Linköping Studies in Arts and Sciences No. 815

A parental perspective on child chronic kidney disease: The lived experience of caregiving in Portugal

Andréa Bruno de Sousa

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Linköping Studies in Arts and Sciences No. 815
Faculty of Arts and Sciences
Linköping, 2021

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Distributed by:
Department of Culture and Society (IKOS)
Linköping University
581 83 - Linköping

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Edition 1:1

ISBN 978-91-7929-041-2 (print)
ISSN 0282-9800

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Department of Culture and Society (IKOS)

Cover by Andréa Bruno de Sousa, Ana Cristina Bruno de Sousa and Michelly M. T. L. Trevisan

Printed by: LiU-Tryck
Linköping, 2021

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TO MY FAMILY

Especially to the memory of my beloved Mother

Abstract

Paediatric chronic kidney disease (CKD) requires complex care and radically transforms the everyday life of the child's family. This thesis examines parents' lived experience of dealing with a child's CKD; how social and economic circumstances impact on families' opportunities to manage the care; and how parents view and practise their parenthood. The thesis takes inspiration from the phenomenology of practice, material culture studies and parenting culture studies. The research is based on ethnographic fieldwork in a paediatric hospital in Portugal and in the participating families' home environments. Thematic analysis was used to analyse the empirical material.

The first study addresses the ethnographic methods used in the study and the challenges involved in examining parents' lived experiences of managing caregiving. It demonstrates that the challenges involved in carrying out fieldwork among families in crisis can function as openings for discovering the multifaceted and complicated realities the families encounter. The second study shows that parents use all the available financial and human resources to manage the technically demanding care and create normality. It also shows that, while parents experience becoming confined and close relationships as strained, the mundane practices and social relations of care bring hope and meaning to the family. The third study demonstrates that good parenthood for the participants means focusing on the child's survival and well-being, and requires constant vigilance and readjustments, what I term "readiness parenting".

This research contributes to creating knowledge about the complexity of caring for a chronically ill child, the relational and material aspects of caregiving and how norms about responsible parenthood are negotiated. It also demonstrates the need for qualitative research methods to understand parents' lived experiences and create knowledge about their meaning-making, needs and competencies.

Keywords: child chronic kidney disease, ethnography, phenomenology of practice, material culture studies, parenting culture studies.

Sammanfattning

Vården av barn med kronisk njursjukdom (CKD) är mycket komplex och förändrar en familjs vardag radikalt. Denna avhandling undersöker föräldrars levda erfarenhet av att vårda ett barn med kronisk njursjukdom: hur både sociala och ekonomiska omständigheter påverkar en familjs möjlighet att hantera vården och hur föräldrarna uppfattar och utövar sitt föräldraskap. Avhandlingen hämtar inspiration från praktisk fenomenologi, studier av materiell kultur och föräldraskapsstudier. Forskningen bygger på ett etnografiskt fältarbete på ett barnsjukhus i Portugal och i de deltagande familjernas hem. Tematisk analys används för att analysera det empiriska materialet.

Den första studien behandlar etnografisk metod och vilka svårigheter det kan innebära att undersöka föräldrars erfarenheter av att hantera vården av ett njursjukt barn. Studien visar att utmaningarna i att genomföra ett fältarbete bland familjer i kris kan fungera som ingångar till att upptäcka de mångfacetterade och komplicerade verkligheter som familjerna möter. Den andra studien visar att föräldrarna använder tillgängliga ekonomiska och mänskliga resurser för att hantera den tekniskt krävande vården och samtidigt skapa normalitet. Studien visar också att medan föräldrarna upplever stora begränsningar och att deras nära relationer får utstå påfrestningar, skapar vardagliga göromål och nya sociala nätverk hopp och mening för dem. Den tredje studien visar att ett gott föräldraskap för deltagarna innebär ett fokus på barnets överlevnad och välbefinnande, och kräver ständig vaksamhet och anpassning, vilket jag benämner "readiness parenting".

Avhandlingen bidrar till att skapa förståelse för komplexiteten i vården av kroniskt sjuka barn, de relationella och materiella aspekterna av vårdandet och hur normer om ett ansvarsfullt föräldraskap förhandlas. Avhandlingen visar också på behovet av kvalitativa forskningsmetoder

för att kunna förstå föräldrars situation och skapa kunskap om deras behov och kompetenser.

Nyckelord: kronisk njursjukdom hos barn, etnografi, praktisk fenomenologi, materiell kultur, föräldraskapsstudier.

Acknowledgements

I would like to thank everyone who contributed in various ways to this research and to my life experience during this journey. First, my heartfelt thanks go to my family for supporting my choice to be far away from home and to keep travelling around Europe. Being apart from them has been the hardest condition that my choice of pursuing the PhD imposed upon us. My deepest gratitude goes to my brother Luis, who since day one has supported me in many ways, emotionally, financially, and even helping with the literature search and reading over my drafts and having long telephone conversations about my research. Many thanks also go to my sister Ana, who has been my private designer, assisting with PowerPoints presentations and posters.

This research received funding from the Phoenix Erasmus – Erasmus Mundus Joint Doctoral Programme in Dynamics of Health and Welfare of the European Union, and my enormous gratitude must therefore be expressed to the scientific committee that believed in my research. I am extremely grateful for the opportunity to conduct my research in different countries and within a variety of academic environments, which has enriched my research, my professional experience, and my life experience. Throughout this journey, countless colleagues and friends have made significant contributions to the final “result” – the thesis and articles. I would like to thank my main supervisor, Anette Wickström. I am grateful for her meticulous attention to detail, support throughout my PhD journey, and making it a valuable learning experience. Thanks, Anette, for the detailed reading of my outline’s innumerable versions, your constructive comments that helped me to improve my work and your reassuring words during this process. I also thank my co-supervisor, Ana Rita Goes, for her insightful feedback on my work and her keen interest and revisions of my drafts. I thank Laurinda Abreu for always being supportive and for providing detailed guidance throughout the various steps of the Phoenix Programme, for supporting me during the most challenging times and encouraging me to pursue the programme. I am also very grateful to Emme Vida for giving me the important opportunity to work with her at Keele University during my internship. I am very grateful to Anna Sparrman, who was my opponent in the 60% seminar, for her constructive and inspiring discussion which provided me with invaluable comments on my project and helped me to move forward with my thesis and article writing.

My sincere gratitude also goes to the families who participated in the study. This dissertation would never have been possible without the parents who kindly agreed to participate in the investigation, sharing their experience and knowledge that is not yet available in any books, which is to say, their unique treasures. Many thanks go to the health professionals who welcomed me to the Paediatric Hospital in Portugal, and for being supportive and encouraging during my fieldwork and also for reassuring guidance during my fieldwork.

I am also grateful to Bengt Richt, for welcoming me to LIU and helping me to develop my initial ideas for this project. I thank Ingemar Nordin, who supported me during the initial phase of the programme at LiU, and during my stay in Sweden. In addition, I thank Sam Willner for his support in dealing with administrative and practical issues. I would like to thank everyone who has helped me to navigate the many Phoenix requirements in Sweden, Portugal, and the United Kingdom. I am grateful to the administrative staff at Liu, ENP, and the EU (Marta, Suzana, Marieta, Isalia, Monica, Eva and many others who supported me, but the limited space does not allow me to list everyone) for always being there to help me navigate the many mobility requirements and for guiding me through the bureaucracy issues, from visas to registrations and conference participation. Many thanks to the Child Studies Department for welcoming me into the department, for the noteworthy discussions during the weekly seminars and weekly meetings to update the department's projects over Fika, and for the remarkable conversations and exchanges. I thank my colleagues in the P6 seminar (Body, Knowledge, Subjectivity) for their constructive feedback and inspiring discussions, which enriched my drafts and views of my subject with their multidisciplinary point of view. Thanks to Maria Cristina (Cris), Matias, and Klein for our interesting conversations over Fika, lunches, and dinners, and for the vital support during the time we spent together at LiU. Thank you Cris for your genuine friendship and for the memorable moments together, long conversations about life and scientific insights, and for becoming my family overseas. Also, huge thanks go to my office mates, Gosia and Vanessa, and all the colleagues from the Phoenix Programme to Felipe and Slavica for always encouraging me. Thanks to Fabiola and Pedro, who welcomed me into their home, hosting me for a semester. Thanks to SAS Nova residential student staff, who always welcomed me to Portugal. I am very grateful to John for improving my English and supporting me with kind words. I am also truly grateful to APIR

association for the tremendous help during my fieldwork, with special thanks to Marta. In summary, my deep gratitude to everyone whom I met on my journey of making this PhD, as everyone was an essential part of the accomplishment of this work.

My deep gratitude to everyone!

THANK YOU!

Andréa Bruno de Sousa

Brazil, October 2021

List of Studies

This thesis is based on three studies:

Study 1 - Bruno de Sousa, A. (2018) Adapting to parents in crisis: Tracing experiences of having a child with chronic kidney disease. In Plows, Alexandra (Ed.) *Messy Ethnography in Actions*, pp. 131–139.

Study 2 – Bruno de Sousa, A. and Wickström, A. (2021) Material and relational challenges of home-based renal care: A parental perspective on child chronic kidney disease. *International Journal of Care and Caring*. DOI: <https://doi.org/10.1332/239788221X16316492108700>

Study 3 – Bruno de Sousa, A., Goes, A.R. and Wickström, A. Readiness parenting: Practices of care by parents of children with chronic kidney disease in Portugal. (currently under review, after major revisions, with *Families, Relationships and Societies*).

