiredness'*

Tiredness is a predominant feature of CKD and through the telling of this story Maggie processed the debilitating nature of this chronic body experience.

> *M: The one at home [peritoneal dialysis] used to tire ya out because it used to make you really dry. It used to take all the water out so you'd feel really bad. You just want*

> *to sleep. But then you could sleep for 12 hours and then wake up, but still be exhausted. It’s like you could sleep 12 hours when you go to sleep tired and you sleep for 12 hours and you wake up even more tired. You could sleep for 12 hours and get up and feel nothing, no difference. All the time. That tired!*
>
> *C: Really?*
>
> *M: Ya, it was just a side effect of it [kidney disease]. Just really tired everywhere. And you don't want to go and do anything because you're too tired. It's like if you ran a marathon and then you went to bed, and you woke up the next day and you couldn't move. Sometimes you couldn’t go to school. Some days, you had to like just ring up [school] and be like, 'she's out because of chronic tiredness and not being able to walk'. Sometimes you’d just get on with it, just carry on as normal. Just carry on as normal. I’m used of being tired.*

This story, in its use of tone and diction, vividly describes Maggie’s experience of whole-body tiredness and her struggle to adjust to a physically exhausted body. She blames the PD machine for draining her body of fluid. This relates back to her earlier story of water, which was portrayed as a source of bodily discomfort. However, in contrast to her earlier story, she now portrays the drying effect of PD. There is no escape from the fluctuating and debilitating effects of PD. She quickly moves away from the topic of PD to describe the inescapable experience of tiredness. Tiredness disrupted her ongoing involvement in the world and at times she was unable to attend school. Her use of the term ‘*chronic tiredness’* to report her school absence is instructive. It confirms her as someone in possession of medical knowledge. She attempts to minimise this experience by reporting it as a part of her everyday life. Maggie continues her account of tiredness in her visual narrative (Figure 16).

Three Z shapes to represent tiredness

Figure 16: Maggie's image of tiredness

Her visual depiction of tiredness conveys a powerful image of an exhausted body consumed by tiredness. The repeated use of the letter Z in this image indicates tiredness and a need for sleep. ‘ZZZ’ is generally accepted worldwide as a representation of sleep. The size and position of the ZZZ are also noteworthy. The ZZZ are drawn in large bubble writing and placed across her body to demonstrate how tiredness is experienced everywhere in her body. This visual image resonates with her verbal account; tiredness is a feature of her illness and treatment that is constant and experienced *‘everywhere’* in her body.

These stories reveal the physical disruptions to Maggie’s life caused by the impact of CKD and its treatments. Dialysis in particular left her body tired and exhausted. She endured haemodialysis for a further three years. At the age of 14, she received her second transplant; this time from her father. While the transplant freed her from dialysis, in the following story Maggie begins to realise that she will not achieve the optimum healthy state she had envisaged and had been led to believe. She must continue to strive for wellbeing but always in the context of her disease and treatment.

7.2.4 Story 4: *'Chronic kids are always chronic kids'*

> *M: Before the transplant, they'd kind of be like: 'Oh, nothing's going to go wrong. You're going to get a transplant and leave really well.' I think they make you excited for it. Yeah, they try and make it good. It would be better if they told you, because they don't. They like [pause] not lie to you, but they just promise stuff, and then it doesn't happen. I think it would be better if they said that there could be complications, and not: 'You're going to get it and then go home. It'll be grand.' They still kind of sugar coated it, like. No, they never even told me. Like, they said that I could go and do anything, and then afterwards they give you loads of rules [laughter]. Like, okay I can do that, but no, not really. Like [pause] yeah; like at the start, they're like, 'You can go play football', but then you can't. I don't know. And then I got angry at them.*
>
> *C: And what is life like after transplant?*
>
> *M: People don't realise that chronic kids are always chronic kids. After transplant you're going to be in clinic every month and you're going to have to take medication for the rest of your life. Still have medication. Yeah. That just really hits randomly sometimes. I'd be like: 'Okay [pause] I have other things that are for life. I still have to take those.' Well Doctor A is really happy. Yeah. Every time we go in it's, 'You're great'.'You're great' because they're talking medical-wise. So it's just all medical, they don't even think about that [social side of illness]. The medical side of the story, it's important to learn about the medical side, but once you've learned there's other stuff to it as well [pause] other stuff to the story. But they [doctors] just don't ask that question to bring up that stuff.*

Here, Maggie draws a sharp distinction between what she was told life would be like after transplant and the reality of how her life is now. The potency of her representation is in its immediacy, with the despair she is experiencing after transplant contrasting starkly with the expectations instilled in her before the procedure; '*You're going to get a transplant and leave really well. I think they make you excited for it'*. Once again the medical promise of restoration of agency and freedom, does not materialise. Maggie had envisaged being free of all this and returning seamlessly to the normal life of a young girl, post body trauma, however the painful realisation is dawning that she will remain a '*chronic kid'* having to experience ongoing complications and medical intervention, including taking medication for the rest of her life. She is angry that the medical evaluation of what constitutes '*wellness'* which ignores many of the wider life achievements and body freedoms that are important to Maggie. For Maggie, being well goes beyond the physiological state of the body. She is frustrated with HCPs' lack of interest in finding out about other aspects of her illness experience and wellness expectations. For Maggie important issues are her identity, body agency and human relationships, issues that lay outside the circumscribed medical world. She is on the brink of re-entering this world and the next extract highlights some of Maggie's challenges in making this lifeworld transition.

7.2.5 Story 5: *'You've got to go back'*

> *M: It's more like the stuff you miss out on, not the actual illness. Like the way you're not in school. It is more important to be well but then you've got to go back. It's like you didn't learn the social skills that everyone else did, because you missed out on making friends and school. So it's like trying to fit in with that again.*

Maggie portrays herself as a young teenager struggling to adjust to severe disruptions in her physical and social development. In light of her current 'healthy' state she is expected to return to normal everyday activities. Maggie wants to be a normal teenager, however, she remains uncertain about her social skills and her ability to integrate back into the real world of adolescence. Her anxiety about lost social skills expresses the considerable difficulty in adjusting to customary adolescent social life after transplant. Her use of the past tense *suggests* that past disruptions have left a lasting effect, and are continuing to have an impact in the present. She has not had the same opportunities for developing peer relationships and achieving important developmental milestones. Time spent out of this social milieu, with a focus on illness and its treatments have made her development trajectory different, possibly alien to the experiences of her peers. In the following image from her body map (Figure 17), Maggie describes how her frail looking physical appearance draws attention to her difference and marks her as '*sick'*.

Figure 17: Maggie's self portrait

A distinctive feature of Maggie's portrait is her pale white face. This is the only part of her colourful body map that was left white. Her pale skin revealed her identity as a sick person.

> *M: One time I had a student teacher and she kept asking, 'Are you okay? Are you okay?' I think it was just because I was pale. Then she called me up and was like, 'Are you sure you're okay?' and I was like, 'I'm going to have to tell her'. She didn't even know or have an idea. She thought I was sick or something. It was in fifth class so I was like, 'Yes, I have kidney failure so I'm always pale.' Then she was like, 'Oh,' and was like, 'Okay, go sit down.' My cheeks wouldn't turn pink or anything. I'm still pale*

> now. *Even when I go to appointments, they're like, 'You're looking a little pale today,' and I'm like 'Yes, I know. I'm like* [pause] *'that's every day.'*

Maggie explained how her pale complexion revealed she was ill and placed her at risk of being noticed by others, which frustrated her. Her teacher singled her out amongst her peers because of her paleness. This was a source of embarrassment. While Maggie could not control her ill body, she asserted control in the way she responded to those who noticed. She actively downplayed the significance of her paleness and reluctantly informed her teacher that her paleness is a result of kidney failure, rather than a transient sickness. Her pale skin revealed her identity as a sick person.

There is also a temporal element to Maggie's story. She specifically references an incident that happened 6 years previously, when she was in fifth class. This experience still resonates for Maggie in terms of her embodied identity in a social world. After recounting that incident, she brought the story back to the present, observing how her paleness persists. Her body continues to be viewed and scrutinised by others. Maggie is aware of the constant monitoring of her body by her teacher and health professionals, many of them remarking on her pale completion. Interestingly, in her self-portrait she has overlaid parts of her face, including one eye, with angular shapes. Maggie did not explain the significance of these at the time. Perhaps these are a means of masking/hiding her pale face from public view or they could be a way of making her face more noteworthy for other reasons than paleness. Perhaps the angularity or sharpness of the shapes represent pain. Her social pain and suffering was further evident in her visual image of faceless people (Figure 18).

Image of faceless people to represent social isolation

Figure 18: Maggie's image of faceless people

Her image moved me in a way that I was not expecting. The stark image of faceless people drawn in black re-inforce the description of feelings of isolation that Maggie alluded to in her above extract. Drawing the people as faceless has the effect of depersonalising them. Maggie’s visual and verbal stories portray the physical and social suffering of a young girl returning from a world of bodily dysfunction and medical treatment and grappling with the imperatives of teenage life.

In summary, Maggie’s stories pivot on the breakdown of the physical body and the fallibility of medical science. She represents key events in her life that caused her bodily suffering and pain. Her stories also demonstrate the social suffering that she endured. Her stories from a narrative of biographical disruption which adversely affected her young life. The following section discusses this further.

7.3 Maggie's Narrative: *A Narrative of Biographical Disruption*

Maggie's overall account of her illness could be regarded as a narrative of biographical disruption. She describes an ongoing process of living with and enduring disruptive events in her life. The failure of her first transplant represents a major and serious biographical disruption. She reveals how difficult it was for her accept the need for transplant surgery, viewing it as unnecessary, unwanted and imposed. She was not ready or prepared for this event. This lack of preparedness was not because medical professionals failed to explain why the transplant was necessary, but was rather symptomatic of the confusion, fear and emotional disruption she experienced in the rupture caused to her sense of self and identity. Her former definition of a healthy self was discredited by the need for a transplant. Despite living with a diagnosis of CKD since the age of three, Maggie did not see herself as sick. She presents a physically-well body in her account. This sentiment is reflected in her statements, *'I was well before', 'I was fine'* and *'I wasn't sick'.* With these words, she created a counter-narrative for herself - a narrative of being well. However, transplant represented a sudden and irreversible rupture to her sense of self and her ability to produce a healthy narrative. Her experience of transplant gave rise to a biographical disruption, which quickly subsumed her into the medical world. Transplant was followed by a series of escalating disruptions, beginning with the kidney rejection, and followed by the realisation that renal replacement therapies were necessary. These disruptions constituted a series of blows to her expected narrative of being well. Her experience of a loss of a health identity led to a changed self. Her need for renal replacement therapies marked her sick identity further and forced her to adapt to a new role in life, one where she was more passive and vulnerable.

Her stories reveal the effects of treatment on her body. Dialysis is described as dangerous, destructive and damaging to her body, especially when unmonitored technology malfunctions. It is seen as physically invasive and causing a series of negative physical side effects, including a substantial degree of tiredness. Similarly, failures in medical interventions and discrepancies between medical and embodied perceptions of 'wellness' leave Maggie feeling vulnerable, at risk and not understood or cared for. These disruptions, with the accompanying realisations that the medical world is not necessarily safe and she is likely to be 'chronic' indefinitely, reinforce Maggie's distance from the normality that she strives for. In Maggie's stories, it is clear how being adolescent, makes illness and treatment even more disruptive, particularly because of its impact on her developing social skills. She identifies how her illness and treatments have disrupted her social development in the past with the need for hospitalisation and continuous medical intervention, and in the present with the necessity of adjusting to life after transplant. Yet, she shows determination, in her narrative account, to continue with her everyday life. This drive for biographical continuity is evident in her insistence to, *'carry on as normal'*. This displays an awareness and possibly an acceptance of the fact that her life will inevitably continue to be disrupted by CKD and its multiple treatments.

7.4 Conclusion

This chapter presented Maggie's narrative of her illness experience, which emerged from her stories. In the next chapter the stories of the only male participant of this study is presented. His name is Jack and he is the oldest of the study participants.

Chapter 8: *'It's like being a vampire'*: Jack's Story

8.0 Introducing Jack

This chapter presents the narrative of Jack, a 16-year-old boy who has been living with CKD since late childhood. Up until the age of 11 years, Jack was a healthy child. His illness appeared suddenly and revealed itself through bodily changes such as swelling and tiredness. He was subsequently diagnosed with nephrotic syndrome and stage five CKD. He received home peritoneal dialysis for over two years. At the age of 13, Jack received a cadaver kidney. At the time of meeting Jack, his transplanted kidney was starting to fail and he was facing the possibility of reverting to dialysis and re-joining the transplant list, a situation that caused Jack distress and frustration.

Jack lived 3 hours from the hospital and he had weekly appointments, so our conversations took place mostly in a room in the outpatients' department of the hospital. He was the only participant not to partake in body mapping; instead, Jack opted for regular informal conversations. He informed me that he was not good at art and this seemed to influence his decision not to engage with the arts-based method of collecting data. Jack seemed to be comfortable in the position of storyteller, often performing parts of his stories and regularly doing so with tough language i.e. language used to portray himself as forceful and aggressive. During data collection, Jack celebrated his 17th birthday and the stories he shared with me covered a period of six years of his life.

8.1 Overview of Jack's Stories

Figure 19 presents the main storied accounts of Jack's experience of living with CKD. Jack places considerable focus on the effect CKD and its treatments had on his developing body. Each story corresponds to a chronological phase of his illness. For example, he began by recalling his early experiences of being diagnosed with CKD, before moving on to the present day and describing his continuing health problems following transplant surgery.

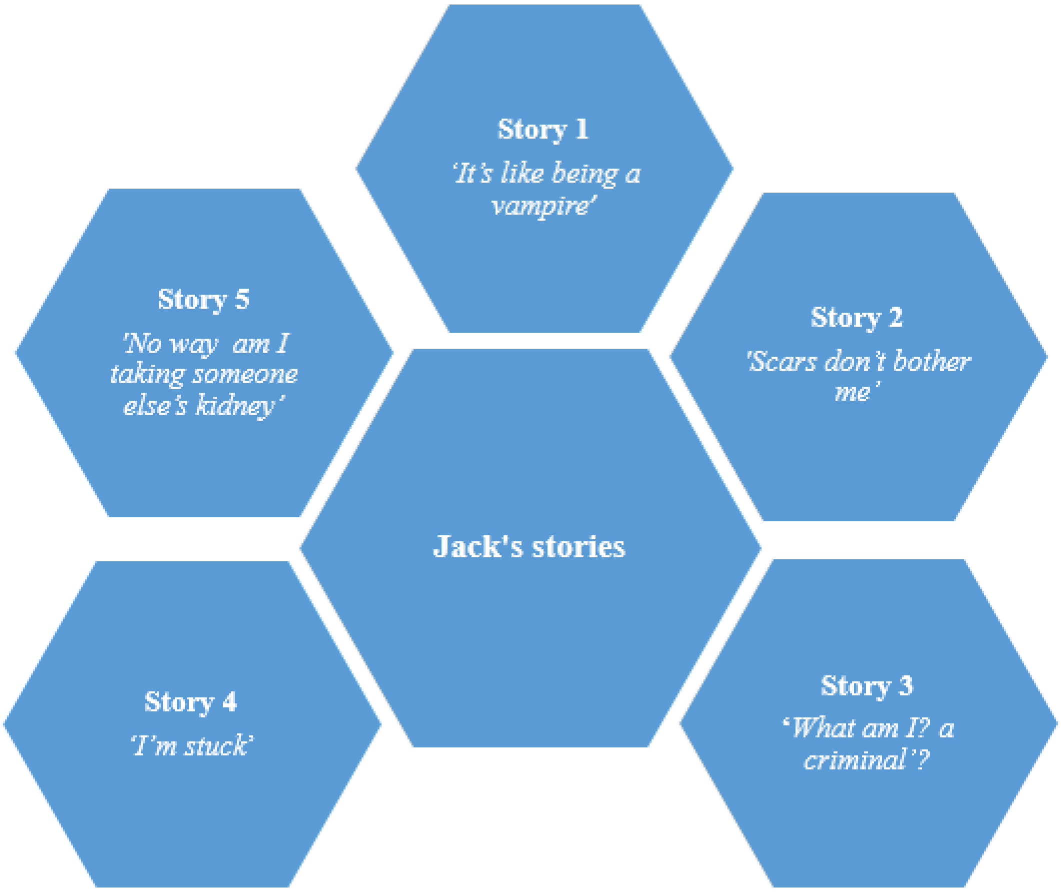


Figure 19: Overview of Jack's stories

8.1.1 Story 1: *'It's like being a vampire'*

Chronic kidney disease had a negative impact on Jack's body image. He experienced significant changes in appearance and a loss of control over his own body on a daily basis. Here he recalls:

> *J: When I was still on P.D. like my face used to swell. Every day I wouldn't go outside until about 6 o'clock, until it had come down completely. You see nephrotic syndrome is a kind of swelling like. Look, that's me there [Jack shows me a photo on his phone when his face was swollen from kidney disease]. I couldn't even recognise myself in the mirror. I didn't even look like myself. I stayed in for 24 hours after that. It came down to a point where you couldn't notice it.*

> *C: I see, and how did that make you feel?*

> *J: Sometimes you'd get fluid in your stomach and it would be tight to breathe and your face. And you wouldn't want to go outside, and your legs would be sore to walk cause your face is swollen and you just look like an alien or something. Sometimes my eyes there [pause] they would be shut. It was just sore and you can't see in sunlight. It's like being a vampire or something, when you'd go out in the sun. It's like sore eyes when you go outside and it stings your eyes and you're like [pause]. I'm pitched out by the sun. I never went outside because I was a vampire. I never went outside because I was basically a vampire. So nobody asked questions.*

Here, Jack expresses how CKD ruptured his sense of being at home in his own body. The swelling of his face and body brought his body into full consciousness and out of taken-for-grantedness. Jack felt separated from himself, and his body was foreign to him. The dramatic changes affected not only his body image, but also Jack's body integrity and functioning. His body was behaving like an adversary; like a vampire. This vampire-like body was forcing him into a nocturnal, reclusive existence. His response was to withdraw, hiding himself away in the safety of his own home until the swelling receded; elsewhere, he describes taking measures to conceal his disfigured face and body from the outside world. His choice of the vampire persona is interesting; a mythical character who was cast out from the world during the day yet enacts power at night. Throughout Jack's stories there was the contrast between feelings of alienation and powerlessness and the drive to become potent and invulnerable. This tension permeated the following story, where Jack discussed his scars.

8.1.2 Story 2: *'Scars don't bother me'*

Jack had many scars on his body as a result of different renal treatments. These scars were visible reminders of the changes that his physical body had undergone as a result of chronic kidney disease. In the following story, Jack provides a litany of his scars accompanied by a snapshot of the accompanying body trauma.

> *J: I have 5 scars actually. One under my bellybutton. It's just an old thing from the catheter [P.D. catheter]. There's like a small mark there. It's the P.D one and there's the scar where they put it in and took it out again. That's where it exits out of [his*

> *body]. I got one here too from the other dialysis haemo line, but I didn't use it for that, but I had it for plasma exchange. It's just a small dot though. I hated it, dialysis. Like you'd have to be at home at a certain time. Like I was well pissed off with that. NO-WAY am I ever going back. Never. Just what's the point in having that life? You'd rather be better off with no life. No I'll never go on dialysis again. You'll just have to die. Cause I had no life and I had to be home by 8 o'clock. I'm not going through all that again. IT WAS THAT BAD. This is my transplant scar. I don't notice them. They don't bother me. I don't care. Scars don't bother me. These scars don't bother me you know.*
>
> *C: They don't bother you?*
>
> *J: I bought bio oil for it [referring to the transplant scar] and I was like this is a waste of time. I just gave up after 2 days. I was just fed up every night. Every day you have to put it on for half an hour and it'll go on your t-shirt and I was like I had enough of that. Stuck in the room with no t-shirt on and freezing and waiting for that stupid oil to dry. One of the nurses told me to get it. It wasn't me taking notice of them.*

CKD treatment left lasting marks on Jack's body. He navigated me through his various wound sites and in doing so he exhibited what his body had gone through. Minimisation of the indicators of body invasion appeared to be a feature in Jack's body representation and performance. Jack's tone was light-hearted, which served to underplay the magnitude of his experiences. Perhaps minimising the psychological impact of the scars was Jack's way of maintaining control. Here, he downplays the significance of each scar; 'small mark' 'small dot.' In using this minimising language, he positions himself as impervious and brave. In this story, Jack also portrays the dialysis machine as a damaging rather than a meaningful treatment. His experience of dialysis was '*that bad*', and he would rather '*die'* than return to treatment. Returning to the main point of this story, Jack firmly and repeatedly asserts that scars do not bother him. Jack wants to enact body mastery and to assert body prowess as a young male. However, as demonstrated in the next story, this drive was compromised by a disease and treatment process that infantilised and emasculated him.

8.1.3 Story 3: *'What am I? A criminal?'*

When I first met Jack, I was struck by his small frame and childlike appearance, which is consistent with his illness. This is illustrated in the following reflective excerpt:

> *'Jack is 16 going on 17 years yet he does not look it. He is small, thin, and glowingly white. I am taken back by his delicate appearance. Jack does not seem out of place amongst the young children running around the outpatient's department and I wondered how this made him feel'.*
>
> *(Reflective diary January 2015)*

Throughout my time with Jack, he offered several stories that conveyed how he felt marginalised because of his childlike appearance. For example, cinema trips were difficult as he was frequently turned away from 12-rated movies, despite his age. Similarly, trips to his local swimming pool were also challenging. The following account powerfully conveys how being mistaken for someone younger caused Jack such distress and frustration.

> *J: Wait till I tell ya what happened in the Jacuzzi pool. Some big heavy person went out and complained for nothing. And they put me out and I was like, 'I'm allowed in here'. The woman said, 'Don't be getting all cheeky'. I didn't say nothing cheeky to her. I just said, 'I'm allowed in here'. She made me walk out and expected me to go to the front desk in my shorts and in front of everyone. I'm 17, and do you know what I said to her? I said to her, 'There's 14 and 15 year olds in there and just because they look 18 they get to stay in'. My little cousin gets in and he is only 15 and just because he looks older than me he gets in.*
>
> *C: I see*
>
> *J: Not all rules have to be obeyed. Like some rules are set to be broken. But I wasn't breaking any rules in the pool. I wasn't carrying on or anything. I wasn't doing anything. I said, 'I'm allowed in here'. I say, 'the Duty Manager allows me in here' and she says, 'NO you're not allowed in here'. And the big loud voice of her. I say, 'I have my I.D. too. I'm 17'! 'Well it says 18. You have to be 18. It's against the law to be in here'. I say: 'What am I? A criminal?' I said, 'I'm a criminal am I'? I was pissed*

> *off at that stage. I'm actually allowed in. It's not just that, its discrimination as well cause there's a boy in there, and I know a pile of them, and they pay as an adult while they are 15 years old. No I.D. asked or anything. But all of a sudden I come in they just automatically think I'm younger. They ask me for I.D. but they don't ask them. Oh, I was just pissed off. It's just annoying having to go through it every time when everybody else just goes in does their thing and leaves. I said to Mammy, 'the next time I'm just going to go in and I'm just going to be blunt ignorant about it'. I'm still fuming about it. I just want to go in and do my thing and go home. That's all I want [pause] peace.*

Through his long account, Jack explains how his boy-like appearance attracted unwanted attention and caused him to be the victim of unfair treatment. The performance of his interaction with the female worker has the effect of portraying contradictory positions of 'powerful' and 'powerlessness'. Using direct speech, Jack portrays the female worker as an unkind person who used her position of power to humiliate Jack. Jack positions himself as a victim of '*discrimination'* because of the delays in body development, which have resulted in him looking much younger than his chronological age. As a result, he was treated differently than his more masculine younger peers. Asserting his rights and sense of injustice to the pool manager was a way for him to counteract the humiliation and to portray his masculinity through a display of toughness, strength and bravado. He compares himself to a criminal, which further serves to position himself as a powerful character who stands up to authority.

I was moved by Jack's account of his humiliation in front of his peers. Being humiliated in public is a distressing experience, and I admired Jack's openness to recount such a personal, yet public, experience of humiliation. I was conscious that revisiting painful experiences of being devalued and disempowered could trigger or reinforce feelings of shame. However, Jack was determined to assert and record this indignity, and retold this experience to me on more than one occasion. Interestingly, in this account, Jack identifies two sources of comfort; his mother and home. In the next story, Jack appeals to these two strengths against the apparent tyranny of medical colonisation.

8.1.4 Story 4: *'I'm stuck'*

For Jack, frequent hospital stays were particularly challenging and he shared many accounts about being kept in hospital. For example, in the story below Jack recounts his reaction and frustration at being kept in hospital against his wishes:

> *J: I want to go home. Dr A said if its [blood pressure] not down tomorrow, start a new tablet. Then they have to trial it out for 48 hours. 'Oh my fucking God,' I says. I just said it the minute I heard that. I jumped out of the bed, clothes on, packed my bag and I was like, 'For fuck sake anyway, I'm always fucking stuck in here'. And then I rang Mum and I said, 'Mammy, they're trying to keep me'. I'm going one way or another even if my blood pressure is 300.*
>
> *J: He's not going to trial it until tomorrow but I'm not staying for it. I'm not doing that because I'm just going home and I'll just get a stroke. I will tell him I'm not staying for the stupid treatment. I don't care about it. I'm not coming back. I'll take my tablets and stuff but I'm not coming here. I'm going away home. I can buy a bus ticket you know, and I get out by the bus. I'm going home today, that's it! I don't want to be here. I just don't want to be here. Let me home! Let me home! I'll go out now and say: 'Mummy will take my blood pressure more often. She'll take it more often.' I'm going to say, 'If you can't get it down by tomorrow it's not my problem'. If the blood pressure is not down by tomorrow, I'm going.*
>
> *C: I see.*
>
> *J: Anything I can do at home; I don't care what it is. I'll do it, but when they bring me in. If I'm getting kept in that's the bad form time. I don't like staying in because like I hate it. I don't mind coming up for the day and then go home. That's alright. At home I can do what I want, I can go out. I'm stuck in a room [in hospital]. I like being at home with my own stuff and my own way of going on at the house. And there is nothing to do in here. It's worse if you don't feel sick and you're in for monitoring. Like when you feel sick you don't really care because your that sick. But I'm never sick hardly when I'm in. And I'm just sitting there going, 'Ahhhhhh'. I know why they're keeping*

> *me, but it's stupid. I just don't like being in hospital, end of. I'm not coming back for 6 months again. Everybody else gets 6 months. They get 6 months and I'm still here every flipping week. I'm going to relocate to somewhere, some country [pause] Hawaii.*

Jack positions the doctor as the person taking control of his body and attempts to resist the doctor's decision to keep him in hospital. He uses strong language to make known his frustration and his use of the word '*stuck'* conjures an image of Jack as a helpless, powerless adolescent who is a prisoner. Once again, he tries to assert agency and gain control by actively resisting. In using the metaphor of the beleaguered prisoner making a break for freedom, he confers masculine and agentic power on himself in the telling of the tale. He downplays the serious nature of his high blood pressure and is willing to ignore the possible complications in exchange for his freedom. There is a poignant mix of frustration, anger, bravado and child-like naïveté in Jacks responses, which are the hallmarks of many adolescent struggles. Here these are augmented further by debilitating illness and treatment.

This story highlights Jack's attempt to gain control over a situation in which he was 'stuck'. CKD socialised Jack into a medicalised world that isolated him from his habitual world. In hospital, his body is under the care and control of the medical system. Jack uses this narrative space and me as audience, to voice what he would have liked to have said to the doctors but did not. In retelling this story to me, a researcher; not a doctor, Jack performed himself as an active agent, a position he could not attain in the medical world. Despite his repeated claims to the contrary, Jack did not tell the doctor that he was going home and never attempted to leave the hospital. Jack was subsequently admitted to hospital, and found himself once again '*stuck'* in a medical world. Here, in an attempt to escape his sick identity and the medicalised world, Jack avers he is going to refuse to go to hospital for a 6-month period, and even claims he will seek exile in a foreign land. As I listened to Jack tell this story I began to see him as a small boy distressed and overwhelmed by the world of illness, and trying to escape to the normality of his home. Jack's reference to his mother further accentuated the image of a small boy dependent on his mother to save him from hospital. This story highlights Jack's lack of body agency and disempowerment, which contrasts with the powerful characters he identified with in his earlier stories, e.g. vampire, criminal - an identification that made him feel more powerful, enabled the performance of agentic embodiment. In his next story, which details him receiving a donor kidney from a stranger (a situation which he had no control over) Jack continues to position himself as the person in control.

8.1.5 Story 5: *'No way am I taking someone else's kidney'*

Having spent two years on peritoneal dialysis, Jack received an anonymous donor organ. For Jack, the idea of having another person's body part was difficult to deal with. He struggled with combining self and other. He recalls:

> *J: I was like: 'You think I'm taking someone else's body part! No way am I taking someone else's kidney.' I just thought it was, well disgusting. Somebody else's like [pause] God knows it could be a grandpa's kidney for all I know. Imagine that there [points to the grandfather in the YouTube video he is watching on his phone]. Like some boy getting his kidney.*
>
> *My uncle got a liver transplant and his donor was a 46-year-old woman. He gets slagged a lot because he's got a woman's [laughter]. He's got well into fitness and he never was into fitness before. He never walked 2 yards in his life. Now he is doing running and training and he is jiving. This woman must have been really fit [laughter]. Well the one I got must have been really lazy then. Cause I've got lazier since I got mine. It had to have been a teenager. Must have been.*
>
> *C: Did you ever find out where?*
>
> *J: NO!*

This story reveals Jack's internal struggle with the idea of incorporating an alien body part into his own body. Unique to this story was the role gender plays in the conceptualisation and integration of the donor organ into Jack's embodied identity. Jack did not want to know the gender of his donor. He feared the embarrassment that may have ensued if his donor was a female. The potential incorporation of aged or female components into his body threatens Jack's masculine embodiment. Therefore, he refers to the transplanted kidney as '*it'*, which avoids attributing a gender to his new body part. For Jack, not knowing the true biographical details of his donor's identity makes it easier for him to integrate the new body part into his own embodied identity.

In summary, Jack's stories centred on the chaotic changes CKD caused in his body, which had the result of making him feel vulnerable in social circumstances. His CKD rendered him unrecognisable to himself; a feeling captured in his observation that he possessed the superhuman characteristics of an alien and vampire. These powerful characterisations helped Jack make sense of the dramatic changes that were occurring in his body. The theme of masculine identity runs through all of Jack's stories. His stories reveal that he felt discriminated against as a result of his delayed masculine development. His ill body did not equate to society's expectation of what a masculine body should look like. As a result, he was treated differently to his more masculine-looking peers. Jack positions himself as a victim of social injustice. He is a victim of 'discrimination' because of his delayed body development, which has resulted in him looking much younger than his chronological age of 17. These stories form a narrative of a body being controlled and colonised by CKD and its treatments, as detailed in the following section.

8.2 Jack's Narrative: *A colonised and controlled body*

Jack's account takes the narrative form of chaos, and a tone of powerlessness and frustration permeates his stories. His body is colonised by CKD and its treatments, which dominate and control his life. For example, he feels stuck with a body that is unruly and his stories depict the struggles and the internal chaos he endures while living with CKD. Jack narrates the great bodily difficulties and suffering he experiences because of CKD and its treatments. His illness moves randomly; he never knows when his body will swell and change its appearance. This leads to chaotic situations, which leave him feeling like a stranger, an alien/vampire in his own body. These dramatic changes make him feel different from other people and he is treated differently as a result. Jack is trapped between hospital and home. He is caught within an immovable and complex situation. Consistent medical problems feel like an insurmountable obstacle, and one which blocks movement toward any kind of meaningful home life. He is also torn between a desire to assume a sense of manhood and a state of childlike dependence. Jack attempts to portray himself as being emotionally tough, which is central to his masculine identity. He depicts himself as an active and powerful agent, a strong masculine character who stands up to those in power. Yet, his vulnerabilities and feelings of child-like dependency are also evident throughout his stories. Crossing the threshold into manhood is inhibited by his vulnerabilities and a dependence on his mother. Although he uses tough talk, his *'mammy save* *me'* moments reveal that he also inhabits the world of a frightened and distressed little boy. Jack attempts to narratively portray himself as an agentic young man, yet he is stuck in a child's body, dependent on his mother and entrenched in an infantilising medical world away from his familiar home environment.

8.3 Conclusion

This chapter presented five stories that exemplified Jack's experience of living with CKD. His narrative expressed his frustration at his illness and the impact it was having on his outward body appearance. In the cross-case analysis chapter, the content of Jack's stories will be examined further, in order to identify common themes to emerge from the stories. Core themes to emerge from Jack's stories (and other participants) will also be critically discussed in Chapter 11. The next chapter introduces the final and youngest participant of this study - Tara.

