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

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Material and relational challenges of home-based renal care: A parental perspective on child chronic kidney disease
Andrea Bruno de Sousa and Anette Wickström (2021)
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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.

Keywords: paediatric chronic kidney disease (CKD), home-based renal care, phenomenology of practice, materialities of care.

Introduction
A chronic condition interferes with both an individual’s life and their family’s life. The practicalities entail continuous restructuring of the families’ mundane routines (e.g. Corbin and Strauss, 1988). When a child is chronically ill, the family’s routines must be adapted to the child’s condition and treatment. In caring for a chronically ill child, parents must also balance the child’s medical care needs with the tasks of everyday family life (Park et al., 2019; Trnka, 2017). Consequently, a child’s chronic disease presents distinct forms of challenges and engagement to their family.

Parents’ experiences of meeting the challenges of caring for a chronically ill child, for whom a cure is not likely, have been of interest in a wide range of social science and
caring science research. A consistently emerging theme concerns social processes and the broader picture that influences patients’ and families’ situation and experiences. In her pioneering work on the experiences of parents of children with cystic fibrosis, Myra Bluebond-Langner (1996) demonstrated that parents’ strategies developed over the course of the illness and were guided by their efforts to control the disease. At the same time, parents did not want to have the child labelled as different, but wished to have others see the family as normal (Bluebond-Langner, 1996). Parents of children with chronic and severe health problems try to overcome the challenges and have a good life despite crisis and suffering (Mattingly, 2010). Still, their responsibilities concerning treatment and medication are far-reaching, and parents are reported as developing expert knowledge because of the peculiarities of the disease (Park et al., 2019 on haemophilia; Trnka and McLaughlan, 2012 on asthma).

In the case of child chronic kidney disease (CKD), the demands placed on parents are greater than those of many other chronic diseases, due to the complexity of the care involved (Mantulak and Nicholas, 2016; Ong et al., 2021; Swallow et al., 2009, 2011). The disease demands constant adjustments, in which renal replacement therapy using dialysis and kidney transplants form the prognosis (Tong et al., 2010). The quality of the care provided by parents is crucial for their child’s health outcome. To provide suitable care, parents must embark on a learning process that involves knowledge about nutrition, the risk of infection and operating a dialysis machine (Sanderson and Warady, 2020), as well as finding the financial and human resources to do so (Medway et al., 2015). These material aspects of care need greater understanding in international research (Buse et al., 2018). In terms of the child with CKD, things that need more attention include mundane materialities, such as the arrangement of a child’s room and a weekly menu, as well as the advanced technologies that are central to the treatment of the disease. It is also crucial to look at how frequent trips to the clinic and absence from work have an impact on parents, because emotional and psychological stress can influence the child’s health (Medway et al., 2015).
In this article, we examine the parental experience of caring for a child with CKD, in terms of how materialities and human resources shape parents’ experiences. The different voices, perspectives and concerns presented show that the life situation is constantly changing depending on individual and structural factors. Parents’ abilities, financial resources and relational support are negotiated through processes in which materialities and socialities are at stake.

Previous research on the impact of illnesses and treatments on children and families in the Portuguese context has been conducted by means of self-report measures examining quality of life in paediatric cancer (Santos et al., 2015) and paediatric asthma (Silva et al., 2015). While these studies provide insights into how parents and children value different facets related to the family’s functioning and well-being, they do not help us to understand the dynamic process of managing the child’s chronic condition in everyday life, and the specific material and social aspects that contribute to or complicate the situation. Given the complexity of care required for children with CKD, this is an important disease for understanding the experiences of caregivers.

**Chronic kidney disease and the Portuguese context**

The incidence and prevalence of paediatric CKD in renal replacement therapy are higher in Portugal than in many other European countries (Nascimento et al., 2015). The overall prevalence has notably increased since the survival of children with kidney disease has improved due to significant medical advances such as improved dialysis techniques and surgical procedures (Becherucci et al., 2016). Furthermore, Portugal has one of the largest renal transplant programmes per million inhabitants in Europe, and its kidney transplantation services are said to be leading in Europe and worldwide (Nolasco et al., 2017). However, the supply of donors is limited, and the programme requires the child’s weight to be 12 kilograms which makes the average waiting time about five years longer than other international centres (Deuchande et al., 2016).