Notes regarding the studies included in the thesis:

Study 1 This is a draft version of Bruno de Sousa, Andrea (2018) Adapting to parents in crisis: tracing experiences of having a child with chronic kidney disease in the book *Messy Ethnographies in Action* edited by Plows, Alexandra published in 2018 by Vernon Press, link: <https://vernonpress.com/book/385>

Study 2 This is a post-peer-review, pre-copy edited version of an article published in *International Journal of Care and Caring*. The definitive publisher-authenticated version, Bruno de Sousa, A. and Wickström, A. (2021) Material and relational challenges of home-based renal care: a parental perspective on child chronic kidney disease, is available online at: <https://www.ingentaconnect.com/content/tpp/ijcc/pre-prints/content-ijccd2100008>

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CHAPTER 1: INTRODUCTION

A chronic condition interferes with the patient's and their family's life to a great extent. The diagnosis of chronic disease in a child generates a crisis in the family, as it brings uncertainties and worries (Hanson et al., 2017; Tong et al., 2008; 2010). The parents' experiences are not only about dealing with a shorter or longer stay in hospital. They are facing a lifelong struggle to manage the disease. Parents' experiences are related to clinical practice, daily life and the arrangements for handling the condition at home (Santos, 2010; Swallow et al., 2011; Tong et al., 2010; Trnka and McLaughlan, 2012). The disease disrupts the family's routines, as it demands extensive care both in and beyond the hospital. In many cases, the parents' daily life is transformed from having a healthy child to having a child who needs constant medical care. Therefore, a child's chronic disease becomes a family condition or a family illness (Nijhof, 2018; Mol, 2008). A severe chronic condition changes the course of the entire family's life. It requires a new lifestyle centred around the treatment, sick leave from work and changing daily habits such as diet, meal schedules and remodelling of the house. Taking a break or a vacation requires detailed planning (Tong et al., 2010; Trnka, 2017).

In their classic study of managing chronic illness at home, Corbin and Strauss (1988) describe in detail the experience and impact of living with chronic illness and demonstrate how multifaceted the chronic illness condition is for families, including the critical role of balancing the tasks of everyday life, medical care and personal accommodation to the illness. Parents must adapt financially, emotionally and socially owing to the significant social, economic and psychological impact on both the ill person and the family (Tong et al., 2010; Swallow et al., 2009; 2011; Trnka, 20017; Medway, 2015). Management of the illness, which includes many doctors' appointments combined with daily tasks such as controlling diet, school issues, parenting other children, work and personal life, entails continuous and unending (re)structuring of routines and much flexibility

(Medway et al., 2015; Charmaz, 1991; Cimete, 2002). The new situation is not temporary but long lasting, often even permanent. It creates a crisis that is chronic and constitutes a pervasive context for people's lives (Vigh, 2008).

Owing to the difficulties associated with a child's chronic kidney condition, it is important to investigate and theorize how families make sense of and handle the situation. In addition, it is important to study how issues relating to the intensive and complex treatment intertwine with the family's daily life, and how the parents manage to keep up ordinary life. This thesis concerns families' experiences connected to their child's chronic kidney disease (CKD) condition and how parents develop knowledge from the onset of the disease, manage the condition and its treatment and make meaning out of the new situation. The thesis complements existing knowledge, revealing how parents handle the crisis and the chaos that the disease brings to their family. The research is relevant to health services that implement support for parents of children with CKD as it offers new perspectives on how parents manage their daily lives. It contributes to a broader understanding of parents' experiences and management of their child's CKD condition in everyday life, in that it extends beyond the investigations of the suffering subject and the impact of the disease.

In this thesis, I not only examine the continual doings in the hospital and at home, but also look for how parents develop strategies to handle the challenges they encounter, and what the disease and the caregiving bring to them, in the form of capacity and engagement. The thesis is based on ethnographic fieldwork in a Portuguese paediatric hospital and in the families' home environments, and creates knowledge about parents' lived experiences.

CHAPTER 2: THE PORTUGUESE CONTEXT

Chronic kidney disease (CKD) results from a variety of causes that can damage the kidneys. It involves five stages, ranging from stage 1 (mild kidney damage) to stage 5 (complete kidney damage). CKD causes loss of kidney function, and progresses to end-stage kidney disease (ESKD), at which point there is permanent loss of renal function (Darbyshire et al., 2006). CKD can develop at any stage during childhood (Heath et al., 2011), and because of its progressive nature, families must go through the different stages of the disease from the first symptoms to ESKD. In many cases renal replacement therapy is needed, through haemodialysis, peritoneal dialysis and/or renal transplantation (cf. Deuchande et al., 2016; Tong et al., 2008; Swallow et al., 2011).

The CKD treatments are conducted with medication and blood pressure control, and at some point, a kidney transplant is required (Furth, 2006). The main goal of the treatments is to slow the deterioration of kidney function (Becherucci et al., 2016; Furth, 2006). The literature reveals that a child with chronic kidney failure may not experience any symptoms until 80% of their kidney function is lost, and that only then do they start to feel sick. It also reveals that improved dialysis techniques, surgical procedures, medical advances in kidney transplantation and new medications hold out a positive prospect for children with ESKD (Heath et al., 2011).

According to Diseth (2011), the development and establishment of more potent immunosuppressive medication and improvement of pre- and post-transplant care have resulted in improvements in transplant survival rates worldwide and made it possible to include infants less than two years old with ESKD in the kidney transplant programme. The preliminary objective of kidney transplant is to advance from prolonging life to aiming for long-term survival and enabling a quality of life that is as close to that of the healthy population as possible (Becherucci et al., 2016; Deuchande et al., 2016; Furth, 2006). Portugal has one of the largest

transplant programmes per million inhabitants in the world, and the kidney transplantation programme is said to be leading in Europe and worldwide (Nolasco et al., 2017). Paediatric kidney transplant, however, is complex and aspects such as the size of the donated organ, the recipient's diagnosis and available surgical methods are crucial. The fragile condition of small children with CKD creates a surgical challenge and criteria regarding transplantation in small children are often lacking (Vitola et al., 2013). Additionally, the supply of donors is limited and the programme in Portugal requires the child's weight to be at least 12 kilos, which makes the average waiting time about five years longer than in other international centres (Deuchande et al., 2016).

Many consequences are also connected to the CKD, including during the post-transplant period, with the obligatory use of immunosuppressive medication. This medication can cause adverse effects on growth, weight gain, physical functioning, glucose tolerance and hyperlipidaemia (Diseth, 2011). Some of the common complications may be anaemia, nerve damage and short stature (Becherucci et al., 2016). Children can be at greater risk of cardiovascular disease, infections and malignancies after a few years of the intense treatment for CKD, which can add to increased long-term morbidity and premature mortality (Furth et al., 2006).

The Portuguese National Health Service (NHS) predominantly provides primary care and specialized hospital care, while renal dialysis and rehabilitation are commonly provided in the private sector (but with a considerable amount of public funding) because the NHS is not able to respond to all the care needs (Simões et al., 2017). Children are usually hospitalized during the diagnostic phase for exams and until their health condition is stabilized. At the same time, parents must acquire sufficient skills to carry out the home treatment and, during the child's hospitalization, parents are taught the necessary knowledge and skills. The health services provided include surgery and dialysis treatment in hospital. Pharmaceutical needs and peritoneal dialysis machines are covered by the NHS (Simões et al., 2017; Coelho et al., 2014). Community care services, long-

term care and social services for the chronically ill have been characterized as scarce in Portugal (Simões et al., 2017). Parents must bear the expenses for travel, diet supplements, special nappies, bandages, etc. Thus, social determinants such as geography, income and health literacy create inequities (Ferrinho et al., 2014; Simões et al., 2017; OECD, 2011).

In Portugal, women have commonly been deemed responsible for the care of chronically ill children. This is still the case today, even though more women work outside the home (Simões et al., 2017). Parents of children with CKD need to find their own way of managing their child's treatment and everyday life at home without specialized assistance. They are left with the tradition of relying on the family for care, a tradition that is difficult to uphold in these times of changed demographics and urban migration (Simões et al., 2017; OECD, 2011). Also, depending on where the family lives and where the hospital overseeing the child with CKD is located, geography becomes crucial in parents' experiences of caring for their child.

Public paediatric nephrology care in Portugal is centralized in the three metropolitan areas: Lisbon, Oporto and Coimbra, meaning that families from smaller cities and rural areas must regularly travel from their home to the hospital for physician appointments, specialist care and treatment training. Geography accentuates the financial issues inherent in caring for a child with CKD. The visits and dialysis treatment leave parents suffering from time constraints, loss of income and risk of dismissal from work. The organization of healthcare and social services, and the tradition of family care, form the background to these challenges.

CHAPTER 3: AIM AND RESEARCH QUESTIONS

The main aim of this thesis is to create knowledge about parents' lived experiences of managing the care of a child with a chronic kidney disease (CKD). To fulfil this aim, three research questions were formulated.

- 1- What are the challenges in doing research among families in crisis and in what way can they further our analysis?
- 2- How do parents manage caregiving and make meaning of a child's CKD?
- 3- How do parents view and practise good parenthood in the context of paediatric CKD?

CHAPTER 4: THEORETICAL FRAMEWORK

Under the umbrella of interpretive research, this study draws upon the theoretical frame of phenomenology to explore in depth the daily life and lived experience of parents dealing with a child's chronic kidney disease (CKD).

Phenomenological approach

Phenomenology has been applied to ethnographic work, focusing on the everyday experiences, challenges and strategies that are such a crucial part of people's lives (e.g., Desjarlais and Throop, 2011; Kleinman, 2006; Mattingly, 2010). It aims to identify phenomena by means of how they are perceived by the actor in a situation. Davidsen (2013) describes the goal of phenomenology as providing a descriptive investigation of the phenomena under study. It is built on the concept of personal knowledge and subjectivity and highlights the importance of the personal perspective and interpretation regarding individual experiences. The researcher is called upon to attend to participants' ideas and ways of acting and their own understanding of their experiences. Therefore, phenomenology is a useful approach for understanding subjective experiences.