Chapter 9: *'It's too big'*: Tara's Story

9.0 Introduction

This chapter presents the stories of Tara, an 11-year-old girl diagnosed with renal dysplasia at birth. At the age of 10 years, she started haemodialysis treatment. At this time, she was also placed on the transplant waiting list. She attended hospital every second day for dialysis treatment and her journey to hospital took an hour and a half each way. She is part of a close-knit family of three brothers and four sisters. Frequently, Tara required extra dialysis sessions and in-patient admissions due to a failure to adhere to treatment regimen at home. Our conversations and body mapping activities took place in the busy dialysis unit and renal ward, where Tara was an in-patient. Her father was often present during our conversations.

I met with Tara every couple of weeks over an 18-month period. During that time, she remained on haemodialysis while waiting for a kidney transplant. For our meetings, the location switched between the renal ward and the dialysis unit. She was often silent, and she liked to watch TV and play cards. Creating her body map gave Tara a chance to reflect on and re-tell her stories of living with CKD. She decided what images to draw and which stories she wanted to portray onto her body map, a process that she found challenging at times. Image 16 presents Tara's completed body map.

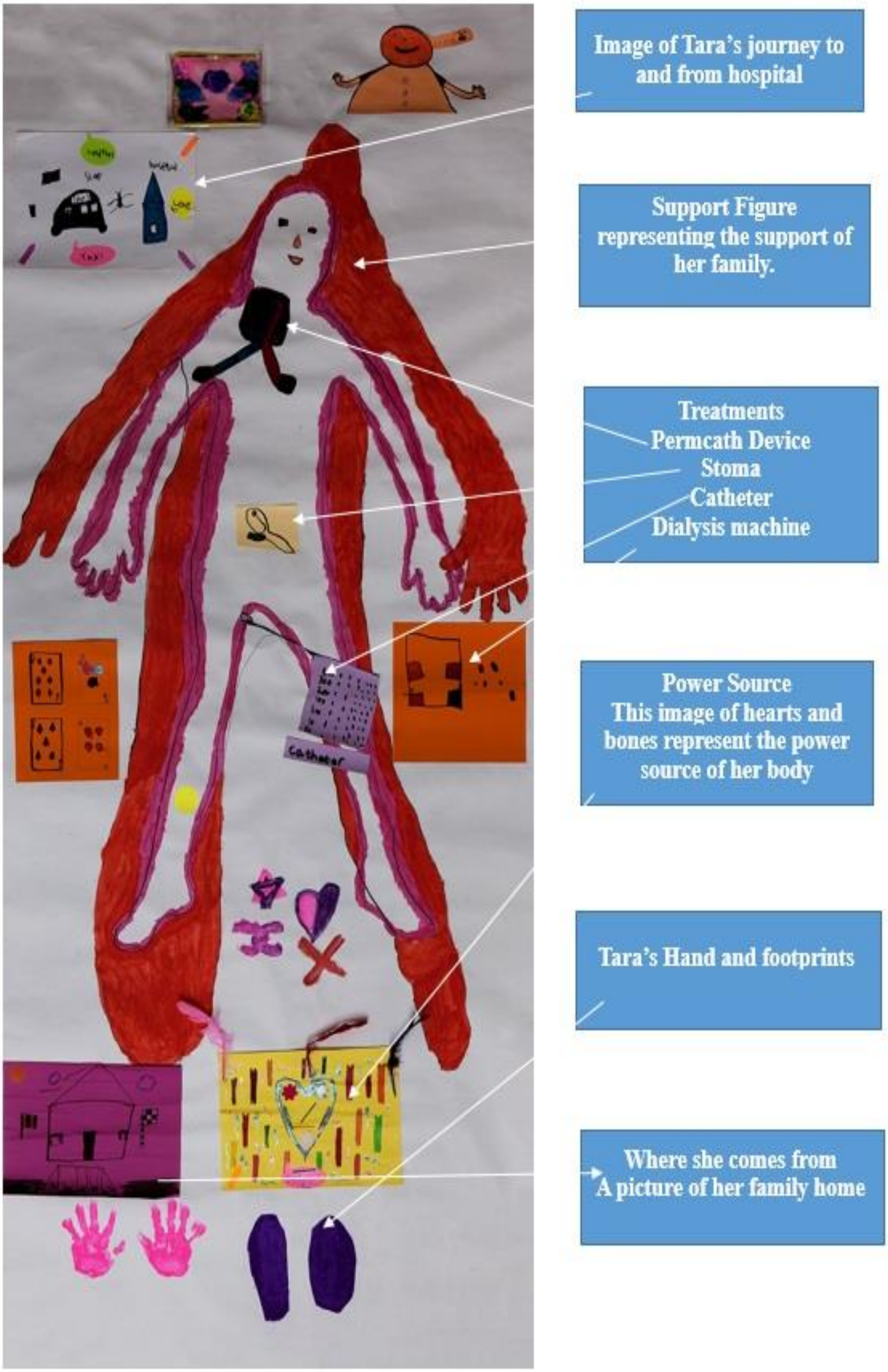


Figure 20: Tara's completed body map

9 .1 Overview of Tara's body map

Tara liked to draw but appeared to have difficulty in working with the life-size body map as demonstrated in her following comments:

T: It's too big!
C: The map is too big?
T: Ya [sighs].
C: Too big for what?
T: I just think it's too big!
C: Right okay. You just don't like the size of it.
T: Ya it's too big.

Tara repeatedly stated that her body map was '*too big'*. This difficulty may be due to the fact that all body-mapping activities took place while she was on dialysis, which restricted her movements. To overcome this difficulty, smaller A4 blank pages were used. Tara created images on these pages and then transferred them onto her body map. Tara also found creating a personal message that captured her CKD experience difficult, and she chose not to complete this BM activity. In her body map, she assumed an open posture with her arms extended and her hands open. She outlined her body in pink. In contrast, her support figure is depicted standing erect, coloured bright red and occupying more space on the map. The inside of her body map is dominated by three images, namely; her permcath, her stoma and a large catheter extending from her body. These images convey the technological aspects of her treatment. Such images made me wonder how these technologies were affecting her body, as seen in the following reflective excerpt:

> *'As I analyse Tara's body map I am struck by the three images she has chosen to construct inside her body. These images fragment and objectify her body into a body of a patient. The permcath is her medical lifeline, it connects her to the dialysis machine to maintain life in her body. It marks her as a patient. Her image of a catheter demonstrates how her body is extended beyond its normal boundaries. Her image of her stoma portrays to me how her body is invaded by technology. Her map is devoid of individual marks of personal identity beyond that of a patient'*
>
> *(Reflective Diary, April 2015)*

Tara's body, marked by these images, suggests a body colonised by medicine, a theme that is evident in her stories. The images on the outside of her body are positive images. For example, she drew a picture of a house to represent her home life. She drew a heart surrounded by bones, which represents the power source in her body. On the outside of her body, in between her legs, she places random images of different shapes (i.e. heart, cross and triangle shape). When asked what these shapes represented, she replied *'I don't know'*. Tara did not complete all of the body mapping exercises. For example, unseen marks, creating a symbol or creating a slogan to represent CKD. When asked why she did not what to do these activities, she simply replied '*I just don't want to*'. I respected her wishes. I will refer to some of the images in her body map at specific points throughout this chapter.

9. 2 Overview of Tara's Stories

In her stories, Tara portrayed how CKD and its treatments affected her body and sense of self. Figure 21 outlines the stories that represent Tara's experiences of living with CKD.

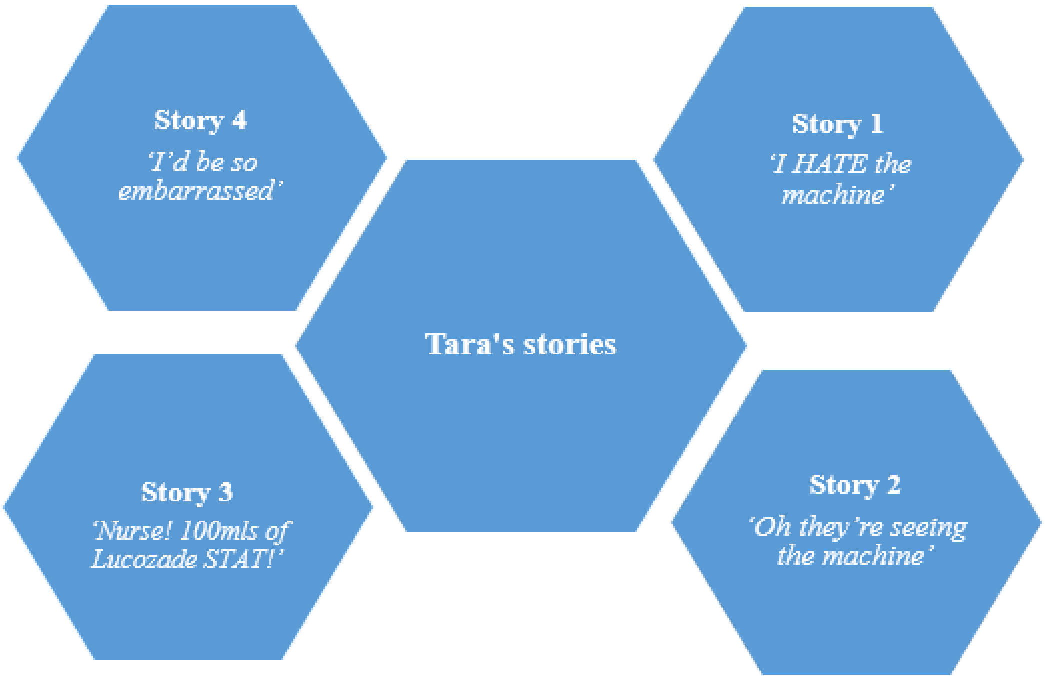


Figure 21: Overview of Tara's stories

9.2.1 Story 1: *'I HATE the machine'*

Tara began her story by remembering the day she had surgery to embed a permcath device deep under her skin. This device connected her body to a dialysis machine. Tara chose to present this device on her body map (Figure 22).

Tara's image of her permcath device

Tara's image of the tubes that carry blood in and out of her body during dialysis sessions.

Figure 22: Tara's image of her permcath device

In drawing this image Tara articulated the anxiety and fear she felt when the permcath device was first implanted in her body. She vividly recalls:

> *T: I was crying. I was crying going down. I was afraid like if I felt anything. Like I had operations before, but like I didn't want to get this in [points to her permcath]. So I was crying. Then I was alright because I wiped my tears and I thought my mother was going to stay for the whole thing. She said she would but they wouldn't let her. She sneaked out on me. Then straight away afterwards: OH MY GOD. I was in very bad pain that day.*
>
> *C: So you were in bad pain. What was causing the pain?*
>
> *T: See, I'm not sure like. [Pause]. It's complicated to say, but I thought I felt it [the permcath] but I didn't'. It was jerking too much [pause] you're kinda afraid. And then dialysis. I was afraid, like especially with all the blood. The blood comes back in the blue line [pause] in the shorter one. They put caps on the lines when I am finished the dialysis, so it doesn't leak. It beeps if it's over excited or if there is something wrong with it. Like if the machine is broken: I HATE the machine.*
>
> *C: Why do you hate the machine?*
>
> *T: It's too long. I'm on it for 4 and half hours. I'd prefer to be at home playing with my sisters.*

Through the telling of this emotionally painful experience, Tara positions the surgical placement of the permcath as a major event in her life. This surgery marked a major change in her life, the start of dialysis treatment. She articulates her vulnerable emotional state as she recalls being afraid. To maintain a sense of self-control in the face of adversity, she portrays herself as a resilient character. Nevertheless, dialysis, and its dehumanising effects, inhibited her attempts to move forward. Watching her blood leaving and entering her body was frightening. This fear is heightened by the risk of blood leaking from her body if the caps were placed incorrectly on her permcath lines, which reinforced her lack of body stability and integrity. She uses the word '*HATE*'- to use to describe how she felt about dialysis. She suggests that the machine exhibits human traits, emotions specifically. This story could be Tara's way of making sense of the invasive procedures that radically changed her life. Her account highlights the dominating and dehumanising effect of dialysis on her body. In her next story, she continues to narrate her struggle to incorporate this technology into her embodied identity.

9.2.2. Story 2: *'Oh they're seeing the machine'*

The presence of the dialysis machine placed Tara at risk of becoming the object of an inspecting gaze. The unwanted attention generated by the dialysis machine frustrated her, as seen in the following excerpt:

> *T: I'm so shy when people just pop in. Ya, when they just pop in. Ya because I think like then they're just coming in for [pause] to just walk in to see the machine or something like. If they pop their head in and you can't see their dress, then you think like, 'Oh they're seeing the machine'. And then they walk in, and then you're like, 'Was that the girl who popped her head in'? [Laughter.] Ya, they don't see us.*
>
> *C: So you think they don't see you*
>
> *T: Ya.*
>
> *C: And why do you think they do that?*
>
> *T: I don't know actually. Do you know they want to name our dialysis machines? Oh, you've to name them. I don't really want to do it. But guess who came up with that?*
>
> *C: Who?*
>
> *T: Nurse A [whispers]. Ya, it's not fair on the kids like. Because like imagine you coming in and like say one kid named it Nicki Minaj, and then Nicki Minaj was actually standing in the floor ready [pause] to do a show. Oh, I would be so desperate. I'd be like 'oops'! Imagine walking in and the nurse like said 'welcome to Nicki Minaj' and your like 'what?', and there is someone who didn't pick the name, a name for the machine. It isn't really fair to them then.*

This story demonstrates how dialysis had rendered Tara's body invisible and the machine has come centre stage. The presence of the machine dominates how others view her. The tendency of others to stare at Tara and the machine contributes to her sense of objectification. The machine serves as a centrepiece for spectators to gaze at; while she disappears into the background the machine came to the fore. In this story, the machine is humanised while Tara is depersonalised. In this sense, she is en-framed in technology. Interestingly, the people who *'pop'* in are also disembodied i.e. she does not see them as entering the room as such, but rather their heads appear, as if separate from their bodies. Dialysis, therefore, disrupts the appreciation of a full intact body in both herself and her viewers. She vividly creates imagery of fragmented and compartmentalised bodies of both self and others. This impacts Tara's own conceptions of embodied identity and her relationships with other embodied humans which I remarked upon in my reflective journal at the time.

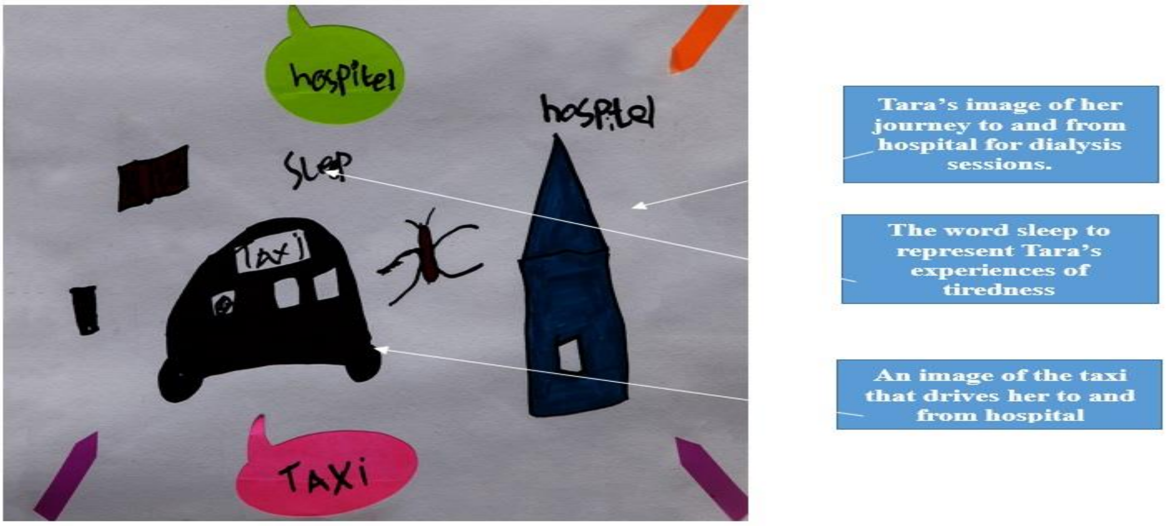
> *'Reflecting on my time with Tara today, I am beginning to realise how she perceives the dialysis machine as something that threatens her identity because it alters her social standing and ties with others. It appears that the machine is threatening not only because others perceive her as different, but also because she perceives herself as different. I was eager to take this discussion further, however, Tara quickly progressed on to a different topic'.*
>
> *(Reflective Diary, August 2015)*

The perceived negative reactions from others could be attributed to self-objectification as well as the actual experience of other-objectification. Tara presumes other persons have pejorative perceptions of her. She, therefore, fears being judged and measured in relation to the machine. This places a strain on her social interactions, as she is conscious of how others perceive her.

Her aside about naming the dialysis machine, a concept she did not agree with, further emphasises her negative feelings towards the machine. In imagining the naming of the machine, she reveals a sense of body alienation; and outlines the confusion and unfairness that could arise if she proceeded to personalise the machine. She resists humanising the machine by refusing to enter any names for the competition. She instinctively fears and resists the blurring of machine and human. Naming the machine is another example of how this medical technology is enabled to take control of her body function and body presentation in the world. By refusing to personify the machine, Tara asserts some control over the machine she hated. Her story displays an instinctive heightened awareness of the potential tyranny of the dialysis machine. Tara continues to discuss her dislike of dialysis treatment in her next story, which concerns the impact fluid restrictions had on her body.

9.2.3. Story 3: *'Nurse! 100mls of Lucozade STAT!'*

Tara's life was dominated by hospital and treatments. Tara was on a regular dialysis program (3 days a week), which meant she spent a great deal of time in hospital. In figure 23 Tara visually reflects on her journeys to and from hospital.



Tara's image of her journey to and from hospital for dialysis sessions.

The word sleep to represent Tara's experiences of tiredness

An image of the taxi that drives her to and from hospital

Figure 23: Tara's image of hospital

Part of her dialysis treatment required her to comply with a strict and challenging fluid regime. Her fluid regime was continually changing depending on her weight. Tara explains:

> *T: Usually, I am allowed 1,200. Well it depends like in here what my weight is. They measure it and it depends then how much I am allowed drink. So they say 200mls, 100mls, 250mls, 150mls, something like that. Or maybe 100mls - that's how much I'm allowed today; 100mls. I have 50mls. Another 50mls and then 20mls and it lasts longer. And then in the morning; then I'll only get 50mls. And then 50mls during the day, and before I go to bed, 50mls like that.*
>
> *C: Would you ever feel thirsty?*
>
> *T: Sometimes I'd be dry. Because if I have say 50mls in the morning and then 50mls again afterwards and if I get thirsty again that morning - say if it was 9 o'clock and I got 50mls - then I'm not allowed until 1 o' clock. If I got some Lucozade at 10 o' clock well I won't be allowed get 50mls at 1 o' clock because I'll have already drunk 100mls.*

> *Cause I write it down. Ya, they would be very mad if I drunk more; more than 150mls. I still have 100mls left to drink. I never drank it yet. Nurse! 100mls of Lucozade STAT [laughter].*

Tara experiences fluid limitations as externally imposed by Health Care Professionals (HCPs). In her account, she positions the HCPs in a superior role and herself as a passive agent. She describes the physiological condition of her body within the context of this restrictive regime; her body is '*dry'* and '*thirsty'.* Relieving these feelings requires a lifestyle modification, and she has to invent new ways to approach her drinking habits. She fragments and compartmentalises her daily fluid allowance by configuring fluid into carefully measured units. By quantifying her fluid allowance into *mls,* she exercises body control and body vigilance, performing herself as a cooperative patient, actively doing her best not to exceed her daily fluid allowance. She also engages in additional self-care measures such as documenting her daily fluid intake.

The issue of adherence arose many times during our conversations and the following, an excerpt from my reflective notes, helps to illustrate Tara's ongoing struggle with fluid restriction.

> *'Tara is very quiet today. Her eyes appear red as if she had been crying. She tells me that she is not having a good day because she has an extra-long dialysis session today. The dialysis nurse had a firm conversation with her earlier regarding their concerns about her not adhering to the fluid restriction. She will continue to have longer dialysis sessions until she starts to adhere to her fluid allowance, which appears to me to be a source of frustration for her. Tara has not spoken to the nursing staff because of this. I ask her if she feels like talking about it but she shakes her head. I am eager to inquire more but I sensed pushing the conversation further would only have helped my agenda'.*
>
> *(Reflective Diary, September 2015)*

Tara's non-adherence to recommended fluid restrictions was a particular source of strife between her and the HCPs. Staff responded to the ongoing issue of her non-adherence by giving her longer dialysis sessions and threats of future longer sessions if she did not comply with their orders. Because she deviated from medical and nursing staff expectations, she was at greater risk of receiving negative attention from staff. In response to such situations, Tara became silent and unresponsive. I interpret this as Tara's way of coping with being constantly monitored and scrutinised by others. Her silence serves as a protective mechanism from further 'punishment' from staff. For Tara, this is an incredibly difficult experience; the body feelings of dryness and thirst, the constant self-monitoring and measured life as well as the accompanying medical surveillance and ensuing retribution, produced feelings of powerlessness. In her final story, Tara continues to narrate her struggles with her illness and its impact on her body.

9.2.4 Story 4: *'I'd be so embarrassed'*

Tara experiences urinary incontinence on a daily basis. While not a life-threatening symptom of her illness, this bodily dysfunction, nevertheless, has a profound impact on her self-esteem. Tara explains:

> *T: I can't really go to the bathroom. I have like they're like nappies, but they're pull ups. Ya, they are actually good for me. I used to be on nappies but like now I'm not cause they're too small.*
>
> *C: The nappies are too small. So you have special underwear. How do you feel about that?*
>
> *T: If other people didn't know [about my illness] I'd be like embarrassed. Even if I'm outside. I'd be very embarrassed if I haven't got a jumper with me and if I'm going to the park. I'd be like….*
>
> *C: What would you be embarrassed about?*
>
> *T: The wet at the back of my pants sometimes if it's a light jeans or light pants. But I always have to bring along a jacket or jumper to put at the back. Once I just leaked all over me and I had a jumper at the back luckily. I had the jumper with me because if I didn't [pause] oh my God I'd be so embarrassed.*

This account illustrates the breakdown of a taken-for-granted bodily capacity, in this instance eliminating bodily fluids. This is an example of an adversarial body- her bladder no longer functioned as it should. Tara suggests that not being in control of oneself, in terms of bodily functions, results in feelings of infantalisation. This interpretation is supported by the fact that Tara needed nappies and pull-ups at the age of 10 years. This situation reinforces her vulnerable child-like state. Obtaining bladder control is symbolic of the gaining of childhood independence. Tara's loss of control over this function as a teenager threatens her autonomy, sparks feelings of embarrassment and creates a sense of powerlessness. In this account, her adversarial and unpredictable body gives rise to uncertainty and a heightened self-consciousness. Tara's story resonated with me and reminded me of a similar occurrence in my son's life which I wrote about in my reflective diary

> *'In listening to this story I reflected on a personal experience that helps me understand some of what Tara might have felt. I remember a time when my 13-year-old son had a wetting accident in school. Like Tara he frequently experiences incontinence. He lost control of his urine during class and urine flowed down his leg. He felt very embarrassed. Because the 'accident' happened inside the school, urine was visible on the classroom floor and visible to his classmates. This made him feel even more embarrassed. Later that evening I asked him about the incident. He refused to talk about it and wanted to forget it ever happened. Remembering this now and writing about this incident helps me understand how embarrassing urine leakage is for young people who do not want to stand out amongst their peers. I feel empathy for Tara as I listen back to this story and I begin to realise that such experiences are often a taboo subject for young people to openly discuss because of the private and potentially embarrassing nature of body leakage'*
>
> *(Reflective Diary, July 2016)*

Reflecting on this incident helps me empathise with Tara, but it also makes me realise the importance of listening and bearing witness to embarrassing situations as young people attempt to make sense of such experiences. Getting wet in public meant that her private toileting became public. She is constantly fearful of public detection of her incontinence. Feeling embarrassed, or the fear of being embarrassed, threatens her self-esteem. Being able to carry on with her usual activities and maintaining an outward public appearance of being in control of her bladder is important to Tara. She engages in self-reflexivity and reconfigures a sense of self that accommodates her leaking body. This reconfiguration of self is achieved by developing strategies that enable her to conceal her incontinence and minimise its significance in her life. Medical management of her incontinence consists of regular intermittent catheterisation. On her body map, she drew a catheter with a bag attached to it (Figure 24)

Tara's drawing of a catheter tube.

Catheter tube and catheter bag and carries and holds her urine

Figure 24: Tara's image of a catheter

In this image, the catheter is placed at the foreground of her body and is visible for others to see. This image reveals how a catheter can impinge on a person's sense of privacy and dignity, as the urinary catheter draws attention to specific anatomical parts (i.e. the genital area) that are exposed by the technology. The presence of this foreign object reminds Tara that her body is unable to perform the bodily function of elimination and is in need of foreign medical technology to fulfil and repair the broken down body. The medical device becomes a constant, visible, and tangible reminder of her illness and vulnerability. In the following excerpt, she explains her image:

T: This is the big long tube and then the bag and the numbers represent the amount of

> *pee!*
>
> *C: Why do you have the catheter? Do you know?*
>
> *T: No I don't know why. Well I do know why but I forget [Laughter].*
>
> *C: What does that feel like?*
>
> *T: It's alright. Sometimes I use the bathroom. I hate the night bag, it's very complicated.*
>
> *C: Why is it complicated?*
>
> *T: Because sometimes I don't really use it any more cause sometimes I don't use it. It use to come out and my mum would have to take the balloon out of it and she'd have to throw out the water and she'd have to get a new tube and a new bag. Ya I hate the night bag.*

Interestingly, Tara does not use the medical term catheter to describe the catheter. One interpretation is that if she identified the catheter by its medical term, she may have brought unnecessary medicalisation into her everyday life. Tara does not incorporate the device into her habitual every day routine, which suggests a rejection of the body invasion that this technology brought. Her characterisation of the experience as *'complicated',* is interesting. I wondered whether her use of this term reflected her difficulty in expressing some illness experience. She also used the word *'complicated'* in an earlier story, to describe her dialysis experience. For Tara, dealing with incontinence was a particularly challenging aspect of living with CKD. She displayed strong emotions as she recounted experiences with her leaking body and explained her need for intermittent catheterisation. She asserted some control over her incontinence by engaging in self-care measures to conceal leaks. However, she resisted the use of a catheter and night time drainage, revealing her dislike of medical technology or foreign devices that invaded her body and caused discomfort.

In summary, Tara's stories centred on the bodily struggles she endured and suffered. She disliked dialysis treatment, a technology that seemed to alter Tara's sense of embodied self. She felt objectified, dehumanised and powerless in the face of medical technology. Her stories highlighted her perceived threat of her body becoming more mechanised and less human as machines and technology took over.

9.3 Tara's Narrative: *A Fragmented Sense of Self*

Several threads underpin Tara's narrative of her experiences with CKD. Her narrative pivots on the vulnerability and fragmentation of her body and the methods used to address body dysfunction which result in feeling of body alienation and body colonisation. Medical technologies, such as the dialysis machine and the catheter device, shed light on the binaries inherent in the human/machine relationship. Technologies caused a loss of self and gave rise to her experience of a disrupted embodiment. Tara is sharply critical of these technologies. She does not see them as simply instruments used to treat her failing body parts. They are also instrumental in how she experiences herself and how she appears to others. Negative perceptions of these technologies prevail throughout her narrative. Feelings of being depersonalised and objectified are evident, as are feelings of dehumanisation. Negative interpersonal interactions cast the medical technology in a negative light. The dialysis machine is experienced as alienating and estranging, rendering her body fragmented and invisible and described in terms associated with objectification and disembodiment. For example, in her story '*Oh they're seeing the machine'* the dialysis machine is portrayed as an active subject while she is positioned as a passive object. In telling this story, she reflects on her own sense of marginalisation, exemplified by the body/machine struggle she endures. Tara feels devalued, inferior and invisible as the presence of the machine objectifies and oppresses her personal identity. In this way her body is arguably a hybrid figure i.e. machine–body or cyborg which blurs the separation of the human and the machine.

The experience of powerlessness also causes a disruption to Tara's sense of self. Feelings of powerlessness arise from a variety of different sources. For example, technology renders her body powerless and docile. In other situations, medical authority prompt feelings of powerlessness. Tara feels she had lost control over decision making in her life, particularly in relation to fluid regimes. Medical authorities control her fluid restrictions. However, other sources of powerlessness include feelings of loss of control over body functions such as thirst and incontinence. Her body and its boundaries are threatened. Her body becomes a source of instability and uncertainty. The fact she did lack control over when and where her body leaked urine supports this interpretation. Thus, there is a sense of unstable embodiment. Loss of control over these aspects of her life results in both the requirement for and her simultaneous rejection of imposed body control of medical and technological intervention. Despite her attempts to gain control, through personal body vigilance and repudiation of medical technology, she remained powerless. Her narrative remains fragmented, as it lacks a coherent sense of self; she remains unable to repair the ruptures between body, self and machine. Tara had difficulty in conceptualising her body as a whole and this is evident in her body map, which she perceives as '*too big'* for her to manage and where she can only create the map through the use of separate and individual paper portions and images.

9.4 Conclusion

This chapter presented Tara's narrative of her illness experience. At times, Tara felt overwhelmed by the impact of dialysis. Her sense of self was challenged and, in some ways, altered, so instead of feeling whole she felt profoundly uncomfortable within a body that was invaded and disturbed by treatment and disease. In the following chapter, a cross case analysis of all participants' stories is presented.

Chapter 10: Cross Case Analysis

10.0 Introduction

The previous chapters (5 to 9) presented the narrative accounts of Emily, Lucy, Maggie, Tara and Jack. The accounts revealed their individualised embodied experiences of living with CKD. While each of the narrative accounts differed from each other, they shared several common themes. This chapter presents the findings from the comparative analysis of the five cases. The findings demonstrate the ways in which CKD and its treatments can effect an adolescent's sense of embodiment.

10.1 Comparative analysis approach

Having analysed all of the participants' stories individually in a case-centred manner (Riessman, 2008) I identified a number of comparative themes. As previously outlined in Chapter 4 the cross-case analysis followed Riessman's Comparative Approach. Riessman (2008) notes that a case-centred approach can identify theoretical concepts and general processes across narratives. In line with Riessman's comparative approach to narrative analysis, I focused on the content of each narrative with the purpose of identifying common thematic areas. The primary attention was on '*what'* was said in stories rather than on *'how', 'to whom'* or *'for what purposes'* (Riessman, 2008, p.54). As outlined in section 4.4 narrative cases were read and reread several times in order to interpret the content of the stories. All stories reported in the five narrative cases were coded and subthemes were identified. Appendix O is an example of how a story from a narrative case was coded. Following this, overarching themes were generated from the subthemes (refer to Appendix P). A thematic map outlining the stories relating to each of the cross case themes is presented in Appendix Q.

10.2 Cross-case thematic findings

In addressing the research objectives of this thesis (chapter 4 section 4.1), five comparative thematic areas each with a number of sub-themes were identified. Table 5 provides an overview of these themes and sub-themes each of which will be discussed in the sections to follow.

Table 5 - Overview of themes and sub themes from cross case analysis

Story Theme	**Sub theme**	**Overarching Theme**
CKD caused a disruption in adolescents' lifeworld, which limited their engagement in everyday activities. Changes in body function, sensations and in puberty development caused a loss of bodily control and changed the way the adolescents viewed themselves and their bodies in the world.	*Biographical disruption.* *The out-of-control body.*	Experiencing the ill body.
Treatments, both medical and surgical, caused considerable upheaval and intrusion to the intact body. Adolescents experienced their bodies as strange and unfamiliar because of invasive treatments.	*Body invaded by medical treatment.* *Body invaded by foreign body parts.*	Body invasion.
The effects of CKD and its treatments challenged adolescents' sense of agency and previously held assumptions of self. This in turn had a disrupting effect on the adolescents' sense of self and identity.	*The healthy self versus the ill self.* *The altered and changed self.*	Loss of habitual self.
How the ill body and the adolescent is regarded in the course of the medical encounter, through experience of exclusion, asserting body knowledge and medical discourse and practices.	*Invisibility and exclusion through objectification and medicalised language*. *Tensions between embodied and medical knowledge.* *Social suffering and desire to communicate beyond the bio-medical plot.*	Regarding the ill body.
Performing bodies as strong and resilient in the context of CKD. Exhibited through bodily stamina and optimistic attitude.	*Enduring and surviving CKD.* *Remaining Positive.*	The strong and resilient body.