CKD is a complex chronic condition with an array of origins that can impair the kidneys and lead to loss of renal function (Becherucci et al., 2016). The disease can develop at
any stage of childhood (Nascimento et al., 2015). The child is usually hospitalised during the diagnostic phase until they stabilise, and the parents have acquired sufficient treatment skills (Swallow et al., 2011). Public paediatric nephrology care in Portugal is centralised in the three metropolitan areas: Lisbon, Oporto and Coimbra (Simões et al., 2017). This means that families from smaller cities and rural areas must regularly travel to the hospital for treatment training, as well as for physician appointments and specialist care (cf. Medway et al., 2015).

The Portuguese National Health Service (NHS) predominantly provides primary care and specialised hospital care, while renal dialysis and rehabilitation are commonly provided by the private sector (but with considerable public funding) since the NHS is not able to respond to all care needs (Simões et al., 2017). Health services include surgery and dialysis treatment at hospitals. Pharmaceutical needs and peritoneal dialysis machines are covered by the NHS (Coelho et al., 2014). However, community care services, long-term care and social services for the chronically ill have been characterised as scarce (Simões et al., 2017). Parents must bear the cost of travel, dietary supplements, special diapers, bandages, etc. Thus, social determinants such as geography, income and health literacy create inequalities (Ferrinho et al., 2014).

The family is usually relied upon for care support, especially in rural areas (Simões et al., 2017). But demographics have changed in Portugal and the number of women working full time has become one of the highest in Europe (OECD, 2011). This impacts upon parents’ ability to take on the duty of caring for a chronically ill child. Nevertheless, caring for sick children remains within the domain of women (Simões et al., 2017). This presentation of the organisation of healthcare and community services, and the tradition of family care, form the background to what parents of a child with CKD in Portugal must deal with.

Theoretical perspectives
In analysing parents’ subjective experiences of caregiving, we 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). In the case of illness and suffering, which have far-reaching effects on human life, anthropologists have argued for a focus on people’s experiences, uncertainties and dilemmas (e.g. Kleinman, 2006). Phenomenological work, for example, has directed attention towards illness and medical treatment as processes that transform life (e.g. Wickström, 2017, Zeiler and Wickström, 2009), and has examined the effects of providing care for somebody with a severe illness or disability (e.g. Kleinman, 2010), in trying to make sense of people’s experiences and sense of agency.

To examine life and disease in phenomenological terms, Cheryl Mattingly (2010) suggests that social theorists focus on both macro and micro factors, on the structural conditions as well as on the worlds of the individuals and families experiencing chronic diseases. Central to this reasoning is the idea that a focus on specific practices, events and persons makes it possible to examine both the experiences and the conditions that motivate and control them (Mattingly, 2010). The efforts that people make, argues Mattingly (2010), show how they struggle to rebuild their lives and embark on journeys that involve transformations, not only of the sick person but often of the whole family and their community as well. This applies to our article, because we need to look, for example, at how parents of children with CKD relearn care and reorganise their routines, as well as the efforts they make to overcome the challenges involved.

However, even though phenomenological anthropology has paid attention to people’s connections to physical objects and things, our interest in the lived experience of caregivers using advanced technology benefits from being combined with a focus on material culture (Miller, 1997). According to Miller (1997), studying objects helps us to understand not only artifacts but also social values and challenges as well. The lack of attention paid to material culture within health and social care research has meant that mundane activities and the role of medical technologies have passed relatively unnoticed (Buse et al., 2018). Material culture is co-constitutive of care; thus, examining the “materialities of care” can contribute to understanding the role of both everyday practices and advanced technology (Buse et al., 2018). In the field of caring architecture, it is argued that materiality, such as buildings, rooms and furniture, influence the emotions
and sense of self of the people living or working there (Friesinger et al., 2020). This is particularly relevant for this article, in that we look at the role of aspects such as the dialysis machine, children’s rooms, and food recipes.