The phenomenological approach allows the researcher to obtain information through inductive, qualitative methods such as interviews, informal conversations and participant observations, interpreting that information from the viewpoint of the participants. It has directed attention towards medical treatments as processes that transform bodies (e.g., Wickström, 2017; Zeiler and Wickström, 2009), and the consequences of caregiving for severe illness (e.g., Kleinman, 2010) in order to generate knowledge about people's experiences and sense of agency. In exploring the parents' subjective experiences of caregiving in this project, I also take inspiration from phenomenological anthropology and understandings of how lived experience relates to other people, as well as to

sociocultural factors and norms (see for example Desjarlais and Throop, 2011).

This thesis examines how the parents of a child with CKD work to handle the situation and find hope. It also considers how they build new daily routines related to the intrusive treatment, which initially constituted their greatest fear. Mattingly (2010) calls upon researchers to reflect upon how social theory attends to “the personal, intimate realities faced by on-the-ground people, the small realities that phenomenological projects have been committed to interpret” (p. 40). As researchers, we need to be committed to our participants’ unique experience and attempt to demonstrate their distinctive circumstances, rather than circumventing them in an attempt to fit our observations within existing social theories. We need to recognize the individual’s action from the individual’s perspective and according to the specific context. The individual’s action and experiences are connected, for example, to their social and economic context, the healthcare system and their social network.

Scholars have been attempting to develop new ways to speak about personal experience while at the same time exploring how subjectivities are shaped by the politics in which people dwell and by the social problems they endure. (Mattingly, 2010: 41)

The social environment influences individual experience, but it does not determine that experience.

Mattingly (2010) discusses how narratives are fundamental to understanding experiences of illness and healing, and proposes a narrative phenomenology framework. She developed this theory to help attend to lived experiences at various levels: personal, interpersonal and discursive. It is based on her assumption that:

As everyday actors, we locate ourselves in unfolding stories that inform our commitments about what is possible and desirable,

our narrative anticipations and judgments about how things should and will unfold, and an understanding of the motives and actions of our interlocutors. (Mattingly, 2010: 43)

As human beings, we comprehend our current conditions in relation to our future and our past. Mattingly (2010) argues that an actor's circumstances are related to numerous histories, including their own. "Events are moments, short stories within histories that are at once biographical, intimately interpersonal, and social in the broadest possible sense" (p. 44). The parental perspective on handling a child's CKD is influenced by a variety of circumstances, such as the parents' work, their family and friends, financial situation, geographical location, the child's school and so on.

In *The Paradox of Hope*, Mattingly (2010) develops the concept of hope based on her investigation of the experiences of African American families of children with chronic and severe health problems and disabilities. She examines hope not only as an existential issue but also as a cultural and practical endeavour. She demonstrates that hope is a mode of being in the world that is associated with principled concerns and projects. Hope is constructed based on life and history and not on sentimentalism (Mattingly, 2010). Hope explores the meaning of having a good life and what it means to be a good person during crisis and suffering. She shows that hope is a personal practice for those handling serious health issues, which involves constant reflections about interpersonal relationships, the healthcare system and culture (Mattingly, 2010). Focusing on the lived experiences of patients and their families, she demonstrates the efforts that people make as they try to overcome the challenges of dealing with chronic or severe illness (Mattingly, 2010).

Defining hope as a border practice that extends beyond social contexts and evolves from differences in race, class and disease, she demonstrates how people actively work to create hope in the midst of difficulties and misunderstandings, in both clinical settings and at home (Mattingly,

2010). She articulates that, “paradoxically, hope is on intimate terms with despair. It asks for more than life promises. It is poised for disappointment” (p. 3). She adds, “to hope is to be reminded of what is not and what might never be” (p. 3). Mattingly (2010) claims that the possibility for transformation that life offers, regardless of social structures, reveals the potential for ordinary people to act in their conventional setting. Even though they are struggling to recreate their lives in adverse circumstances, their endeavours make a difference.

According to Mattingly (2010), social life is more than personal and intentional. The attention to specific events elucidates how effective her participants’ pursuits and efforts are under certain circumstances. Those specific events are also associated with the practical consequences of individual meanings and perceptions. When parents first hear about their child’s diagnosis, it is a very important moment in their life; it is a specific event for the family. As Mattingly (2010) argues, it is not only a social event, but also an event that changes the family’s life. “Events take their meaningful shape (are lived experiences) for actors depending upon what they bring to the encounter and what is at stake for them personally” (Mattingly, 2010, p. 48). In my research for this thesis, the data show that the diagnosis drastically changes both the family’s and the child’s life, but in different ways depending on their life situation.

In this thesis, the participants’ narratives are analysed in order to explore parents’ experiences of having a child with CKD, and the specific actions that create meaning for them. Narratives help to re-establish meaning when it is threatened, as in the case of illness and, in particular, chronic illness (Kleinman, 1988; Frank, 1995). Narratives offer the possibility to redefine the self, or shape a new life path (Mattingly and Garro, 2001). Nevertheless, the interpretive act on the part of the researcher requires an evaluative and contextual approach to patient narratives (Bury, 2001).

Grounded in the theoretical concepts described above, this thesis looks into the adjustment to the child's chronic health condition and how the different families make meaning out of this life circumstance.

Practices and materiality

In the context of child CKD, the demands on the parents are weightier than those for many other chronic diseases, due to the complexity of the care involved (Mantulak and Nicholas, 2016; Ong et al., 2021; Swallow et al., 2009). To examine what this learning process entails, the thesis also takes theoretical inspiration from interdisciplinary studies of “materialities of care” (Buse et al., 2018) and examines the challenges and possibilities faced by parents. According to Buse and colleagues (2018), the material aspects of care need greater understanding in international research, because these materialities are co-constitutive of care (Buse et al., 2018). They state: “mundane materialities act as a lens for (re)examining care practices in health and social care contexts” (Buse et al., 2018: 245). Materialities including rooms, furniture, even toys, can provide a useful everyday portrait of a family home (cf. Friesinger, Topor, Boe and Larsen, 2020). Hence, the material environment demonstrates the families' strategies and the dealings they undertake in their everyday lives. Moreover, materiality elucidates our practices and sense of self. In the case of a family caring for a child with CKD, the dialysis machines, or counters or cabinets filled of medicines, reveal the materialities of the healthcare involved in the childcare and the family's adaptation to caregiving. Therefore, the exploration of materialities of care can bring light to the practical aspects of child CKD care.

From this perspective, the thesis examines the parental experience of caring for a child with CKD, and how both materialities and economic and human resources shape parents' experiences. In terms of this thesis, things that contribute knowledge include mundane materialities, such as the arrangement of a child's room or a weekly menu, as well as the

advanced technologies that are central to the treatment of the disease. Also, important to consider are the frequent trips to the clinic and absences from work, and how these impact upon parents' lives. Finally, materialities matter to the ill child because parents' emotional and psychological stress can influence the child's health (Medway et al., 2015).

Zygmunt Bauman (1973) argues that "the continuous and unending structuring activity constitutes the core of human praxis, the human mode of being in the world" (p. 56). Inspired by these words, this thesis takes as its object of study the practical ways in which parents manage their child's condition, how it affects their daily life, and the implications of this. According to Bauman (1973), human activity consists of turning chaos into order or substituting one order for another. Therefore, the new order generated by the child's CKD is the focus of this thesis. It examines families' perspectives on the practicalities required to manage the new situation.

In her praxiography of the body in medical practice, Mol (2008) discusses how patients are asked to make decisions and to take care of themselves and argues that "making a choice appears as yet another practical task" (p. 93). "In the logic of care actors do things: they inject insulin, [...] and they calculate what they eat" (p. 92). The practical work imposed on a child and their family by child CKD is not a question of choice, but of doings to ensure that the practical work can be completed (Mattingly et al., 2011). Parents need to be active, tenacious and adaptive to the child's condition, but also resigned to the child's suffering when the child undergoes surgery or dialysis treatment. This requires a dual effort in all aspects, from emotional work to attending to the practical healthcare requirements (Swallow et al., 2011; Trnka and McLaughlan, 2012).

Considering the context of a child with chronic illness, it is also necessary to pay attention to parents' caregiving. As demonstrated, managing a child's kidney illness entails the unending reorganization of everyday life, which Cheryl Mattingly and colleagues (2011) have so tellingly

termed “chronic homework”. This term was coined in order to suggest a similarity between employer–employee and clinician–caregiver relationships due to a global process of the responsabilization of patients. Here, I look at this process in relation to the need for parents to integrate clinic-based treatment into their home context, which involves social, economic and family relationships and an unpredictable course of events.

Parenthood as a social and cultural practice

Parenthood has been the object of moralization and guidance throughout history and has been replete with conflicting discourses around the ideal approach to raising a child (Faircloth et al., 2013). Every culture has its own customs and practices regarding how to care for a child (Lee et al., 2014; Sparrman et al., 2016). The routine everyday work involved in the upbringing of children is today called parenting, a concept that includes norms about parental responsibility for their children’s health, welfare and success (Lee et al., 2014). In most cultural contexts, parenting is seen as influential on a child’s future, and parents’ responsiveness to uncertainty and risk is pivotal to their children’s lives and future (Lee et al., 2014).

The sociocultural context in which parents carry out their daily activities is also permeated by expert knowledge and political decisions, which makes parenting the subject of discussion and problematization (Lee et al., 2014). Thus, parents’ desires and practices relate to the ideals in their local context and are established on a social basis (cf. Lind et al., 2016). This means that the practice of parenting must be examined in the milieu in which it occurs, and should be understood according to those circumstances (cf. Dermott, 2016).