10.3 Theme 1: Experiencing the ill body

This comparative analytical theme, '*experiencing the ill body'*, illustrates the impact CKD has on adolescent bodies and lives. In a number of stories, participants described the physical symptoms and effects of living with CKD and its treatments, and produced a vivid picture of their embodied experience of living with CKD. These are represented in the sub-themes of (1) '*biographical disruption*' and (2) '*the out-of-control body'*. These sub-themes describe the disruptive nature of CKD; the first sub-theme highlighted how CKD caused a series of disruptive events in the lives of adolescent sufferers; the second subtheme detailed the physical disruption to bodily functions and development.

10.3.1 Biographical disruption

This sub-theme represents the biographical disruption that adolescents endured while living with CKD. Biographical disruption refers to the way CKD disturbed participants' sense of living their expected life trajectories through time. Biographical disruption entailed a disruption to the adolescents' ability to enact an embodied orientation towards the world. Biographical disruption was not simply a result of CKD as such, but from the ways that CKD impinged on the adolescents' physical ability to engage with daily life. Some of the adolescents, Emily, Maggie and Tara for example, were born with and had lived with CKD from early childhood. For others (i.e. Jack and Lucy) they developed the condition later in childhood. Nevertheless, CKD had been a large part of their biographies. Despite some having lived with the condition for many years, these adolescents continuously experienced biographical disruptions. CKD disrupted the fundamental structures of their daily routines. They experienced recurring bodily losses, disruptions and disappointments. Their desire for 'normal' adolescent body development was frequently disrupted. Treatments were identified as a cause of biographical disruptions. Treatments impacted on the adolescents' sense of self, negatively affecting their emotions, their sense of freedom and their ability to engage in meaningful activities. The time taken to perform treatments, and the time lost in being physically constrained by technologies such as dialysis machines and catheters, incurred a loss of freedom. The need to constantly plan treatments into everyday life was viewed as a loss of spontaneity, particularly amongst adolescents who were of an age associated with increased freedom and spontaneity. For example, the need for hospital-based treatment introduced Jack into a medical world, which limited his ability to engage in the outside world; as he expressed it: *'I'm stuck'* (see section 8.1.4). Jack's home life was disrupted and his ability to engage in his own familiar world was restrained. This made him aware of his own precarious being in the world. Tara also experienced a strong disruption to her life, which she attributed to her need for treatment (see section 9.2.1). Throughout her narrative case, Tara portrayed the disruptive impact of dialysis in her life. She revealed the confinement and constraint she experienced as a result of dialysis, a process she stated was '*too long'*. This limited her ability to move freely and restricted her movements in the world. Being unable to engage in normal adolescent activities, and being more restricted socially, resulted in feelings of helplessness in many adolescents. Feelings of helplessness and restriction can have profound implications for an adolescent's personal and social identity, as evidenced in the case of Maggie. She narrated how her need for hospital based treatments such as dialysis and transplant disrupted her school attendance (see section 7.2.5). These disruptive events affected her social development and her ability to engage with peers. Thus, adolescents experienced a biographical disruption, which reduced social engagement and made them unable to engage in normal everyday activities.

In the adolescents' accounts, CKD appeared as something that disrupted their whole existence. For example, Lucy also narrated the impact CKD had on her being in the world (see section 6.2.5). Her familiar being in the world was changed into unpredictable encounters with the world. In describing this biographical disruption to her lifeworld, Lucy used metaphors such as 'o*rganised chaos'* versus '*chaos'*. When discussing her dialysis experience, Lucy described hospital life as being full of '*organised chaos'*. Following transplant, the disruption to her life continued albeit in a different way. Lucy had to adjust to a new unfamiliar way-of-being-in-the-world; she had to live in the 'chaos' of the everyday world. Lucy's story illustrated how CKD, as an ever changing and dynamic process, can cause disruption to the life world of adolescents who suffer from the illness in stages and over a longer time-period. Likewise, because of her illness and the treatments following transplant, Maggie experienced ongoing disruptions. In her story '*Chronic kids are always chronic kids'* (see section 7.2.4) she revealed her expectation that transplantation would bring a renewed sense of life and engagement in normal everyday activities. She felt disappointed when she continued to experience ongoing disruptions to her life after transplant. Other adolescents used unequivocal language to describe the disruptive nature of living with CKD. For example, language such as '*it sucks'* (Emily) '*it's complicated'* (Tara) and *'I'm stuck'* (Jack), to communicate the unambiguous nature of CKD. With these words, the adolescents revealed the chaotic and inescapable nature of their illness, and how it caused considerable disruption to their lives. Experiencing disruptions to their everyday lives was part of their experience of living with CKD. Similarly, they experienced ongoing disruptions and changes to their physical bodies in the course of their illness trajectory, something which will be presented in the following sub-theme.

10.3.2 The out of control body

The sub-theme '*the out of control body'* refers to the bodily and functional processes that the adolescents were unable to self-regulate or control. The narratives included situations where CKD caused a loss of control over bodily functions. This disruption to body function meant that adolescents were no longer in control (consciously or unconsciously) of their bodies. Through their narratives, the participants positioned their bodies as being out of control, and described corporeal experiences such as excessive tiredness and thirst, disfigurement, scarring, leaking bodily fluids such as blood and urine and delays in puberty. For example, in Maggie's story *'Chronic tiredness',* she described the profound exhaustion she experienced while living with CKD, a body experience she had no control over (see section 7.2.3). Maggie used the metaphor of running a marathon to describe this uncontrollable bodily experience, which affected her physical functioning and her being in the world. Additionally, her body map revealed how significant this tiredness was to her. She drew large ZZ*Zs* that extended across her body, in order to portray the tiredness, she felt all over her body.

Other participants also revealed bodily experiences that were out of their control. For example, in Emily and Tara's narratives, unbearable thirst was a consequence of their CKD treatment. In Emily's narrative, for example, she explained how powerless and frustrated she felt for not being in control of the most basic human need - water. Emily had a strange and unpleasant feeling in her mouth, causing a pervasive feeling of extreme dryness: '*Dry as a sandpit'* (see section 5.2.1). Her experience of thirst was distressing: '*It was actual real torture for me.*' Her bodily suffering was also conveyed through her image of a teardrop. She visually explained her bodily suffering by drawing a teardrop with a ball and chain on it. Through this image, she conveyed the emotional ordeal that accompanied her experience of fluid restriction and thirst, a bodily situation she had no control over. Thirst was an extremely bothersome symptom for Tara; it was a bodily state that left her '*dry'* (see section 9.2.3). The participants also reported the negative effect CKD had on the functioning of various parts of the body. CKD not only affected kidney functioning, it also affected organs such as the bladder, heart and lungs. In Maggie's story '*My lungs filled up with water'*, for example, she revealed the serious impact her kidney disease was having on her other body parts i.e. her lungs and heart (see section 7.2.2). Her out of control body filled with water. The adolescents referred to these instances of loss of control over their bodies as '*frustrating*' (Emily) '*annoying'* (Lucy) and *'embarrassing'* Tara). Tara provided a vivid description of being let down by her body, which no longer function in expected and habitual ways. Tara experienced unprompted and unexpected urine leakage (see section 9.2.4). This is an excellent example of an adversarial body- the bladder no longer functions, as it should. The adversarial and unpredictable body gave rise to uncertainty, as Tara did not know when or where her body would fail her (see section 9.2.4). She revealed how episodes of body leakage brought her body into full consciousness and out of taken-for-grantedness. The body leaked and its untidiness violated her biological and normative boundaries. She experienced her adversarial body as a source of embarrassment. Tara now had to pay attention to her damaged body and she was acutely aware of how her damaged body left her vulnerable in the world. Tara had no control as bodily boundaries were threatened. Her body was unpredictable, a state which threatened her body integrity. Similarly, Emily, who was born with CKD, revealed how her body failed to produce urine and following transplant she had to adjust to a new bodily process of urinating, which she found challenging (see section 5.2.5). On the one hand, her newfound ability to urinate was received with joy, and even inspired a song; '*2,4,6,8 Peeing is so great!*'. Yet, despite her claim that '*peeing is so great*', Emily expressed frustration over the need to continuously urinate; a bodily disruption she blames on her new kidney, '*Ciara'*. Both Tara and Emily described being let down by their bodies, which no longer functioned in expected and habitual ways. The adversarial and unpredictable body gave rise to uncertainty. They revealed how body disruption brought their bodies into full consciousness and out of taken-for-grantedness.

Viewing the body as being out of control, as strange and unfamiliar, was evident in Jack's story '*It's like being a vampire'* (see section 8.1.1) where he described himself as '*alien'* and *'vampire'.* Similarly, Emily used metaphors connected to fictional wizard Harry Potter. These metaphors symbolised bodies that were out of control, non-human, and in some cases even repulsive. The participants also reported being unable to exercise full agency over their bodies. For the adolescent participants, the out of control body sparked feelings of disempowerment and frustration. The adolescents' difficulty in making meaning of out-of-control bodily experiences, experiences that were positioned outside of normality, was evident in the words used to describe these experiences: ‘*Strange’, ‘weird’, ‘ridiculous’, (Lucy) ‘disgusting’, (Jack) ‘sucks’, (Emily)* and *‘really bad*’ *(Tara).* The use of such language suggests that the body is constructed outside discourses of ‘*normality’.*

The cross case indicated that delays to physiological functioning signified a body out of control, and the adolescents’ bodies were therefore outside the boundaries of normal pubescent development. Emily, Jack, Lucy and Maggie reported feeling different because of they lacked the embodied markers of adolescence. These markers included accelerated growth, development of sexual characteristics as well as independence and social skills. The out of control body disrupted bodily rituals of development, which contributed to feelings of being different. For example, Emily reported being self-conscious about her underdeveloped body and continually compared herself to her peers (see section 5.2.4). The unpredictable nature of the pubescent body in kidney disease also contributed to their feelings of uncertainty. Similar to Emily, Lucy’s experience of puberty left her in a state of confusion and uncertainty. In Lucy’s story, ‘*Which pain am I looking for here*’? (see section 6.2.2), Lucy used her CKD to frame her difficulty with understanding and interpreting her body’s signal of menstruation. Menstruation signals are difficult to distinguish from CKD symptoms. This caused a state of confusion for Lucy. Lucy’s body demanded attention through bodily discomforts such as pain and cramps but she had to decipher which discomfort her body was signalling. Her body became both unfamiliar and unknown. Lucy engaged in intense body vigilance in an attempt to become attuned to which bodily organ was demanding her attention. Her body became a project and her internal bodily processes were experienced and observed through a bio-medical lens. Lucy’s out-of-control body demanded much of her attention and she did not have time to dwell on the pubescent changes in her body. Consequently, her changing pubescent body, and her embodied experience of it, was rendered secondary due to her underlining CKD.

In their narratives, the adolescents revealed that changes in their bodily capacities, as well as the body’s ability to behave as expected, had dramatic repercussions in terms of identity and provoked strong reactions from others. The participants experienced increased awareness of themselves and their out of control bodies, and they also grew more aware of how they appeared to others. This heightened self-consciousness is apparent in many of the adolescents’ stories. In Jack’s narrative, for example, the loss of a mature masculine pubescent body caused him significant bodily distress and unwanted attention in public (see sections 8.1.1 -8.1.3). For Jack, his short and thin stature affected not only how he perceived himself but how others perceived and treated him in the broader social world. Jack's ill body did not equate to society's expectation of what a masculine body should look like, thus provoking instances of public curiosity. Because of the public gaze toward his body, Jack experienced a change in social positioning, where his subjectivity was reduced to his childlike body that symbolised his illness. Similarly, Emily described how her body failed to meet social expectations of what a body should look like '*for an average 13-year-old'* (see section 5.2.4.). The regulatory social gaze was reflected in the adolescents' social constructions of their bodies as "different' and difficult to place within available and legitimate social meanings. This was particularly the case where body appearances and functioning did not signify the presence of CKD, which can lead to adolescents experiencing exposure and vulnerability.

In narrating their experience of illness, adolescents referred to bodily experiences that signified a loss of bodily control and a childlike state. This was evident in Tara's narrative case. In her story, '*I'd be so embarrassed'* (see section 9.2.4), she described how her leaking body required her to wear nappies and pull-ups, all of which signalled a regression to a childlike state. Bodily events, such as this one, breached social norms and signified body failure and loss of independence. Tara reported how she would be embarrassed if her leaking body became public knowledge. Her need for nappies and pull ups to conceal her out of control body contributed to her liminal childlike state. The adolescents narrated the progressive nature of CKD, which limited their opportunities to exert control over their bodies and lives, and which complicated their transition to a full independent existence. The adolescents were torn between assuming a premature sense of adulthood on the one hand, and a state of childlike dependence on the other. However, they relied on parents to support them, explain their condition and manage its impact, thus perpetuating their state of dependence. Indeed, at times the adolescents needed to call on their parents, specifically their mothers, to come to their rescue in times of distress. For example, Jack's childlike state was evident in many instances. This is seen in his stories '*What am I? A criminal?' (see section 8.1.3)* and '*I'm stuck'* (see section 8.1.4). In these stories, Jack referred to a loss of control over his appearance and his treatment options, which caused him distress. In these situations, he depended greatly on his mother to come to his assistance and protect him, contributing to his state of childlike dependence. There are many instances of *'mammy save me'* moments where his childlike state becomes apparent. Similarly, Lucy, Maggie and Emily express the need for paternal support in their narratives. The restrictions on social development as well as their dependency on their parents contributed to their state of powerlessness. Gaining mastery over one's body and developing independence are important developmental tasks of adolescence. However, for the adolescents in this study, this process was constrained by a childlike state of dependence caused by the impact of CKD on their bodies.

In summary, adolescents experienced a series of disruptions to their lives because of CKD, its treatments and the disruptive impact on puberty development as evidenced in the sub-theme '*Biographical disruption*'. The '*out-of-control body'* represented the physical challenges adolescents experienced in living with CKD. The next theme *'body invasion'* represents the adolescents' experience of CKD treatments and presents the intrusive nature of these treatments on the body.

10.4 Theme 2: Body invasion

This overarching theme of body invasion was recounted in all five adolescent storied experiences of living with CKD. In this theme, adolescents describe the intrusive nature of CKD treatments on the body. They described how their bodies were attacked, harmed and in some cases altered, all of which affected body integrity and intactness. Body invasion was represented by two sub-themes; (1) '*bodies invaded by medical treatment'* and (2) '*bodies invaded by foreign body parts*'. The common thread of body invasion connects these sub-themes.

10.4.1 Bodies invaded by medical treatment

Medical treatment had a significant impact on how adolescents experienced their bodies. Particular technologies and modes of treatment added to the adolescents' fears of body invasion. The two major issues were the impact of medical technologies and the impact of surgical procedures on their bodies. Medical technologies were experienced subjectively and emotionally and gave rise to negative experiences of the body. Medical technologies such as catheters and dialysis machines served to disrupt body integrity. Some participants expressed somatic concerns, such as having one's body stabbed (Lucy), cut (Emily) or in some way invaded (Maggie) as a direct result of their treatment. For example, Lucy's illness had subjected her to many different treatments which invaded her body. This was evident from her body map, which illustrated the various medical devices that intruded on her body, most notably her image of a catheter extending from her body. In her story '*I know I'd be able to (move) if this bloody catheter wasn't stabbing me'* (see section 6.2.3) she explained how a catheter, which caused her additional bodily suffering, invaded her body. Lucy used words such as '*really painful'*, '*so bad'* and '*so much pain'* to express this intrusive impact on her whole body. The catheter was so debilitating and invasive (it was '*stabbing'* her body) Lucy could no longer move freely. Like Lucy, Tara also experienced the intrusive nature of a catheter (see section 9.2.4). She described the catheter as a '*big long tube'* that she visually depicted in her image of a large device stretching out from her body.

In conversations with Maggie, Emily, Jack and Tara, dialysis arose on numerous occasions. Dialysis was an invasive and frightening process for these adolescents. Dialysis violated their body boundaries. Maggie's story (see section 7.2.2.) illustrated how the body's boundaries could be extended and penetrated in dialysis. She described how her body was '*attached to a machine'* that *'drained'* her body of fluid 10 times over night. Maggie also described dialysis as dangerous and destructive. She recounted a time when the dialysis machine did not work properly, which caused fluid overload and deterioration in her health. This experience resulted in anxiety and distress for Maggie. Similarly, Jack's experience of dialysis was '*THAT BAD'*; it impacted on his future self (see section 8.1.2). Jack's description of his narrative future - he is never going back on dialysis '*NO-WAY am I ever going back. Never'*- supports this interpretation. For Jack, the prospect of returning to a life of dialysis was unconscionable. He would rather put his life in danger than go back on dialysis: '*you'll just have to die'.* His use of the general *'you'* in this statement served to distance himself from the consequence of refusing dialysis treatment in the future.

Dialysis also contributed considerably to feelings of objectification, depersonalisation and dehumanisation. Tara's story '*They are only seeing the machine'* (see section 9.2.2) is a good example of this. Tara explained how the dialysis machine determined the way she was viewed by others. In this story, Tara discussed how 'others' were fixated with the machine and how this drew into question the distinction between human and machine. Tara was reduced to a machine. Tara is not acknowledged as a person but as a body attached to a machine. In her account, feelings of disappointment, frustration and anger are expressed both implicitly and explicitly. Moreover, Tara revealed how she viewed the dialysis machine objectively, rather than as part of her own self. This can be seen in her reluctance to personify the dialysis machine by assigning the machine a name. Instead, Tara distanced herself from the machine by referring to the machine as ‘*it’*.

Surgical intervention was an another example of body invasion. Emily, Tara and Jack’s stories illustrate how surgery caused a destruction of bodily intactness and created visible scars. Surgery was experienced as frightening and physically invasive. For example, Tara revealed in her story (see section 9.2.1) how her body was invaded by the surgical placement of a permcath device. The surgical placement of this device, *‘jerking’* deep inside her body, altered her sense of body intactness. Emily also revealed similar experiences of body invasion following surgery (see section 5.2.2). In her *‘zip’* story, she narrated how her body boundaries were altered. She illustrated both verbally and visually her scarred body. Surgeons invaded her body and created her ‘zip’. Subsequently, she experienced a lack of body confidence and body integrity which disrupted her sense of embodiment. In this sense, surgery became less about offering comforting and lifesaving possibilities and more an invasive transgression of bodily boundaries that heightened vulnerability. Similarly, Jack also expressed his experiences of bodily vulnerability and trauma (see section 8.1.2). Throughout his illness trajectory, Jack accumulated five scars, each representing different surgical procedures, all of which left lasting marks on his body. It was difficult for these adolescents to achieve a sense of wholeness in their bodies when they felt invaded by medical technologies and treatments. A feeling that also emerged from their experiences of receiving foreign body parts.

10.4.2 Bodies invaded by foreign body parts

In their narratives, the participants described how donor body parts invaded their bodies, which left them feeling different and strange. In this context, the invasion of a ‘foreign’ organ brought attention to the body, which caused an alteration in their embodiment. Emily, Jack, Maggie and Lucy all described the corporal awareness that accompanied the experience of body invasion following transplantation. For some adolescents the transplanted organ was seen as a paradoxical entity, both real and surreal, both necessary and unnecessary, both life-saving and alienating. To illustrate this further, I refer specifically to Lucy and Maggie’s narrative cases, which revealed that their sense of bodily invasion emanated from the insertion of a foreign body part into their bodies. For Lucy, receiving a cadaveric kidney was a surreal experience. Following her operation, Lucy woke to the tangible presence of a new organ invading her body. In her story, Lucy revealed the corporal awareness that accompanied her experience of body invasion (see section 6.2.4). Her description of how her body came to be invaded by a newly implanted mass of flesh is fascinating. The new body part felt heavy and uneven and protruded out of her skin. The weight and capaciousness of the foreign kidney left her feeling uneven, an experience that was not visible to others externally. She described the experience of having a new body part as feeling weird and not belonging to her. The reality was her body was being invaded by a body part that once belonged to another living human being. Lucy's use of laughter may represent her attempt to use humour as a form of defence in the psychical processing of a transplant. Although she makes light of the situation, there is still a hint of the horror that could be evoked in a young girl by this reality. This experience exemplified her sense of body invasion. Similarly, Maggie, revealed the difficulty she experienced in adapting to a new foreign organ that she received from a stranger (see section 7.2.1). As a result, Maggie experienced psychological distress and, on occasion, something resembling a panic crisis, due to the presence of an unwanted foreign object (transplanted kidney). This negative experience effected how her body integrated the foreign organ. As a result, within 8 hours her body had rejected the kidney. In Maggie's case her body immunologically rejects the kidney that invaded her body, but there appears, from her narrative, to be a direct link between the immunological and psychological "rejection" of the transplanted kidney. Maggie's psychological awareness of the presence of something alien invading her body caused her immune system to reject it. The presence of a 'foreign' organ invading her body threatened her body integrity. Managing the effect, a transplant can have on identity and these adolescents' sense of self was challenging. Participants reported how replacement kidneys, which directly affected their embodied selves, invaded their bodies.

In summary, adolescents found themselves struggling to incorporate transplanted body parts and medical technologies into their embodied self-identity, which created a rift between the body and self. A disruption to adolescents' sense of self and identity was a common thread throughout these stories, which is presented in the following theme '*Loss of habitual self'*.

10.5 Theme 3: Loss of habitual self

This theme concerns how the adolescents grappled with disruptions to their identity as a consequence of changes in their altered body integrity and altered self. Adolescents with CKD reported a profound sense of alienation from their bodies, which created a rift between the body and self. This was reflected in the two sub-themes of (1) '*The healthy-self versus the ill self'* and (2) *'The altered and changed self'*. In each of these sub-themes, adolescents presented the different ways they experienced a change or alteration in their sense of self and identity in the context of their illness experience.

10.5.1 Healthy-self versus the ill-self

This sub-theme, healthy-self versus ill-self, illustrates how adolescent participants experienced a liminal state between illness and wellness. Despite having suffered from CKD for many years, the adolescents saw themselves as being healthy and their experience of being ill was at odds with their sense of self. Some adolescents were capable of living life with a sense of well-being. This could be interpreted as a means for them to avoid viewing themselves as chronically ill or, indeed, vulnerable to illness. Participants were reluctant to describe themselves as ill, as seen in statements such as *'I'm never sick' (Jack)* or *'I'm not sick' (Jack)* or *'she thought I was sick' (Maggie).* The disease may have advanced, but it was still possible to experience oneself as healthy. The participants understanding of health was twofold. Firstly, it meant an absence of feeling physically sick and secondly, the absence of dialysis and other forms of treatment was a prerequisite for experiencing oneself as being well. This is evident in Maggie's story (see section 7.2.1). In this story, she positioned herself as being '*well'* and she did not view herself as sick in the absence of the need for treatment such as dialysis or transplant. Correspondingly, Jack (see section 8.1.4) did not see himself as sick and repeatedly insisted that he is '*never sick hardly'* despite his chronic condition.

By creating a discourse where they were able to portray themselves as healthy, adolescents like Maggie and Jack were able to eschew some of the changes imposed on their sense of self as a result of their illness and treatment. Adolescent perceptions of being healthy went beyond the physiological state of the body, to include mental well-being. Statements such as '*You're great. You're great' because they're talking medical-wise*' (Maggie) and '*I know I have an interesting* *story but it's not the only story'* (Emily) revealed a frustration with the medicalised view of what it means to be healthy. Focusing solely on the physical body and ignoring other dimensions of the body does not give a complete picture of a person, and this is testified to by these adolescent narratives. They created a different discourse of health, one that was not just about being well medically.

However, while the adolescents resisted portraying themselves as ill, when narrating bodily problems their experiences of being ill became apparent. For example, despite Maggie's claims that she was well, she revealed, though her narrative, significant signs of bodily distress and sickness (see sections 7.2.2- 7.2.3). The cross case analysis illustrated the deleterious effects of illness and treatment on adolescent bodies, which, by signalling a move away from a healthy self, often caused rifts in the self-identity of these adolescents. The erosion of the healthy-self became more apparent as the adolescents discussed bodily problems such as '*dying of thirst'* (Emily), '*chronic tiredness'* (Maggie) and '*very bad pain' (Tara).* Former definitions of self were discredited in the presence of these bodily symptoms, as it was no longer possible for the adolescents to experience wellness. Physical damage to the body restricted the adolescents' bodily functioning, dominated their thoughts and profoundly altered their experience of self. In the participants' accounts, curiosity from members of the public often challenged their self-identification as healthy selves, and exposed them as being ill. The fact the symptoms of their illness were often so visible also put their well identity at risk. Despite this, as Maggie and Jack's stories illustrate, some participants made pronounced attempts to preserve a sense of being well.

10.5.2 The altered and changed self

The adolescents were also aware of the changes to their bodily appearance, which had a profound impact on their sense of embodied self. Their narratives revealed changes to self, which were triggered by changes to bodily appearance and the effects of treatment and transplantation. The adolescents made clear that the changes in their physical appearance, through scars and disfigurement, had a profound impact on their self-perception and identity formation. They felt disfigured and unrecognisable to themselves because of kidney disease. The bodily changes the adolescents experienced and confronted, impinged on their sense of self, preoccupied their awareness and refused to let them feel like themselves. They described how living in a body changed by CKD involved looking and feeling different, which disturbed their habitual sense of self. In Jack's story, (see section 8.1.1), for example, he described how his experience of body affected his appearance and sense of self. His comments '*I couldn't even recognise myself in the mirror'* or *'I don't even look like myself',* pertain to a sense of changed self. The changes experienced were frightening, they threatened his sense of bodily self and created fears of alien appearance. The alterations in bodily appearance impacted both on the adolescents' sense of self and on their relationship with others. They felt dejected and ashamed of their bodies, feelings that were triggered by the stares of others. Returning to Jack's story, (see section 8.1.1) his changed appearance forced him to avoid social encounters, so that '*others'* would not notice or question his changed appearance. In other stories (see sections 8.1.2 story 2- 8.2.3), Jack described how his changed appearance singled him out, which frustrated him. Similarly, Emily was conscious of her scarred body and took measures to conceal her body from others (see section 5.2.2). Equally, Maggie narrated how 'others', in her case her teacher, noticed her pale body (see section 7.2.5). Concerns about how people would respond to the fact they looked different to others, contributed to the adolescents feeling of isolation within their embodied selves. They felt alienated from their own disfigured bodies and felt a sense of loss with regard to their former selves.

A nuanced finding, identified in the cross case analysis, was how the encounter with a foreign body part (i.e. kidney) caused a disrupted sense of self and identity. The participants mentioned how they struggled to incorporate a new kidney into their embodied self. This caused bodily distress and identity disruption, as evident in the accounts of Jack, Emily and Lucy. Emily, in her story '*Ciara Kidney*' (see section 5.2.5) depicts her new kidney as a separate person to herself, testifying to her experience of an altered self. Ciara is a calm cheerleader, who has spent time living in another country. She likes yoga and meditation. For Emily, the kidney will always retain part of her original donor Sara, whose characteristics and personality are something separate from Emily. Emily believes that Ciara remembers something of her original owner's habitual routines, such as getting up early to go running**.** This is impacting on Emily's governance of her own internal bodily processes**.** Emily behaved as if the donor was still alive inside her. In her fantasy, her donor Sara was part of her and so she felt as if she had two lives - that of her donor and her own. It is almost as if Emily is a hybrid of two people - her and her donor Sara. This hybrid identity challenges and disrupts Emily's previous sense of body self and embodied identity. However, maybe designing a narrative past and present for Ciara is a form of configuring and integrating the kidney into her identity. Emily may be attributing qualities and attributes to Ciara that she wants to integrate into her own identity. Emily seems to be aware of her own personality and her donor's at the same time; she fantasized about the incorporation of the donor and some of the donor's personality traits into her own personality. Her story reveals the different personae that exist in Emily's life, so that Emily is not a single, unified and unchanging character but an ambivalent amalgam of donor and self. Emily's performance of Ciara as a powerful character that is in control of her body is a strategy of personification and rationality, a social process of identification, an attempt to make the strange organ into part of the one's self – a new, mixed self. This provided Emily with an avenue for explaining the hybrid experience she endured following transplantation. Other adolescents, for example Jack, Maggie and Lucy, reported similar experiences to Emily. They all struggled to incorporate donor kidneys into their embodied identity. The idea of another person's kidney inside them was viewed as '*disgusting*' (Jack), '*weird'* (Lucy) and *'foreign'* (Maggie). The adolescents were conscious that their lifesaving operation depended on the death of another human being; part of whose body now resided within them. Lucy, for example, struggled to view the transplanted kidney as her own: '*It's still someone else's kidney. It's not yours - well, technically it is'*. Instead, she conceptualised the kidney as '*a dead person's kidney'* (see section 6.2.4).

Correspondingly, Jack also struggled with his new corporeal relationship and conveyed how difficult it was to incorporate a body part that once belonged to another person. Like Emily, Jack was concerned he would develop the personality characteristics of the donor. He explicitly performed and contrasted several possible identities of his donor (see section 8.1.5). He speculated that his donor kidney could have originated from an old body, a possibility that repulsed him. He was also perturbed by the idea of receiving a female body part. Subsequently, he actively resisted finding out the identity of his donor. By choosing not to find out, Jack attempted to distance himself from the donor and in a way was attempting to protect himself from having to deal with the consequences of discovering the donor's gender and identity. Interestingly, Jack performed his own preferred identity by suggesting that his donor must have been a lazy teenager, a behaviour he has acquired since transplantation. The body had become a stranger to itself and for the most part, the adolescents viewed the foreign organs as not part of them. It could be argued they experienced the body objectively, rather than as part of the self, which consequently threatened their sense of self and identity and caused an alteration in their embodiment. The adolescents' sense of self-identity was also affected by the way they were treated in medical encounters. The participants' struggle to be acknowledged, included in medical discourses, and valued as a source of bodily knowledge, is presented in the next theme, '*regarding the ill body'*.

10.6 Theme 4: Regarding the ill body

The fourth overarching theme, *'regarding the ill body'*, represents adolescents' embodied experience of medical treatment. Specifically, this theme portrays how the adolescents' ill bodies are regarded in the medical encounter and in their relationship with health care professionals; which was explored in the three sub-themes of; (1) *invisibility and exclusion through objectification and medicalised language*; (2) *tensions between embodied and medical knowledge* and (3) *social suffering and the desire to communicate beyond the bio-medical plot.* The construction of the body as a site of illness that required medical attention and treatment created a wrestle for power between adolescents and HCPs.

10.6.1 Invisibility and exclusion through objectification and medicalised language

This subtheme exemplifies adolescents' experiences of invisibility and exclusion in medical encounters. Adolescents described how HCPs frequently dominated clinical conversations, which often left them feeling invisible, excluded and angry. The participants' stories revealed many instances where they felt excluded from medical conversations about treatments and care, as evidenced in the following statements: *'I didn't have a choice' (Maggie); 'apparently I don't have an input on this' (Emily)* and *'they're not acknowledging that I have an opinion on this'(Lucy).* Emily described how HCPs (see section 5.2.3) ignored her in clinical conversations, which left her feeling invisible; as seen in her statement '*I'm just standing there 'Hi I'm still in the room!'.* Moreover, HCPs attending to the dialysis machines and medical processes before/instead of engaging with the adolescents on a human level, caused many of the adolescents to feel invisible. Lucy, for example, narrated her frustration with HCPs who disregarded her during treatment procedures (see section 6.2.1). Equally, Tara narrated how she was overshadowed by HCP's focus on the dialysis machine. Her statements '*Oh they're seeing the machine'* and '*they don't see us'* illustrated how she perceived herself to be trapped and invisible in medical encounters (see section 9.2.2). Jack described similar experiences and recalled interactions where he felt ignored and excluded: *'I'm just sitting there going 'Ahhhhhh'* (see section 8.1.4). These interactions illustrated how experiences of invisibility and exclusion from medical encounters caused the adolescents to feel objectified and depersonalised. Adolescents felt like passive and powerless observers of their bodies in the context of medical discourse. From the perspective of the adolescent participants, HCPs treated their bodies as parts rather than as a whole. They felt de-personalised and reported that staff were only interested in their kidney disease and so the focus of care was primarily on this body part. While the need for treatment legitimised medical access to the body, the adolescents frequently reported feeling invisible as a consequence of being objectified in medical assessment and treatment. When treated like objects, the adolescents felt objectified. The need for treatment legitimised medical access to the body which contributed to feelings of objectification as seen in Emily (see section 5.2.3) and Jack's stories (see section 8.1.2.). Emily and Jack had to endure people *'poking and prodding'* their bodies, which caused them to feel they were being worked on as a 'patient', in a way that objectified them, rather than treating them as individuals. This also incurred feelings of depersonalisation.