**Methods**

An ethnographic approach allows researchers to recognise different realities and contribute to an understanding of lived experiences of health and illness. It enables people’s lives to be studied in their everyday settings, focusing on the routines of daily life (Draper, 2015). It also involves the process of learning about and understanding another human group situated in its social and cultural contexts, which means that the character of ethnographic research is exploratory, and decisions such as where the participants will be interviewed are developed over time (Hammersley and Atkinson, 2007). In this fieldwork, the settings were professional institutions and parents’ home environments. Ethical approval was granted by the Ethics Commissions of the Regional Health Administrations (N° 33872016) and the Portuguese Data Protection Authority (No. 12607/2016). The major paediatric hospital in Lisbon and the related patient kidney association gave permission for the research to be carried out within their organisations. The clinicians at the nephrology unit and staff at the kidney patient association informed parents throughout Portugal who were caring for a child in any phase of CKD about the research project and referred them to the first author. Through the snowball technique, the first author then identified additional families who were interested in participating in the study. In total, 21 families (21 mothers and five fathers) agreed to participate in the study. Table 1 shows the socioeconomic and marital status of the families.
Table 1 – Families’ socioeconomic status

<table>
<thead>
<tr>
<th>Family income per month</th>
<th>Families</th>
<th>Married/Cohabiting</th>
<th>Single</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-income level (&lt; 1,400 EUR)</td>
<td>10</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Middle income level (1,401 to 2,400 EUR)</td>
<td>9</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>High income level (&gt;2,401 EUR)</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

The ages of the 21 children (17 boys, four girls) ranged from 2 to 16 years, with an average age of 10.5. Fifteen of the children had kidney failure that required replacement therapy in the form of transplants and/or dialysis. The children’s treatments at the time of the interviews are presented in Table 2.

Table 2 - Children’s treatment

<table>
<thead>
<tr>
<th>Children’s treatment at the time of interview</th>
<th>On transplant waiting list</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant</td>
<td>10</td>
</tr>
<tr>
<td>Conservative treatment</td>
<td>6</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>4</td>
</tr>
<tr>
<td>Haemodialysis</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

The first author conducted six months of fieldwork, interviewing the parents, conducting observations three to four days per week at the nephrology unit, and holding informal conversations with professional healthcare staff at the hospital and the patient kidney association. Since the parents’ hectic schedules made it difficult to interview them on the
day of their child’s physician appointment, the first author expanded the fieldwork to include the parents’ home environment (for details of the process see Bruno de Sousa, 2018). Of the 21 families, 15 were interviewed in the evenings or at weekends in their home or at a neutral nearby location, within a 365-kilometre radius of the hospital.

Prior to each interview, consent forms were discussed, including information about the participant’s right to withdraw at any time, and written consent was granted by each participant. The first author, who speaks Portuguese, conducted the interviews in the parents’ native language and recorded them digitally. The interviews lasted between one and two hours and focused on the child’s illness trajectory, the family’s daily routines related to the child’s CKD, and the management of everything from nutrition to social life. Open-ended and follow-up questions were asked to enable the parents to talk freely and narrate their experiences.

The recorded interviews were transcribed by the first author and analysed by both authors using thematic analysis in a data-driven inductive way, with the intention of providing a rich description of the data overall (Braun and Clarke, 2006). The contextualist approach of thematic analysis allows for theorising about the structural circumstances identified in participants’ narratives. It highlights the setting in which an action takes place and seeks to comprehend the action relative to that context (Braun and Clarke, 2006). After a close reading of the transcripts, we sorted them according to content with a focus on shared meaning-based patterns (Braun et al. 2019). The key findings concern a process in which the disease created a new reality on a personal, social, and financial level and impacted on family routines and plans, on school and work. To manage the new situation the parents had to learn the treatment, search for information, reorganise family life, and adapt their parenting and work. The parents were supported by the staff at the hospital and by their family network. The process made them knowledgeable about the chronic disease and changed their attitudes toward life. Based on the initial codes related to the strategies that the participants spoke about (e.g. learning the treatment skills, involving grandparents, or inviting friends home to dinner) we created a thematic map. Both researchers were involved in the coding process to ensure reflexivity and a nuanced
reading of the data. To understand the broader meaning of the statements, we also related them to the circumstances in which the parents lived. Finally, we combined the initial codes into broader units of analysis and sorted the participants’ experiences into three themes of strategies. In table 3 we present the themes and their key principles.