In the case of parenting a sick child, parents engage in dealing with hazards related to their childcare (and healthcare) and in finding a way to balance contending discourses and attitudes towards parenting and

caregiving (Almack et al., 2009). According to Almack and colleagues (2009), parents are simultaneously confronted with the moral risk linked to constructions of parental competence and with the concept of being *good enough parents*. Childhood, according to Almack and colleagues (2009), is a governed sector of personal life linked to the moral liability and obligation of parents (and mothers in particular) to safeguard the health, welfare and raising of children. Parents of sick children have even been recognized as people who are constantly exposed to the scrutiny of experts and professionals (see Almack et al., 2009).

Usually, the parenting of a sick child increases the predicament of being perceived as overly or insufficiently protective in many societies (Almack et al., 2009; Lee et al., 2014). Parents must determine their parental practices based on their own understandings, knowledge and experiences; but must also untangle the discourses and moral dilemmas determined by different cultures (Lee et al., 2014; Mattingly and Garro, 2000). Hence, parents must carefully assess their practices of parenting.

This research examines how parents of children with CKD in Portugal use their financial and human resources to manage the situation and keep their child alive, with the goal of achieving a normal childhood according to their social context and culture. It includes negotiating the norms of responsible parenting that are circulating in the wider society. As I try to understand the context of raising a child with CKD and its implications, I also examine the concept of “good parenthood” (Sparman et al., 2016) as part of this thesis. I focus on exploring the parents’ efforts to educate their child to be independent and responsible for their own treatment.

“Good parenthood” also involves the practices and interactions of any other guardians/caregivers of the child, such as grandparents and school staff. According to Sparman and colleagues (2016), “doing good parenthood” involves a succession of procedures that fathers, mothers and every person involved in the child’s care re engage in regularly (e.g. fulfilling their basic needs: nourishing, housing, assuring education and

safety) in a variety of settings. Hence, parents' desire to do their best is an essential element to be taken into consideration in that process (cf. Sparrman, 2016). Good parenthood is accomplished through parents' actions and interactions, including those with the child and any caregiver engaged in the childcare.

In this thesis, I examine the relationship between parents and children concerning dependence, independence and interdependence. This is a process that extends from the child's total dependence on their parents while they are hospitalized (or receiving skilled treatment, e.g., dialysis), throughout the phase when parents can negotiate treatment tasks with the children and eventually transfer responsibility for the treatment to the child.

CHAPTER 5: PREVIOUS RESEARCH

Research into parental perspectives on chronic care have been conducted in relation to numerous issues, such as parents' management of daily work (Tong et al., 2010; Swallow et al., 2008, 2009, 2011), parent–physician interactions (Trnka, 20017), financial issues of caring for a chronically ill child (Medway, 2015), parents' constructions of their child's illness (Lauritzen, 2004) and parents' risk management in relation to their child's health (Stjerna et al., 2014). Social science and nursing research into chronic kidney disease (CKD) focuses on specific treatments, such as dialysis, and children's experiences (Tjaden, 2012; 2014; 2016), the social impact of the treatment on children (Kari, 2014; 2015), the psychosocial effects on caregivers (Tsai, 2006), quality of life (McKenna, 2006; Gerson et al., 2010; Iorga, 2015), the needs of parents with chronically ill children (Fisher, 2001; Geense, 2017) and the stress and burden on families caring for children with CKD (Watson, 1997; Zelikovsky, 2007). Additionally, the literature is related to young adults' and adult patients' perspectives, as demonstrated in Gunnarson's (2016) study. Gunnarson recounted the physical constraints inherent in the treatment and the practicalities of haemodialysis and kidney transplantation, describing how patients negotiated these interventions, as well as the daily realities of living with kidney failure. There is also a study related to the development of health information skills, tools and services for people living with CKD (Godbold, 2013).

The parental experience of caring for a child with CKD is described by Mantulak and Nicholas (2016) as having a “profound impact on both the diagnosed child and the family across the bounds of social, emotional and physical functioning” (p. 580). The diagnosis of chronic kidney disease, or kidney transplant, can be very complex and worrying for the parents, because it requires intense care, medication, procedures and many doctor appointments (Soliday et al., 2000, 2001; Tong et al., 2010).

Children with CKD and their families face a lifetime of medical treatment and uncertainty, because children with the disease have a permanent condition (Tong et al., 2008). Care is complex and often requires many medications. Home-based interventions, including dialysis and nutritional supplementation via enteral tubes and pump devices, are technically demanding, and in hospital are provided by highly trained nursing professionals (Tong et al., 2008).

In their study of parents' experiences, Swallow et al. (2009) demonstrated that parents become nurses for their children, because these invasive procedures require complex skills, precise information and know-how. Parents need to monitor their child's health and recognize symptoms that require more specialized assessment and intervention (Fedewa and Oberst, 1996; Swallow et al., 2009). Many of these practices are requirements for the parents of a child with any chronic disease, but the demands on parents of children with kidney disease are greater because of the complexity of the care, especially for children who are on home dialysis and younger than 10 years (Watson, 1997).

A child's CKD changes the life of the whole family, as stated in the Introduction. In their research on families' trajectories, Tong and colleagues (2010) describe four aspects that families need to deal with when their child is diagnosed: "absorbing the clinical environment, medicalizing parenting, coping strategies and support structures to the disrupting family norms" (p. 552). In relation to these four core spheres that parents must deal with, their research highlighted the intense and demanding treatment (diagnostic measures, frequent check-ups, dialysis treatment and transplant surgery) that obliged parents to face unfamiliar surroundings when entering a medical setting. In this unknown environment, which is intimidating and adverse, parents must surrender control over their child to the health staff, and also, they have to observe their child in physical pain. The situation also brought with it ambiguity about the child's outcome and future. Parents had to find intrapersonal psychological and emotional skills to deal with their reactions, such as reshaping

the problem and concentrating on the ill child. Additionally, they had to rely on external support from family and friends. Consequently, the dynamics of the family became unsettled: the home routines, employment and finances, as well as the leisure activities of the family (Tong et al. 2010).

To conclude, parental perspectives on childhood CKD demonstrate that the demands placed on parents are excessive due to the complexity of the care involved, especially for children who are on home dialysis. The home-based interventions that parents are expected to manage are technically demanding. This places an incalculable burden on parents.

CHAPTER 6: METHOD

Ethnographic approach

Ethnography is an emergent methodology in healthcare research (Draper, 2015; Savage, 2000; Zaman, 2008). Embedded in the “interpretative paradigm”, it recognizes various realities and contributes to meaningful understandings of health and illness (Draper, 2015). It encourages engagement with the meaning of events, instead of relying on measurements. Ethnographic fieldwork offers the opportunity to investigate crisis situations and how merciless life can be, without neglecting people’s resilience (Vigh, 2008).

The focus of ethnographic research is the process of learning about and understanding another human group situated within its social and cultural contexts. Therefore, in the healthcare field, interest in meaning-oriented methodologies, such as interviews and/or participant observations, provides space for ethnographic approaches. According to Losekoot and Wright (2012), the interpretative paradigm includes seeking an understanding of the world as it is through the subjective experiences of individuals. The methodology enables investigators to study people’s lives in the everyday settings in which they live, focusing on the routines of daily life. Ethnographic research is exploratory, and decisions such as where the participants will be interviewed are developed over time (Hammersley and Atkinson, 2007). The methodology seeks to examine human experience, portraying it in a way that tells a meaningful story, reveals a possible pattern or suggests a theory or explanation (Holloway, 2005).

In this research, I have focused on parents’ narratives of having a child with chronic kidney disease (CKD) and analysed narratives of struggle as well as narratives of capacities and engagement that the parents cultivate in order to manage their new life situation.

Gaining access and doing fieldwork

The data was collected in Portugal. Portugal was chosen because it is a European country that has a high number of CKD cases, as mentioned above. As I am a Portuguese speaker, it made Portugal approachable for the fieldwork.

The fieldwork was conducted in two parts. During the first period of three months, I negotiated access to the field, and during the second period, a further three months, I conducted interviews and observations. During the first period, I contacted and visited hospitals and kidney associations to find people who would agree to let me conduct the study with parents.

Following my research presentation to him, the director of the leading paediatric hospital in Lisbon gave me formal permission and introduced me to the nephrology unit-managing physician and the chief surgeon. With them, I discussed the prospects of research, and negotiated their formal permission. I needed to include their written consent in the ethical application and, of course, needed their permission to carry out the research at the renal unit. The second institution I needed access to was the Portuguese Kidney Patients Association (APIR). After a few unsuccessful attempts by email and phone calls, the clinic manager at the hospital connected me to the association, introducing me and my research. As a result, I gained the opportunity to present the project to them as well.

The Portuguese kidney association linked me to families from different parts of Portugal. Gaining formal access to the hospital and the association were not the only challenges, nor did it mean free entrance. Gaining access to the hospital entailed the ratification of the research, and me as the researcher, by the clinicians and ethical boards. I had to gain the cooperation of the staff and the trust of the participants. Access was not a single event, but an ongoing process that continued throughout the fieldwork.

After obtaining ethical approval from the hospital board (Comissão de Ética para Saúde, Centro Hospitalar de Lisboa Central EPE, nº 3387/2016) and from the National Data Protection Commission (Comissão Nacional de Protecção de Dados, nº 12607/2016), I had a meeting to present the project to the nephrology unit and to negotiate formal entry to the hospital. The nephrology clinic manager was the “gate opener”, acting as ice-breaker between myself and the paediatric nephrology department, as well as the participants. She endorsed the research and gave continuous support, even with the practicalities and challenges that I faced when interviewing the parents at the hospital. As an example, several times she lent me her consulting room to allow me to interview parents, and once she looked after a child to enable me to interview the child’s mother. The unit secretaries helped me to find a room on a daily basis, checking with the doctors who had finished their consultations or were going for a lunch break, to find a room where I could talk to families, present the research or interview them.