Lack of explanation from HCPs, as well as failure to ensure understanding and consent for medical interventions, also represented a form of objectification. The use of complicated medical/technical terms by HCPs left adolescents feeling confused and they conveyed their desire for HCPs to use plain and simple terminology when communicating with them. Emily's case is a good illustration of this. Emily explained how HCPs used to speak to her in '*English'* when she was younger but speak to her in *'doctorish'* now that she is older (see section 5.2.3). Similarly, Lucy explained her difficulties in understanding kidney disease even when HCPs tried to explain it to her: '*You just don't know what the hell's going on, even when you get an answer*' (see section 6.2.5). Maggie called for HCPs to provide open and honest information and to avoid *'sugar coating'* the realities of treatments (see section 7.2.4). While some adolescents acknowledged the value of a parent acting as an advocate/translator for them in communicating with HCPs, they viewed this interaction less positively when they remained excluded from these conversations. This was clearly the case with Lucy: *They talk straight to my mam instead of me, and then I have to sit there and go: 'Yeah. I'll just jump into this conversation, then, since you haven't asked me anything'* (see section 6.2.1). Correspondingly, Maggie, Jack and Emily also revealed how HCPs spoke to their parents on matters concerning their bodies and treatment. Adolescents frustration with medical interactions is continued in the next, related subtheme, '*tensions between embodied and medical knowledge',* where adolescents revealed that HCPs failed to recognise their bodily knowledge.

10.6.2 Tensions between embodied and medical knowledge

In this sub-theme, the adolescents, rather than their HCPs, presented their bodies as knowing subjects. The adolescents believed they were experts on their condition and that they possessed a knowledge grounded in their awareness and understanding of their bodies that lay outside what was medically known. This embodied knowledge concerned both the experience of normal and abnormal body processes as well as treatment regimens and their efficacy. They were keen observers of their condition and the effects different treatments had on them. The adolescents' narratives included reflections on their body experiences, the self-management of their symptoms and medical interventions. For instance, Lucy protests that she is a knowledgeable agent of her body, stating that '*I know I'd be able to (move) if this bloody catheter wasn't stabbing me*' (see section 6.2.3). In this story, Lucy directly contrasts her knowledge of her body and illness and the knowledge held by healthcare practitioners. Lucy had personally experienced a catheter so she knows about it in a very particular way, referencing the embodied source of her knowledge. This way of knowing provided her with a level of understanding that people who had never experienced a catheter do not have. Correspondingly, Maggie revealed her embodied knowledge of her dialysis (see section 7.2.2). Maggie closely monitored her body during dialysis and interpreted the signals from her own body. Maggie concluded that dialysis, '*made you more healthy, but it didn't make you feel better. It made your blood test levels good, but it didn't make you good. Just too much side effects'*. Maggie had distinctive body knowledge; she knew the bodily effects dialysis was having on her body even before medical personnel became aware of the faulty machine. Other adolescents also positioned themselves as knowledgeable agents in their own health. For example, Jack in his story *'Scars don't bother me'* (see section 8.1.2) demonstrated his embodied knowledge by giving an account of the realities of living with dialysis. The bodily effects of dialysis treatment were so devastating that he knows that he will never return to 'a life on dialysis' again.

The adolescent participants asserted themselves as knowledgeable agents of their bodies and they performed their body knowledge with language. For example, they used medical terminology in their narratives to assert their own knowledge and expertise of their illness and bodily experiences. The adolescents used terms such as *'side effects', 'chronic tiredness', 'foreign object' (Maggie), 'antibodies'(Maggie), 'irregular periods'(Lucy), 'weight fluctuates'*

(Lucy), 'symptoms' (Lucy), 'new organ' (Lucy), 'leaked' (Tara), 'stat' (Tara), and 'normal functioning' (Emily). By using such language, they demonstrated their understanding of medical terminology, acquired through living with this chronic illness. However, despite their evident knowledge, valuable perspectives and lived experience, the adolescents reported that their expertise and opinions, as knowledgeable agents of their illness, were not always acknowledged or appreciated by HCPs. In their stories, the adolescents positioned HCPs as authoritative on medical matters. Statements such as *'they just won't listen to me'* or *'he won't listen'* were interwoven throughout adolescent narratives. From adolescents' perspective HCP's failed to realise that young people had distinctive knowledge in relation to their bodies, privileging medical/technological knowledge instead. Such experiences often left them feeling ignored and frustrated. In Emily's narrative, for example, the fact HCPs did not trust her to adhere to her treatment, caused her to feel hurt and betrayed, especially because she considered the relationship she had with them to be a trusting one; '*I've known him for nine years. I thought we had a level of trust, a good level of trust'* (see section 5.2.1). Emily's call for an annual *'live like me'* day echoes a view shared by other participants; that HCPs need to demonstrate more interest and empathy with regard to the embodied experience of young people living with CKD. They need to respect and incorporate adolescent knowledge and preferences into treatment plans and interventions. In the next sub-theme, adolescents' frustration with HCP's is continued.

10.6.3 Social suffering and desire to communicate beyond the bio-medical plot

This sub-theme illustrates another facet of adolescents' experience of communicating with HCPs. It is related to the fourth theme *'regarding the ill body',* through the adolescents' representation of bio-medical focused communication and interactions. While the adolescent participants appreciated that HCPs needed to focus on the medical care of CKD, they also insisted that they, the adolescents, had other stories to tell about their everyday experiences of living with CKD that extended beyond the medical narrative. Consequently, some adolescents expressed a reluctance to engage in communication with HCPs who were not interested in finding out about other aspects of their illness experience. Participants relayed that their relationship with HCPs was mainly focused on biomedical topics, with limited dialogue regarding the social implications of living with CKD. As a result, the adolescents' perception was that HCPs were not interested in them or their everyday life, but rather solely concerned with the medical and technical aspects of their kidney disease - as evidenced in Maggie's narrative case (see section 7.2.4). Maggie highlighted how the dominant focus of HCP-interactions was 'the medical side' of her illness. Emily expressed similar sentiments in her story '*I know I have an interesting story; but it's not the only story'* (see section 5.2.3). In this story, Emily expressed her frustration toward HCPs who focused all their attention on the medical needs of her physical body, with limited attention to other aspects of her embodied being.

The adolescents expressed a need to discuss the wider aspects of their illness experience with HCPs. More specifically, they wanted to discuss the psychosocial implications of living with CKD. For example, adolescents spoke about the implications CKD had on their social worlds. This phenomenon was identified as '*social suffering*' in the cross case analysis. The participants specifically spoke about - and visually illustrated in their body maps - their desire for social connection with peers, and expressed a fear that they would miss out on social opportunities. In Maggie's narrative case, for instance, she depicted the suffering associated with living with CKD: '*People don't realise that chronic kids are always chronic kids'* (see section 7.2.4). Her illness and treatments prevented her from achieving important developmental milestones such as social skills. Maggie experienced extreme difficulty in communicating with her peers as she '*didn't learn the social skills that everyone else did, because you missed out on making friends and school'.* Her social suffering was further evident in her visual image, where she drew faceless people to represent her experience of isolation (see section 7.2.5). Similarly, Emily revealed her struggles with living with CKD through the messages she drew on her body map: '*My life is less sparkly than others*' (see section 5.0). Emily also worried about losing social skills as a result of being *'miles and miles'* away from peers as she was enmeshed in a 'technical' world. She expressed a need '*be prepared socially'* before she could fit in again. The social implications of illness were also evident in Jack's narrative case (see section 8.1.1-8.2.3). He expressed the concern that HCPs' fixation with illness and treatment regimes were impacting on his social world. There was limited evidence that the adolescents' social suffering was acknowledged or addressed by HCPs, a situation which caused the adolescents further distress; as evidenced by Maggie's comment '*they (doctors) just don't ask that question to bring up that stuff'.*

The adolescents' experiences of communicating with HCPs were interactions focused on the medicalised aspects of their illness. This finding is related to other participant experiences of the medicalised approach to care, as evidenced in the previous subthemes: *'invisibility and exclusion through objectification and medicalised language'* and '*tensions between embodied and medical knowledge.'* Some of the adolescents attempted to challenge the medical dominance and impede the routine exercise of power, through a process of bodily power and endurance. This is presented in the fifth theme '*the strong and resilient body'*.

10.7 Theme 5: The strong and resilient body

The final overarching theme *'the strong and resilient body'* refers to the way adolescents performed their bodies through bodily stamina and an optimistic attitude. This theme offers a counter narrative to the frail and sick adolescent's bodies of earlier themes. Represented under two subthemes (1) '*enduring and surviving CKD' and* (2) *'remaining positive'*, this theme constructs the body as strong and resilient in the context of CKD. A commonality linking these two sub-themes is the positivity displayed by adolescents, which is significant given the importance of the mind/body unity in the concept of embodiment.

10.7.1 Enduring and surviving CKD

This sub-theme exemplifies adolescents' bodily stamina to endure and survive CKD. Military imagery was used to convey pride at having '*survived'* and endured the '*battle*' of CKD. This was most evident in the account of Emily (see section 5.2.2). In her story, Emily likened herself to Harry Potter, who like her had survived a battle. However, the language used by other adolescents also focused on battle words – such as *'criminal'* and *'injustice'* (in the case of Jack) - all suggesting they were locked in an enduring battle to survive their illness. In doing so, they portrayed their bodies and selves as robust and therefore able to endure and survive CKD. Maggie's narrative, particularly her story '*My lungs filled up with water'* (see section 7.2.2), supports this interpretation. In telling this story, Maggie displayed her internal strength and resilience even under the most painful and draining conditions. She described the '*dangerous*' impact dialysis had on her body as it put pressure on her internal organs. Equally, CKD and dialysis caused her '*chronic tiredness'*. Yet, despite facing emotionally and physically fraught experiences, Maggie asserted herself as strong and resilient. She endured CKD with stoicism and composure, evident in her statement: *'Sometimes you'd just get on with it, just carry on as normal. Just carry on as normal.'* Comparably, other adolescents such as

Lucy and Emily demonstrated their strength to endure illness with a stoical attitude as demonstrated in their statements: *'You just can't go over you just can't'(Emily), 'I have to work around it'(Lucy)* and *'You've just got to go with the madness' (Lucy)* (see sections 5.2.1 and 6.2.4/ 6.2.5). In this discourse of enduring, the adolescents engaged in self-mastery in terms of keeping control over their bodies and lives. Jack's story '*I'm stuck*' (see section 8.1.4), supports this interpretation. Jack demanded more medical rationale for his admission stays. He positioned himself as an active and resourceful person who was prepared to make demands and question medical judgments. In Tara's story she engaged in self-care measures such as documenting her daily fluid intake (see section 9.2.3) and developing strategies that enabled her to conceal her incontinence in order to minimise its significance in her life (see section 9.2.4). Similarly, in Lucy's case, she displayed attempts to control the negative aspects of her illness experience. She attempted to regain a sense of control by asserting her knowledge of her body (see section 6.2.3) and tried to minimise the disruption illness was having on her life (see section 6.2.5). For instance, Lucy downplayed the seriousness of renal disease and its treatments to help her through her experience. This can be seen in statements such as, '*So, I might actually die, but don't worry, I probably won't'* and *'It doesn't seem like a serious topic'.* Through positioning themselves as people who needed to be strong in order to live with CKD, the adolescents found empowerment and countered the more negative constructions of adolescent bodies in living with CKD. This is linked to their optimistic attitude that is presented in the sub-theme '*remaining positive'*.

10.7.2 Remaining positive

This sub-theme presents the ways adolescents channelled positive aspects of their illness into their lifeworld. Despite pain and suffering, they found positive elements in their embodied illness experience. Some adolescents talked about positive changes in their sense of self and lives as they integrated their experiences of illness into a larger perspective on life. Lucy, for example, reported that despite having scars and marks on her body, her experiences of living with CKD resulted in her taking a different perspective on life: CKD *'makes you see things differently* '(see section 6.2.5). Furthermore, she narrated the positive aspects of living with CKD, viewing the hospital as a supportive place ('*it's like a community in there')* where she could be herself. A change in perspective was also evident amongst other participants. Emily, for example, chose to position her suffering in a positive light (see section 5.2.1). She posited that although she had to suffer she chose to be '*happy with suffering'.* Similarly, Jack chose not to focus on his scarred body in his story '*Scars don't bother me'* (see section 8.1.2). With positive statements such as *'scars don't bother me'; they don't bother me'* and *'these scars don't bother me you know',* Jack positioned himself as being resilient. A positive attitude was also present in the adolescents' visual stories. In Maggie's body map, for example, she wrote her message to the world *'Laugh or you'll cry'* (see section 7.1). This message was her way of explaining life with CKD. While on one hand this message alluded to the negative emotions, (i.e. crying) associated with living with CKD; it also presented Maggie's chosen way to live; which was to laugh rather than cry about her situation. Equally, Tara in her body map drew an image of a hospital and wrote the word '*love' beside* it, representing the positive aspect of her experience (see section 9.1). This corresponds with Lucy's earlier comments regarding the positive impact of hospital in her life. These examples illustrate how adolescents are able to evaluate and make sense of their illness experiences in a positive sense.

For the adolescents, an important source of strength and resilience stemmed was their ability to draw the support of others and be in the comfort of their own environment. For example, some adolescents felt that being at home amongst their own possessions and belongings helped them to remain positive. Jack, for example, felt comfortable and free to move and engage in his own familiar world which in turn helped him to remain positive (see section 8.1.4). Statements such as '*I like being at home with my own stuff and my own way of going on at the house'* and *'At home I can do what I want'* support this interpretation. Likewise, Tara preferred to be at home playing with her sisters (see section 9.2.1).

10.8 Summary of Cross Case Analysis

The cross case analysis identified five thematic areas, each with a number of sub-themes. The first overarching theme, '*experiencing the ill body',* represented adolescent narrations about disruptive events in their lives and the bodily disruption they experienced. These experiences are illustrated through two sub-themes; (1) '*biographical disruptions'* and (2) '*the out of control body'*. The bodies of adolescent participants were marked and changed by CKD, albeit in different ways. The bodily changes negatively affected the adolescents' perceptions of their bodies and created heightened awareness of their fragile and ill bodies. In the participants' narratives, many examples were given of how their out of control body disrupted social norms of body functioning and appearances. This had the result of moving what had been private bodily experiences into a broader social regulatory gaze. The familiar and taken for granted body was no longer available to them and was replaced with a strange and discomforting body. Adolescents also faced a unique challenge; contending with an ill body that failed to perform and meet the expected biological and development changes of puberty. Enduring pain, exhaustion, and experiencing delays in their pubescent bodies added to feelings of being changed and vulnerable. The adolescents expressed, either directly or indirectly, a strong need to assert control over their illness. However, their out-of-control body dominated their illness experience.

The second theme, '*body invasion',* represented the bodily instruction that adolescents experienced in the context of medical treatments. Two sub-themes (1) '*body invaded by medical treatments'* and (2) '*body invaded by foreign bodies'* presented adolescents' experience of body invasion. The physical effects of CKD and its treatments on the body were experienced as dangerous and destructive. The participants' narratives concerning bodily disruption and body invasion, conveyed a paradoxical sense of self and identity, and a strong and resilient body despite CKD.

Theme three, '*loss of habitual self,*' was characterized by two sub-themes: (1) *the healthy self-versus the ill self'* and (2) *'the altered and changed self'*. CKD and its complex and multiple treatments resulted in serious ruptures in these adolescents' experience of self and identity. The loss of self, as presented in this theme, emerged from their experiences of CKD and its treatments. The adolescents' sense of self was challenged and in some cases altered, so instead of feeling whole they felt profoundly uncomfortable within bodies that were disturbed by treatment and disease. Furthermore, the impact of CKD on their sense of embodied self was demonstrated through a heightened awareness of the changes and lack of changes to their bodies.

The fourth overarching theme, '*regarding the ill body',* presented adolescent experiences of medical interaction in the context of living with CKD. In telling their stories about everyday experiences of living with CKD, a wider narrative of medical hegemony emerged. This was represented in the three sub-themes (1) *invisibility and exclusion through objectification and medicalised language;* (2) *tensions between embodied and medical knowledge* and (3) *social suffering and the desire to communicate beyond the bio-medical plot*. Adolescents highlighted the need for HCPs to acknowledge them as knowledgeable agents in their illness trajectory. However, what their stories revealed more than anything was their struggle to be listened too and considered active agents in their illness trajectories. The adolescents wanted to understand and know more about their illness, but the HCPs held the medical knowledge, which put them in the position of power. HCPs viewed the adolescents' bodies and illnesses through a bio-medical lens. HCPs adopted a clinical medicalised view of adolescents' bodies, which frustrated the adolescents in this study. HCP's focus on the medical aspects of the adolescents' illnesses detracted from other aspects of adolescents embodied experiences.

Finally, the fifth theme, '*the strong and resilient body'*, consisted of two sub-themes (1) '*enduring and surviving CKD'* and (2) '*remaining positive'*. In this theme, the adolescents exhibited internal strength and resilience in dealing with the changes to their bodies and sense of self. Notwithstanding their negative experiences, they presented a positive attitude and spirit of perseverance in order to endure their illness. They attempted to fit illness into a coherent life story, to establish positive meaning and to construct images of themselves as strengthened by their experiences of living with CKD.

The five overarching themes and associated sub-themes, presented in this cross-case analysis chapter are interconnected, as each theme signified the impact that CKD and its treatments had on an adolescent's body. The main narrative tread, running through the five cases, concerns the bodily changes adolescents experienced in living with CKD. These findings will be critically discussed in relation to existing literature and theories in the following chapter.

Chapter 11: Discussion Chapter

11.0 Introduction

In this chapter, I will critically discuss my findings in light of the study's objectives set out in Chapter 4: which were; 1) to explore the experiences and perceptions of adolescents with CKD in relation to the physical functioning and physical sensations of their bodies, 2) to examine the impact of CKD and its prescribed treatments on adolescents' sense of self and embodied identity and 3) to explore adolescents' embodied experience of medical treatment and their relationships with health care professionals in the context of CKD. The findings will be discussed in the context of empirical literature, and the theoretical underpinning of embodiment as previously outlined in Chapter 2.

11.1 Adolescents' experiences of living with chronic kidney disease in relation to the physical functioning and physical sensations of their bodies

The findings of this study provide a nuanced understanding of adolescents' (suffering from CKD) experiences of their bodies, which are in a dysfunctional state as a result of the illness. The adolescent participants acknowledged the debilitating effects CKD and its treatments had on their bodies, which in turn affected their ability to engage in meaningful activities. These experiences will be further discussed under the headings of 1) *body awareness and vigilance*, 2) *biographical disruption* and 3) *liminality.*

11.1.1 Body Awareness and Body Vigilance

Adolescent participants in this study experienced a diverse range of bodily experiences, producing symptoms such as tiredness, thirst, pain, changes in bodily appearance and disruption in body functions. Phrases such as 'paying attention' and 'being sensitive' to bodily changes appeared in the various narratives. For example, Emily described the unbearable experience of thirst. Emily's experience of needing water is interesting in light of Merleau-Ponty's (1962) observation of how senses complement and communicate with each other in an immediate way. In Emily's case, the body knew that something was wrong (i.e. *dry as a sandpit and dying of thirst*) which compelled the young person to seek out what the body needed i.e. water. These bodily experiences changed from day-to-day, and sometimes even within the same day. In line with previous literature, the study found that CKD causes debilitating symptoms (Nicholas *et al.*, 2011; Wells *et al.*, 2012; Tongs *et al.*, 2013), and heightened body awareness (Waters, 2008). However, this study provides additional insights into adolescents' experiences of body vigilance while living with CKD. For the purposes of this study, body awareness is defined as the ability to recognise subtle body cues and sensations. Body vigilance refers to the way in which the adolescents actively monitored their bodies. Through their narratives, the participants mentioned numerous forms of body vigilance. These included sensitivity to changing bodily processes and states, 'monitoring cues' of bodily threats and dangers and a tendency to observe bodily sites for leakage of body fluids. Adolescent participants deemed constant bodily vigilance necessary to ascertain bodily ordeals and deal with them accordingly. For example, Lucy engaged in intense body vigilance in an attempt to become attuned to which bodily organ was demanding her attention; illustrated in the story: '*Which pain am I looking for?'* (see section 6.2.2). Lucy's body demanded attention through bodily discomforts such as pain and cramps and she had to attend to her painful body. Leder's (1990) seminal work, a work that characterises the body through a dual regime of absence–presence, provides one way of viewing the kind of body vigilance engaged in by adolescents in this study. For example, Leder's (1990) explanation of how the body comes out of a state of equilibrium when the body experiences something is wrong (i.e. pain), sheds light on Lucy's experience of bodily suffering. As outlined previously (see Chapter 2) the body is largely absent in day-to-day living, but when a person experiences pain or other forms of 'dys-ease' the mind becomes fully aware of the body (Leder, 1990, p. 84). When bodily symptoms or treatments were absent, the adolescents in this study did not focus on their bodies. Using Leder's (1990) terminology, their bodies disappeared from awareness because a state of equilibrium existed. However, when bodily symptoms such as tiredness, thirst or pain were present, the adolescents, like Lucy, had to attend to bodily states that brought their bodies into focus.

The findings from this study provide a unique contribution to the study of CKD. It illustrates how heightened bodily awareness and body vigilance was central to adolescents' embodied experience of living with CKD. While a number of previous studies on adolescents with CKD have revealed the demanding workload associated with living in a non-functioning body (Waters, 2008; Wells *et al.*, 2012) heightened body awareness and vigilance have not been reported in these studies. While the focus of this current research is on adolescents with CKD, research on adolescents with diabetes have reported similar results, finding cases of self-care vigilance and self-monitoring of bodily processes (King *et al.*, 2017; Eva *et al.*, 2018).

However, some adult studies suggest that heightened awareness and body vigilance of somatic states may be potentially distressing, maladaptive and may lead to undue dwelling on bodily functions and sensations (Mehling *et al.,* 2009; Ginzburg *et al.,* 2014). In contrast, the findings in this current study found that body awareness and body vigilance were central constructs that helped adolescents to make sense of the changes in their bodies. In addition to heightened awareness and body vigilance, this present study also found that a deterioration in the capabilities of the body i.e. alterations to the physical functioning and sensations, impinged on adolescents' ability to engage with daily life. These deteriorations caused recurrent disruptions to the lives of the adolescents studied, something which will be explored in the following section, 'biographical disruption'.

11.1.2 Biographical Disruption

The results of this study indicate that disruptions caused by changes in physical functioning and physical sensations are integral to adolescents' experience of living with CKD. Drawing on seminal work by Bury (1982), the concept of biographical disruption denotes how illness leads to a breakdown of normality and in the structure of people's lives. Based on a study of adults with rheumatoid arthritis, Bury (1982) highlighted the complex and multifaceted ways in which chronic illness can force a person to fundamentally re-think their biography and self-concept. Bury's (1982) findings drew attention to how pain and discomfort could change a person's perception of their body and how chronic illness could disrupt the ordinary flow of life. However, Bury has been criticised for excluding contextual factors such as age, which can impact how disruption is experienced (Llewellyn *et al.,* 2014). For example, the adolescents in this narrative study were born with, or had lived with CKD, from early childhood. Yet, as their stories (Jack and Maggie cited earlier for instance) clearly illustrate, their lives were repeatedly interrupted by dysfunctional bodily states such as tiredness, pain and discomfort or from episodes of acute illness and lengthy treatments sessions (i.e. dialysis). Jack expressed, through his narratives, the various bodily changes and disfigurements caused by CKD, and how they caused him to retreat from the world. He also expressed his dislike of being in hospital, which disrupted his usual routine of being at home and going to school. Maggie narrated her frustrations at having to navigate hospital appointments, interact with health professionals and enact treatments, all of which caused disruptions in her life and affected her wellbeing and functioning. Therefore, in this study, I did not view biographical disruption through the lens of

Bury's (1982) schema of a single disruptive event such as diagnosis, but rather as a pattern of cyclical and recurrent disruption caused by debilitating bodily states and CKD treatments. Recurrent biographical disruption affected the adolescents' sense of freedom and their ability to engage in meaningful activities.

Lifestyles restrictions and loss of freedom was a recurring theme found in previous research on adolescents' experiences of CKD (Abrahao *et al.,* 2010; Ramos *et al.,* 2015 de Souza and de Lione Melo, 2018). These studies mention how the time taken to perform treatments can cause a loss of freedom, as well as how being physically constrained by technologies such as dialysis can be experienced as a loss of liberty. However, the quality of these studies was difficult to assess due to the poor standard of reporting with no indication of interview topic guide, leaving potential for important themes to remain hidden due to limited questioning and this study did not report the cultural or ethnic background of study participants. de Souza and de Lione Melo, (2018) previous research on adolescents' experiences also reveal how a loss of freedom can cause an existential sense of not being 'carefree' which affected the adolescents' sense of being-in-the-world. Similarly, adolescents in this present study saw the pressures of dealing with bodily states and dysfunction, as well as incorporating treatments into their daily schedule, as disruptive. This is supported by previous studies on adolescents' and young adults' experiences of chronic illness, which identified the biographical disruption caused by diabetes (Sanders *et al.,* 2019), cystic fibrosis (Lowton and Gabe, 2003) and cancer (Grinyer *et al.,* 2007). The findings from this study supports and contributes to the limited research available on how adolescents experience biographical disruption in the context of living with CKD. For example, Lewis (2012), in a study of young CKD patients (aged between 16–26 years) suggests that biographical disruption had a far more severe impact on adolescents because of their development stage; adolescence. This current study also suggest that the fluctuating and unpredictable nature of adolescents' bodily experiences caused specific, negative affective states. These affective states included anxiety, fear, anger, and uncertainty, which are associated with the unpredictable and life-threatening trajectory of CKD. For example, Lucy used the metaphors of a black hole and atom to refer to the uncertainty of living with CKD. Similarly, Emily described how she felt like her life was orbiting around hospitals. Consistent with the findings of this study, other research studies have reported the negative emotional consequences of living with CKD (Kilicoglu *et al.,* 2016; Francis *et al.,* 2019). However, in this study, adolescents' illnesses hindered their habitual engagement with the world, which further added to the biographical disruption they reported in their lives.

Drawing on Merleau–Ponty's concept of embodiment, this study advances existing research on how adolescents experience living with CKD. It contributes to our understanding of biographical disruption by highlighting how living with CKD impinges on adolescents' ability to enact an embodied orientation towards the world. Their experiences of biological disruption could be interpreted as a disruption or detachment from their habitual relationship with their bodies and environment. Biographical disruption does not, from an embodiment perspective, result from CKD as such, but from the ways that CKD impinges on adolescents' physical ability to engage with daily life. Specifically, because CKD affects the body's capabilities i.e. the physical functioning and sensations, biographical disruption disrupts the habitual behaviours that govern daily life. From an embodiment perspective, the mind is not posited as something distinct from the body, as the Cartesian position portrays, but rather the body is understood as the seat of subjectivity. From this nondualist standpoint, the body is viewed not as an object but as a mode of 'being-in-the-world' (Merleau-Ponty, 1962). Through CKD and its treatments however, this mode of being is interrupted as the sick body comes to the forefront of awareness and disrupts the adolescent's ability to enact familiar routines and activities. The recurrent biographical disruption cycle identified in this study, and the different responses observed in the five adolescents - as being caught in an ongoing cycle of profound recurrent disruptions - sheds new light on the embodied experiences of adolescents with CKD. A population not previously explored through the lens of embodiment or biographical disruption. These findings also highlight how important it is for us to understand the continuously disruptive effects of CKD. How CKD can continue to have a disruptive effect on adolescents at different points in their illness trajectory, both in terms of its significance and consequences; insights which can inform healthcare provision for this group. Such understandings can enable appropriate support to be offered to adolescents at these times. The notion of biographical disruption illuminates much of the experiences of adolescent participants in this study. However, some other experiences can be further interpreted through the lens of liminality.

11.1.3 Liminality

In the context of adolescent experiences of the physical functioning and physical sensations of their bodies, this study provides rich insights into the diverse and unique experiences of adolescents living with CKD; experiences that were filled with contradictions and challenges.

The findings in this current study suggest that adolescents with CKD are *'stuck'* and live in pervasive in-between states, thus embodying a state of liminality. Liminality is a situation where individuals do not fit into any one space, classification or definition, but exist somewhere in between (Van Gennap, 1960). Turner (2008) described liminality as the state of being 'betwixt and between', a position of being in limbo or 'no-man's land'. In this study, liminality is a useful construct that can help to make sense of the ambiguous and contradictory experiences that the adolescents expressed in their narratives. For example, adolescents narrated liminal states and experiences such as feeling both '*healthy and sick'* and described the state of being 'betwixt and between' '*childhood/adulthood'* - all at the same time. Some adolescent participants in this study reported times when they perceived themselves to be healthy despite being considered medically ill. Similarly, adolescents also reported being chronically sick. For example, Maggie is a juxtaposition between health and illness. Like many participants in this study, she is caught within a polarity: '*I wasn't sick'* and being '*always chronically ill'*. Thus, living with CKD means living with a body that is constantly in a 'state of flux'; inhabiting a liminal state between sickness and health. These adolescent stories of moving in-between contrasting states of health and illness echo similar adult experiences of liminality; a paradoxical experience that does not easily fit within familiar categories of illness experience (Bruce *et al.*, 2014).

Paterson's (2001) theory on the 'Shifting Perspectives Model of Chronic Illness' also sheds light on these stories, particularly the paradoxical experiences of health and illness in CKD. Paterson's (2001) theory describes how people with chronic illness live in a dual world, that of wellness and sickness. According to Paterson, living with chronic illness is not a linear, phased process that follows a predictable trajectory to an anticipated end goal. Instead, the experience of living with chronic illness is an ongoing, continually shifting process, constantly evolving as the ill individual makes sense of his or her experience. The model focuses on changes in perspectives, proposing two opposite outlooks—having illness-in-the-foreground or wellness-in-the-foreground. With wellness-in-the-foreground, the focus of the chronically ill individual is on the self as a person and not as a diseased body. According to Paterson (2001), illness-in-the-foreground involves an ill individual being focused on the illness, and the bodily suffering and loss that comes with the illness. The shift from wellness-in-the-foreground to illness-in-the foreground happens when the person perceives the illness as posing a threat to the self. An example would be an initiation of treatment or advancement of illness symptoms. Furthermore, this model suggests that the experience of living with a chronic illness is a dynamic process that reflects the elements of both wellness and illness. Although the Shifting Perspectives Model of Chronic Illness has not been previously applied to interpret adolescents' experience of CKD, it has been useful in reporting adolescent experiences of cancer (Hinds, 2004). This model, with its movement between illness-in-the-foreground and wellness-in-the-foreground, is particularly relevant to this current study. In this study, adolescents narrated a shift in perspective when experiencing bodily symptoms and other forms of illness intrusiveness such as pain and decreased physical functioning. In addition to illness and wellness, this shifting perspectives model acknowledges parallel and simultaneous contradictions in the chronic illness experience. This is in line with the liminal states that adolescents in this present study experienced.

Liminality has previously been described in adult renal literature (Molzahn *et al.,* 2008; Kerr *et al.,* 2018; Santos *et al.*, 2018). However, it has not been reported in studies of adolescents with CKD. While themes related to burdensome symptoms, dependence, restrictions, normality, and uncertainty have been conveyed in previous studies on childrens experiences of CKD (Waters, 2008; Nicholas *et al.*, 2011) liminality has not been described within the field of adolescent nephrology and, in that sense, provides a unique perspective on the topic. It does however support previous studies that have highlighted liminality as a key theme in the adolescent experience of chronic illness, including cystic fibrosis (Tierney *et al.,* 2013), diabetes (Sanders *et al.*, 2019), and cancer (Marshall *et al.*, 2018). The concept of liminality in these studies proved useful in understanding the uncertainty and ambiguity inherent in living in a body that is chronically ill. It also suggests that the impact of liminality is far more severe for adolescents because of the development phase of life. For example, Marshall *et al.* (2018) described how 17 adolescents with cancer were in a state of liminality, an unsettling period of transition between one social state and another in living with cancer. The findings from the Marshall *et al.*, (2018) study also report the dual liminality that adolescents with cancer experience; the liminality of both adolescence and cancer**.** *A limitation of Marshall et al.'s, (2018) study was that participants were interviewed several years after their diagnosis and subsequent recovery allowing for a retrospective perspective to emerge increasing the risk of possible recall bias*.However, in the context of this current study adolescent perspective emerged and found that adolescents with CKD faced the daunting task of dealing with the liminal state of adolescence while simultaneously experiencing the disrupting biological and developmental changes of puberty.