Table 3 - Families’ strategies

<table>
<thead>
<tr>
<th>Families’ strategies to meet the challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes</td>
</tr>
<tr>
<td>Surpassing oneself and developing expertise</td>
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<td></td>
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<td></td>
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<tr>
<td>Managing materialities and socialities of</td>
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<tr>
<td>home-based renal care</td>
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<td></td>
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<tr>
<td>Building a network of care</td>
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</tbody>
</table>

Besides strategies the three themes also represent a trajectory from chaos to finding new ways of living and seeing life in a new way. Thus, the three themes present a development over time, from learning in the hospital setting, to transferring the complex treatment to the home, and finally, to build new relationships and gain new attitudes towards life. The excerpts used to support our interpretation in the following sections were translated into English by the first author with the intention of maintaining the meaning of the original spoken language while also making the quotes understandable to
the reader. To ensure anonymity, the participants’ names and those of their children were pseudonymised.

**Surpassing oneself and developing expertise**

This first theme demonstrates the overwhelming impact of a child’s CKD diagnosis on their families, and how material and social assets influence the families’ ability to overcome the challenges. It also shows how hospital staff can provide support and, to some extent, compensate vulnerable parents.

When the interviewed parents were first informed about the treatment they would have to learn and carry out, they found it extremely difficult and did not know how to manage it. Home-based CKD treatment is accomplished through nutritional supplementation via enteral tubes and pump devices (e.g. Becherucci, et al., 2016). Peritoneal dialysis, which uses the inner lining of the child’s body as a filter, means that the caregiver must connect the child to a dialysis machine daily using a catheter placed in the child’s abdominal wall (e.g. Sanderson and Warady, 2020). The technically demanding interventions that parents are expected to manage are provided by highly trained nursing professionals in hospitals (Tong et al., 2008) which provides a picture of the burden of care placed on the parents of children with CKD. The intensive treatment is vital to postpone the advancement of the disease and reduce the likelihood of associated problems, such as cardiovascular complications and the impact of the disease on growth (Becherucci et al., 2016, Sanderson and Warady, 2020). Parents must also learn to recognise symptoms that require more specialised assessments and interventions (Swallow et al., 2011). The interviewed parents reported that they needed to find strategies to manage the care, and at the same time continue with their ordinary tasks. Of note, during the fieldwork, we encountered a case in which the parents had made the extremely difficult decision to put their newborn child up for adoption. Considering their obligations and resources, some parents may find themselves unable to take on the care that the ill child requires.

The interviews demonstrate that the processes of developing technical skills and hygiene measures with the help of hospital staff varied. One of the interviewed parents, Lia,
whose son was two years old when he was diagnosed with CKD, explained that she was scared:

I was very nervous about performing the dialysis on my own at home, but I had no choice. I had to learn the procedure of the peritoneal dialysis and how to run the machine. It was very complicated at first, it seemed like a “seven-headed hydra”.

Referring to the learning process as a “seven-headed hydra” highlights how difficult Lia found the task of performing the treatment. As soon as one challenge had been met, two more challenges would emerge. As with the monster in the legend, she found that the treatment was never-ending. Another mother, Carla, explained that because only one parent could stay at the hospital, she tried to learn the treatment skills quickly so that she and her husband Leo could take care of their 12-month-old son together at home as soon as possible after the hospitalisation:

I learnt to do the peritoneal dialysis, to set up the machine in five to seven days, because I wanted him to be at home.

After only one week at the hospital, Carla returned home with her son to be reunited with the rest of the family. For several other parents, it took more than a month to learn the procedure and be able to carry out the treatment at home. Being in a vulnerable situation, however, can complicate the learning process. Joana was an unemployed single mother with two children, one of whom was Iris, who had been diagnosed with severe kidney failure when she was six months old. Joana’s social and financial situation was difficult at the time, and she did not know how to manage the care demands placed on her. As a result, she stopped visiting her daughter in hospital for a while. She recalls the initial period:

At the beginning of the treatment I was too young and on my own. I felt powerless seeing her [Iris] suffering because of the intrusive treatment. I was unemployed and I didn’t have any support or financial stability. It was a very difficult time.
The staff at the hospital intervened and emphasised Joana’s responsibility to visit more frequently and learn to take care of her daughter. So that she could stay with Iris during the periods of hospitalisation and learn about the treatment, Joana moved to a shelter close to the hospital, supported by a charitable organisation, and lived there for almost a year. When she was not in hospital, Iris lived with her at the shelter. With the help of the hospital staff, Joana began to learn, and she eventually moved close to her mother’s house to get help with Iris’s care.