The section of fieldwork in which I collected data lasted from February 2017 to July 2017. I spent three or four days a week at the hospital, interacting with the health professionals and the families, conducting interviews and making observations. I committed two shifts (morning and afternoon) in the hospital unit to where families came for their consultation with the doctor. I was present on the ward, observing and talking to staff and families. Participants were referred to me by the clinicians in the nephrology unit. In addition, I applied the snowball technique, which meant that the families who were interested in the study referred me to other families who might also be interested in participating in the research. In the first meeting, I explained the project to the participants and invited them to participate in the study. In accordance with the ethical rules for medical research in Portugal, I allowed them ten days to think about their participation in the research. At the end of the ten days, I contacted the participants again to obtain their definitive answer and negotiate the interview details.

As soon as I started my shifts at the hospital clinic in February 2017, the paediatrician nephrologist doctors introduced me to the families as “doctor”. I am a trained psychologist, and in Portugal, a psychologist has the status of “doctor”. They thought it would be a good way to “open the doors” and to encourage parents to talk to me and participate in the study. However, it had the opposite effect. I noticed that families declined meeting with me, and the families whom I had met with had questions and doubts about my position as a psychologist. Some commented that it would be good to have support from me as a psychologist to help them, and some stated that they did not need a psychologist’s service or did not want to participate in the research before knowing what the project was.

After reflecting upon these events, I discussed the situation with my main supervisor and a local psychologist and decided to change the way the doctors introduced me to the families. I explained this to the paediatrician nephrologist physicians and asked them not to introduce me as a psychologist, because I was not there in that capacity, but as a researcher. The doctors agreed to change their strategy about how to introduce me to the families. Thereafter, families became more willing to see me and obtain information about the project.

At first, I presented the project to the families chosen by the doctors, but slowly, with my constant presence in the hospital clinic, I asked the doctors to refer all the families who came for consultation and met the inclusion criteria. These criteria were: the participants should be at least 18 years old and must have a child aged between 0 and 18 years old undergoing CKD treatment in Portugal. None of them (participants or child) should have any special needs or have been diagnosed with any mental illness or disorder not related to the chronic kidney condition. They had to be fluent in Portuguese or English to ensure that they would have no difficulty in understanding the information, the consent form or the interview questions. Table 1 reports the recruitment outcome at the hospital clinic.

Recruitment outcome	Numbers
Families invited	41
Families who accepted	28
Dropouts	19
Families included	9

Table 1: Recruit outcome at the hospital clinic.

The total number of patients in the paediatric hospital clinic was 54, but ten of these were in transition to majority age, which meant that they were 18 years old and attended the consultation alone. Three families did not wish to obtain information about the research project. As a result, I ended up presenting the research to 41 families at the paediatric hospital clinic. Twenty-eight families agreed to participate in the research but only nine families ended up doing so. The reasons for dropping out were different for each family, and included the critical health condition of the child at the time, or not finding energy or time for the interview (one family cancelled the interview while I was travelling to their town to conduct it, and three others cancelled the interview only a few hours before). Table 2 reports the recruitment outcome outside the hospital.

Recruitment outcome	Numbers
Families invited	18
Families who accepted	14
Dropouts	2
Families included	12

Table 2: Recruitment outcome outside the hospital clinic.

With the assistance of the Portuguese Kidney Patients Association (APIR) and using the snowball technique, I presented the project to 18 families. Fourteen families accepted and four did not answer. Two families who had agreed to participate lived far away from Lisbon and I could not make

the arrangements to visit them at their homes to interview them. In the end, I was only able to interview 12 of these families. The nine families at the hospital, together with the 12 families from APIR and the snowball technique, made 21 families in total.

At this time, due to the logistics, I had an ethical dilemma about how to communicate with the families, because some did not use email and I was prohibited from giving my phone number to them. To solve this issue, I obtained a separate cell phone with a local number to communicate with them. I used a code to add them to the contact list. Remaining in contact with them was essential in order to gain their attention to participate in the project. With some families, I presented and discussed the project over the phone, and with a few families through emails and Skype meetings. They called or texted me with their questions. Individuals from a few families wanted to discuss my proposal with their partner before agreeing to participate in the programme. Harcourt and Quennerstedt (2014) discuss the importance of ensuring that “ethical integrity is seen as integral and critical across the entire research” (p. 7). Ethics are more than rules, and are fundamental to the practice of research. Thus, I paid attention to the participants’ motivations and challenges during the whole research period and presented the possibility of not participating or finding alternative ways of participating in the research.

For every contact at the hospital, I sought an opportunity to understand the participants’ environment and gain their confidence. I had to spend time learning about them as well as enabling them to become familiar with my presence in the hospital. The fact that I had formal authorization and spoke the same language as the participants was not enough on its own to gain access and enable us to become acquaintances. Therefore, I kept going to the hospital on a regular basis, and slowly the families became familiar with my presence, as they saw me at the hospital every time they came for their child’s consultation. On some days I felt that I was misusing my time at the hospital, but I learned to acquire information by

“hanging out”, because it created confidence and generated opportunities for the initial conversation (cf. Zaman, 2008).

In order to learn about the complex issues surrounding the paediatric chronic kidney condition, I spent many days sitting in front of a computer with a doctor responsible for the nephrology unit, discussing paediatric CKD in the Portuguese context (for example, the challenges, available treatments etc.) and searching for information about the disease. This time was valuable, as I learned about what it could mean to families to get their child’s diagnosis, the different stages a patient (the child and their family) goes through and how the care is organized.

After spending a few months at the hospital, I realized that I had to be flexible and adjust to the families. The hospital might be convenient for me to gain access to the participants, but it was not a good time for the families, because the day of a child’s appointment is very stressful for the family and their attention is focused on the child. In addition, the hospital environment brings uncertainties and worries for families because everything there reminds them of their child’s condition and what they have gone through since the child became ill. Therefore, I gave the families the option to be interviewed in their hometown during weekends and holidays. Changing my approach and adapting the schedule to the participants’ availability were crucial for gaining the parents’ interest and willingness to participate in the study. Another critical point was to show understanding for their situation and assure them of my interest in their knowledge about dealing with their child’s condition. I reassured them that my aim was to learn about their experiences, because they had the knowledge that I was looking for.

Following the families to multiple places revealed more factors than those that were evident in one site. According to Marcus (1995, 1998), to comprehend an event in a broader context requires tracing it across different settings, as the same phenomenon elicits different responses, or a need for different actions. Thus, the fieldwork was a rich learning process. The

logistics involved finding a room at the hospital, handling the travel arrangements, and following the procedures to find a private and secure place to interview the participants in different venues. Negotiations and bureaucratic issues were a constant part of the fieldwork. In the hospital, rooms were usually a scarce resource. Therefore, every day I had to negotiate a room to use, and on several days, I had to change room a few times. I did not wear a white coat, I just blended myself into the area allowed only to doctors. I was attentive to the parents who were there with their child for the doctors' consultations. Qualitative research in the health field can be very demanding of time because it requires going back to the field many times and rescheduling appointments. During the time I spent in the field, there were expected disruptions such as holidays, and unforeseen disruptions such as a health professionals' strike and interview cancellations. To be able to conduct the fieldwork, I had to adjust my schedule to different circumstances daily.

The fieldwork was enlightening and also included emotional work. The interviews required careful management of both the participants' and my own emotions. The challenges I encountered in the hospital demonstrated that the hospital environment was not a friendly setting to inspire families to talk about their experiences, because everything there triggered their worries. However, when I gave the families the option to meet in a place that would be more comfortable for them, this revealed how geography came to matter for them in making sure that their child got the needed hospital care. My own experiences of travelling and the fatigue it caused contributed to my understanding. I also reacted emotionally and gained insight into their daily struggles and grief.

I took other steps to achieve the desired results, including adjusting to the families' availability, being compliant, showing understanding of their situation and assuring them of my interest in their knowledge about dealing with their child's condition. The best type of relationship I established with the families was as an investigator, giving the power to the families,

reassuring them that they were the ones who had the knowledge, and that the aim of my research was to learn about their experiences.

In summary, qualitative data from observations and in-depth interviews with 21 caregivers in Portugal is used to explore and critically examine the families’ practices in managing their child’s condition and to generate knowledge about how families deal with and give meaning to their child’s CKD condition.

Participant overview

In total, I conducted 26 interviews – 21 with parents/legal caregivers of a child with CKD, and five informal interviews with health professionals to gain knowledge about the hospital context and the treatment. I also had numerous informal conversations with the hospital staff. Out of the 21 interviews with parents, 16 were with the mother, four with couples and one with an aunt who was the legal guardian. See Table 3.

Interviewees	Numbers
Mothers	16
Couples	4
Aunt (legal caregiver)	1

Table 3: Categories of interviewees.

Additional information that is important for the analysis of the parents’ situation is the status of the parents. The sample included 13 guardians in legal relationships, two families in which the father lived and worked abroad, two mothers in new partnerships, three single mothers and one aunt who was the legal single guardian after the mother had passed away. Of 21 children, 17 were males and four were females. The children’s ages ranged from two to 16 years old. Table 4 reports the children’s treatment.

Treatment		
Transplanted	10	
Conservative treatment	6	1 on transplant waiting list
Peritoneal dialysis	4	3 on transplant waiting list
Haemodialysis	1	

Table 4: Children's treatment at the time of the interview.