Being marked out as different during this time, through bodily changes, delayed puberty, restrictions in participation and medical interventions, was one of the experiences this study captured through adolescent narratives. For example, Emily, Jack, Lucy and Maggie all reported feeling different because of the lack of embodied markers of adolescence, such as accelerated growth, development of sexual characteristics, loss of independence and social skills. Although the literature demonstrates that delayed growth and puberty is an expected consequence of CKD (El-Gamasy *et al.,* 2018), previous studies have largely focused on the pathogenesis and the pathophysiology of delayed puberty (Beier *et al.,* 2010; Haffner and Zivicnjak, 2017; El-Gamasy *et al.,* 2018). This present study contributes new insights into adolescent perspectives on being stuck in a liminal state between childhood and adulthood. Adolescent participants had to regress to more childlike and dependent state, while simultaneously having to cope with the dysfunctional state of their pubescent body; a dysfunctional state arising from the loss of normal expected functioning. A return to a childlike state was seen as a backward step, as evidenced in Tara's narrative case. She described how her dysfunctional body required her to wear nappies and pull-ups, signalling a regression to a childlike state and contrary to 'normal' adolescent development. Adolescent participants in this study also narrated the difficulties they experienced in establishing a sense of adulthood in the midst of a dependency reminiscent of childhood states. This is evident in Jack's narrative. Jack repeatedly relied on his mother to come to his aid and defend him. Participants in this current study often told stories that both welcomed and resented parental support; this state of dependency has previously been reported in childhood nephrology literature (Nicholas *et al*., 2011; Tjaden *et al.,* 2011; Clavé *et al.,* 2019). However, caution must be exercised in interpreting the evidence from these studies as participants age range varied widely (from 5 to 18 years) which restricts the application of the study's finding to adolescents in particular. Issues of dependency are likely to be different for adolescents compared to young children.

The findings of this study suggest that participants can become marginalised, inhabiting complex liminal zones outside of society as they fluctuated between hospital and home. Contact with medical professionals and adhering to prescribed medical regimens such as dialysis enframed the young adolescent body in a highly technical and medicalised world. This altered their experience of embodiment, as the adolescents' life-worlds was controlled by medical interventions and a dependency on others. Adolescents in this study felt 'stuck' between a medicalised world and an adolescent world. The findings revealed, in common with other research studies, (Tian *et al.*, 2015; Linder and Seitz, 2017), that when adolescents enter the medical treatment milieu, they feel distanced from their normal social lives and the loss of everyday activities, such as school and interaction with peers, is a major source of concern. For example, Pennafort *et al.*, (2012), in their ethnographic study of the educational-therapeutic care of children and adolescents with CKD, found that being removed from a school routine was seen as a missed opportunity to learn social skills, such as making friends. The requirement for socially and developmentally appropriate school support, scholastic competence and social acceptance has been identified as crucial for adolescent well-being (Tian *et al.,* 2015). However, the adolescent participants of this present study perceived themselves to be deficient in social skills. Additionally, this study found participants feared losing their social skills in an alien and medicalised environment.

Bourdieu’s (1999) concept of social suffering offers another perspective to interpret these findings further. Bourdieu’s (1999) draws attention to the painful pressures of everyday life and how they leave people with an overriding sense of alienation and engrained attitudes of despair. In this current study, adolescents’ experiences of ‘social suffering’ exist in the context of their liminal states, how they are caught between a medicalised world and the habitual world of adolescence. This ‘social suffering’ damages the adolescent’s sense of dignity and worth. This is a novel finding in relation to adolescents undergoing CKD residential inpatient treatment far from home. An NICE (2018) review of the information, education and support available for people receiving treatment for CKD, including adolescents, reported that HCP’s are not always aware of the emotional and social distress associated with CKD illness and treatments. The implications of this for HCPs is that adolescents and families need guidance on how best to navigate the competing demands of two opposing worlds, where social needs are not the primary focus.

This study adds to this body of literature. It elaborates on previous adult research by highlighting adolescents’ experience of liminality in living with CKD during the adolescent period. Recognizing the experience of liminality is important as it foregrounds the central role of bodily experience in illness. This is congruent with the embodiment paradigm (Merleau-Ponty, 1962). Wehrle (2019) notes that embodiment and liminality are closely interrelated concepts in his explanation of liminal cases of bodily experiences, such as having a body and being a body. The body is what allows us to perceive, and it is in this sense the subject of perception, but it is also a perceived object (Wehrle, 2019). Paying attention to the uncertainty and ambiguity inherent in living a liminal life is an important consideration for HCPs working with adolescents with CKD and such considerations may help HCPs to support adolescents who dwell in such in-between states.

11.2 Embodied self and identity in CKD

A central objective of this study was to investigate the impact of CKD and its treatments on adolescents' perception of embodied self and identity. In this study, the concepts of embodied self and identity in CKD are very relevant for understanding the adolescents' narrations. How their illness and treatments affected how they viewed themselves and the disruption in their emerging identities as young people living with CKD. As outlined in Chapter 2, this study adopts a Merleau-Pontian perspective on the concept of embodied self and identity. Specifically, embodied self refers to how one experiences one's sense of self in and through one's body, while embodied identity refers to who we are as a result of our interactions with the world around us (Merleau-Ponty, 1968). Adolescent participants in this study acknowledged the effects CKD and its treatments had on their sense of embodied self and identity. These experiences will be discussed by drawing on the concepts of 1) *hybrid identity*; 2) *transliminal self* and 3) *illness centrality*.

11.2.1 Hybrid Identity

The findings of this present study revealed how CKD and its treatments caused a disruption to adolescents' embodied identities. The adolescent narratives revealed how they struggled to incorporate medical technologies into their embodied identities. They also revealed how they viewed themselves as changed and altered as a consequence of their illness and treatment regimes, as reflected in Tara and Maggie's stories. For instance, adolescents narrated a sense of alienation and unfamiliarity with their sense of self because of medical technologies. Previous research on young people's perspective on living with kidney failure, found that medical technologies, such as dialysis, were viewed as a constant threat to identity construction, as the devices remained a physical and symbolic reminder of 'difference' (Zitzelsbergeret *al.*, 2014; Bailey *et al.*, 2018). The findings from this present study advances findings from these previous studies by identifying the different hybrid identities adolescents experienced in living with CKD and its treatments. A hybrid perspective provides some explanation for adolescent experiences of the changes and disruptions they experienced in their sense of embodied self and identities. The term 'hybrid' is used in this study to convey the mixed identities adolescents experienced as they incorporated medical technologies into their embodied sense of self and identities. The concept of hybridity has been reported in previous childhood studies outside the field of CKD, which have described children's bodies as hybrid entities (i.e. simultaneously technological and natural) because their embodiments are inseparable from artefacts, machines and mechanical devices (Prout, 2000, 2011; Lee and Motzkau, 2011; Ryan, 2011; Oswell, 2013). In this present study, hybridity resulted from the incorporation of mechanical parts, such as a permcath and catheters (Lucy and Tara), artificial organs (Emily, Lucy and Jack) and dialysis machines (Maggie, Emily and Tara) into adolescents' sense of embodied self. These technologies changed the way adolescents perceived themselves and they used terms such as '*disgusting*' (Jack), '*weird'* (Lucy) and *'foreign'* (Maggie) to express it. The findings from this study supports and adds to the limited research on how technologies impact and shape human embodiment in childhood illness (Place 2000; James and Hockey, 2007) and in paediatric renal disease specifically (Zitzelsberger *et al.*, 2014). These previous studies revealed how children's bodies become particular forms of human-technological hybrids through attachment to monitors, pumps, probes and machines, all of which can profoundly affect how children experience their bodies. In an ethnographic study of a paediatric dialysis unit, Zitzelsberger *et al.*, (2014) found that children and adolescents aged between 7-17 years were enframed by technology, which ultimately affected the nature of their embodiment. Zitzelsberger *et al.*, (2014) used the term 'conjoinment' to signify the coupling of children and adolescent bodies with a haemodialysis machine. However, Zitzelsberger *et al.'s*, (2014) findings provided limited understanding about hybrid or embodied identities beyond the dialysis unit. However, hybrid identity has not been previously used to interpret the impact of technologies on adolescent embodied identities in childhood CKD. Previous research on adults' experience of haemodialysis have documented the hybrid identities that renal sufferers experienced as they attempted to incorporate medical technologies such as dialysis machines into their identity and sense of self (Giles, 2003; Kierans, 2005; Shaw, 2015). Therefore, this study offers a unique hybrid perspective on embodied identities in the field of childhood nephrology studies.

Another theoretical perspective that might further explain hybrid identities as reported in this present study is the concept of a cyborg. The term 'cyborg', derived from 'cybernetic organism', describes a hybrid of biological and technological components (Haraway, 1990). It is a complex and controversial topic as it draws into question what precisely it means to be ‘human’. When the body and the mind have been technologically enhanced to such a degree that the person can no longer be identified as natural and organic (Haraway, 1990), is that person still human? Haraway (1990) argued that when constructed as part-human/part-machine, a person’s sense of identity becomes blurred. This ‘cyborg’ concept is relevant when it comes to interpreting how adolescents in this current study experienced an alteration in their sense of embodied selves. Although adolescents did not use the term cyborg, it is implied in the way they described how the technologies affected their embodied identity and sense of self. For example, Tara battled with the idea that her identity was clouded and constrained by her cyborg body. She narrated how she became trapped and invisible when she was attached to a dialysis machine. Heidegger (2008) contends that assimilation of the medical technology into the embodied self and identity depends on how the technology is conceptualised. For example, if the patients receiving dialysis experience the distinction between their sense of self, body and the machine as minimal, then dialysis is seen as relatively manageable, and the dialysis machine becomes what Heidegger (2008) calls a ready-to-hand tool. However, if the machine cannot be connected perceptually to the patient’s body, or if it breaks down then the patient is more likely to see the machine as a ‘thing’ or present-at-hand object. If this occurs, the dialysis machine is experienced as alienating and estranging, leading to objectification and disembodiment, as experienced by some adolescents in this study (Tara and Maggie). Facilitating the integration of medical technology into their sense of embodied self and identity was a specific issue for the adolescents in this study. Drawing on the concept of cyborg to interpret these findings offered one potential way of explaining the impact of hybrid identities on adolescents’ perceptions of themselves. However, given the limited research on cyborg and hybrid identities in adolescents with CKD, further research needs to investigate these issues further.

11.2.2 Transliminal Self

This study provides rich insights into adolescents’ experience of the embodied self-following transplant. Adolescent participants described the tension they experienced in their sense of embodied self as a consequence of transplant. They narrated how their bodies were no longer their own and expressed difficulty in incorporating a body part that once belonged to another person. For example, one adolescent participant conceptualised her newly transplanted kidney as '*a dead person's kidney*' (Lucy). Another participant described the experience of receiving a donor kidney as '*disgusting'* (Jack). Adolescents grappled with incorporating the transplanted organ into their sense of self and a state of limbo was experienced. The concept of 'transliminal self', as described by Kerr *et al.*, (2018) offers a useful lens through which to understand the experience of the self as narrated by some adolescent participants in this study. Kerr *et al.*, (2018) used the term 'transliminal self' to explain the various liminal states that young-adult kidney transplant recipients experience. For example, Kerr *et al.*, (2018) suggests that transplantation can hijack a person's body and result in a complex relationship between self and other. The ambiguous state of the transliminal self can render the patients' experiences, and thus their needs, invisible to health professionals (Kerr *et al.,* 2018). This corresponds to the findings of this present study which found that adolescent participants expressed difficulty in incorporating a body part that once belonged to another person. For example, Maggie grappled to adjust to her donor kidney and referred to it as a foreign object in her body. She suggested, in her narrative, that her body rejected the donor kidney because her body did not accept the organ as part of her.

The transliminal self has not been reported in adolescent studies of CKD. Previous studies on adolescent experiences of kidney transplant demonstrate that transplantation enhances young people's quality of life and increases adolescents' self-esteem (Tong *et al.,* 2011; Thys *et al.,* 2015; Kim and Choi, 2016; Bailey *et al.,* 2018; Walker *et al.,* 2019). However, the transliminal self has not been described. The findings of this present study therefore provides a unique perspective on the topic. The findings of this study do however support previous studies from wider literature on adolescents' experiences of organ transplant. Many of which have highlighted the difficulties adolescents experience in their sense of self following transplant (Anderson *et al.,* 2017; Anthony *et al.,* 2019). For example, in a qualitative study of adolescent experiences of lung transplant, Anderson *et al.,* (2017) found that participants struggled with the experience of 'self' following transplant, as it required adolescents to adjust to and communicate a new identity. Similar findings have been reported more recently in Anthony *et al*., (2019) study of adolescents' experience of heart transplant, which found that adolescents had psychological concerns when it came to accepting foreign hearts as their own. The adolescent participants in the aforementioned study described how the transplantation process was more than the exchange of a faulty heart for a more competent one; rather it required an integration of "other" and "self" and a reconceptualization of self. Congruent with these previous studies, adolescents in this present one struggled with their new corporeal relationship. Jack's narrative, for example, is representative of the struggles adolescents experienced in this present study. He was concerned about developing personality characteristics of the donor and was repulsed by the thought of having someone else's kidney residing in him.

The findings of this present study also resonate with evidence reporting adult experiences of intrusion and an altered sense of embodied self-identity. For example, in *The Intruder*, Jean-Luc Nancy (2000; 2010) provided a philosophical reflection of his own experience of transplant in which he was confronted with the reality of living in a body that he perceived as foreign due to the presence of a donor heart. Nancy's (2000; 2010) seminal writings about his personal experience of being an organ recipient, revealed that implanting a stranger's organ into a body unleashed a whole series of subsequent intrusions. He described the foreign organ as an intruder, an alien and uncanny object that created an awkward sense of emptiness in the intimacy of the body (Nancy 2000; 2010). His corporeal integrity and identity was altered as he felt like a stranger in his own body. Nancy's (2000; 2010) writings on the corporeal upheaval that he experienced following organ transplantation is supported by other research conducted on adult experiences of organ transplantation (Hadow, 2005; Kierans 2005; De Pasquale *et al.*, 2014; Spiers *et al.*, 2016; Ó Lonargáina *et al.*, 2017). For example, research with adult participants has highlighted the way in which the body and self is experienced differently following transplant. Adults report feeling that they 'are no longer themselves' after transplantation, since they have someone else's organ in their bodies (Waldby, 2002; Hadow, 2005; Blackman, 2010; Shildrick, 2012; De Pasquale *et al.*, 2014, Mauthner, *et al.*, 2015). These experiences often fall outside the scope of biomedical focus, which rarely extends beyond the medical intervention itself (Richards, 2012). This present study offers a valuable contribution to this body of evidence reporting adolescent struggles in adjusting to the presence of a foreign organ and by suggesting that adolescents experienced a transliminal self following transplant. Although it must be noted that adolescent experiences of a transliminal self may differ to adults' experience, given that adolescents are at a different developmental stage of life, one where identity formation is ongoing. This finding has implications for future research.

The theoretical underpinning of embodiment, as postulated by Merleau-Ponty (1962), may shed some light on the adolescent participants' experience of embodied self following transplant. Merleau-Ponty (1962) uses the term intercorporeality to explain the relation between one's own body and that of the 'other'. In the context of this study, 'other' refers to the organ donor. In transplantation, the body of the recipient mixes with organs from the donor which modifies and changes the flesh and inevitably transforms the self (Shimazono, 2013). From Merleau-Ponty's viewpoint, incorporating a transplanted organ should not be seen as unusual, but rather a predictable experience as the person comes to terms with intercorporeality (Merleau-Ponty, 1962). This viewpoint in some way offers an explanation to the internal struggles, reported by adolescents in this present study, in adjusting to a body and self that once belonged to another human being. For example, Lucy struggled to view the transplanted kidney as her own. She concluded that the donor kidney was not technically hers as it belonged to someone else. This is an important finding as previous research suggests that failure to reconcile transplantation and self is associated with poor medical adherence, depression, lower self-esteem and social isolation (Kaufman *et al.,* 2010; Anderson *et al.,* 2017). This has implications for HCPs to understand that, from an embodiment perspective, incorporating a kidney into one's embodied self and identity is a matter of both mind and body.

Findings from this present study also revealed that adolescents navigated different individualised ways to cope with the transliminal self. Jack, for example, tried to distance himself from the strange organ and engaged in denial mechanisms. Other adolescents, like Emily, tried to personify her newly transplanted organ by creating a separate identity in the form of '*Ciara Kidney'*. This finding is consistent with organ transplant research that reports that adults engage in different defence mechanisms such as depersonalization and repression in order to cope with their transplanted organ (Goetzmann *et al.,* 2006; Pisanti *et al.,* 2017; Carswell and Noble 2018). For example, denial helps the person avoid feelings that may be unbearable for them at the time. However, these distracting activities and thoughts can hinder the post-transplant regimen (Pisanti *et al.,* 2017). Other studies have indicated that organ recipients may personalise their transplanted organs and therefore bolster their self-image as owners of a newly assembled body (Sharp, 1995; Shildrick, 2012; Shimazono, 2013). The findings from this study are critical to educate HCPs on the complex experience of self that may occur post-transplant for adolescents. If HCPs are to fully support adolescents post-transplant, they need to encourage adolescents to express their anxieties and concerns about the realities of receiving a foreign body organ. New supportive interventions, both pre and post-transplant, are required in order to prepare and counsel adolescents through the challenges they may face in incorporating a new body part into their sense of embodied self and identity.

11.2.3 Illness Centrality

In this present study, CKD played a prominent role in the embodied identities of adolescents. The findings of this study revealed that adolescents varied in the extent to which they incorporated CKD into their sense of embodied self. For instance, some adolescents came to define themselves in terms of their kidney disease, while other adolescent participants tried to separate the illness from the rest of their lives. This finding correlates with previous research on chronic illness in adolescents (Compas *et al.,* 2013; Wicks *et al.,* 2019; Zheng *et al.*, 2019). The concept of illness centrality offers another viewpoint through which to interpret adolescents' experiences of CKD and its impact on their sense of embodied self and identity. Illness centrality is a concept that refers to the way people perceive and think about their disease (Benyamini, 2012). Illness centrality also pertains to the way people define themselves in terms of their illness and the degree to which the illness becomes integrated into one's sense of self (Charmaz, 1995). The impact of illness centrality on health outcomes depends on the individual's attitude toward the illness, that is, whether the individual perceives the illness in positive or in negative terms (Wiebe *et al*., 2002). Previous research has examined the centrality of illness in adolescents in conditions such as diabetes (Helgeson and Novak, 2007; Oris *et al.,* 2016), cystic fibrosis (Horky *et al.,* 2017) and young people with cancer (Haidet, Kroll and Sharf, 2006). These previous studies of chronic illness suggest that the more central the illness is to an adolescent's identity, the more detrimental the illness is to the adolescent's well-being and psychosocial adjustment to illness. In line with these previous studies, the present study suggests that CKD negatively affected some adolescent participants' view of themselves, as evidenced by the narratives of Maggie and Jack. These adolescent participants, for example, narrated how much of their current embodied identity was centred on their CKD experience. However, this study builds on previous work by highlighting the different ways adolescents with CKD managed negatively viewed aspects of the self. In some of the narratives, for example, adolescents likened themselves to strong and powerful characters, which allowed them to deal with the changes in their sense of self and identity. In the face of adversity, they displayed their preferred identity, which perhaps helped them to accept their situation positively and make a positive adaptation through actions focusing on their strengths.

In this present study, adolescents also drew on fictional and metaphorical creatures to describe themselves and their illness, and to express their experiences in ways that were meaningful to them. This process offered the adolescents studied a way to address the illness centrality in their lives. Clarke (2016) suggests that adolescents reframe meaning through the use of narratives, metaphors, and fictional characters, which helps them revisit and reframe the troubles they encounter in illness and treatment, thereby contributing to resilience. This is also evidenced by the findings in the present study. In the process of identity exploration, adolescents in the present study drew on discourses of modern literature to develop identifications with others. This study found that by identifying and working through fictional characters and metaphorical creatures (such as *alien* and *vampire*) adolescents portrayed themselves as strong and resilient characters, which helped them make sense of their evolving and changing embodied identity in the midst of living with CKD. Emily, for example, began to notice similarities between her own experiences and the experiences of Harry Potter, which became a useful lens through which to view her own struggles in living with CKD. This finding is congruent with previous research from broader literature which has found that using fictional characters and literature can help adolescents cope with bereavement (Merkell and Merkell, 2008), mental health issues (Noctor, 2006) and help develop resilience in the cases of illness (Clarke, 2016). These studies suggest that adolescents can create connections between the characters in books with events and people in their own lives. The information and understanding engendered by this interaction may then be used to cope more effectively with difficult situations or emotions (Noctor, 2006; Clarke, 2016). Consistent with this literature, the findings from this present study indicate how some adolescents seem to benefit when they draw on a literary text and fictional characters in order to process their experiences and to reduce the impact of CKD in their lives. This thesis offers a unique contribution to evidence in the field of nephrology, with adolescents drawing on childhood fantasy literature to make sense of their illness experience. Thus, these findings have implications for the way in which HCPs approach and communicate with adolescents regarding their illness experience.

This present study also found that some adolescents could distance themselves from their CKD while also accepting it. Illness acceptance is closely linked to the concept of illness centrality. Previous research has highlighted how adolescents who are able to accept and adapt to their illness reap a number of positive benefits, including improved self-esteem, improved quality of life, resilience, stronger identity, and better disease control (Casier *et al.*, 2013; Lee *et al.*, 2016; Zheng *et al.*, 2019). Adolescents in this present study acknowledged CKD as an important part of who they are, but CKD was not always the adolescent's primary focus. Adolescent participants did focus conversations on non-CKD-related adolescent activities, such as school, friends, family events, activities and hobbies. Most adolescents stated or demonstrated that in some way they had adapted to CKD in a way that allowed them to accept it. Acceptance and adaptation were apparent in participants' maturity, evidenced through their ability to make meaning of their illness. For example, some adolescents talked about positive changes in their sense of self as they integrated their experiences of illness into larger perspective on life. Lucy, for instance, reported that despite having scars and marks on her body, her experiences of living with CKD resulted in a changed perspective on life. She explained how her illness helped her to view the world differently. This finding mirrors findings from similar research, that acknowledge the positive sense of self that can transpire in adolescents with chronic illnesses (James and Carney, 2014; Horky *et al.,* 2017; Wicks *et al.,* 2019). These previous studies support Charmaz's (1991) contention that people tend to ignore and minimise their struggles in order to adjust and find meaning in chronic illnesses. Similarly, in this current study, adolescent participants frequently downplayed the serious nature of their condition and portrayed themselves in a more positive light. For example, Emily used humour when discussing the physical discomfort of thirst and suggested that she was happy with her suffering. Likewise, Lucy used humour to downplay the reality of her own mortality when narrating the risks associated with her impending transplant surgery. The narratives of these adolescents were consistent with Arthur Franks' (1995) 'quest narrative', where a person gives meaning to illness and there is value in finding ways to adapt to chronic illness. The successful integration of CKD into the adolescents' sense of embodied self and identity should therefore be acknowledged as an important developmental task, and one which healthcare providers should support in adolescents living with CKD.

11.3 Adolescents' embodied experience of medical treatment and relationships with health care professionals in the context of CKD

The final and third objective of this study was to explore adolescents' experiences of medical treatment and their relationships with health care professionals. The non-dualistic concept of embodiment refers to the bodily process of absorbing and interacting with others in the world. Merleau-Ponty (1962) reports the benefits of connecting with other people and states it is through dialoguing and interacting with others that people access the world. However, medical interventions and interacting with medical professionals can threaten the mind-body unity and dehumanise existence (Kierans, 2005). In this present study, adolescents portrayed their relationships with HCPs as challenging, as a result of HCP's depersonalised approach to care, and an over emphasis on medical issues. Adolescents' experiences will be discussed under the following two headings; 1) *objectification and depersonalisation in medical encounters* and 2) *asserting body knowledge in medical encounters.*

11.3.1 Objectification and depersonalisation in medical encounters

Adolescent participants in this study reported feeling objectified, depersonalised and in some cases dehumanised as a result of their interactions with healthcare staff. Feelings of objectification were incurred when adolescents were not treated as social persons but rather, as objects. For example, Emily and Jack both felt as though they were being *'prodded'* and *'poked'* in medical encounters. In such instances, adolescents experienced their bodies as an object and some adolescents reported feeling no longer in control of their bodies. Previous systematic reviews have identified feelings of powerlessness and loss of control as key themes in children's experiences of dialysis and transplant (Tjaden *et al.*, 2011; Tong *et al.*, 2013). These systematic reviews and synthesis were rigorous. While the number of included studies was small, highlighting children and adolescents as an under-researched groups, the number of participants included was large and multinational. The emergent themes were represented across the included studies, supporting the validity of the findings. In these previous reviews, children and adolescents expressed a sense of helplessness and perceived themselves to be manipulated and controlled by medical interventions and HCPs. Similarly, the findings from this present study also revealed a loss of control and autonomy in medical encounters. However, this study extends previous research by highlighting adolescents' experiences of objectification that impacted negatively on their relationship with medical staff. In their narratives, adolescents portrayed HCPs as having a greater locus of power and authority over their bodies than the adolescents themselves.

Foucault's (1963) notion of disciplinary power, offers one lens that could explain some findings in the adolescent narratives. Institutional discourses and practices within the medical system provide particular conditions for experiencing and constructing the body in the context of illness (Foucault, 1963). In medical encounters, patients are subjected to a mechanism of objectification and thereby to the exercise of power. Foucault's (1963) concept of 'disciplinary power' suggests that the medical system of surveillance and assessment, disciplines the bodies of patients to conform to medical treatments and to behave in expected ways. Applying this perspective to this current study, adolescents were expected to hand their bodies over to others to work on them and to do so willingly, which was a source of great frustration for participants. Furthermore, as has been reported in previous critiques of medicalization (Busfield, 2017; Correia, 2017; Kaczmarek, 2019), in the present study medical discourse and practices were seen by adolescent participants as a way of delimiting the agency they had over their bodies in the context of illness, by constructing 'the patient' passively in relation to discourses of illness and treatment.

In medical discourses, adolescent participants in this present study reported feeling ignored and invisible because of HCPs' focus on medical technology and initiating clinical treatments without adequate explanation or involving them, the patients, in the process. Dialysis was one example of this, as evidenced in Tara's narrative case. Her account exemplifies how the dialysis machine rendered her invisible to HCPs. The dehumanizing and alienating effect of technology on interpersonal relations between HCPs and patients has been well-documented in both adolescent and adult studies, a finding that resonates with this present study (Kierans, 2005; Zitzelsberger *et al.*, 2014). Some research has observed the potentially dehumanising effects of medical technology, both in HCP accounts of technology interfering with their ability to connect with or relate to patients (Kongsawan and Locsin, 2011) and in patient accounts of technology rendering them invisible to HCPs (Archibald and Barnard, 2018). Other research has warned that technology brings the risk of increasing the distance between the patient and the HCP (Seely and Mount, 1999) or leading to the objectification and depersonalization of those it is intended to benefit (MacLachlan, 2010). In their ethnographic study of a paediatric haemodialysis unit, Zitzelsberger *et al.*, (2014) discuss their notion of "technological time" (p. 35) that refers to how children and young people experience their bodies while on dialysis. Adolescents in Zitzelsberger *et al.*,' s (2014) study report that HCPs in the unit engage in human–technological relations, meaning that many of the staff, especially the nurses, focus their attention and time on the machines, as they interact with 'it' rather than interacting with the children/young people. Attending to the ways in which the needs of the machine often overtake the needs and comfort of persons is crucial in healthcare settings (Zitzelsberger *et al.*, 2014). CKD care has historically been delivered using a biomedical framework, which privileges disease-specific treatment. This model has been criticised for failing to account for the complexity of living with a chronic disease and the need for a patient-centred approach to care (Ronco *et al.*, 2014). This finding has important implications, as feelings of objectification have the potential to impact on adolescents' engagement with HCPs and patients' response to treatment. It highlights the need for a model of care that avoids objectifying adolescents in clinical and medical encounters.

Lack of explanation and failure to ensure understanding of information also represents a form of objectification. Within the findings of this current study, it became apparent that adolescents were not always satisfied with the information they were provided with by HCPs, which left them powerless in the healthcare relationship. Not only did adolescents clearly articulate the need for more information, they also emphasised the importance of receiving timely and trustworthy information. Maggie, for example, expressed a need for HCPs not to '*kind of sugar coat'* the realities of living with CKD. This is consistent with previous research demonstrating that adolescents with chronic illnesses want more open and honest healthcare information (Young *et al.,* 2003; Woodland, 2013; Kim and White, 2018) in order to navigate treatments and life changes in living with CKD (Hannigan and Turner, 2011; Woodland, 2013; Tong *et al.,* 2015). Adolescents in this current study also expressed a need for more information on aspects important to them, such as psychosocial issues. Previous research suggests that psychosocial distress among adolescents requires acknowledgement and support from HCPs through sensitive assessment and communication (Kim and White, 2018). However, the findings from this study illustrate a lack of engagement by HCPs in this important area. Adolescent participants in this present study did not perceive HCPs as interested in their embodied psychosocial needs; HCPs focused predominately on medicalised care with little attention given to other aspects of their lives with CKD. By focusing solely on the medical and technical aspects of treatment, HCPs neglected the illness experience from the adolescent perspective. The implication of this, as highlighted in this study, is that adolescents' views, concerns and worries regarding their psychosocial needs remain largely unexplored. Other research concerning chronically ill adolescents also found that young people want less medically-focused conversations with HCPs, with more time allotted to topics other than their illness (Konstantynowicz *et al.,* 2016). Health professionals must be prepared to explore and address embodied experiences and the specific needs of adolescents if they are to provide an adolescent-responsive health system, as recommended by the WHO (2015).

Adolescent participants in this present study felt excluded from medical encounters when HCPs used incomprehensible medicalised language. This finding mirrors previous studies investigating communication challenges with adolescent populations in healthcare (Marshall *et al.,* 2011; LeBlanca *et al.,* 2014; Konstantynouicz *et al.,* 2016). These aforementioned studies have reported that the use of technical and medicalised language can lead to ineffective communication and can be exclusionary, hindering adolescents' ability and willingness to engage in medical encounters. Similarly, in this present study adolescent participants reported feeling confused, angry and alienated, which ultimately undermined their willingness to participate in their own treatment decisions and care (Street *et al.,* 2009; Clayman *et al.,* 2010); findings common to other studies (Castro *et al.,* 2007; Marshall *et al.,* 2011). Previous research has offered explanations for the use of technically complex information and medical jargon by HCPs. For example, LeBlanca *et al.,* (2014) suggest that HCPs become so familiar with the everyday, routine use of their medical discourse that they 'forget' that technical language is unfamiliar to laypeople. Other research suggests that HCPs find it difficult to translate complicated information (Roter, 2011); some research concludes that HCPs do not amend/explain jargon even when they know that their communication is unclear (Bourquin *et al.*, 2015). Another explanation offered for the excessive use of medical jargon is an attempt to reduce medical anxiety among HCPs; a defence mechanism referred to as intellectualization (Bernard *et al.*, 2010). However, the adolescent participants of this present study did not offer any possible explanations for HCPs use of medicalised language, highlighting the need for further research to determine HCPs' perspective on their use of medicalised language in clinical encounters. One implication of HCPs use of medicalised language in this current study was that it served to alienate adolescents from engaging in medical encounters as it necessitated parental engagement to translate medical information.

Some adolescents in this study reported that they did not understand the dialogue in medical encounters, as evidenced by Emily's displeasure when HCPs spoke in *'doctorish'*. In such situations, Emily did not understand what HCPs were saying and relied on her parents to provide understandable explanations. This lends support to previous studies that report that children and adolescents rely on their parents to act as translators. (Lambert *et al.* 2011; Hariharan *et al.,* 2014). Conversely, adolescents in this present study also felt excluded from medical encounters when HCPs directed conversations towards their parent(s). Some adolescents commented on HCPs talking over them or about them while not addressing them directly. In such instances, the adolescents felt excluded and invisible. This finding correlates with Merleau-Ponty's (1962, p. 413) view that people make sense of their bodily experiences through language and engagement with others as he states '*[M]y thought and his are inter-woven into a single fabric, my words and those of my inter-locutor are called forth by the state of the discussion, and they are inserted into a shared operation of which neither of us is the* *creator'*. However, the common ground of shared interaction between individuals described above becomes somehow skewed for adolescents in this present study as they are excluded from dialoguing and interacting with HCP's. This marginalised position was obvious in a number of instances, mainly when adolescents were not allocated a turn to speak. For example, Lucy recalled listening to the nurse asking her mother what particular way she liked to have her permcath dressing changed. In such instances, Lucy was a passive bystander. Such strategies prevented adolescents in this present study from actively participating in the medical encounters. These findings concur with previous studies investigating medical interactions, which found that HCPs dominate conversations and primarily communicate with parents, with adolescents having limited conversational contribution (Coyne and Gallagher, 2011; Livesley and Long, 2013; Rawdon *et al.,* 2019). The consequence of this, for adolescents, was that it not only inhibited their inclusion in the medical encounters but also enabled both HCPs and parents to retain power and control in medical encounters. As a result, adolescents were less empowered and their bodily concerns and bodily experiences remained unheard.