Joana managed to overcome the challenges that arose in caring for her child. She explained with confidence that Iris did not contract any infections when under her care, a sign that she was receiving good care:

After a while I learned how to manage the treatment; how to cook the specific food, how to do the dialysis and all the essential care. Iris never had any infections after I started taking care of her at home.

The experiences of successfully managing the dialysis machine and preventing bacteria from entering the catheter made Joana proud.

The examples above demonstrate that the first strategy developed by the interviewees was initially a kind of panic measure. The parents went through a process of feeling trapped due to the diagnosis their child had received. The diagnosis put them in a situation they barely knew anything about. They encountered a new world of thought, concepts and medical devices, and they had to create conditions for developing knowledge and familiarity with the disease, treatments and risks. Developing knowledge was a common response of parents to the experience of their child being diagnosed with a life-threatening disease (cf. Bluebond-Langner, 1996) – a situated learning process (Lave and Wenger, 1991) that took place in interaction with medical staff, and with artifacts such as pumping devices and dialysis machines. From feeling trapped in the context of their child’s diagnosis, parents experienced the learning process as an opening up and a
development which inspired hope for their child’s survival. It created an image of a possible future in which their child’s disease was part of everyday life.

Managing the materialities and socialities of home-based renal care
The second theme shows what happens when renal care is transferred to the home. The child’s complex treatment, which was previously part of specialist medical activities in hospital, is transferred to another everyday activity and context. The parents must rearrange their home and meals while trying to maintain a social life and perform their other tasks.

On leaving the hospital and returning home, the parents’ everyday lives were transformed into a state of constant attention and readiness. As a result of hospital staff not being around, parents often telephoned the specialist physician for support. The parents stated that they trusted, and commonly worked in partnership with, their child’s specialist physician. In contrast to studies on chronic diseases such as asthma and haemophilia, which report that parents develop more expertise than physicians (Trnka, 2017; Trnka and McLaughlan, 2012; Park et al., 2019), this study demonstrates that the materialities of CKD care involve technically demanding interventions that leave little room for improvisation. Even though the interviewed parents developed expertise about their child’s condition, they relied heavily on the doctor’s assessment concerning the treatment.

The condition of their chronically ill child necessitated detailed planning of the child’s diet. The interview with Alice and Manoel took place at their home, which was a 45-minute drive from the renal consultation clinic. Alice and Manoel showed the meal calendar they created every week as well as the packed lunches and snacks they prepared so that Davi would be fed correctly at preschool. The couple were proud of their accomplishments and their ability to find and prepare new recipes, especially since Davi, like many other children with CKD, had difficulties eating (Fernandes, 2018; Tong et al., 2010). The restricted diet prevents the children from trying different types of food, and their appetites suffer as a result. Alice explained:
Our son never eats much, he has difficulties eating, so we must adapt the recipes according to his needs. He has a poor appetite, and we always create new recipes and measure out the amount he must eat.

Alice and Manoel’s latest recipe invention had allowed Davi to enjoy his very first birthday cake at the age of five. The everyday innovations created meaning for the family because they improved Davi’s appetite. When the parents in our study talked about how they adapted their homes, meals and social lives, a common theme was that they tried to achieve as close to a “normal childhood” as possible for their child.

While food and meals could be made close to normal, adapting the child’s treatment to the home required more complicated rearrangements. To carry out peritoneal dialysis, a child’s room must be remodelled. The guided tour that Alice and Manoel gave of their house showed the consequences of performing dialysis at home. Entering Davi’s room felt like entering a private hospital ward. His toys had been replaced with a dialysis machine, and the room seemed bleak because it was kept extremely clean to avoid the threat of infection while performing dialysis. Elza, the mother of two-year-old Joel, described how her son’s stuffed animals and books had been replaced by the dialysis machine:

I had to change his entire room because it had to be extremely clean to avoid infections when doing the dialysis. I had to take away all his toys and books. His room became very plain.