Of the 21 children involved in the research, 10 had received transplants. Six children were in conservative treatment, which meant that the treatment consisted of a special diet and medications. Four children were in peritoneal dialysis, which is performed at home through a catheter using a cleansing fluid that flows into a part of the abdomen to filter waste products from the blood. One child was in haemodialysis treatment, which was conducted at the hospital. The blood is taken from the veins and filtered via a machine called a dialyzer or artificial kidney, to clean the blood waste. Of the six children in conservative treatment, one was on the waiting list for a kidney transplant and five were taking mandatory medications and under strict dietary control.

Interviews and observations

Interviewing is one of the tools used in ethnographic research. It can be achieved through informal conversations or formal interviews. The ethnographic interview method allows the researcher to describe “the ways that people understand and account for their day-to-day situations” (Maggs-Rapport, 2000: 220). In order to conduct interviews, it is essential to build a good rapport with the participants, according to Hammersley and Atkinson (2007). Therefore, being aware of the sensitive theme of my research, I spent time building a positive relationship with the participants to make them feel comfortable talking about their unique and

personal experiences around their child's condition. Flick (2014) argues that verbal (interview) data in health services research is useful for investigating patients' experiences of specific diseases. In addition, it is essential to examine populations or groups that are hard to reach, as they may be underrepresented in surveys, and interviews may present a solution to reach them (p. 197). Despite the use of an interview guide to start the ball rolling (see Appendix), the aim was to turn the formal interview into an informal conversation.

The interview guide was used as a starting point for the conversation and for me to check that the key points were being discussed. As the main purpose of the interview was to gain knowledge about the parents' experiences of managing their child's kidney disease, I allowed them to talk freely. The open-ended questions were designed to lead the participants to talk about how they dealt with their child's condition and what their daily life was like. As a result, I did not follow the interview guide question by question, because most of the participants answered the questions while they were telling me about their experiences. Consequently, the interview guide was used primarily as a checklist.

The interviews were divided into five key subjects: symptoms, diagnosis, implications and management of the condition, support, and knowledge. The interviews took place in several different venues, such as: the family home, a work office, a restaurant close to the participant's workplace, a hotel meeting room, a public library and some at the universities in Lisbon and Évora. The interviews each had their own flow and length of time. They lasted on average between one and two hours. The flow and length were influenced by the participants. A few interviews were conducted in two parts; the three main reasons for this were: the child was not feeling well, the participant had to go back to work, and the participant became very emotional, struggled to talk and could not continue. In another case, one mother cancelled our meeting and asked me to send her some topics for our conversation by email, as she wished to think about

the questions and was not comfortable talking at that moment. However, she dropped out of the research.

Field notes

Field notes allow the researcher to access situations and record observations in an unobtrusive manner. According to Hammersley and Atkinson (2007), it is a conventional method used in ethnography for documenting observations and interview data. The authors explain that the process of writing field notes is an essential research activity and should be done conscientiously and with care (Hammersley and Atkinson, 2007). Writing field notes involves taking into account matters such as: considering the role of the ethnographer, the setting of the fieldwork, reflections on what issues can be covered and if field notes can be written at all, and if so how, and where. All these issues depend on the nature of the research and the location. In my case, in the hospital I was allowed to take notes only in the room that I had been assigned, and I could not voice-record informal conversations.

After having talked to a respondent at the hospital, I tried to recall the informal conversation, making notes in the room I had been assigned. After each interview, I made notes about the participants' experiences, my observations, emotional reactions and reflections on the subject discussed. I used the field-note process for reflections and descriptive information. At the descriptive level, it provided information about time, date and description of the setting. As reflections, it concerned what I had observed, questions the interview had raised, doubts to be discussed with my supervisor, strategies to be changed, preliminary analytical thoughts, concerns and new ideas related to the research. Field notes are expected to corroborate and support an analysis and contribute to the understanding of the phenomenon (Hammersley and Atkinson, 2007). However, field notes are selective information, as it is not possible to portray everything, and choices need to be made about the details in order to remain focused

on the subject of the study. The field notes were recorded in line with what was relevant to the investigation. They were also important in this study, because frequently, after I had turned off the voice recorder and prepared to leave, that was when the informal conversation started with parents. They usually added important information and gave me more details and talked about their feelings and worries. One mother even commented, when I had just turned off the voice recorder: “Oh, now I can tell you about my worries” (mother of a six-year-old girl).

I also considered the emails and messages that the participants sent during the process of negotiating the time of the interview to be part of my field notes, as they contained important information and taught me about the families’ situations and dealings.

Thematic analysis

The data was analysed using thematic analysis (Braun and Clarke, 2006; Clarke and Braun, 2013). Thematic analysis (TA) is a type of analysis that examines themes or categories as its unit of analysis, and can be used for searching across data from different sources to identify themes. TA looks at the data in depth in order to identify both implicit and explicit ideas within the data, through the process of coding, to create established meaningful patterns. According to Braun and Clarke (2006), TA is not connected to any pre-existing theoretical framework, giving the freedom for it to be used within different theoretical frameworks and to do different things within them. TA allows the investigator to reflect on reality or to unstitch reality. I used TA in this research because of the freedom and flexibility it provides to explore the participants’ experiences and perspectives and to find patterns and themes across data, providing “a rich and detailed, yet complex account of data” (Braun and Clarke, 2006).

TA can take an essentialist or realist approach, casting light on the experiences, meanings and the reality of the participants, or it can take a

constructionist approach, investigating how events, realities, meanings and experiences are the outcomes of a range of discourses functioning in society (Braun and Clarke, 2006). Or, a third, contextualist approach (lying between the essentialist and constructionist approaches) can be used. This recognizes how individuals make meaning of their experiences and how the wider social context imposes those meanings, while maintaining a focus on the material and other aspects of the “reality” (Braun and Clarke, 2006: 81).

This study collected data from the hospital and the families’ home environments, where they were dealing with the paediatric chronic kidney condition. The contextualist approach of TA was used to highlight the setting in which an action takes place, following the reasoning that the action can be comprehended in relation to that context (Braun and Clarke, 2006). Grounded in this approach, meaning and experiences are understood as socially created and replicated. To give an example, the contextualist approach allows me to theorize about the structural circumstances that support the participants’ narratives. The data demonstrates how parents understand health and illness and what their child’s CKD imposes on them, and how they create their own meaning about caring for their child. The medical discourse presented medical facts about the disease and its treatment, while the parents’ lay discourse concerned making the child’s condition commonplace, in that the family’s “doings” and “dealings” became a normal part of their everyday life.

Clarke and Braun (2014: 1950) state that “coding and theme development in TA are always guided by the research question, but this question can be developed and refined throughout the analytic process”. TA comprises six phases: familiarizing oneself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report, as described by Clark and Braun (2006). The ethnographic approach that I used generated a large quantity of field notes and interview transcripts to be analysed. Since I had collected, transcribed

and translated all the data myself, I had prior knowledge of the content and initial analytical thoughts.

To familiarize myself with the data, I read through the field notes, which included observation notes, interview notes and my diary notes. I sought to gain a sense of what was being said and to help identify the key themes in each interview. I read the transcripts line by line and generated initial codes by assigning open, descriptive labels to the interviews. The initial coding list was used to interrogate the texts and summarize the themes according to the question: “What did the participants say about their experiences of dealing with their child’s chronic kidney disease?”

The next step was searching for themes and organizing them by classifying and grouping the themes. I organized and visualized the themes with the aid of a mind map on a board where I could move the codes around, thereby reviewing the themes. Braun and Clarke (2006) specified that “a thematic map” is used to visualize the relationship between themes and, after reviewing the themes, to help verify that they reflect the meaning of the data as a whole. Subsequently, I identified and named the themes, using them to theorize the essential points related to my research question.

In agreement with Braun and Clarke (2006: 84), I believe that “latent codes” permit the researcher to step away from the explicit and evident narrative of the data to reach a deeper, more implicit level underlying the participants’ accounts. Built on “latent codes”, the data was searched for ideas not identified in the parents’ spoken words. For instance, the recurring interview cancellations showed me that it was difficult for the parents to find the time or strength to do anything else apart from actions directly concerned with the child’s treatment. They organized their lives around the child’s treatment and its requirement. Also, the difficulties in finding spare time to participate in the interviews revealed the burden that the child’s condition imposed upon them.

Ethical considerations

As I described above, in Portugal, approval from two ethical boards (the hospital board and the Data Protection Commission) is mandatory to ensure the security of the participants and the integrity of the research. During every phase of the investigation, I made sure that I was always following the ethical guidelines. Therefore, the ethical guidelines were an important concern, not only in the fieldwork, but during data collection and writing up the thesis.

Their child's disease drastically transforms the everyday life of a family, making this population difficult to reach. To gain the parents' attention, it was necessary to be flexible, and therefore it was essential for me to adapt to their schedule and requirements. In this study, the focus was on the primary caregivers' perspectives, and thus the interviews were conducted with the parents. As the subject is quite sensitive, I negotiated with the participants the possibility for them to bring someone with them who could be with the child during the interview. A few families were able to bring their partner or a grandparent, but some families could not bring any relative, and the child was therefore present in the room during the interview. I saw this situation as an ethical dilemma, because I did not have the ethical clearances to interview children. If a child were present in the room, they might engage and take part in the interview. To avoid this situation, I gave the families the option to be interviewed in their hometown during weekends or holidays. Nevertheless, in two cases, a child was present during the interview, and I will return to this below. Hence, following the ethical standard, prior to each interview, I discussed the consent forms with the participants. In view of the possibility that the interview may bring up sensitive subjects, participants were reminded that, if they wished, they could refrain from answering any questions if they did not feel comfortable.