Adolescents in this present study desired respectful interactions and collaboration with HCPs. They expressed a desire for HCPs to display more empathy and insight; as evidenced by one adolescent suggestion for HCPs to '*live like me'* (*Emily*). These findings corroborate with previous studies investigating chronically ill adolescents' preferences for health care providers' attributes, which found that treating adolescents appropriately and establishing rapport and trust were essential (van Staa, 2011; de la Pena *et al.*, 2012; Moreau and Eady, 2017). Kim and White (2018) noted comparable topics in their systematic review of interpersonal interactions with young people in health care settings. Their review found that adolescents want health professionals to treat them as persons, spend time getting to know them beyond their diseases, and be honest and empathic when interacting with them; findings similar to this current study. Based on the stories narrated by adolescents in this study, it was evident a lack of empathic characteristics from HCPs led to strong feelings of anger, hurt and betrayal among some adolescents (for example Maggie, Emily and Jack). The lack of these empathetic qualities from HCPs affected the way the adolescents in this present study engaged in their interactions with health care providers. For example, Emily described the lack of trust in her relationship with her doctor, which affected their relationship, despite the fact they knew each other for nine years. In the context of embodiment, trust in others is important as it can directly affect a person's perception of their world (Bredlau, 2019). The implication of this finding is that HCPs' need to develop strategies for improving therapeutic, interpersonal relationships with adolescents living with CKD.

11.3.2 Asserting body knowledge in medical encounters

Based on the finding of this current study, one strategy adopted by adolescents in an attempt to bring themselves, and their agenda, to the forefront of medical encounters was to assert their embodied knowledge. The findings of this study suggest that adolescents developed embodied knowledge from living with CKD. Embodied knowledge, which is people`s bodily sense of how to live in their own bodies, is regarded as an untapped resource with the potential to strengthen peoples` health (Tanka, 2011). In this present study, adolescent participants expressed a strong belief in the legitimacy of their own embodied knowledge. For example, Lucy proclaims *'I know what I'm doing here. I know. I tend to be quite good at explaining what a symptom feels like and that kind of thing, and if I just say, 'It's just not working for me' then that's all I'm saying'.* This quotation exemplifies how participants consciously chose to acknowledge their bodies and to listen to their bodies' signs and reactions. Through their experiences of encountering and managing CKD they asserted their knowledge and expertise grounded in their awareness and understanding of their bodies. This finding corroborates and builds upon a previous ethnographic study investigating children and adolescents' experience of haemodialysis (Waters, 2008). This study revealed that children and adolescents had knowledge and insight about illness and suggested that the body was a medium for understanding illness (Waters, 2008). Largely, this finding emerged as an incidental finding and in reporting this finding Waters provided no indication about what type of bodily knowledge the participants had. This current study provides additional insight into how young people perceive their bodily knowledge to be undervalued and unrecognised in dialogue with health professionals. There was little appreciation of adolescents' own theories or understandings of their bodily symptoms and experiences; a finding that is similar to previous research on adult experiences of embodied knowledge in chronic illness (Thorne *et al.,* 2000; Wilde, 2003; Kierans, 2005).

Merleau-Ponty`s (1962) theoretical position provides some explanation for the embodied knowledge reported by adolescents in this current study. As previously outlined in Chapter 2, Merleau-Ponty`s (1962) perspective on embodiment emphasises the body as central to human experience, and it recognises the importance of body knowledge and ways of knowing. In this view, the body rather than the mind is the primary site of knowing about the world (Cox, 2018). Embodied knowledge is what a person's body does and knows without conscious thought; it is the knowledge that is imprinted in the body (Tanka, 2011). In applying this to the current study, it is interesting to examine how the adolescents drew on examples of how they interpreted bodily symptoms and ways of knowing. In their stories, adolescents could feel and know what was happening in their bodies without being able to state the principles that underlie them; equally, adolescents could state what their body needed without being able to know exactly why. Lucy, for example, explains how she does not consciously know what she needs but gets ‘feelings’ or ‘pointers’ from her body. Similarly, Emily in her narrative case gives her body a voice and explains how her body communicates to her telling her it is time for her to get a kidney so that she can start to grow. These examples demonstrate how the body held information without conscious thought. It is vital that HCPs acquire an understanding of the subtle sensory information and bodily knowledge that adolescents develop in living in a body that is chronically ill. In identifying corporeal knowledge as an important source of information, HCPs can help adolescents to utilise this knowledge in order to manage their own chronic condition.

Heggdal (2013) emphasises the importance of the body in promoting health in chronic illness and offers a theoretical framework of Bodyknowledging that provides a useful lens to interpret findings of this present study. Bodyknowledging is defined as ‘a fundamental process for the development of personal knowledge about one's own body, coping skills, health and wellbeing' (Heggdal, 2013, pg. 65). The Bodyknowledging model illuminates how the patient’s bodily knowledge develops through a dynamic and non-linear process of learning and health-related change in interaction with the environment (Heggdal, 2013). The theory asserts that people have bodily knowledge that constitutes an important resource for handling the uncertainty and lack of bodily control in chronic illness. Bodyknowledging model is consistent with Merleau-Ponty’s (1962) understanding of the body, in which the body is understood as an object and subject at the same time and as a primary source of meaning and knowledge (Heggdal, 2015). Bodyknowledging model chimes with how adolescent participants in this study described the embodied knowledge they developed in living with CKD. From this model, Heggdal (2013) developed the Bodyknowledging programme, which is an intervention that utilizes the bodily knowledge of patients with chronic illness in order to promote coping and health. Previous adult studies investigating the benefit of Bodyknowledging intervention programme have reported benefits such as increased patient awareness of their bodily knowledge of health and illness (Engevold and Heggdal, 2016; Heggdal *et al.*, 2018). Engaging in a Bodyknowledging intervention program may provide additional support to adolescents with CKD. This intervention programme could teach adolescents how to recognise and use the dialogue between body and mind as a resource for understanding bodily changes and altered bodily processes in living with CKD.

11.4 Conclusion

This discussion chapter critically discussed the findings of this present study in line with the study's objectives. The first objective of this study discussed adolescents' experiences of living with CKD in relation to the physical functioning and physical sensations of their bodies Adolescents actively engaged in '*body awareness and vigilance'* to detect changes in body functioning and sensations. This ability to notice subtle bodily sensations and monitor for internal bodily changes was an integral and embodied part of living with CKD. Adolescents exhibited a wide range of bodily experiences, some of which were manifested as '*biographical disruption'*. Adolescents described an ongoing process of living with recurrent disruptive bodily events, for example tiredness, pain and embodied changes such as disfigurement. These bodily experiences interfered with their ability to engage in everyday life. The concept of '*liminality'* was also significant to the experiences of adolescents living with CKD; experiences that appeared to be characterised by numerous transitions and thresholds of uncertainty. Adolescents expressed being within an in-between state of health and illness, which in many ways prolonged the liminal phase they were already experiencing as an adolescent. The findings also depicted adolescence as a fragile stage, which was easily disrupted by CKD.

In addressing the second objective of this study, a critical discussion of the findings revealed the ambiguous state of adolescents' embodied self and identity, which continuously changed, evolved and regressed throughout their illness trajectory. Adolescents with CKD reported a profound sense of alienation from their bodies, which created a rift between the body and self. Medical treatments such as dialysis and permcath devices changed the way adolescents perceived themselves. The concept of a '*hybrid identity*' provided some explanation for the changes and disruptions adolescents' experienced in incorporating medical technologies into their embodied sense of self and identities. Through their narratives, adolescents also constructed the way in which kidney transplant affected their embodied sense of self and identity which was interpreted through the lens of the '*transliminal self* '. Adolescents grappled with incorporating the transplanted organ into their sense of self and a state of limbo was experienced. The concept of '*illness centrality'* offered another viewpoint to interpret adolescents' experiences. Illness centrality referred to the way adolescents perceived their illness. Adolescents adopted both positive and negative strategies to incorporate CKD into their embodied sense of self and identity. The findings of this study revealed the ambiguous state of adolescents' embodied self and identity, which continuously changed, evolved and regressed throughout their illness trajectory, highlighting the need for HCPs to develop supportive interventions to help adolescents in living with CKD.

Adolescents experiences of '*objectification and depersonalisation in medical encounters'* was an important finding related to the final objective of this study; which was to explore adolescents' embodied experience of medical treatment and relationships with HCP's. Adolescents stories suggested that their ill bodies were positioned as objects and this objectification carried into interactions with the HCPs throughout their illness trajectory. This incurred feeling of depersonalisation. Adolescent participants wanted their psychosocial needs to be recognised, but they also wanted to be involved in their medical treatment. However, they felt excluded from doing so because they felt objectified and depersonalised through HCPs distancing behaviours and lack of trust. Participants wanted HCPs to relate to them in ways that validated them and recognised their struggles and strengths. Participants valued their own '*embodied knowledge*', gained through lived experience of disease and body management and desired to have this expertise and insight valued by HCPs and incorporated into their treatment programmes.

Chapter 12: Conclusion and Implications

12.0 Introduction

In this concluding chapter, I will consider the original contributions the present study makes to existing literature. Following this, the strengths and limitations of the study will be outlined. The chapter will also present the implications the research has for practice, future research, education, and policy.

12.1 The original contribution of the present study

To my knowledge this is the first narrative study that has used stories and body mapping to explore five adolescents' embodied experiences of living with CKD. More specifically, the findings provide rich and nuanced insights into adolescents' experience of heightened bodily awareness and body vigilance while living with CKD. The adolescents went through various bodily experiences, including tiredness, thirst, pain, changes in bodily appearance and disruption in body functions, all of which caused them to focus their attention on their bodies. This ability to notice subtle bodily sensations and monitor for internal bodily changes was an integral and embodied part of living with CKD. The findings from this present study also suggest that adolescents develop embodied knowledge from living with CKD. The adolescents studied had developed a comprehensive knowledge base around their bodies and illness, knowledge gained from living and experiencing CKD. This current study highlights how adolescents perceived their bodily knowledge to be undervalued and unrecognized in dialogue with health professionals.

This thesis offers a unique contribution to the field of childhood nephrology by reporting adolescents' experience of liminality in living with CKD. The study found that adolescents with CKD faced an overwhelming task. They had to deal with the liminal state of adolescence while simultaneously experiencing the disrupted biological and developmental changes of puberty. This study also offers fresh insights into how adolescents perceive their own liminal state, particularly the state of being 'stuck' between childhood and adulthood. The findings place the concept of adolescent 'social suffering' on empirical foundations. 'Social suffering', in this context, being the experience of being 'stuck' between a medicalised world and the habitual world of adolescence. As previously stated, failure to recognise liminality can be detrimental to adolescents' psychosocial well-being (Marshall *et al.*, 2018). This has important implications for practice. The empirical evidence, revealed within this study, confirmed the impact CKD and its treatments can have on an adolescent's sense of embodied self and identity. Identity development is an important developmental task for adolescents. However, the findings from this study suggest that adolescents' experience of their embodied self and identity is complicated by CKD and its various treatment modalities (i.e. dialysis; transplant surgery). The concepts of hybrid identity and transliminal-self offer unique perspectives on this disruption to adolescents' sense of embodied self and identity. These findings have not been previously reported in the field of childhood nephrology and therefore, by reporting the impact CKD and technologies can have on adolescent embodied identities, provide a valuable contribution to existing research. To the author's knowledge, this is the first study to utilise a narrative approach to explore adolescents' embodied experiences of living with CKD. The use of body mapping as a data collection tool in this study demonstrates originality. Body mapping, a novel research technique, succeeded in generating discussions relating to the body. The study therefore contributes to the emerging body of knowledge on the use of body mapping in research. This will be discussed in the following section.

12.2 Strengths and limitations of the study

This section presents the main strengths and limitations of this present study. The use of a narrative inquiry, derived from young people who were experiencing kidney disease in and through their bodies, helped to provide a nuanced, contextualised account of living with CKD. It was through extended narrative dialogue with adolescents that the understanding of CKD as an embodied experience was developed. In nephrology research, little use is made of narrative inquiry. However, to understand and respond to how adolescents experience CKD it is critical to listen to the stories young people have to tell us about their ill bodies. This is demonstrated in the adolescents' narratives provided by this study. One distinct methodological contribution the present study makes, is the use of body mapping as an innovative and creative tool to engage adolescents in conversations about their illness and bodies. In this study, body mapping was a guided but flexible method that allowed adolescents to choose to focus on the data that was most important to them. This flexibility encouraged adolescents to draw and then discuss topics that were most salient to them and led consequently to a breadth of information. The use of images also allowed adolescents to process complex thoughts before revealing the thoughts behind the images. This led to particularly rich research data, and further strengthened the case for body mapping as a method for data collection. While there are some examples of research that has used body mapping as a research tool with youth participants, body mapping has not been used as a data collection tool with the adolescent population in the context of CKD. Findings from this study illustrate how health care researchers can use body mapping to engage adolescents in participatory research. Another strength was the insights into adolescents' lives at home, as well as in the hospital settings, which led to a more comprehensive understanding of adolescent experience, a limitation noted in previous studies (Waters, 2008). Meeting with adolescents in a space where they had a real sense of belonging (Daley, 2013) was a valuable way of appreciating the life they had beyond the hospital. The findings of this study is representative of five adolescents, this sample size is consistent with narrative research which aims to gather in depth, unique and contextualised data. A limitation of this study was that the sample consisted of predominantly female adolescents recruited from one renal unit in Ireland. Notably, males were underrepresented in the present study. Of the five participants, only one was male. Thus, when interpreting the findings, it is important to note the predominant female voice among participants, which may have concealed potential differences in perspective between genders. More male perspectives may have presented different viewpoints. Finally, this study captures adolescent perspectives, but it is also important to understand HCPs' and parents' perspectives of caring for adolescents embodied needs in living with CKD.

12.3 Implications for practice, education, future research and policy

In this section, the implications of the findings of the present study for practice, future research, education and policy, will be highlighted. The present research is innovative in its approach as well as in its investigation of adolescents' embodied experiences of living with CKD. The result is findings that are multifaceted. This investigations of embodied experience are relevant to the question of how healthcare can be improved, as well as containing practical suggestions for how healthcare staff can help adolescents with CKD.

12.3.1 Practice implications

In considering the present study's practical implications, a number of key implications for practice are highlighted in this section. Communicating key findings to audiences inside and outside the academic community is critical for knowledge exchange and translation of findings to real-life practice and contexts. Researchers have a responsibility to present findings in an accessible way to different audiences including the participants (Carless and Douglas, 2016). Using story extracts from participant's narrative cases proved a useful way to make information more understandable and accessible to different audiences. One of the strengths of using a narrative approach is that stories assist in communicating findings; stories allow the reader to experience an embodied somatic response (Ellis and Bochner, 2000; Barone and Eisner, 2012). Stories are universal in that they can bridge cultural, linguistic and age-related divides. The stories reported in this study have practical implications for HCP's working with adolescents living with CKD.

HCPs, working closely with adolescents, can play a pivotal role in assisting adolescents to navigate the many difficulties associated with living with CKD. For instance, HCPs need to recognise the complex nature of CKD, the implications it has and the limitations it imposes on the adolescent body. Limitations imposed on the body as a consequence of CKD, such as fluid restrictions, tiredness and pain, are difficult tasks for adolescents to deal with. HCPs need to avoid rationalising bodily limitations as an inevitable part of CKD diagnosis. HCPs need greater knowledge of CKD and its impact on adolescents' bodies. It is recommended that an '*Annual live like me day'* should be organised. This recommendation originated from one participant in the study (Emily) who suggested that HCPs, working with CKD patients, should restrict their fluid and diet intake for one full day every year. HCP's need to experience the bodily consequences of CKD such as thirst and the limitations imposed on the body in order to understand the difficulties of adhering to such strict regimes.

The findings of the current study indicate the significance of body awareness and vigilance in adolescents' experience of living with CKD. Self-care strategies of bodily experiences may include being proactive in seeking help and making decisions on how to attend to changing bodily states. Using this approach, HCPs may help adolescents re-frame their heightened body awareness and body vigilance as a positive thing, a potential ally in the healing process. Furthermore, understanding the bodily foundations of patients' embodied knowledge could help HCPs uncover adolescents' experiences of living with CKD. This is critical for creating the supportive policies and implementing the best practices that assist adolescents as they adapt to bodily changes during CKD. In order for professionals to consider each adolescent's uniqueness and whole person, it is necessary to acknowledge the adolescent as resourceful and knowledgeable. Adolescent participants in this study articulated that they were experts on their lives, yet they did not feel that HCPs valued their expertise. A greater understanding of the bodily foundations of adolescents' embodied knowledge could help HCPs develop supportive interventions for adolescents' living with CKD.

Paying attention to the uncertainty and ambiguity inherent in living a liminal life is an important consideration for HCPs to be aware of when working with adolescents with CKD. Acknowledging liminal spaces opens HCPs to the complexities of living with CKD and may help them support adolescents who dwell in such in-between spaces. In addition, an understanding of the liminalities of living with CKD can help HCPs develop a model of care that is reflective of the needs of adolescents. Specifically, developing care pathways that accommodate and facilitate the navigation of the liminalities commonly encountered by adolescents might improve the quality of life for adolescents. The concept of biographical disruption was useful for interpreting the impact CKD had on adolescents' sense of the taken-for-granted world. This study illustrated the way in which adolescents with CKD understood this biographical disruption as something recurrent and persistent. Knowledge of the process of recurrent biographical disruption, as well as identifying new and old ways to overcome it, can be the foundation from which HCPs help adolescents with CKD.

The adolescents in this study emphasised how the technical and physiological focus of medical care created a barrier to effective communication. Healthcare professionals tended to focus more specifically on the scientific and technical characteristics of CKD, which was a source of frustration. Furthermore, HCPs overlooked adolescents in the communication cycle and instead communicated directly to parents. Subsequently, HCPs failed to attend to the adolescents' ongoing need to be included in conversations about their illness and bodies. The need to communicate and interact with adolescents on an ongoing basis should be seen as a high priority objective on the renal ward and the haemodialysis unit. HCPs need to listen attentively to the adolescents in their care. After all, these adolescents are the ones in a position to teach

HCPs about their experiences of their bodies, things that matter to them and the measures that they find appropriate and helpful. Adolescents expressed a need to discuss personal and psychosocial issues**.** From a clinical perspective, a multifaceted and holistic adolescent-centred care approach, one that acknowledges the challenges adolescents face in comprehending their complex renal condition, is needed. Such an approach demands working closely with young people in order to help them develop the self-management and coping skills necessary if they are to manage their CKD. The implementation of psychosocial screening tools such as HEEADSSS, which focuses on assessment of the **H**ome environment, **E**ducation and employment, **E**ating, peer-related **A**ctivities, **D**rugs, **S**exuality, **S**uicide/depression, and **S**afety from injury (Klein, Goldenring and Adelman, 2014), into routine clinical practice would be positive. This screening tool can assist health professionals engage with young people, gain insight into adolescents embodied perception of their lives as well as identify the areas where they may require additional support.

Interactions between adolescents and HCPs can be understood as embodied interactions. As this current study illustrates, medical treatment can disrupt embodied experiences which consequently results in the fracturing of self-identities and the disruption of everyday life. Understanding the diverse ways in which HCPs can contribute to adolescent experiences of the embodied self and identity is important. In this study, it seemed that HCP's attention was focused more on the dialysis machine, as well as other technological aspects of care, which made the adolescents feel invisible. One implication of this finding is that HCPs need to understand the ways in which medical technology can impact on adolescents' sense of embodied self and identity. HCPs are in a unique position, as they provide support and advice to adolescents on how to facilitate the integration of technology into their sense of self and identity. If HCPs are to fully support adolescents, they should encourage adolescents to express the anxieties and concerns they may have about their situation; requiring medical technologies to survive. New, supportive interventions are needed. Interventions to prepare and support adolescents through the challenges they may face in living with CKD, including how to incorporate medical technologies into their sense of embodied self and identity.

By providing psychological support, the adolescents' concerns would be identified and managed more proactively. HCP's need to provide support and advice to help adolescents navigate their way through their illness. HCP's could assist in the development of early interventions for young people with CKD. These interventions would assist adolescents in developing adaptive coping strategies to deal with the changes in their bodies. Incorporating these strategies at an early stage, before the changes become deep-rooted, may help to reduce the negative experiences reported in this study. Furthermore, supportive strategies that facilitate bodily mastery in living with CKD will help adolescents to adjust to their illness experience. For example, the adolescents reported they struggled with developing the social skills necessary to integrate into school and the world outside of hospital. It is suggested that an adolescent support group may provide that necessary channel of communication, one which would allow adolescents to speak to peers going through similar experiences. A support group would allow common concerns and experiences to be identified and shared amongst adolescents. The mutual support received from this type of group may help remind adolescents that they are not alone on their journey through CKD.

12.3.2 Education

The findings also suggest that more specialised education of health care professionals is needed to improve HCPs' understanding of the diverse ways in which CKD can affect the body during adolescence. In discovering that kidney disease is a dynamic and chronic condition, and one that affects multiple dimensions of daily life over the trajectory of adolescence and beyond, this study invites educational strategies that encompass an adolescent-centred approach to care and incorporate embodied perspectives into the healthcare curriculum. This supports the vision of the Irish government as outlined in the 'Houses of the Oireachtas Committee on the Future of Healthcare Sláintecare report' (2017). The report known as 'Sláintecare' is an Irish government initiative aimed at transforming the health and social care services to people in Ireland. Part of this programme is to provide person centred care which calls for health training programmes to be re-oriented from an acute and episodic care model to an integrative and preventive care model that acknowledges the importance of the body in illness experience. This shift also aligns with WHO's (2015) vision for designing competency-based educational programmes that emphasise the developmental and contextual aspects of adolescent health.

Adolescents with CKD need education on an ongoing basis. It is essential in order to enable them to manage the long-term and progressive nature of their illness and treatment. In particular, the need to provide adolescents with open and honest information about their illness and treatment is required. Adolescents need information related to their kidney disease, information that is tailored to meet their bodily concerns and is delivered in at an age-appropriate level. HCPs need further education around the importance of providing developmentally appropriate information to adolescents. They need to be cognisant of the challenges adolescents experience in understanding the information given to them about their complex condition. With many different treatment regimens at different points of their illness trajectory, HCPs need to tailor their communication to each adolescent's need for specific information regarding their renal replacement therapy and its associated side effects and complications. This can be accomplished by including adolescents in conversations about their illness and by avoiding an overly medicalised approach to care which is laden with complex medical terminology. There is a need for HCPs to be cognisant of the language they utilise during clinical appointments hospital admissions, particularly in reference to how they discuss CKD and its treatments with adolescents. Overly complex language and medical jargon should be avoided by HCPs. When speaking with adolescents about CKD and its treatments, such language has the potential to result in misunderstanding and only exacerbates the difficulties adolescents may have in understanding their life-long chronic condition. By enhancing adolescents' understanding of their condition and treatment modalities, HCPs have the potential to instil greater confidence in adolescents and help them manage and cope with their condition.

12.3.3 Future Research

The previous dearth of qualitative research in this area of CKD suggests that further research on adolescents' perspectives of living with CKD is needed. There is limited evidence on the views and perceptions of this population group. There is also a need for research that examines embodiment in CKD and how this chronic illness affects a person's body and mind. Furthermore, the disproportionately high number of female perspectives, as well as the relative paucity of research on a male population, suggests a need to address this imbalance and conduct future research studies on male perspectives of living with CKD. It is also suggested that a replication of this study using a larger sample of narratives, drawn from both male and female adolescents, would prove beneficial in exploring gender differences in living with CKD and how it is narratively expressed. Future research should also endeavor to explore the perspective of other stakeholders, such as parents and HCPs. The use of body mapping is transferrable to other research contexts. For example, future research in other chronic illnesses (such as cystic fibrosis and diabetes) may reveal the embodied experiences of these chronic illnesses. Further research on developing methodological guidance specifically for the analysis of body maps would be beneficial.

The present study leaves unanswered some specific questions relating to CKD, which deserve further research. For example, body awareness and body vigilance are under researched concepts in CKD research. The reasons for this may lie in the tendency of health-related research to focus on cognitive-emotional aspects of the illness, thus excluding bodily aspects of the self (Lyons and Chamberlain, 2006; Ginzburg *et al.,* 2014). However, further research is needed to determine whether heightened body awareness and body vigilance can be considered adaptive or maladaptive in living with bodily experiences of CKD. More research is also needed to investigate the benefit of intervention programmes such as the bodyknowledge program as developed by Heggdal (2013) and discussed in Chapter 11. Intervention programmes such as bodyknowledge programme, could support and encourage adolescents with CKD to trust their own body awareness and embodied responses, and therefore take more responsibility for their own illness and care. This could support adolescents in becoming more effective in the self-care management of their CKD.

The findings of this study also suggest adolescents use fictional and mythical literature to make sense of their illness. Future research might help uncover the underlying meaning behind adolescents use of childhood fantasy literature to make sense of their illness experience. Understanding and acknowledging the role of fictional and mythical characters offers HCPs a way to approach and communicate with adolescents regarding their illness experience. This present study suggests that adolescents embodied sense of self and identity is altered in CKD, particularly on account of medical technologies. Given the limited research on cyborg and hybrid identities in adolescents with CKD further research is needed to investigate and unearth these issues further. For example

- How do medical technologies shape embodied experiences of CKD?
- How can adolescents with CKD be helped to retain their embodied sense of self in the midst of adjusting to medical technologies?

- What are the long-term psychological effects of receiving a donor kidney and how does this effect one’s sense of self?

The findings of this study identified psychosocial issues that require further investigation. For example, adolescents experienced significant social suffering as a result of hospital based treatments. Future research is needed to develop interventions that could address the psychosocial needs of this population.

12.3.4 Policy implications

The findings of this narrative study have many implications when it comes to public policy. Policies should aim to create a renal service that meets the needs of adolescents using the service. This research is of particular importance in light of the objectives of the National Clinical Programme for Paediatrics and Neonatology (2016). The programme includes a detailed model of care for paediatric nephrology. In this model of care, it is not just essential to maximise the physical health of those living with CKD, but also the psychological and social health. The findings from this study suggest that from an adolescent’s perspective, HCPs tended to focus on the medicalised aspect of their condition with limited attention to the psychosocial implications of CKD. The findings from this study highlight that the embodied experience of CKD is highly individualised. Policy directives must address the need for an adolescent-centred approach to care in order to meet the specific needs of this population group. This research will be instrumental in contributing to this agenda. Consulting directly with adolescents will enhance our understanding of their perspectives, which will in turn assist policy-makers and health professionals devise and implement adolescent-centred healthcare and renal care for this specific age group.

In Ireland, adolescent patients have been identified as a vulnerable group in terms of health policy (Department of Children and Youth Affairs, 2019). Importantly, healthcare systems for adolescents have been designed, by authoritative or professional adults, without adolescents being involved in the process (WHO, 2015). There is also an over-reliance on data generated from research on HCP and /or parent perspectives of living with CKD (Hanson *et al.*, 2017). The findings of this study support the suggestion that future policies on renal services be inclusive of adolescents, and not just providing a tokenistic acknowledgement of this population, which has been the case to date. Further explorations are needed in order to envision ways to co-create with adolescent’s policies that merge and balance medical and technological care with adolescent-focused care. Recommendations from this research will contribute to nephrology support organisations such as the Irish Kidney Association (IKA), which endeavours to improve the lives of those living with kidney disease. The IKA should take cognisance of the need to develop support services that are aimed at empowering adolescents to cope with the struggles they experience in their bodies. To the author’s knowledge, no such supports are currently available to adolescents with CKD in Ireland.

12.4 Key message of study findings

1) Adolescents with CKD possess embodied knowledge and this knowledge is an untapped resource for health and recovery that is not fully recognised by HCP’S or parents. Adolescents need to be acknowledged as knowledgeable agents in their illness trajectory. Adolescents with CKD need to be encouraged to use heightened body awareness and body vigilance to engage in self-care management strategies.
2) A key message of this study is that CKD and its complex and multiple treatments result in serious ruptures in adolescents’ experience of embodied self and identity. Adolescents need to be encouraged to express their anxieties and concerns about experiences of hybrid identities and ‘transliminal self’ in living with CKD. New supportive interventions are required in order to prepare and counsel adolescents through the challenges they may experience to their sense of embodied self and identity in living with CKD.
3) HCP’s need to recognise the liminal states that adolescents with CKD experience and develop care pathways that accommodate and facilitate navigation of liminal states that adolescents with CKD encounter.

12.5 Concluding comments

To my knowledge, the present study is the first to examine the embodied experiences of adolescents living with CKD in the island of Ireland. Furthermore, this research is the first to investigate how adolescents experience their bodies in the context of kidney disease at a time of significant developmental growth and maturation. The findings of this present study suggest that the body is situated at the core of adolescents' experience, for it is through their bodies that they experience the true extent and implications of CKD. This study identified the diverse ways in which the young body is changed and altered during the course of the CKD journey. CKD challenges the familiar taken-for-granted bodies of everyday life. Adolescent participants had to endure disruptions to their bodily functions, sensations and disruptions to their developing bodies. Adolescents were aware of the changes in their bodies and these changes' subsequent impact on their embodied identity and self. The research adds to the limited body of evidence on young people's experience of CKD, particularly embodied experiences. The exploration of the embodied experience of CKD, as presented in this study, will enhance healthcare professionals' understanding of adolescents' experience of their bodies during their renal trajectory. This vital knowledge will enable them to offer more effective support.

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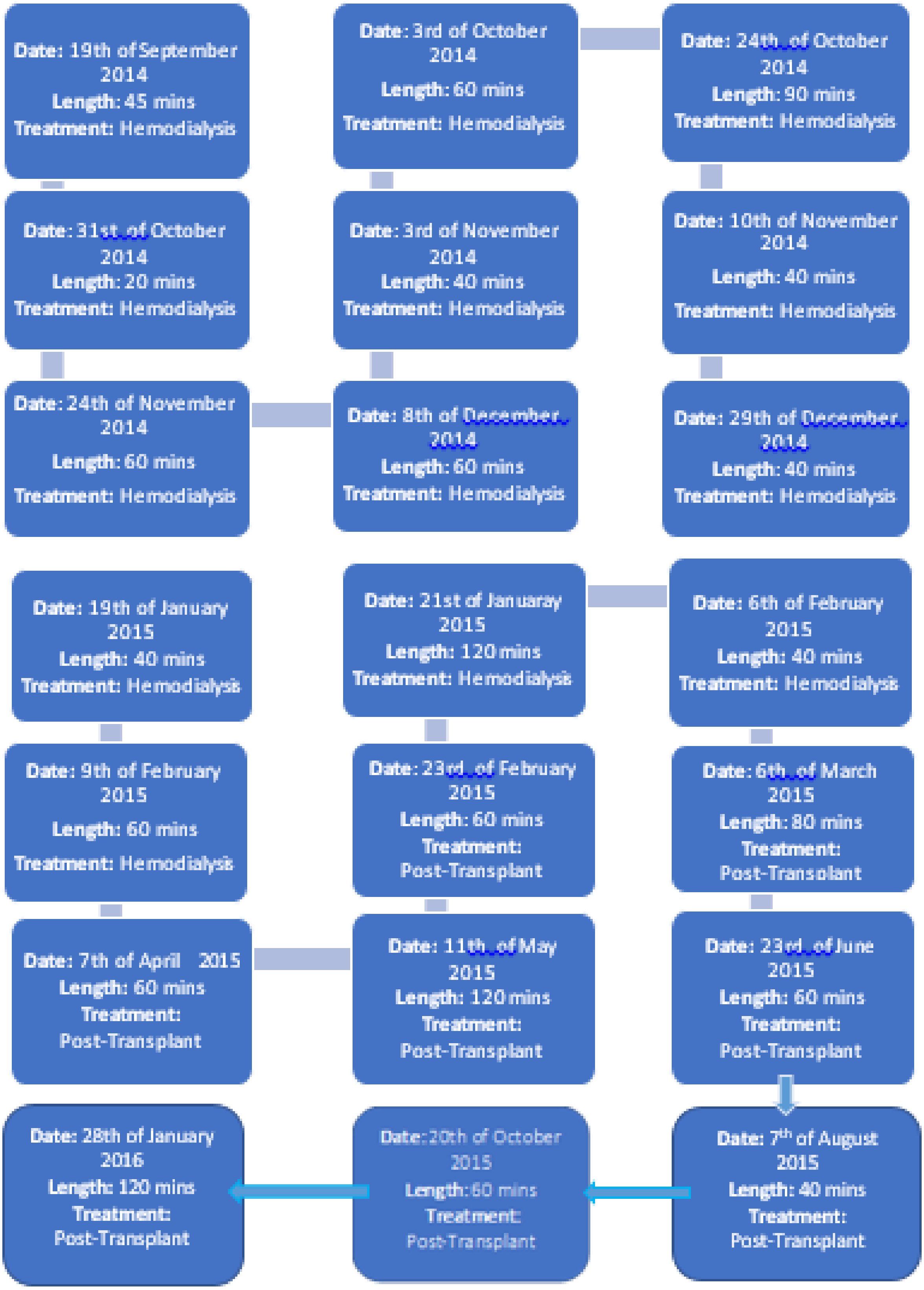
Appendix A: Story gathering Process

Journey Map of Data Collection with Lucy



Appendix B: Body Map Framework

Adopted from Solomon's Facilitators Guide (2002)

Introduction to Body Mapping

Exercise 1: Body Tracing

Purpose	To trace an outline of the adolescent's body in a posture that is most representative of who they are. This outline of the body will form the foundation for all future body mapping sessions.
Instructions	Today we are going to do an activity to called body tracing. This involves drawing an outline of your body on a large white sheet of paper using a black pen. Ask the adolescent to remove any extra clothing and also remove his/her shoes. This is to ensure additional clothing does not hinder the body tracing. Ask the adolescent to think of a posture that represents who they are. Invite the adolescent to lie down on the sheet of large paper in that posture. The adolescent's body outline is then traced. It is important to be vigilant and follow the shape of the body. Be conscientious not to draw on the clothes of the young person. Once an outline of the adolescent's body is completed, then the parent or the researcher/facilitator positions him/herself on the adolescent's body map and the adolescent then traces on outline of the parent or researcher. This step is to represent support persons in the adolescent's life. At this stage the support person is only outlined and will be revisited at a later session.
Questions to guide this exercise	I would like you to think about a position which you use most often or which you think represents who you are or your life. A position means a stance or posture of the body. Give examples i.e. sleep position or the type of position while on dialysis.
Issues to Consider	Adequate space is required to do a body trace as body maps can be as long as 2 meters. In the hospital setting, the researcher will liaise with the renal play specialist regarding an appropriate environment/space in which to facilitate body mapping. In addition to the issue of space, some positions may be difficult to draw, especially if the adolescent is confined to bed or attached to a dialysis machine. In this situation, the initial tracing may be done prior to the adolescent starting dialysis. Or alternatively tracing may be carried out while the person is in a standing position against a wall. Adolescents may struggle to think of a position that symbolises them. The adolescent may feel embarrassed during this exercise particularly when tracing around particular areas of the body. It is important that the young person does not feel that their personal space is invaded or feels uncomfortable with the researcher potentially coming in direct contact with his/her body. The researcher will need to discuss this issue with the adolescent and give possible solutions. For example give the option of having one of the parents trace the outline of their body.