Elza felt her son’s room was somewhere he had to suffer due to his treatment, rather than being a warm and cozy place where he could play and feel comfortable. While the dialysis machine allows children and their carers to stay at home and ensures that everyday activities are as close to normal as possible, the dialysis itself requires careful supervision, and the accompanying material takes up space.
As a result of the new tasks and of being tied to the home, the family’s social life and interactions with friends and relatives became a challenge. Adapting to the situation required striking a balance between isolating the family and exposing the child to certain risks. Half of the interviewed parents reported that they had stopped attending birthday parties and dinners with friends. Other families began to invite people to their own homes instead. Even though this entailed more work and preparation, they were then able to enjoy family traditions without risking family isolation or their child’s health. As shown in previous research, celebrations and traditions have a symbolic meaning and contribute to family cohesion (Santos et al., 2015). Bluebond-Langner (1996) found that parents of children with cystic fibrosis wanted both the child and themselves to lead as normal a life as possible. One strategy was to extend the realm of the normal so that the cystic fibrosis and the situation created by the disease were included (Bluebond-Langner, 1996). In the present study, the strategy to strive for a normal childhood led the parents to transform meals and celebrations into activities that suited their child. The parents who invited friends to their home made the home a hub where they could control the situation and at the same time maintain social interactions. The transformations of meals and centralising their social life to the home meant that the child’s dietary requirements were extended to close family and that the home became central for the extended family. As a result, the parents, siblings and relatives became disciplined by the intensive medical regimes that the child with CKD needed.

Our analysis also demonstrates that the technically advanced treatment and requirements for extreme cleanliness in the case of CKD limits the degree of normality, which led to parents hoping for a kidney transplant. The fragile condition of young children with CKD, however, creates a surgical challenge, and criteria regarding transplantation in young children are often lacking (Vitola et al., 2013). Furthermore, the normality that is expected to result from transplantation has not emerged as an obvious result because the disease is constantly present even in life as a transplant recipient (Gunnarsson, 2016). A kidney transplant, however, would be the nearest thing to a cure (cf. Mantulak and Cadell, 2018). It would mean a transplanted kidney taking over the job of the child’s
failing kidney. It would also lead to the dialysis machine no longer being needed, leaving room for other things and activities.

According to the participants, children in Portugal usually become eligible when they weigh about 14 kilograms, which means that those children with CKD who have problems gaining weight are usually five or six years old before they can have a transplant. While some families found opportunities to get a transplant abroad, others referred to their financial situation and decided to wait until their child could have a transplant in Portugal. When Mattingly (2010) theorises hope as practice, she refers to the efforts people make to find continuity and use all the available resources. The interviewees hoped either to keep life as it was (i.e., preventing the CKD from progressing and reducing the likelihood of side effects) or to lighten the burden by finding a new kidney. Practising hope, as parents of a child with a life-threatening chronic disease, can be a matter of finding a means of controlling the disease, if not of curing it, and of creating normality as much as one can (cf. Bluebond-Langner, 1996).

**Building a network of care**

While the parents’ strategies to manage home-based treatments reveal the home to be a strong hub that brings together all the treatment activities, and sometimes also the social life, in one place, the situation caused by the child’s CKD puts a lot of pressure on partner relationships. The third theme addresses these close relationships and how they are affected by this new situation where life revolves around caring and caring practices. The interviews show that some parents cooperated well, while others’ marriages broke down, but also how a caring network could compensate for losses and increased needs.

The parents’ ability to adapt to their child’s chronic disease while at the same time managing their ordinary responsibilities was determined by structural conditions such as the parents’ financial resources and working conditions. All families in the study stated that the child’s condition affected their ability to work, and nine mothers had had to resign in order to provide care for their child. For some, the pressure and the
responsibility for their child’s treatment changed their life in a way that broke their family apart. Angela, the mother of Rui, reflected on her relationship:

Rui’s father was physically present and accompanied us to the physician’s consultations. Being physically present is one thing but being present in body and soul are quite different.

Angela divorced Rui’s father and stopped working during Rui’s hospitalisation, but managed to keep her job. Maria, whose daughter was diagnosed with CKD at the age of five months, and whose husband was frequently absent from the family due to work, explained that the situation surrounding her daughter’s CKD had far-reaching consequences because her employer had decided not to renew her work contract. One third of the participating mothers commented that the situation had negatively affected their relationship with their partner. Five of them had seen their relationship come to an end. Privileged couples with flexible jobs could rearrange their working hours, and the situation did not seem to radically interfere with their careers. Izabel explained that she and her husband Gabriel worked closely together and shared all the practical aspects of care:

My husband and I became very close, we became a team. We shared everything. We made schedules to share all the activities and our time between the children, to make sure that both our children had our time and attention.