The participants were informed that their participation was voluntary, and that they could withdraw their participation, even after the interview was finished. According to the ethical standards in medical research in Portugal, the rules for withdrawal are ten days after the interview, but I allowed them the full six months that I was in Portugal, as they could easily contact me or meet me at the hospital. I reminded them that their participation was not associated with their child's treatment, and that consequently their choice to participate or not would not affect the child's treatment in any way.

The ethical clearance and the doctors' approval and support justified the study. It promoted the parents' confidence and willingness to participate in the study. This was confirmed when I obtained access to the kidney patient association after my failed attempts during the early stages of negotiating access to them. Furthermore, when I contacted families through family referrals, they asked me about the ethical authorization. In the hospital clinic, I experienced different scenarios during the interviews, as I mentioned above. In one interview, the managing physician of the nephrology department took care of a five-year-old boy, as he was very energetic and loud. One interview was conducted with a couple and their six-year-old girl at the NOVA University of Lisbon on a Saturday morning. I tried to keep the girl aside, drawing and playing. Even though she was a quiet little girl and was busy drawing, the parents seemed concerned about her hearing our conversation. They spoke very softly and tried not to show their emotions. Every time one of them became emotional, the other one picked up the conversation, allowing time for the partner to regain his or her composure. A few times, I had to change the subject and return to it later when they felt more comfortable. In this particular interview, I also had to divide my attention between the couple and the girl, as I found it important to keep her busy at the table that I had set up for her, separate from the table where we were having the interview.

In another interview that was conducted at the hospital, a 14-year-old boy was in the room with his parents during the interview. This interview did

not require any special strategy, as he sat to the side and was busy with his cell phone. His presence did not bother his parents, as the boy seemed comfortable not taking part in the conversation. He did not participate in the interview or show that he was listening or interested in our conversation. However, in retrospect, I do not find the solution to this ethical dilemma satisfactory. Still, that was the only possible way to gain the information from these two families, a benefit that hopefully outweighed the risks.

I transcribed the recordings and analysed them, guided by my main supervisor. After transcribing the interviews verbatim, I translated into English the parts that I wanted to use to exemplify the findings, with the intention of maintaining the meaning of the original spoken language, while also making the quotes understandable for the reader. To ensure anonymity, the names of participants and their children are pseudonyms.

CHAPTER 7: SUMMARIES OF THE STUDIES

Study I

Adapting to parents in crisis: tracing experiences of having a child with chronic kidney disease

Bruno de Sousa, Andrea (2018) In Plows, Alexandra (Ed.). *Messy Ethnographies in Action*. Pp. 131 – 140. Wilmington, Delaware: Vernon Press.

Abstract

This chapter addresses the challenges involved in understanding parents' concrete experiences of managing a child with a chronic kidney disease (CKD). This disease causes suffering for the child, disrupts daily routines and transforms the everyday life of the family. On the basis of ethnographic methodology, participant observations and interviews with primary caregivers were conducted at a major paediatric hospital in Portugal. However, the stressful environment at the hospital led the researcher to seek access to the parents' home environment. The multi-sited approach of this investigation revealed a typical trajectory involving back and forth visits to the hospital and in addition, parents had to manage a variety of practices depending on the setting. Attending to the parents' emotions rather than avoiding them was vital in understanding how their lives became stressed and in how they grew as individuals. The challenges involved in carrying out fieldwork among families in crisis can work as openings for discovering the multifaceted realities the families encounter.

Study II

Material and relational challenges of home-based renal care: A parental perspective on child chronic kidney disease

Bruno de Sousa, Andréa and Wickström, Anette (2021). Material and relational challenges of home-based renal care: A parental perspective on child chronic kidney disease. *International Journal of Care and Caring*. DOI: <https://doi.org/10.1332/239788221X16316492108700>

Abstract

Caring for a child with chronic kidney disease (CKD) requires parents to reorganise mundane routines and develop advanced technical skills. Parents' strategies used to meet these challenges need greater understanding. This article takes inspiration from phenomenology of practice and material culture studies to analyse interviews with parents in Portugal. It shows that, although home-based care leads to worsened social inequities, parents use the available financial and human resources to manage the situation and create normality. While they experience becoming confined and close relationships are strained, the mundane practices and social relations of care bring hope and meaning to the family.

Author contribution statement:

A.B.S. carried out the ethnographic field work, conducted the interviews, analysed the data, and wrote the manuscript with support from A.W. who supervised the project.

Study III

Readiness parenting: Practices of care by parents of children with chronic kidney disease in Portugal

Bruno de Sousa, Andréa; Goes, Ana Rita and Wickström, Anette. Readiness parenting: Practices of care by parents of children with chronic kidney disease in Portugal (currently under review, after major revisions, with *Families, Relationships and Societies*).

Abstract

Parents of a child with chronic kidney disease (CKD) must safely perform advanced care and treatment while at the same time allowing the child some freedom and maintaining everyday parenting and family tasks. Drawing upon interviews with primary caregivers of children with CKD in Portugal, we examine the context of raising a child with CKD and how the parents practise their parenthood. The study takes inspiration from parenting studies and child studies and explores how good parenthood is constructed. Based on thematic analysis (TA), three core themes emerged: protecting the child, involving the child in their own treatment, and transferring responsibility. The transformation of life-limiting circumstances into a life that worked well for both parents and their child represent what we call “readiness parenting”. Assessing risks, supporting the child’s autonomy, and relating to social norms required constant vigilance and readjustments as well as negotiations about parental responsibility.

Author contribution statement:

A.B.S. carried out the ethnographic field work, conducted the interviews, analysed the data, and wrote the manuscript with support from A.R.G. and from A.W. who supervised the project.

CHAPTER 8: CONCLUDING DISCUSSION

The purpose of this thesis was to investigate parents' management of their child's chronic kidney disease (CKD), with an emphasis on parental perspectives and lived experiences. I examine how parents managed everyday routines and supported their child in the treatment at home, and how they slowly worked to transfer the responsibility of the treatment and management of the condition to the child. The research demonstrates the value of qualitative research related to families dealing with disease, as it is a very delicate issue to examine. Qualitative research makes it possible to ensure that the fine distinctions in meaning and participants' interpretations are taken into consideration; for example, the new normality that the family creates.

Structural and relational aspects of caregiving

In this thesis, I have used many ethnographic examples of how parents of children with CKD in Portugal relearn care and reorganize their home and everyday life. These examples demonstrate that the experience of caring for a child with severe kidney disease is a situated process that takes place within a larger economic and social framework. When a child leaves the hospital, the burden of the disease becomes relative to the individual family's financial and social situation. Situating parents' experiences within the Portuguese political and sociocultural context contributes to an understanding of both the possibilities and challenges that Portuguese parents encounter and how differently the child's chronic illness plays out in their lives.

The responsibility of parents to perform technically demanding home-based treatment and be constantly attentive to their child's health needs influences family life in different ways. How they manage is related to their opportunities to act within their everyday setting (cf. Mattingly, 2010), opportunities that are unequally distributed at personal, social and

structural levels. Social and economic status, the geographical location of the home and renal consultation clinic, the involvement of relatives and the resources available at the child's school all have an impact on the families' lives.

Furthermore, in an environment where the social system does not compensate families for the financial costs or disruption to everyday activities, individuals need to use their creativity and mobilize their personal, economic and social capacity in order to manage the new situation. The responses of parents to handling their child's chronic kidney condition and doing the "chronic homework" (Mattingly et al., 2011) are influenced by the everyday settings and structural circumstances under which the families live.

The ethnographic data gathered in this study also shows that the sociocultural context of gendered structures and attitudes towards childcare plays a crucial role. Women shoulder the main burden of caring for chronically ill children but, at the same time, more women work outside the home today. This can be difficult when trying to manage a child with CKD. The multiple ways in which parents manage the challenges they encounter illustrate the interrelational aspect of caring for a chronically ill child, as well as how parents' ability to compensate for the financial costs and disruption of everyday life depends on familial responses. Vulnerable parents who do not have the necessary financial resources or social relationships of care make enormous efforts to meet their responsibilities.

The care stories narrated in this research emphasize the two aspects of parents' chronic homework (Mattingly et al., 2011). While the responsibilities and obligations they encounter are demanding, at the same time, the parents feel meaningful as a result of being a caregiver to a chronically ill child. Constantly searching for new options gives meaning to parents' lives. Parents' hope is nourished by their efforts and practical actions. To be more concrete, planning, buying food, and cooking and serving a special diet for their child nourishes the parents' hope for the child's survival

and improvement. The study also illustrates the relational aspect of care, which is a complex issue for families to deal with. Some families became closer and shared all the aspects involved in their child's condition and household matters. However, in some cases the relationship broke apart and new social relationships of care were created with grandparents or new partners in order to adapt to the circumstances and find a new normal life routine.

Parenthood and children with a chronic disease

The relearning of care and the incorporation of newly integrated knowledge examined in this thesis demonstrate how parents become experts at managing their child's treatment but do not indulge in the possibility of experimenting with advanced treatment, as shown in studies of other chronic illnesses, such as asthma (Trnka, 2014; 2017). Parents "live one day at a time" (cf. Charmaz, 1991), whereby dealing with the child's condition means concentrating on the here and now. Dealing with day-to-day tasks helps parents to focus on what needs to be done in the moment, without considering the issues that will undoubtedly arise in line with the progress of the disease. Parents work to avoid immediate threats, to feed their child correctly, to protect their child from infections and to carefully comply with the treatment.