Exercise 2: Highlighting Your Body Shape.

Purpose	Participants identify the outline of their body shape and highlight it in their favourite colour.
Instructions	Ask the adolescent to choose a colour that best represents him/her (or his/her favourite colour). Once the colour is chosen, ask the adolescent to colour the outline of the body.
Questions to guide this exercise	Colours can have different meanings for different people. We all have a colour or colours that we like. What colour have you chosen? Why you have chosen that colour. What meaning does it have for you? How does this colour make you feel?
Issues to Consider	Risk of infection: Particular art materials may be a potential source of infection. For example, pastel colours are very dirty and using them in a hospital setting may be problematic particularly if residual particles lodge in or on dressings near permcaths or other wounds. This issue will need to be discussed with the healthcare team. It is also important to check if the adolescents have any known allergies; this information can be sought from the healthcare team and the adolescent.

Exercise 3a: Drawing where you come from.

Purpose	To explore adolescent's roots i.e. where they come from.
Instructions	Ask the adolescent to think about and draw symbols on their body map that represent their home Ask them to use colours to represent their homes or their feelings about where they come from.
Questions to guide this exercise	Tell me something about the place where you come from? What symbols come to mind when you think about your home?
Issues to consider.	It is important to encourage adolescents to speak where they are from and decide how they would like their home place to be presented on their body map.

Exercise 3b: Drawing what you are moving towards

Purpose	To explore adolescents visions/goals for their future.
Instructions	Ask the adolescent to think about a symbol or picture that captures what he/she is working towards or what his/her vision for the future is. Ask him/her to draw this symbol or picture on the top left hand corner. Ask the adolescent to choose a colour to represent reaching this goal or vision. The colour chosen can then be used to paint around the drawing or symbol. Once the adolescent has completed the drawing ask him/her to draw or paint an arrow or other symbol to connect where they come from to what they are striving for. The arrow can cross over the body shape.

Questions to guide this exercise	Have you ever thought about your future? What do you think will happen? Do you still think you will be coming into hospital? Where do you think you will be? How do you imagine your future? What is your vision, your goal or your dream for yourself? Explain the symbol you have drawn to show your vision, goal or dream.
Issues to consider	Adolescent may have never thought about their future and may struggle to think about what they are moving towards. Remind the adolescent this can be a vision, dream or goal. This exercise could potential stir emotions for the adolescent as they think about their future especially if he/she feels his/her body may always be reliant on technology/healthcare professional or parents. It is important to have parents nearby in case he/she gets upset and also to have access to a professional counsellor or clinical psychologist should the situation warrant their input.

Exercise 4: Personal Print

Purpose	Adolescent imprint images of their hands and feet onto their body maps.
Instructions	Apply paint onto the adolescent's hand. Then ask him/her to press his/her inked hand onto the body map. Assist the adolescent to ink up and print their feet onto their body maps
Questions to guide this exercise	Creating hand and foot prints is a very old way of showing one's presence in the world. Did you like this exercise? What colour did you use for your feet/hands? Why did you use this colour? Where did you place the images of your feet/hands on the body map? Why did you choose these places?
Issues to consider	Applying paint onto hands and feet can be very messy particularly in a hospital environment where space is limited. Consult relevant health care staff regarding space available. Adolescents may not want to get their feet dirty. Provide alternative options for example the adolescent could draw an outline of his/her feet on newspaper or crepe paper and then stick the cut out prints onto the body map.

Exercise 5: Painting your support

Purpose	To identify key people such as parents, siblings, friends, health care staff, teachers etc. that help support the adolescent in her/his daily struggles. This gives adolescents the chance to acknowledge their support structures. Also, having their supporters' marked on their body maps strengthens the feeling of being supported during the rest of the body mapping process.
Instructions	Ask the adolescent to identify people or things that support them, and then ask him/her to pick a color or symbol to represent the things that support them? Then, ask the adolescent to elaborate on how these people/things show support. What do they do to support them? What does it mean to feel supported?

Questions to guide this exercise	In this exercise, I would like you to identify key people such as parents, siblings, friends, health care staff, teachers etc. or things in your life that support you or help you cope with some of the challenges you face in living with kidney disease? Who gives you support? How do these people show their support? What does this support mean to you?
Issues to consider	Adolescents may want to name specific people and may want to convey this information on their body map. It is important to remind the adolescents of confidential issues. Advise adolescents to avoid using specific names and recommend alternatives such using symbols or nicknames instead of real names. Some adolescents may not know how to paint "support", and you may suggest using symbols or different colours to represent different kinds of support.

Exercise 6: Journey Map

Purpose	To map out the physical journey they have made.
Instructions	Ask the adolescent to think about the journey to and from hospital and draw symbols on their body map that represent this journey. Then, ask the participant to draw pictures or symbols about life in hospital. Encourage the participant to make connections between home and hospital and symbols of things within this trajectory, (e.g. the mode of transportation used to get to hospital, people that accompany them to hospital, etc.).
Questions to guide this exercise	I want you to think about your journey to and from hospital. Which symbols or images represent this journey?
Issues to consider	It is important to encourage adolescents to speak about their journey to hospital and describe their life at home and life in hospital. How did they feel when they first came to hospital? Were they scared? Who did they connect with? Please keep in mind that you want to keep the body map as free as possible for potentially identifying information, so if needed, remind adolescents that the use of specific names of people should be avoided.

Exercise 7: Body Scanning Marking the Power Point

Purpose	This exercise assists adolescents to identify their source of personal power and strength within their bodies.
Instructions	Explain to the adolescent that everyone has different sources of strength that help in overcoming the difficulties that are encountered in everyday life. Different people get their power from different parts of their body. It could be from your shoulders, your thighs, your arms, or any other area of the body. Ask and help the adolescent to identify key experiences that he/she has faced in relation to living with chronic kidney disease. Ask adolescents to think about where in their body or environment they get the strength to overcome the challenges they have faced. Which part of your body does get your power from? Ask the adolescent to mark this place on the body map with a pencil.

Questions to guide this exercise	In this exercise, we want to explore all aspects of your life in living with chronic kidney disease. Have you ever experienced difficulties because of your illness? What kind of difficulties were these? Now I want you to think about your strength and courage when facing these difficulties. Where does your strength come from? Where do you get the courage to keep moving forward? Scan your body map and focus on finding where this personal strength comes from. Does it come from your arms? Your mind?
Issues to consider	It may be difficult for adolescents to think about the challenges they have faced. They may have never thought about these issues before or it may be too difficult to reconnect with those experiences. It is important to have parents nearby in case he/she gets upset and also to have access to a professional counsellor or clinical psychologist should the situation warrant their input.

Exercise 8: Creating a Personal Symbol

Purpose	This exercise aims to give the adolescent the opportunity to express how he/she feels about themselves. It also gives them the opening to think about themselves in relation to their illness.
Instructions	Ask the adolescent to think about a symbol that is meaningful to them. It might be a symbol that relates to kidney disease. Ask the adolescent to explain the meaning of the symbol.
Questions to guide this exercise	Who are you as a person? Can you explain the meaning of your symbol? Does your symbol relate to living with kidney disease?
Issues to consider	It is also common for adolescents to come with a symbol to use in mind, and you can suggest finding it on the Internet and adding it to their body map.

Exercise 9: Self-Portrait

Purpose	The aim of this exercise is to get adolescents to show their personality and character.
Instructions	Ask the adolescent to think about whom they are and what their face tells them. Then, ask the adolescent to think about how they appear to the world and how they see themselves. Then, ask the adolescent to use these ideas to draw in their face or use symbols or clip
Questions to guide this exercise	We all have the same features placed in more or less the same way on our faces (e.g. eyes, nose, mouth), yet we all look different and our faces mean different things to different people. How would you like to represent your face? As it appears? Or in a more symbolic way?
Issues to consider	Some adolescents may be very good at drawing which may in fact put their own identity at risk. If this is the case, remind adolescent of how their body maps will be used.

	For those participants who have a hard time drawing facial features, encourage them to use magazine cut-outs or assist if possible. Some adolescents may want to use their real photos for the self-portrait; however, this is not ethically appropriate for this research study. Explain to the adolescent why this cannot be done.

Exercise 10: Creating a Personal Slogan

Purpose	To understand what motivates or what perspective adolescents have on life through the use of a slogan
Instructions	In this exercise the adolescent is asked to add a personal slogan (motto) or a kidney disease related slogan that gives them strength to deal with their illness or everyday struggles. Your slogan could be the words from a song or a book that is special to you. It could be something your parents, grandparents, family or friends say to you to help you through difficult times. It could be the words of a prayer, or just something you say to yourself to keep yourself going when things get tough. Give the adolescent time alone to think about the slogan/ message. Help the adolescent make the message concise, if needed. Ask the adolescent to write this message somewhere outside their body outline using a black pen.
Questions to guide this exercise	What is your life's motto? What keeps you going? What message would you like to give about your experience of living with Chronic Kidney Disease? What is the meaning of your slogan/message? Where outside of the body outline do you want to put your message?
Issues to consider	Adolescent may struggle to think of a slogan (motto) and may need time to process what is being asked. Do not rush this exercise. If needed give examples or prompts.

Exercise 11: Marks On the Skin

Purpose	To visually represent the impact chronic kidney disease has on the adolescents body (Note: Impacts can be physical, mental, emotional, etc.)
Instructions	Ask the adolescent to scan their body map from head to toe, and identify visible marks on their body. These can be scars, past wounds/injuries. Ask the adolescent to elaborate on such marks by asking questions such as: Where did you get that scar? How did it happen? What shape is the scar/ Ask the adolescent to draw the shape of the scar and the colour of the mark. Adolescents can write something if they wish beside each mark.
Questions to guide this exercise	In this exercise, I would like you to think about marks on your skin. If you look from head to toe on your body map, can you identify any specific marks on your body that are related to your illness either past or current? (e.g. surgery, illness, birthmarks etc.). How did you get these marks on your body? What happened?
Issues to	Adolescents may want to show all or none of their marks on the body

consider	map—respect this and try to support the process by encouraging marks they are willing to describe. Drawing marks might bring up traumatic experiences, so it is important to check in on adolescents, offer them a break, or if needed, refer them to the clinical psychologist.

Exercise 12: Marks Under the Skin

Purpose	To identify hurts (or pain) that may be stored beneath the skin.
Instructions	The body records emotional and psychological marks. Ask the adolescent to think about any internal marks and scars and any other kinds of unseen pain, operations or injuries they have experienced. Ask the adolescent to then draw, paint or write emotional marks. Adolescents can use colour and shapes to show where they feel happy, sad, excited, anxious, or any other important emotion.
Questions to guide this exercise	Encourage participants to show their emotional hurt. Give examples: a broken heart cannot be seen but it is felt in a real way. Sometimes pains like headaches or arthritis are felt in the joints and other parts of the body. Where in the body do you feel stress or upset? Use colour and interesting lines to show the pains you may feel. Remind the adolescent that emotional marks may also be positive? Where in the body do you feel Happiness? Ask the adolescent to discuss the marks they have shown on their body maps under the skin.
Issues to consider	Adolescents may want to show all or none of their marks on the body map—respect this and try to support the process by encouraging marks they are willing to describe. Drawing marks might bring up traumatic experiences, so it is important to check in on adolescents, offer them a break, or if needed, refer them to the clinical psychologist.

Exercise 13: Living with Kidney Disease

Purpose	The aim of this exercise to get adolescents to think about their bodily experience of living with kidney disease. This exercise also gets adolescent to think about what kidney disease looks like to them and how it feels to live with kidney disease.
Instructions	Ask the adolescent to remember the time they first went to the doctor/hospital and were told of they had kidney disease. Ask the adolescent to draw a symbol or a picture that represents this. Ask adolescent to think about the parts of the body that have being affected by kidney disease. Then ask them to draw or paint these areas. These areas may be where they experience pain and discomfort. If they wish, adolescents can write explanations next to each of these places. Ask the adolescent to think about a symbol that reflects their experience of living with kidney disease. Participants draw this symbol on their body map, inside or outside of the body map outline. Ask the adolescent to write outside their body map outline something about what living with kidney disease feels like. Ask participants to draw or paint what they think Kidney disease looks like on a piece of A4 paper.

	Give adolescents some ideas of how to show kidney disease. Once the adolescent is happy with the symbol ask them to locate a position on the map where he/she would like to place the symbol. Colour in and around the symbol using paints.
Questions to guide the exercise	Can you remember when you first got sick? Where did you feel sick? Where did you go? To the local doctor, hospital etc. Who brought you to the doctor/hospital/ Who told you, you had kidney disease? How did you feel? How does it feel to have kidney disease? What symbol can you think of to show this feeling? Choose a symbol that you could use to explain how it feels to have kidney disease to someone who is not living with kidney disease. What do you think kidney disease looks like/
Issues to consider	This exercise may upset participants and bring up painful or traumatic experiences. If necessary, have a trained counsellor available.

Exercise 14: Treatment

Purpose	This exercise aims to get adolescents to think about the treatments they are on and how effective treatments have been. It also aims to get adolescents to think about things they do to look after their health.
Instructions	Ask the adolescent to explain what type of treatment they are on and ask them to draw this onto their body map. Ask adolescents to consider whether they are experiencing any side effects from their medication or treatments. If so, what are these side effects? Adolescents then draw or mark these side effects on their body map in the place where they are experiencing them. Ask adolescents to use colour and shapes symbolically, if possible, to show these side effects without needing to write about them. Ask adolescents to draw the kind of things they do in order to stay healthy e.g. diet, exercise. Ask adolescents to draw or write something that they do to deal with the stress of having kidney disease.
Questions to guide the exercise	You’ve marked points of hurt and injury and shown kidney disease in your body. How do you look after yourself? Are you on any treatment to deal with your illness and help you to feel better? Think about what shape and colour could represent the treatment. How well is the treatment working? How does it help you? Is there any other treatment that could help? If you are not on any treatment, draw or write about the other things you do to take care of yourself and support your health. What kind of diet do you have to adhere too? What kind of foods do you eat to stay healthy? What kind of foods are you not allowed eat because of your kidney disease? How do you deal with stress, do you exercise or what do you do to relax? Do you walk, run, swim or dance? Or perhaps there are some places which you like to visit because they help you to really relax.

Issues to consider	This exercise may upset participants and bring up painful or traumatic experiences. If necessary, have a trained counsellor available.

Exercise 15

Purpose	The aim of this exercise is to give adolescent time to complete their body maps and decorate the body map.
Instructions	Invite the adolescents to add anything else that they feel is important to them and to highlight what they feel are their best features. Ask the adolescent to choose a colour for the background of the body map. When they are finished painting in the background and the paint is dry, the body maps are put up against the wall for viewing. Ask each adolescent if she/he thinks her body map is finished, and if not, what changes are needed. The adolescent makes these changes and adds details until she/he feels her body map is complete
Questions to guide the exercise	Take time and care. If something on your body map doesn't look right to you, you can change or add to it. It must look right and completed to you. It is your body map. Ask the adolescent to choose a colour for the background of the map. Explain that the colour chosen can be their favourite colour or it can represent how they are feeling or it can be a colour that fits in with the rest of the colour scheme.
Issues to consider	The recommended time frame for this exercise according to Solomon (2002) is 2 hours. In order to give adolescents, the required time to finish off their body maps, it may be necessary to divide this exercise into two separate sessions. This is to ensure the wellbeing of the adolescents as a 2-hour session may be physically exhausting.

Appendix C: Lucy's Completed Body Map

Appendix D: Staff Information Sheet

Research Study:
Adolescent's embodied experience of living with Chronic Kidney Disease

What is this study about?

We are doing this study to find out more about adolescent's experiences of living with chronic kidney disease. We are particularly interested in hearing about adolescent's bodily experiences of living with chronic renal disease and how it effects their bodies.

Who is conducting this study?

This narrative study is being carried out by Colleen O'Neill and Dr. Briege Casey and Dr. Veronica Lambert from the School of Nursing and Human Sciences at Dublin City University (DCU). This research was developed in conjunction with Dr. Michael Riordan and Dr. Niamh Dolan in the Children's University Hospital, Temple Street.

I (Colleen) am currently a postgraduate research student at DCU and I am the person who will be carrying out the study. I am completing this work as part of my PhD studies and I am being supervised by Dr. Briege Casey and Dr Veronica Lambert.

What is involved in the study?

- The purpose of this narrative study is to explore adolescents embodied experience of living with chronic kidney disease. A combination of techniques will be used to collect data during the course of this study such as conversational interviews and arts based technique of body mapping.
- This information sheet will outline what is involved for adolescents and will subsequently discuss the implications of the study for the ward and healthcare staff

When and where will the research take place?

- This involves collecting data first hand in real life situations over a prolonged period of time i.e.18 months in both home and hospital contexts to learn about adolescents' daily experiences of living with Chronic Kidney Disease
- The days and times I will spend with adolescents will be negotiated with families and with healthcare staff on an on-going basis.
- Data collection in the hospital settings will take place on different days of the week and at different times of the day and evening for example Day 1 Monday 2-4pm Day 2 Tuesday 10-12.
- Data collection in the home setting will take place at a time convenient to families and may involve the researcher spending 1-2 days in the home context for intervals of 2-3 hours.

Who will I be interviewing?

- Conversational interviews with adolescents will take place in an informal manner throughout the adolescent's stay in hospital.
- Conversations will be digitally recorded as appropriate.

- Interview conversations will in no way interfere with ward routine or medical/nursing care interventions.

What is meant by arts based methods?

- Arts based methods are activities which encourage adolescents to actively take part in research through the use of creative techniques such as drawing.
- In this study adolescents will be asked to draw (or having drawn) one's body outline onto a large surface and using colours, pictures, symbols and words to represent experiences lived through their body.

What will be done with the information collected?

- Only the research team and possibly the examiners of my thesis will have access to data collected and these will be treated in the strictest of confidence.
- The clinical setting of this study takes place in the renal unit (which includes the ward, haemodialysis unit and renal outpatient's clinic) which is a specialised ward within the hospital, therefore it is potentially identifiable.
- However, every effort will be taken to safeguard the identity of participants. The name of the ward and details relating to the ward i.e. layout of ward will be changed as much as possible to ensure the ward is not identifiable in any published reports.
- Any information collected from either written notes or recordings will be transcribed and made anonymous. The information we collect from all the adolescents who take part will be used to write a report on the findings and I will write my thesis using information gathered.
- All information from the study (i.e. recordings, paper documents etc.) will be destroyed after my thesis has been examined.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.

Safety Issues.

- Under the code of Professional Conduct and Ethics for Registered Nurses and Midwives (2013), the researcher has an obligation to share concerns about poor standards of practice or risks identified during the course of data collection.
- If the safety or well-being of an adolescent is affected or put at risk by a staff member's actions, omissions or incompetence's the researcher must first take appropriate action to protect the adolescent for immediate harm and report such conduct to the appropriate personal i.e. the principal investigator and the clinical nurse manager of the ward.

What use will this study be?

- While there may be no immediate benefits for adolescents, the knowledge gained from this study will serve to provide health care staff with a richer and more complete understanding of the embodied experience of living with chronic kidney disease.
- This study will give adolescences a 'voice' allowing for their experiences of chronic kidney disease, to be articulated and valued as a vital perspective in the overall health – care picture. This is keeping in line with Temple Street Children's University Hospital Statement of Intent (2013) to "put the experience and voice of the child at the centre of how services are designed and delivered".

Is there anything else I need to know?

- If you would like to talk informally with me about any questions or queries you may have about this research, my contact details are below. You can contact me with any questions you have about this research on 01 7007157 or colleen.oneill@dcu.ie. I would be more than happy to address any questions or concerns that you may have. Additionally, you can contact my supervisor at briege.casey@dcu.ie.

Appendix E: Information Sheet for Parents and Guardians

Research Study:

Adolescent's embodied experience of living with Chronic Kidney Disease

What is this study about?

We are doing this study to find out more about your son/daughter's experiences of living with chronic kidney disease. We are particularly interested in hearing your son/daughter's views as well as your perceptions as to how chronic kidney disease affects his/her body function and body image. Although there are many body changes and body image issues experienced during chronic kidney disease, we have discovered that this area is under-researched. Therefore, we would like to learn more about the particular experiences and needs of young people who are so that we can help to further develop health care professionals understanding, knowledge and skills in working sensitively with young people living with chronic kidney disease.

Who is conducting this study?

This study is being carried out by Colleen O'Neill, Dr. Briege Casey and Dr. Veronica Lambert from the School of Nursing and Human Sciences at Dublin City University (DCU). This research was developed in conjunction with Dr. Michael Riordan, Dr. Atif Awan and Dr. Niamh Dolan in the Children's University Hospital, Temple Street.

m a qualified children's nurse and currently a postgraduate research student at the person you and your son/daughter, will have most contact with if you agree to m completing this work as part of my PhD studies and I am being supervised by asey and Dr Veronica Lambert.

If I give consent for my child to take part what will he/she be asked to do?

- We would like to have an opportunity to observe and speak with adolescents who are **between 10 and 17 years of age** and who have been diagnosed with chronic kidney disease.
- If you give consent for your son/daughter to be involved in this study, I will spend time with him/her in the hospital setting and in some home/social situations if this is acceptable to you. The aim of this is to get to know your son/daughter and his/her experiences of everyday living with Chronic Kidney Disease in various contexts/settings. I will gather this information through the use of conversational interviews and participatory methods such as body mapping. I would also value the opportunity to discuss with you, your perceptions of how your son/daughter is experiencing Chronic Kidney disease and how it impacts on his/her life.
- If you give consent for your son/daughter to take part, I will remind them that this does not mean they *have* to take part, just that if they want to take part, you have said it is OK for them to do so.
- Your son/daughter will also receive an information letter. We would encourage you to discuss the information letter with your son/daughter.

Some questions you might have……..

What type of questions will we be asked during conversations/interviews?

- I will sit down with your son/daughter and have informal conversations with him/her. This will help me to get to know your son/daughter. I will have conversations about his/her experience of living with kidney disease. This will allow your son/daughter to personally voice his/her views on what it is like to have chronic kidney disease.
- Conversations/Interviews will be audio-recorded as appropriate, with you and your son/daughter's permission (why – to aid my recall of information we discussed).
- ***What is meant by participatory methods?***
- Participatory methods are activities which encourage children/adolescents to actively take part in research through the use of creative techniques such as drawing.
- In this study your son/daughter will be asked to draw (or have drawn) his /her body outline onto a large surface and use colours, pictures, symbols and words to represent experiences lived through their body.

- Artwork produced by your son/daughter may be used in the study findings; however, his/her identity will not be disclosed.
- Participation in this activity is entirely voluntary and your son/daughter is free to refuse from this activity without any negative consequences attached to their decision.

Where will the research take place and how long will it take?

- If you and your son/daughter agree to take part in this study it will involve me spending time with your family over the next 18 months in various contexts both in the hospital and home setting.
- The days and times I will spend with your family will be negotiated with you on an on-going basis. As an example it might involve spending 1-2 hours with your son/daughter on any given day at home or when your son/daughter is an in-patient in hospital. When in-patient in hospital it might involve spending some consecutive days together; whereas when at home it might involve me visiting 1-2 days a month.
- I will work out a plan of meeting times with you and your son/daughter at the start of the study if you decide to take part.

What if we decide not to take part?

- We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your son/daughter's treatment in Temple Street Children's University Hospital.

What will be done with the information collected from us?

- Only the research team and possibly the examiners of my thesis will have access to your answers and these will be treated in the strictest of confidence.
- Any information collected from either written notes or recordings will be transcribed and made anonymous (i.e. the written version of interviews will not have your or your son/daughters name on it, but will be numbered so we can identify it later). All information from the study (i.e. paper documents, artwork, digital recordings etc.) will be destroyed after 5 years. Any personal details recorded during observations or interviews pertaining to you and your son/daughter such as contact details or signed consent forms will be stored separate to the audio recordings.

- All information will be stored in locked filing cabinets and/or on password-protected/encrypted computers in DCU.
- The information we collect from all the families who take part will be used to write a report on the findings. The findings from the study will be reported in the researcher's thesis and may be published in journals however no information that might identify you or your family will be used.
- Anything your adolescent will say to me will be kept private between the research team and your family. We will only break this privacy if there is a concern for a child's safety. In this situation, we are obliged to bring this to the attention of staff in Temple Street. You and your son/daughter will be made aware of this need should the situation arise.

What use will this study be to me and my adolescent?

- While there may be no immediate benefits to your son/daughter, from taking part in the study, the researchers hope that studies such as this one can be used to identify the needs of adolescents living with chronic kidney disease.
- It is believed that knowledge gained from this study will have clear benefits for other children/adolescents in the future as this study will help hospital staff to understand the lives of children/adolescents living with kidney disease. It is also an opportunity for your son/daughter to share your experiences with others.

Are there any risks or downsides to taking part?

There is a chance that you or your son/daughter may feel upset or uncomfortable talking about your/their experiences.

- We realise that while you or your son/daughter is talking about chronic kidney disease, he/she or you may feel upset. If you or your son/daughter becomes upset when talking to me, we will ask you or your son/daughter if he/she or you want to stop or take a break.
- After the study, if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (the renal psychologist) who can advise you on next steps.

What if I, or my* son/daughter*, change their mind?

- If your son/daughter agree to take part but later change your minds, all you have to do is let me know by a phone call or email. You do not have to give a reason for withdrawing and withdrawing from the study will in *no way* affect your involvement in TSCUH.

I need more information before I make up my mind

- If you would like to talk informally with me about any questions or queries you may have about this research, my contact details are below.

You can contact me with any questions you have about this research on 01 7007157 or colleen.oneill@dcu.ie. I would be more than happy to address any questions or concerns that you may have.

Additionally, you can contact my supervisor at briege.casey@dcu.ie. I will contact you, with your permission in one week to see if your son/daughter would like to take part and you would like to support their involvement. If you agree to take part, I will arrange a time and place that suits you to meet to discuss this further and answer any queries you might have. I will also ask you at this time to sign a consent form for both you and your son/daughter's participation.

Appendix F: Parental Consent Form

Research Study:
Adolescent's embodied experience of living with Chronic Kidney Disease

Parental Consent form

We are doing this study to try and find out more about adolescent's bodily experiences of living with chronic kidney disease. In particular, we want to know how living with chronic kidney disease impacts on adolescents' life.

This study is being carried out by Colleen O'Neill (which is me the researcher) and Dr. Briege Casey and Dr. Veronica Lambert from the School of Nursing and Human Sciences at Dublin City University (DCU). This research was developed in conjunction with Dr. Michael Riordan and Dr. Niamh Dolan in the Children's University Hospital, Temple Street.

Participants name (s) *(please list here your name(s) and the full names of all your children aged 10-17 living with chronic kidney disease who you consent to participate)***:**

Parent Name 1: ____________________________
Parent Name 2: ____________________________
Adolescent Name: ____________________________

I confirm that I have read and understood the Information Leaflet for this research study and have received an explanation of the nature, purpose, duration of the study, what involvement my adolescent will have in the study and any possible risks to my family.

I have had time to consider whether I want my adolescent to take part in this research. I understand that participation in the study is voluntary, (that is, I have a choice as to whether I consent to my adolescent and I taking part). I have the contact details of the researchers and they have answered any questions I might have.

I understand also that I am free to end my participation at any time by contacting Colleen and this will not affect my family's or my adolescent's present or future association with any of the services connected with the research, including medical care.

I understand that this study involves the researcher (Colleen) spending time with my adolescent and me over the next 18 months at various times and in different places i.e. both in the hospital and home setting. I understand that it will involve my adolescent taking part in interviews, observations and participatory activities and will also involve my participation in informal observations and conversations with Colleen.

I confirm that I have explained the research to my adolescent.

☐ **I give consent for my adolescent as named above to take part in this research.**

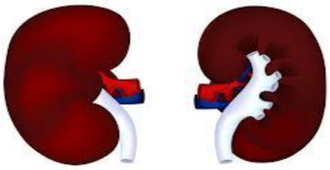
☐I give consent for artwork or photographs of artwork produced by adolescent as named above to be included in the final thesis or publications that may arise from this research.

☐ I give consent for my own participation in this research.
(one or two parent/s please sign below)

Your name	Date	Signature
Researcher’s name	Date	Signature

Appendix G: Young Persons Information Sheet (aged 10-12 years)

- ***What's the project about and who will be doing the project?***

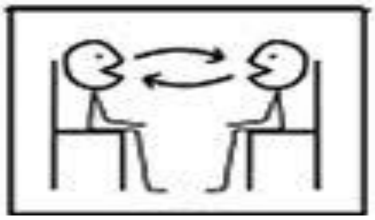


- My name is Colleen O'Neill. I am a student in Dublin City University. I am doing a project (which is a bit like homework) about kidney disease. I would like to know more about what it is like to live with kidney disease. I am especially interested in what issues and experiences you feel are important to you at your age.

Why do I you need me?

- There are lots of books and reports about kidney disease but very few reports have asked young people what they think. I would like to hear about your experience from your point of view. I am really interested in learning about how your body feels and how your body is effected by kidney disease.
- I hope what you share with me will help other young people, parents and people working with kidney disease understand what it is like to live with kidney disease.

- ***What will I do in the project?***



- I will spend time with you and chat to you about what it is like to have kidney disease.

- I will also ask you if you would like to use a different way to explain what it is like to have kidney disease like using body drawings. You do not have to be good at drawing to take part. You do not have to use these if you prefer not to.

- ***How many young people are helping with the project?***
- I will be talking and spending time with young people aged between 10 and 17 years. I will also be talking to parents
- *Where will we meet and how long will this all take?*

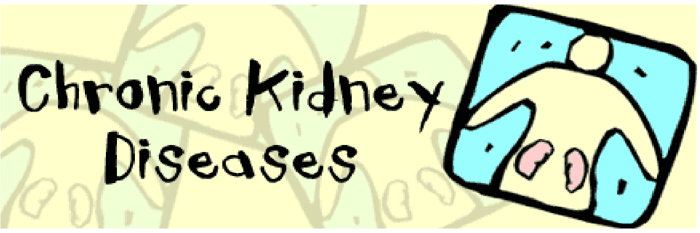
- I will visit you in the hospital and at home for short time on different days that suit you. I will probably stay with you for an hour or two

- ***What will happen to my answers/drawings?***
- With your permission I will take notes and I will also audio record our conversations.
- I will be writing a long essay about what you tell me but I won't mention your name in the essay. If you give me permission, I will take pictures of your drawings and put them in my project. I will not put your name on your drawings.