Izabel and Gabriel developed new parenting skills and made sure that their other children had quality time with them, going on outings and vacations that suited their interests. Another of the interviewed couples hired a private caregiver for their two-year-old son.

To reduce the pressure on family life, the interviewed parents tried their best to mobilise a network of care. During the interview with Alice and Manoel, their five-year-old son Davi was looked after by his paternal grandparents. Manoel explained:
We were able to deal with the demands of the treatment and organise routines because the grandparents always helped us with everything, and they learned how to take care of Davi.

The normal childhood that Alice and Manoel were striving for depended on the support they received from both sets of grandparents. Maria, whose husband was away at work during the critical period, explained that her marriage had ended, but that her parents-in-law had offered practical and financial support following the divorce to help her cope with the critical situation. Half of the interviewed families were supported by grandparents, who helped with everything, in both financial and practical terms, from basic daily tasks and transport needs to the treatment itself. For some families, this support was essential, allowing mothers to keep their jobs and divide their time between caring for their child and working. Other families were afraid of handing over care duties to others because of the difficulties in mastering the treatment. Twelve-year-old Antonio was diagnosed with CKD when he was just five days old. His mother Sara explained that she and her husband managed to integrate treatment into their ordinary life despite the difficulty getting support:

It was difficult for friends and even relatives to help. They were scared when they heard about the CKD and did not know how to help.

The technologically advanced requirements placed on the caregiver set certain limits on the support that others in their social network could provide. The treatment is complicated, and relatives have not been through the same learning process as the parents have.

In spite of the challenges, the interviewed parents emphasised that devising strategies, providing care, and receiving support had led to them gaining more knowledge and learning new tasks. The strategy of building a network of care had also turned CKD into a collective undertaking for the extended family. A recurring theme within the parents’ narratives concerned the transition from an extremely difficult situation to improvements.
such as having good routines and being more confident about the child’s treatment. Furthermore, although the situation was emotionally exhausting and demanding in many ways, all the parents reported that they and their relatives had grown as individuals and that their attitude towards life had changed (cf. Mantulak and Nicholas, 2016). Similarly, in his work on caregiving, Arthur Kleinman argues that caregiving can “enhance our compassion, solicit solidarity, and elicit a fuller, more human presence than we ever realized we possessed” (2010:7). The interviewed parents explained that their child’s condition taught them to see life in a new way, to be thankful, and not to focus on unimportant things. In general, they talked about the challenges they had encountered, and the strategies they had developed, as a gift and a joint commitment.

**Discussion**

The lived experiences of parents of children with chronic kidney disease reveal a dual and somewhat contradictory picture (cf. Kleinman, 2010). As shown, the new situation following a child’s CKD diagnosis causes parents to become confined due to the demanding care and the artefacts used in the treatment. At the same time, they were taking part in situated learning and eventually experienced opening up to a richer and more meaningful life. The situation caused by the child’s chronic condition had led to previously unknown engagements with others and things, in complex negotiations about relations of care and the main purpose of life.

The process of incorporating illness into one’s way of being in the social world is a salient theme in research on families living with different kinds of chronic disease (e.g. Mattingly, 2010). Thus, our results can be read as a reminder of the complexity of performing home-based care and the dual effect of caregiving, i.e., the caregiver’s emotions becoming divided between a sense of burden and compassion (Kleinman, 2010). But our article’s notable contributions are several.

Firstly, we demonstrate the need for ethnographic methods such as participant observations and interviews to examine previously unrecognised aspects of the parents’ situation, and the dynamic process of managing home-based renal care. Examining
parents’ lived experiences is a valuable complement to self-reporting measures that focus on quality of life among the parents of children with chronic diseases in Portugal (e.g. Santos et al., 2015; Silva et al., 2015). It involves listening to people’s own formulations of what they mean and do, i.e., the interpretations they themselves make, and then as researchers interpreting and analysing what they say and do. This is difficult to do without talking to people and observing them within their own environment. Based on interviews and participant observations, the challenges and strategies narrated by parents, and the material aspects of the home-based care observed in their homes, can be taken seriously. This is especially important in relation to the structural prerequisites under which parents live; in this specific case, Portuguese society. In the case of chronic diseases, where a great deal of responsibility and advanced technical care is transferred to the home context, it is crucial to understand parents’ lived experiences and gather knowledge about the challenges and success factors, and their needs and competencies.