The study shows that the main goal for the families was to create a sense of being a "normal family" and having a "normal childhood", which to them relates to norms and values about what parenthood and childhood should be (Sparrman et al., 2016). The parents were keenly aware of the normative expectations on a family and used their inventiveness to create normality. They did so through, among other things, sustaining relevant activities such as birthdays, events and sports activities, what we conceptualize as part of "readiness parenting" in study III. The children and their parents struggled to avoid special treatment and to be like other children or families. Parents' wishes for their children are well described by

Bluebond-Langner (1996: 184) “One of the hallmarks of the future is independence, supporting oneself, leaving home and in some cases having children of one’s own”. The attribute of protection is part of childcare practices, although the goal is to gain autonomy for all participants. Therefore, parents establish goals for the future in order to attain levels of independence appropriate to each age and treatment that the child is going through.

The normality that families create is nevertheless fragile and temporary. The concept of precarious normality, used to describe what health is in relation to a person’s options and prospects for the future (Misztal, 2001), can shed light on the ever-changing process inherited by a child stricken by CKD. The fact is that there is no guarantee of a cure for paediatric CKD, even with advanced medical technologies, or even a transplant. A child with CKD will probably experience several different types of treatment during his or her life. A kidney transplant is not a once-and-for-all procedure, even if it is successful. After some years, the child will probably need another transplant. This makes even the final recourse for obtaining a better quality of life an unpredictable one. However, parents exert themselves to make the child’s life “normal”, which means that they attempt to include most of the elements that they conceive to be essential parts of a “normal childhood”. In so doing, they try to realize specific prospects, while driving others away.

Implications for healthcare and community care practices

This thesis contributes to knowledge about the complex and intensive care associated with paediatric CKD and the strong expectations on, and desire of, parents to raise their child to be an independent adult with a good quality of life. Consequently, the findings can inform social policies and promote community care services to support families caring for

children with chronic conditions. Moreover, this study highlights that family-based interventions should acknowledge the possible concerns of parents of children with CKD and integrate these into their programmes.

The findings also demonstrate a need to level out the unequal conditions under which families live and chronically ill children's childhoods are formed, because social and economic conditions influence children's health. They demonstrate that healthcare providers can help to strengthen parents' opportunities to provide the necessary care. The study shows how crucial such help can be to a parent's ability to develop the specific caring skills needed to sustain the sick child. It is hoped that knowledge about the strategies used by parents to manage the situation can encourage healthcare providers, patient associations and community health services to meet the needs of families of children with CKD and compensate vulnerable parents.

Limitations and need for future research

This study aims to be a detailed examination of parents who are managing a child's CKD, scrutinizing their daily life experiences, including the families' routines, challenges and capacities. Nevertheless, the views of the fathers are scarce, as is the case in many studies related to children and childhood (cf. Lee, 2014). Even though I used strategies to be flexible about the time and location of the interviews in order to reach the fathers, for various reasons the fathers did not often take part in the interviews. However, I conducted four couple interviews and in these I was able to get the fathers' points of view, and especially the couple-common narratives about their strategies and how they cooperated around the child's healthcare. This enriched the research. According to the mothers, the fathers who agreed to participate in the study requested the interview to be conducted as a couple interview and not an individual interview, acknowledging that the mothers performed the main caregiver role and could contribute with more details about the child's illness. This

limitation is, however, mitigated through brief informal conversations that I had with fathers and/or grandparents. In many cases, grandparents are part of the childcare formula. Therefore, another limitation of the study could be the missing views of grandparents, as in many cases, grandparents shared with the mother the role of being the main caregiver of the child. This was even the case with paternal grandparents in one family after the couple had divorced.

An important aspect of this research that would benefit from detailed study is related to siblings' views and their contribution to the process of managing a child's chronic disease. Another essential subject deserving further attention from research is the sick children's perspectives of home-based treatment and their efforts to participate in school and social life. The children's own perspectives, their daily experiences of treatment and their involvement in the decisions related to their treatment, would be a valuable area of research, as would their perspectives on responsibility and independence and the transition from childhood to adulthood.

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APPENDIX

Interview guide (in Portuguese)

Tópicos da entrevista

Os temas a serem abordados na sessão de entrevista serão:

- a reação inicial ao diagnóstico da criança;
- o relacionamento com parceiros e familiares antes do diagnóstico da criança;
- o tempo de espera do diagnóstico;
- a reação ao diagnóstico;
- O acesso à informação sobre a doença

Etapas da entrevista:

1. Conversa informal com o objetivo de conhecer e avaliar a situação emocional dos pais, e de forma a criar cumplicidade/empatia (tempo de duração 5 a 10 minutos)
2. Introdução das questões de acordo com o temas do guião:

Roteiro para a Entrevista:

1- Primeiros Sintomas: Você pode descrever como se apercebeu que alguma coisa não estava bem com o seu filho (a)? Quando percebeu os primeiros sintomas ? O que você fez? Como entrou em contato com um hospital especializado em nefrologia pediátrica? Então, o que aconteceu?

2- Relacionado com o diagnóstico: Você pode descrever como decorreu este processo? Consegue explicar como foi o tempo de espera até conseguir o diagnóstico final? Durante esse período de espera quais foram os seus pensamentos e sentimentos? Neste contexto pode descrever a sua experiência com os profissionais de saúde?

3- Reação ao diagnóstico: Lembra-se da sua reação quando o Pediatra informou-o sobre o diagnóstico do seu filho(a)? Você poderia me dizer em detalhes como foi? O que pensou sobre toda a situação?

4- Rotina infantil: Qual é a rotina da criança após o diagnóstico? Pode descrever com detalhe um dia normal de seu filho(a)? E como é a rotina da criança nos fins-de-semana / feriados e nas férias?

5- Se o participante tem irmão (s): Como é a rotina da outra criança? Como é seu relacionamento com a outra criança? Como é a relação entre as crianças? Pode descrever o seu relacionamento com as crianças?

6- Rotina familiar: Pode descrever a rotina / organização familiar diariamente? Nos fins-de-semana? Nos período de férias? Como a família lida com a condição da criança?

7- Reação prevista do parceiro (a)/pai/mãe: Como o seu parceiro lidou com o diagnóstico? Houve alguma mudança de comportamento? Participou ativamente para encontrar soluções?

8- Reação prevista de parceiro e membro da família: Qual era a sua expectativa em relação à reação da sua família e do seu parceiro quando soubessem do diagnóstico do seu filho(a) e a sua condição renal? E como eles reagiram efetivamente quando tiveram conhecimento deste diagnóstico?

9- Negociação e Gestão: Como está gerindo a situação? Pode por gentileza me descrever?

Como sua família está lidando e gerindo o tratamento? O seu parceiro? Outra filho(a)?

10- Suporte: Que tipo de suporte você recebe? Qual tipo de suporte gostaria de receber para seu filho e para sua família agora? Você pode descrever como o apoio iria ajudá-lo e à sua família?

11- Literacia em Saúde: Você pode me dizer como você conseguiu a informação / literatura sobre a doença de rim (CKD)? Como você pesquisou literatura relacionada à CKD? Onde? Aquilo que leu ajudou-o-a entender o diagnóstico? Como as literaturas ajudaram você, sua família e seu filho a entender o diagnóstico e a gerir a condição CKD? Que tipo de informação falta ou seria mais importante para si e para a sua família?

12- Expectativa / Adaptação à condição e ao tratamento: O que você e sua família fazem para lidar/ viver com essa situação agora? Você pode descrever sobre a adaptação e expectativa diária?

Interview guide (in English)

- 1- **First symptoms and impact:** Can you talk about when you noticed your child's first symptoms?

What did you do? What do you remember from those days? How did you get in contact with a hospital specializing in paediatric nephrology? Then what happened?

- 2- **Impact on the child's development:** How do you describe your child's development? Can you tell me about it?

How do you describe your child's adaptation to his/her CKD condition? Why? Does he/she know about it? Can you tell me how it was when he/she discovered the diagnosis?

- 3- **Related to the diagnosis:** Can you tell me what the experience (process) of getting the final diagnosis was like?

How was your experience of those days? How did you feel about this? Could you tell me about your experience with the health professionals? How did the situation develop?

- 4- **Reaction to the diagnosis:** Do you remember your reaction when the paediatrician informed you about your child's diagnosis? Could you tell me in detail how it was?

What did you think about the whole situation? What did you worry about most?

- 5- **Child's routine:** What is your child's routine since the diagnosis? Can you describe in detail an ordinary day for your child?

Can you tell me about the child's routine on the weekends/holidays and during vacations?

- 6- **If the participant has another child:** What is the routine of the other child? Can you please tell me about your relationship with your children?

How is your relationship with the other child? How is the relationship between the children?

7- **Family routine and actual experience with the CKD condition:** Can you please describe the family's daily routine/organization? On week-ends? Vacations?

How does the family deal with the child's condition now? What changed and why did it change?

8- **Reaction predicted from partner:** How did your partner handle the diagnosis and manage it?

9- **Reaction expected from partner and family members:** How were you expecting your family and partner to handle the child's diagnosis and kidney condition?

10- **Dealing with and managing the treatment:** Can you please tell me how your family is dealing with and managing the treatment? Your partner? Other child?

What were your thoughts about managing the condition when you got the diagnosis? Who would do it, and how could it be done? How are you managing the situation? And how are you taking care of yourself?

11- **Needs and Support:** What do you remember that you needed the most? Can you describe it? (What did you feel you needed most at the time of the diagnosis?)

12- **Health Literacy:** Can you tell me how you got information/literature about CKD? What kind of information do you miss or would be more important to your family? What were/are the facilitators and obstacles to acquiring the skills and knowledge you need to manage the new condition?

13- Expectations of/adaptations to the condition and treatment: What do you and your family do in order to better deal with and live a better life with this situation now? Can you describe the daily adaptations and expectations?

Studies

The studies associated with this thesis have been removed for copyright reasons. For more details about these see:

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FACULTY OF ART AND SCIENCE

Linköping Studies in Arts and Sciences No 815 , 2021
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