- ***Safety and Well being***

- I will keep our conversations as private as possible but if you tell me you or another young person might be in danger, I will have to tell someone about this.
- If you become upset during our conversations, I will ask you if you want to stop, take a break or if you would like to have your parent sit with you to make you feel more comfortable.
- *Who can I ask if I have questions about the project?*
- If you have any questions you want to ask me before I visit you can ask your parents if it is ok for you to contact me. I'd be very happy to answer any questions you have.
- ***What if I don't want take part?***
- That is fine. I won't mind at all.

Appendix H: Young Persons Information Sheet (aged 13-17 years)



What is this study about?

- We are doing this study to find out more about your experience of living with chronic kidney disease. We are particularly interested in hearing your views as well as your experiences of how kidney disease affects your body and body image.

Who is conducting this study?

- This study is being carried out by Colleen O'Neill, Dr. Briege Casey and Dr. Veronica Lambert from the School of Nursing and Human Sciences at Dublin City University (DCU). I (Colleen) am a qualified children's nurse and I am completing this work as part of a degree programme I am the person you, will have most contact with if you agree to take part.

What will I be asked to do in this research project?

- We would like to have an opportunity to observe and speak with young people like yourself who are **between 10 and 17 years of age** and who have been diagnosed with chronic kidney disease.
- I will spend time with you in the hospital and at home if this is okay with you.
- I will gather this information through the use of observations (seeing), conversations (interviews) and participatory activities (art).

Some questions you might have…….

What type of questions will we be asked during interviews?

- I will sit down with you and get to know you. During our conversations you can tell me your views and experiences of what it is like to have chronic kidney disease.
- You will be given the option of having your parents with you or you can speak with me alone. It is your decision.
- I will audio-record our conversations with your permission.

What is meant by participatory methods?

- Participatory methods are activities which encourage young people to actively take part in research through the use of creative techniques such as art/drawing.
- In this study I will ask you to draw (or have drawn) your body outline onto a large surface and use colours, pictures and words to represent experiences lived through your body.
- Artwork produced by you may be used in the final study report; however, your name will not be on the artwork.

How long will it take?

- I will spend time with you over the next year and half. This will mean I will meet with you a few times a month. This could involve a day here and there and then at other times it might involve me spending more time with you for example if you are in hospital. I will work out a plan of meeting times with you and your parents at the start of the study if you decide to take part.

What use will this study be to me?

- While there may be no benefit to you from taking part in the study, I hope that studies such as this one will help to develop peoples understanding, and knowledge of kidney disease. It is also an opportunity for you to share your experiences with others

What if I don't take part?

- That is fine with me and I will respect your wishes. If your parent gives permission for you to take part in the study, this does not mean you *have* to take part. It is your decision.

What will happen to the information I give you?

- I will take notes of what I see and I will also take notes of our conversations. I may also tape record some of our conversations.
- I will keep the notes and any tape recordings locked up safely so that no one else can see or hear them. I will be writing a long essay about what you tell me but I won't mention your name in my project.
- Any photographs of your artwork used in the final report or publications will not contain your name on it anything you say to me will be kept private as possible. I will only break this privacy if there is a concern for you or another young person's safety.

Are there any risks or downsides to taking part?

- There is a chance that you may feel upset or uncomfortable talking about your experiences.
- If you become upset when talking to me, I will ask you if you want to stop, take a break or if you would like to have your parent sit with you to make you feel more comfortable.
- If you feel it might help to talk to somebody, I can put you in touch with someone (the renal psychologist) who can help you.

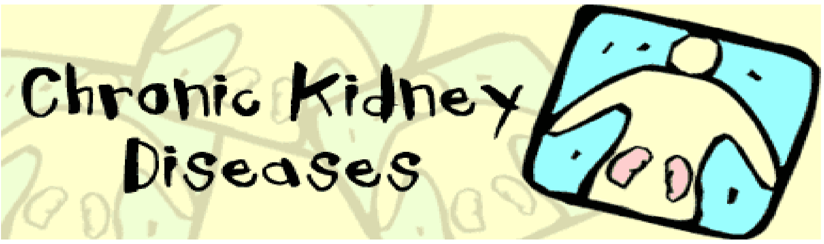
What if I change my mind?

- If you agree to take part but later change your mind, all you have to do is let me know. You do not have to give a reason and your decision will in *no way* affect your care in hospital.

I need more information before I make up my mind!

- I would encourage you to discuss this project with your parents and if you would like to ask me any questions ask your parents for permission to contact me or I can answer your questions the next time we meet

Appendix I: Young Persons Assent Form (participants aged 10-12 years)



- I,________________________ have agreed to be take part in a project to help others to find out about what it is like to live with Chronic Kidney Disease.

- I know that Colleen will chat to me about living with kidney disease and wants to know how my body feels and how my body is changed by kidney disease. Colleen just really wants to know my story.

- I understand that Colleen spend watching me as I live my everyday activities
- I know I can use body drawings if I want but I understand I don't have to. If Colleen wants to put my drawings in her project, I know she won't put my name on it and will ask me first. I understand that I can say no if I don't want her to put my drawings in her project.

- I understand Colleen will visit me over 18 months and spend time with me at home and during my hospital visits.

- I know this project might help other young people like me in the future.

- I know that I don't have to take part in this project even if my parents are ok with me taking part. It is up to me whether I wish to take part or if I decide to stop at any time, I know no one will be annoyed.

- I have been promised that anything I tell Colleen will be kept as private as possible unless I tell her I or another young person is in danger.

- I know that I can ask questions at any time now or later.

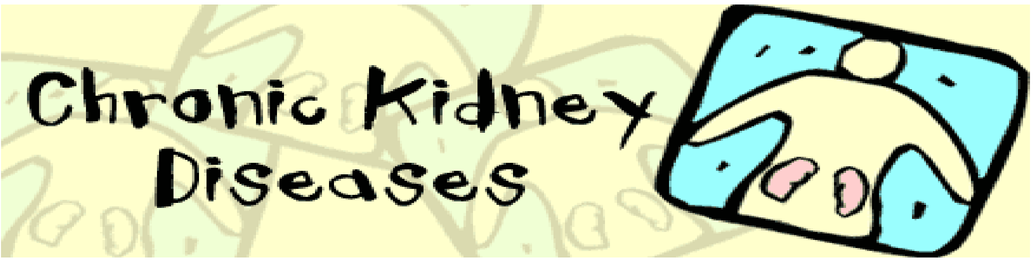
- I really want to take part in this research project.

- **Young Person's Signature: _________________________________**

- **Researcher signature: ______________________________**

- **Date and time: ____________________________________**

Appendix J: Young Person’s Assent Form (participants aged 13-17 years)



- I have read and understood the Information Leaflet for this project and have spoken to my parents about the project.
- I understand that Colleen will spend time talking to me to understand my experience of living with Kidney Disease. I can use art/drawings to explain my story.
- I understand Colleen will spend time with me in the hospital and also at home.
- I understand that I do not have to take part in this project even if my parents give permission. It is my decision.
- I understand that conversations will be audio-recorded.
- I understand Colleen may use my artwork or photographs of my artwork in her final report or in papers she may write.
- I understand that I can change my mind about taking part in this project at any time and this will *not* affect my care in hospital.
- I understand that anything that I say will be kept private as possible. Colleen will only break this privacy if there she is worried about my or another young person’s safety.

☐ I agree to take part in this project.

Your name	Date	Signature
Researcher’s name	Date	Signature

Appendix K: Protocols regarding Child Protection Issues

Protocol if adolescent participant discloses he/she is at risk either in home/hospital setting

It will be stressed at the outset of the study to parents and adolescents that absolute confidentiality cannot be guaranteed. This is when child protection issues arise. If the child discloses any information that she/he or anyone else is at risk (i.e. abusive behaviour) the researcher (Colleen O'Neill) is obliged under the Children First: National Guidelines for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2017) to safeguard the welfare of the child regardless of the effect this will have on the study. The lead researcher will attend child protection training in Temple Street Children's Hospital prior to commencing data collection.

In accordance with the Department of Children and Youth Affairs Children's First document (2011) should an adolescent disclose issues relating to safety, the protocol below will be observed:

1. "………. [*name of adolescent*], you've told me that ……………... [*e.g. someone is hurting you*]. This is something that I can't keep private between us, I need to tell, so that someone can help you. You are very brave to have told me though. I have to tell………… [*name of* designated person in TSCUH] about this so that she/he can arrange things, so that you can be helped."
2. Gently end the particular data collection method, ensuring the adolescent is not distressed or allowing her/him time to recover if he/she is distressed.
3. Depending on the nature of the disclosure, the researcher will make a judgement, based on the best interests of the adolescent, whether or not to inform the parent/s of this disclosure.
4. Agreed staff member at TSCUH is informed of disclosure as soon as is possible (preferably immediately). Any concern of abuse etc. will be reported to the on-duty social worker of the appropriate health board.
5. Outside normal hours or if there is a serious threat to the adolescent or other children the Gardaí will be informed immediately
6. Information will be accurately recorded using templates from the National Guidelines for reporting such allegations.

Protocol if Researcher observes or witness risk to child/adolescent in home setting:

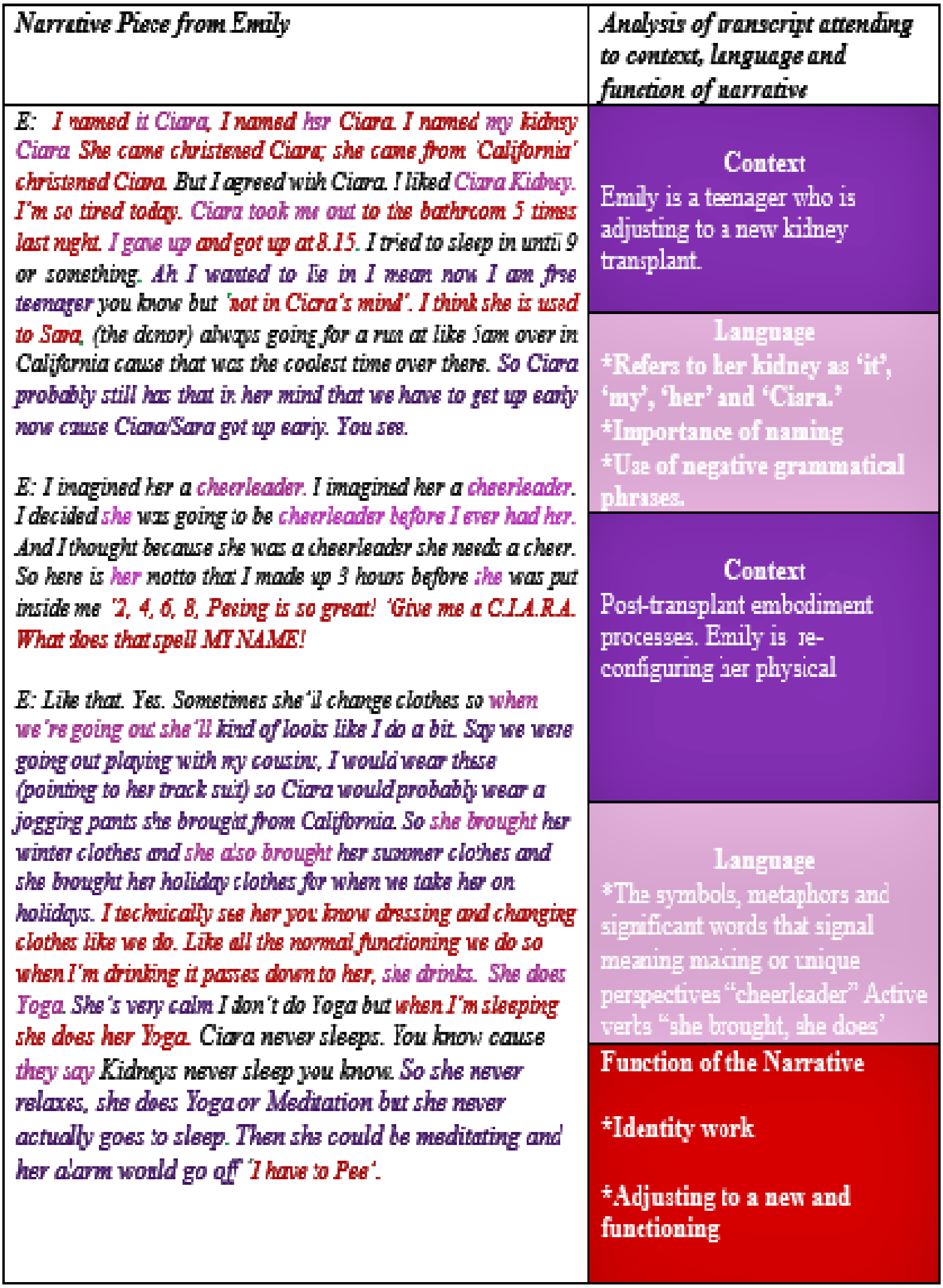
In accordance with the Department of Children and Youth Affairs Children's First document (2017) should the researcher observe or witness any issues relating to adolescent safety in the home setting, the protocol below will be observed:

1. Any concern of abuse, neglect etc. will be reported to local HSE Children and Family Services by the primary researcher (Colleen O'Neill).
2. If the researcher feels the adolescent or other children are in immediate danger and cannot contact the HSE Children and Family Services, the researcher will contact Gardaí at the local Gardaí station.
3. The primary researcher will inform parents if a report is to be submitted to the Children and Family Services or to a Garda Siochanan unless doing so is likely to endanger the child or adolescent.
4. Information will be accurately recorded using templates from the National Guidelines for reporting such allegations.

Protocol for reporting unsafe practice in the hospital environment.

Under the code of Professional Conduct and Ethics for Registered Nurses and Midwives (2013), the primary researcher (Colleen O'Neill) has an obligation to share concerns about poor standards of practice or safety risks identified during the course of her fieldwork. If the safety or well-being of an adolescent is affected or put at risk by a staff member's actions, omissions or incompetence's the researcher must first take appropriate action to protect the adolescent from immediate harm and report such conduct to the appropriate personal i.e. the principal investigator and the clinical nurse manager of the ward. In accordance with the Department of Children and Youth Affairs Children's First document (2011) should the researcher **observe or witness** any concern of abuse, neglect etc. relating to adolescent safety in the hospital setting, the lead researcher will report such concerns to the designated person in TSCUH. The researcher will inform health care staff of this protocol at information sessions and will also be outlined in the staff information sheet.

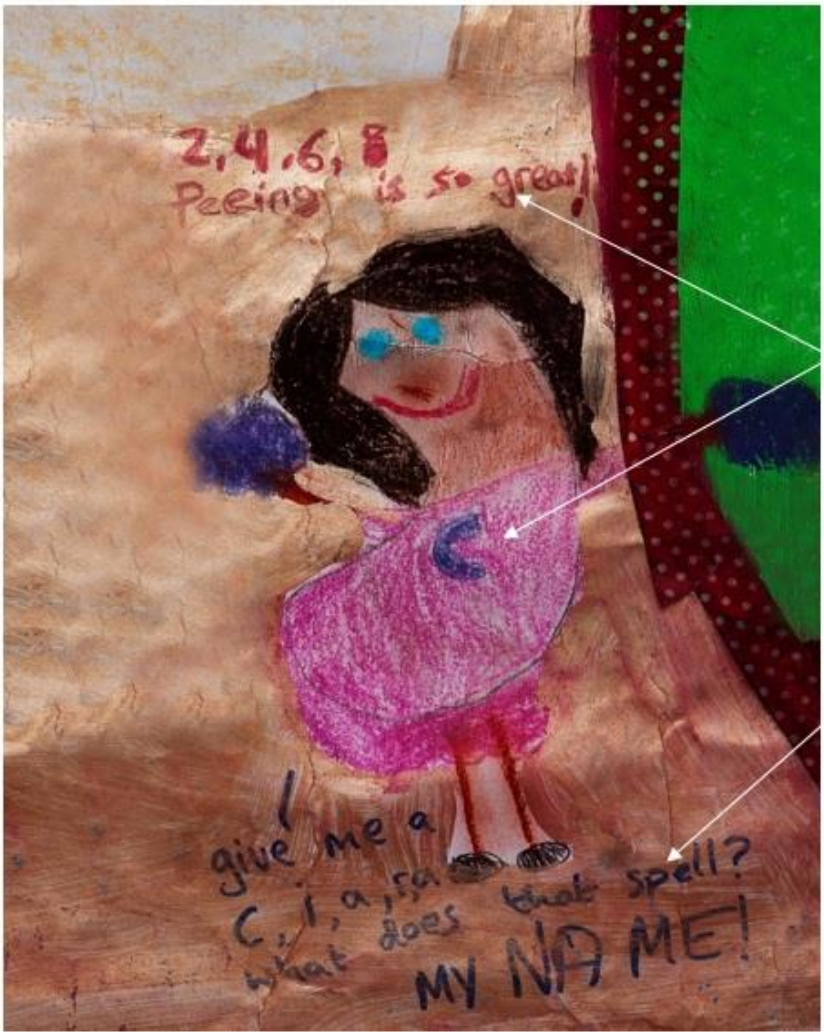
Appendix L: Excerpt from Interview Transcript (Emily)



Narrative Piece from Emily	*Analysis of transcript attending to context, language and function of narrative*
E: I named it Ciara, I named her Ciara. I named my kidney Ciara. She came christened Ciara; she came from 'California' christened Ciara. But I agreed with Ciara. I liked Ciara Kidney. I'm so tired today. Ciara took me out to the bathroom 5 times last night. I gave up and got up at 8.15. I tried to sleep in until 9 or something. Ah I wanted to lie in I mean now I am free teenager you know but 'not in Ciara's mind'. I think she is used to Sara, (the donor) always going for a run at like 5am over in California cause that was the coolest time over there. So Ciara probably still has that in her mind that we have to get up early now cause Ciara/Sara got up early. You see. *E: I imagined her a cheerleader. I imagined her a cheerleader. I decided she was going to be cheerleader before I ever had her. And I thought because she was a cheerleader she needs a cheer. So here is her motto that I made up 3 hours before she was put inside me '2, 4, 6, 8, Peeing is so great! 'Give me a C.I.A.R.A. What does that spell MY NAME!* *E: Like that. Yes. Sometimes she'll change clothes so when we're going out she'll kind of looks like I do a bit. Say we were going out playing with my cousins, I would wear these (pointing to her track suit) so Ciara would probably wear a jogging pants she brought from California. So she brought her winter clothes and she also brought her summer clothes and she brought her holiday clothes for when we take her on holidays. I technically see her you know dressing and changing clothes like we do. Like all the normal functioning we do so when I'm drinking it passes down to her, she drinks. She does Yoga. She's very calm I don't do Yoga but when I'm sleeping she does her Yoga. Ciara never sleeps. You know cause they say Kidneys never sleep you know. So she never relaxes, she does Yoga or Meditation but she never actually goes to sleep. Then she could be meditating and her alarm would go off 'I have to Pee'.*	**Context** Emily is a teenager who is adjusting to a new kidney transplant. **Language** *Refers to her kidney as 'it', 'my', 'her' and 'Ciara.' *Importance of naming *Use of negative grammatical phrases. **Context** Post-transplant embodiment processes. Emily is re-configuring her physical **Language** *The symbols, metaphors and significant words that signal meaning making or unique perspectives "cheerleader" Active verbs "she brought, she does' **Function of the Narrative** *Identity work *Adjusting to a new and functioning

Appendix M: Analysis of Image from Emily's Body

Image of Ciara Kidney from Emily's body map



***Ciara Kidney**: The Cheerleader*

Ciara's Motto

2, 4, 6, 8, Peeing is so great! 'Give me a C.I.A.R.A. What does that spell MY NAME!

Image Analysis Summary
In applying performance analysis, I considered how and when this image was made, the work or function of visual images, the stories behind the images, the language used (including words, captions, colours etc.) and the audiencing process (who the image was made for) and other relevant aspects of the image-making process. As part of analysis, I had to critically engage with this image and in doing so, I had to acknowledge my part in its production (i.e. I provided the stimulus for thinking about image creation through the use of body mapping activities as outline in Section 3.3). In creating this image, Emily is representing her experience of transplant. She draws her transplanted kidney in the form of

person. This person is a young female whom she gives the name Ciara. The image depicts her transplanted kidney as a young cheerleader with long dark hair, blue eyes and a beaming smile. She uses vibrant colors for her image. She is wearing a bright pink dress with the initial *‘C’* on it and she is holding a blue pom-pom in each hand. This image is created six months after receiving a transplanted kidney. The function of this narrative is to visual represent Emily’s internal struggle in assimilating the transplanted kidney into her body and sense of self. The language used in this image is interesting. She creates a motto *‘2, 4, 6, 8’ Peeing is so great!* The language used suggests that she is excited about experiencing the bodily function of *‘Peeing’*. The language in this visual image also alludes to her struggles with identity. Her statement supports this interpretation ‘*Give me a C.I.A.R.A. What does that spell my NAME!*’ Emily is performing *‘Ciara’* as an entity separate to her.

Appendix N: Research Dissemination

Conference Proceedings

O'Neill C, Casey, B., Lambert, V. and Awan, A. (2019) *'I have a dead person's kidney in me'*: *The Struggles of Self-identity among Adolescent Kidney Recipients in Ireland*. 9th Europaediatrics Congress. 13th-15th June 2019. Convention Centre, Dublin, Ireland. *(oral presentation*).

O'Neill C, Casey, B., Lambert, V. and Awan, A. (2019) *Adolescents' use of metaphors to narrate their experiences of living with Chronic Kidney Disease: An Irish Perspective*, 9th Europaediatrics Congress. 13-15th June 2019. Convention Centre, Dublin, Ireland. (Poster Presentation).

O'Neill C, Casey, B., Lambert, V. and Awan, A. (2019) '*Get Me a Kidney so I can Grow': Adolescents Experience of Delayed Growth and Puberty in Chronic Kidney Disease*' CHI at Temple Street Research, Audit & QI Day, 7th June 2019.Children's Health Ireland at Temple Street, Dublin, Ireland. (*Rapid Fire Poster Presentation*).

O'Neill C, Casey B, Lambert, V. and Awan, A. (2019). *'Making Meaning of Illness Experience. Narratives of Adolescents with Chronic Kidney Disease'*. 5th International Irish Narrative Inquiry Conference Exploring Creativity in Narrative Inquiry. May 2nd-3rd 2019. Trinity College Dublin, Ireland. *(Guided Poster Presentation).*

O'Neill, C., Casey, B. and Lambert, V. (2018) *'Using body mapping creatively to engage and communicate with adolescents in health related research'.* 16th International Conference on Communication in Healthcare. 1st-4th September 2018. Faculty of Engineering of the University of Porto (FEUP), Portugal. *(oral presentation*).

O'Neill, C., Casey, B. and Lambert, V. (2018) *'They speak in doctorish': Adolescents' perspectives of communicating with healthcare professionals*. 16th International Conference on Communication in Healthcare. 1st-4th September 2018. Faculty of Engineering of the University of Porto (FEUP), Portugal. *(oral presentation*).

O'Neill, C., Casey, B. and Lambert, V. (2018) *'Organised Chaos': Adolescents perspectives of the impact of Chronic Kidney Disease on their psychosocial wellbeing.* European Working group on Psychosocial Aspects of Children with Chronic Renal Failure 49. Annual Meeting.14th/15th June. Budapest, Hungry. *(oral presentation).*

O'Neill, C., Casey, B. and Lambert, V. (2018) 'I *know what I'm doing here'*: An adolescents embodied experience of living with Chronic Kidney Disease. 4th International Irish Narrative Inquiry Conference April 19th / 20th 2018. Sligo IT, Sligo, Ireland *(oral presentation).*

O'Neill, C, Casey, B. and Lambert, V. (2016) *'Body Mapping: a creative and innovative method of exploring adolescents' embodied experience of living with chronic kidney disease.* 6th Annual Nursing Research Conference Children's University Hospital, Temple Street, Dublin: Ireland, February 24th 2016. *(oral presentation).*

O'Neill, C, Casey, B. and Lambert, V. (2016). *'Adolescent's embodied experience of living with Chronic Kidney Disease'.* Anthropological Association of Ireland Annual Conference. March

15th 2016, National University of Ireland, Maynooth, Ireland. *(oral presentation).*

O'Neill, C, Casey, B. and Lambert, V. (2016) *'So Much Pain': An adolescent's experience of living with Chronic Kidney Disease.* School of Nursing and Human Sciences Research Nov 23 rd November 2016. Dublin City University, Dublin, Ireland. *(oral presentation).*

O'Neill, C, Casey, B. and Lambert, V. (2015) *'Adolescent's embodied experience of living with Chronic Kidney Disease'.* 5th Annual Nursing Research Conference Children's University Hospital. March 5th 2015, Temple Street, Dublin. Ireland.

O'Neill, C, Casey, B. and Lambert, V. (2015) *'Adolescents' embodied experience of living with Chronic Kidney Disease'.* Research Fair**.** April 29th 2015. Dublin City University, Dublin, Ireland. *(poster presentation).*

Appendix O: Coding of Stories

Example of Initial Coding of Stories from Individualised Narratives

Story from Lucy's Case	Story theme	Initial coding
After transplant I was really bloated because obviously there's a new body part in your body. It's new weight. It's a new body part. It's hard to get used to, but it's fine now. It just feels like something under the skin, like a little bit of a bulge there. It's big. It's like where the scar is, so it's all the way down that way. It still feels a bit weird because I feel uneven…because I have a body part that's bigger than what mine would have actually been. This is an actual kidney, whereas mine would have been...I had two kidneys, but they were literally like that size (demonstrates small size through gesture) Non-existent, yeah. [laughter] So it's weird to get used to. Not in a noticeable way but just when I'm like thinking about it, like I have this extra weight on one side. It's weird…right after transplant it was really weird and I didn't feel comfortable with it or anything.	Body disrupted following transplant surgery. Awareness of a new body part that feels heavy. Difficulty in adjusting to new body part. Visceral and sensual awareness Perceived change in internal body-feels uneven/bigger Comparing her kidney to the new functioning kidney. Perceived change in internal body- extra weight on one side Feeling uncomfortable with new body part Fear associated with new body part	Body invaded by transplant Changed body Changed body Altered Self Changed body Body Invasion

For a while I refused to stand up without holding onto it because I felt like it was falling out, weirdly, because I wasn't used to the weight of it, like it felt heavy. Like even after I knew it was all good and I was like wandering round the ward so that I could try and fall asleep, I was still walking around like this and then I was going, ‘No, wait, I don't need to hold on to this,’ and I’d hold onto it again. And every now and then I’d be like, ‘Oh yes, this is like someone else’s kidney’, "I have a dead person's kidney in me..." Then I was like, hm... That's weird. [laughter] I'm mostly just like, 'Thanks,' because, I'm glad that the family made this decision; that this person made this decision, it's... Nice. It's weird, but it's also nice. It's weird but... it's like, 'Oh my god, I have this person's kidney.' [laughter] It's like it's not...yeah, it's still a kidney. It's still someone else's kidney. It's not yours - well, technically it is now,	Protective of new kidney Difficulty in adjusting to new body part. Protective of new kidney despite knowing there is no need hold onto new body part. Realisation that new body part once belonged to another Appreciating and acknowledge the dead person’s decision. Difficulty in perceiving the kidney as part of her	Altered Self Body Invaded by Foreign body part Altered Self Body Invaded by Foreign body part Positive reaction Altered Self

Appendix P: Establishing Overarching Themes

Story Themes	**Initial Codes**	**Sub-themes**	**Overarching Themes**
Inability to engage the world in habitual ways due to CKD. Body function and abilities and development are altered which caused fear and uncertainty and bodily disruption.	Changed body. Bodily appearance. Body dysfunction. Delayed growth and puberty. Body suffering. Loss of control over body.	*Bodily disruption.* *The out-of-control body.*	*Experiencing the ill body.*
Treatments caused considerable upheaval. Disruption to the intact body. Fear of the effects of dialysis and surgery. Strange and unfamiliar body.	Fear of effects of treatment on the body. Loss of body integrity. Disruption and fear. Threatened body stability.	*Body invaded by medical treatment.* *Body invaded by foreign body parts*.	*Body invasion.*
Changed sense of self. Not the same as their former self and this has many negative consequences. Change in way of understanding self. The experience of CKD and treatment caused a lack of body mastery and control over life.	Disruption to Self. Changed Self. Loss of control.	*The healthy self-versus the ill self.* *The altered and changed self.*	*Loss of habitual self.*

Appendix P: Establishing Overarching Themes Continued

Story Themes	**Initial Codes**	**Sub-themes**	**Overarching Themes**
Adolescents struggle to be seen and heard in medical interactions and encounters.	Medicalised language. Medicalised approach to care. Exclusion. Invisibility. Asserting body knowledge.	*Invisibility and exclusion through objectification and medicalised language***.** *Tensions between embodied and medical knowledge.* *Social suffering and desire to communicate beyond the bio-medical plot.*	*Regarding the ill body.*
Positive changes to self and to life as well as a changed perspective on the world.	Stoic Acceptance. Positive Reactions. Changed perspective on life. Body Awareness. Body knowledge.	*Enduring and Surviving CKD.* *Remaining Positive.*	*The Strong and Resilient Body.*

Appendix Q: Thematic Map

Theme	**Emily**	**Lucy**	**Maggie**	**Jack**	**Tara**
Experiencing the Ill Body	**Story 1** *‘Dry as a sandpit’* **Story 4** *‘Get me a Kidney so I can grow'* **Story 5** *'Ciara Kidney'*	**Story 2** *‘Which pain am I looking for here’* **Story 5** *‘Organised Chaos’*	**Story 2** *‘My lungs filled up with water’* **Story 3** 'Chronic Tiredness' **Story 4** *‘Chronic kids are always chronic kids’*	**Story 1** *‘It’s like being a vampire’* **Story 3** **‘***What am I? a criminal’?* **Story 2** *‘Scars don’t bother me’*	**Story 1** *‘I HATE the machine’* **Story 3** *‘Nurse! 100mls of Lucozade STAT!’* **Story 4** *‘I’d be so embarrassed’.*
Body Invasion	**Story 2** *'I'm the girl who survived and Happy Potter is the body who lived'* **Story 3** *'I have an interesting story but it’s not the only story’* **Story 5** *'Ciara Kidney'*	**Story 3** *‘I know I’d be able to (move) if this bloody catheter wasn't stabbing me’* **Story 4** *‘A new body part in your body'*	**Story 1** *‘I didn’t want it. I wasn’t sick'* **Story 2** *‘My lungs filled up with water’*	**Story 1** *‘It’s like being a vampire’* **Story 2** *‘Scars don’t bother me’* **Story 5** *‘No way am I taking someone else's kidney’*	**Story 1** *‘I HATE the machine’* **Story 2** *‘Oh they're seeing the machine'* **Story 4** *‘I’d be so embarrassed’*
Loss of habitual self	**Story 2** *'I'm the girl who survived and Happy Potter is the body who lived'* **Story 5** *'Ciara Kidney'*	**Story 4** *‘A new body part in your body'*	**Story 1** *‘I didn’t want it. I wasn’t sick'* **Story 2** *‘My lungs filled up with water’* **Story 3** 'Chronic Tiredness' **Story 5** *‘You’ve got to go back’*	**Story 1** *‘It’s like being a vampire’* **Story 4** *‘I’m stuck’* **Story 5** *‘No way am I taking someone else's kidney’*	**Story 2** *'Oh they're seeing the machine'*

Appendix Q: Thematic Map Continued

Stories relating to emergent cross case themes

Theme	**Emily**	**Lucy**	**Maggie**	**Jack**	**Tara**
Regarding the ill body.	**Story 1** *‘Dry as a sandpit’* **Story 3** *‘I have an interesting story but it’s not the only story’*	**Story 1** *‘I know what I’m doing here’* **Story 3** *‘I know I’d be able to (move) if this bloody catheter wasn't stabbing me’* **Story 5** *‘Organised Chaos’*	**Story 2** *‘My lungs filled up with water’* ***Story 4*** *‘Chronic kids are always chronic kids’*	**Story 2** *‘Scars don’t bother me’* **Story 3** *‘What am I? a criminal’?* **Story 4** *‘I’m stuck’*	**Story 2** *'Oh they're seeing the machine'*
The strong and resilient body	**Story 1** *‘Dry as a sandpit’* **Story 2** *'I'm the girl who survived and Harry Potter is the body who lived'*	**Story 3** *‘I know I’d be able to (move) if this bloody catheter wasn't stabbing me’* **Story 4** *‘A new body part in your body'* **Story 5** *‘Organised Chaos’*	**Story 2** *‘My lungs filled up with water’* **Story 3** *'Chronic Tiredness'*	**Story 2** *‘Scars don’t bother me’* **Story 4** *‘I’m stuck’*	**Story 1** *‘I HATE the machine’* **Story 3** *‘Nurse! 100mls of Lucozade STAT!’* **Story 4** *‘I’d be so embarrassed’*