Secondly, our article contributes to past research in which phenomenology has been applied to ethnographic work, in that we focus on the everyday experiences, challenges and strategies that are such a crucial part of people’s lives (cf. Desjarlais and Throop, 2011). The meanings of relational and material aspects of care that we analyse expand the field of knowledge concerning parental perspectives on children’s chronic disease. The relational aspects of a child’s CKD draw attention to how the new situation renders certain relationships fragile, while at the same time providing opportunities for different relational ties. The cost for the parents could be a broken marriage or the loss of a job, while the benefits could be new social relations of care and sources of support. Our analysis of the materialities of care contributes to a better understanding of the specificities of CKD. In particular, it demonstrates the dual role played by the dialysis machine in the parents’ efforts to normalise everyday life. On the one hand, it was the hub of the medical treatment and the life-sustaining force in that it replaced the child’s failing kidney. On the other hand, the machine limited the scope for action and required a great deal of space and time, as well as extreme cleanliness. In this way, it encroached on the opportunities to create a “normal childhood” and affected all family members. Thus, a kidney transplant was seen as a promising future. Analysing the technical and social roles
of the dialysis machine in our study helps explain both the important role the machine plays in the processes of survival and the requirements and work it brings with it (cf. Prout, 1996, on the role of metered dose inhalers).

Most importantly, however, our analysis of the materialities of care emphasises how managing mundane materials and technologies connects to the concept of hope as a practice (cf. Mattingly, 2010), in the sense that parents’ hope was encouraged by their efforts and practicalities. In more concrete terms, managing the home-based peritoneal dialysis therapy, planning, buying food, and cooking and serving a special diet for their child nourished the parents’ hope that their child would survive and improve, or simply not change for the worse.

Finally, this article phenomenologically captures the reality of ordinary life, by revealing the oppressive social structures across broad divides, as well as the possibilities for transformation that they present (Mattingly, 2010). Our analysis of lived experience and the structural social picture discloses that the parents used the available medical, financial, and human resources to ensure that their child would survive and have a somewhat “normal childhood”. However, focusing on the individuals’ responsibilities and abilities risks obscuring deficiencies in the healthcare system or in community care services (cf. Trnka, 2017). Therefore, our analysis emphasises 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, i.e. the burden of disease is related to the individual family’s financial and social situations. Community care services and social services for the chronically ill are scarce in Portugal, informal care is more difficult to uphold today, and the technically advanced care can be difficult for relatives to master. Thus, as our focus on materialities shows, the parents have unequal resources with which to take on the task, and because of the space, time and effort home-based renal care require, it is worsening social inequities.

How parents manage is related to their opportunities to act in their ordinary setting, opportunities that are unequally distributed on personal, social and structural levels.
Social and economic status, the geographical locations of the home and the renal consultation clinic, and the involvement of relatives, all have an impact on the families’ lives. The parents’ ability to meet the financial costs and cope with the disruption to everyday life depends on how their families respond. Vulnerable parents who do not have the necessary financial resources or social relations of care make huge efforts to fulfil their responsibilities (cf. Tong et al., 2010; Swallow et al., 2011). In the case of Joana, this responsibility was discharged by herself, as well as by nurses, family, and the charitable organisation. The strategies that led to her becoming an expert clearly demonstrate the vulnerable situation of parents who do not have easy or obvious access to the resources required.

The results of our study therefore show the 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 highlight the importance of support and services that extend beyond health services at hospitals. While more research is needed to help us understand the experiences of healthcare providers in their work with children with CKD and their parents, our research exemplifies how they can help to strengthen parents’ opportunities to provide the necessary care, and how crucial such help can be in terms of a parent’s chances to develop the specific caring skills needed to sustain the sick child and to enact hope for survival or even an improved life situation. It is hoped that knowledge about the strategies used by parents to manage the situation can encourage those responsible for social policy, healthcare providers, and community health services to meet the needs of families with children with CKD and to compensate vulnerable parents.

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References


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¹ One of the interviewed mothers was not a biological parent but a legal caregiver.

² In haemodialysis, the blood is pumped out of the child’s body using tubes connected to the dialysis machine. In Portugal, this treatment is usually performed three times per week at a hospital or a renal consultation clinic.