

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

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# **Readiness parenting: practices of care by parents of children with chronic kidney disease in Portugal**

Bruno de Sousa, Andrea; Goes, Ana Rita & Wickström, Anette (2022)

## **Introduction**

Raising a child with a chronic condition has the potential to impact upon the whole family's life (Bluebond-Langner, 1996). Parents play an essential role in the management of these conditions and need to integrate general parenting tasks, such as providing appropriate socialisation experiences, with disease-specific tasks. In the specific case of paediatric chronic kidney disease (CKD), the family is faced with the need to provide complex care while continuing to carry out everyday tasks. The situation is not a singular event but a pervasive context and something that families must live with, navigate, and manage throughout the child's life (Vigh, 2008). Previous research concerning parents of children with CKD has confirmed that their crucial role in the management of the condition places a heavy burden on them and highlighted these parents' challenges, difficulties, and needs (Swallow et al., 2008, 2009; Tong et al., 2010).

Given the prominence of the parenting role in the management of chronic paediatric conditions, personal experiences of parenthood have been found to represent an important resource for families' adaptation, or an additional source of strain (Patterson et al., 2004). Parenting studies have frequently explored the expectations and negotiations of norms of "good parenthood" (e.g. Faircloth, 2014; Lee et al., 2014; Sparrman et al., 2016), with some authors calling attention to increasing expectations to parent intensively no matter what competing demands may exist. In the case of parents of children with complex care needs, previous research has illustrated the specificities of parenting, reporting the extra roles and efforts involved in raising these children, the complex identities as parents and healthcare providers (Wilkinson et al., 2020), the pursuit of being a good parent (Woodgate et al., 2015) and the negotiations parents engage in regarding protection, autonomy, and the involvement of others (Almack et al., 2009). Given the particular complexity of care required in CKD and the skill associated with the home-based care provided by parents, their experiences of parenthood may inform the provision of family-centred care.

So far, the majority of studies exploring the experiences of parents of children with CKD have looked mostly at disease-specific experiences and tasks, sources of distress, personal and family impacts, and support needs (e.g., Mantulak, 2016; Ong et al., 2021; Tong et al., 2010). Limited information exists about the negotiation of parenthood along the course of the disease. This article draws upon families' lived experience of dealing with paediatric CKD, bringing a theoretical and empirical focus to the parents' views, experiences, and practices regarding good parenthood when raising a child with this condition in the Portuguese context.

## **Childhood chronic kidney disease**

CKD is a complex set of long-term conditions with a multiplicity of causes that can damage the kidneys and cause loss of kidney function (Becherucci et al., 2016). Hospitalisation, delayed growth and development, short stature, and bone disease are frequent complications of CKD (Becherucci et al., 2016). Life expectancy of children in dialysis is roughly 50 years less than that of healthy children and mortality is 30–150 times higher (Becherucci et al., 2016). Paediatric CKD demands constant medical care as well as complex medical treatment at home, a strict diet, and continual care to avoid infections (Swallow et al., 2008, 2009; Tong et al., 2008, 2010). The child and family must start a never-ending transformation that demands continuous adjustments (Ong et al., 2021; Tong et al., 2008, 2010). Together with the child, parents need to monitor the health status, take responsibility for complex aspects of care, and recognise symptoms that demand more specialised assessment and intervention (Swallow et al., 2009). Due to the progressive nature of CKD, children and their families face a lifetime of medical treatment, which greatly impacts upon the child's development and quality of life and brings uncertainty about the disease's progression and treatment (Tong et al., 2008; 2010). Consequently, having a child with an incurable, life-limiting, chronic kidney disease presents additional parenting challenges.

In Portugal, chronic paediatric diseases are responsible for one-third of specialist consultations and paediatric hospitalisations (Santos, 2010). Public paediatric nephrology care is concentrated in three metropolitan areas: Lisbon, Porto, and Coimbra. For families who do not live near the reference hospital, geography brings the additional burden of frequently travelling back and forth to the metropolitan areas for medical care. Additionally, in Portuguese society, women are usually considered to be responsible for the care of chronically ill children (Simões et al., 2017). This tradition is difficult to sustain in modern-

day Portugal, however, due to demographic changes and urban migration (Simões et al., 2017).

## **Theoretical perspectives**

Parental engagement is essential to a child's health and wellbeing. In analysing parents' lived experiences and practices, we take inspiration from parenting studies and child studies (see for example Dermott, 2016). In order to examine parenthood as relational and context dependent, we draw upon the theoretical concept of "doing good parenthood". Sparrman and colleagues (2016) describe it as a succession of procedures that mothers, fathers, and every person involved in childcare are engaged in as regular practicalities including fulfilling basic needs, such as nourishing, housing, and providing education and safety. These parenting procedures include negotiating norms about parents' responsibility for taking care of their children's health, as well as their welfare and success in life (see for example Lee et al., 2014).

Parents' wishes related to their children, as well as their ideals and practices, differ according to time and local context since parenting is an experience that is established on a sociocultural basis. Norms are fashioned by ideas of childhood, family values, education, and socioeconomic context. Thus, "good parenthood" is determined by cultural aspects and shaped through practices that involve different normative standards, demonstrating that it is neither fixed nor stable (Lind et al., 2016). The sociocultural context in which parents carry out their daily activities is also permeated by expert knowledge and political decisions that make parenting the subject of discussion and problematisation (Lee et al., 2014). In studying parenthood in the Nordic context, Böök and Perälä-Littunen (2008:76) conclude that "Cultural pressure on parents to act in the best interests of the child is stronger in present-day society than it was". The culture of "intensive parenting" pressures parents to be responsible for all aspects of their child's development, no matter what hardships may be involved, and turns parenting into an absorbing and demanding task (Faircloth, 2014). An important aspect of the relationship between children and parents concerns dependence, interdependence, and independence and potential conflicts of interest in relation to these (Sparrman et al., 2016).

In the case of parenting a sick child, parents must deal with hazards related to their childcare and balance contending discourses and attitudes towards parenting and caregiving (Almack et

al., 2009). Simultaneously, parents are confronted with the moral risk linked to the constructions of parental competency and with the concept of being good enough parents (Almack et al., 2009). The responsibility that parents face in performing self-treatment at home has been coined “chronic homework” (Mattingly et al., 2011). Woodgate and colleagues (2015) used the term “intense parenting” to describe the additional tasks (e.g., administering medication, mastering medical equipment, exercising clinical judgement) and challenges faced by parents of children with complex care needs. Not only is the family routine massively impacted, but the home becomes a “therapeutic landscape and caring space” (Wilkinson et al., 2021:161). Carter and Bray (2017) described the demandingness of providing skilled care at home as a stressful and imposed “clinical career”.

Merging the duties of treatment into daily family routines requires families to find a “new normal”, minimising the intrusiveness of the condition and enabling the maintenance of a focus on the family. Knafl and colleagues (2012) used the Family Management Style Framework (FMSF) to explain the varying ways in which families respond to health challenges, recognising the diversity of family illness experiences and variations in the extent to which families experience normalisation. This normalisation process contributes to the management of health issues, encouraging families to standardise their treatment undertakings and focus on the child’s capacities, rather than their vulnerabilities (Knafl et al., 2012). Parents transform their concerns about the child’s health condition and wellbeing into practical actions of conscientiousness, such as engaging the child in regular activities (Park, 2019). Studying parental perspectives on child food allergies, Stjerna and colleagues (2013) demonstrate how parents balance between norms of constant vigilance and risk taking.

Along the way, parents construct and negotiate parenthood and the expectations of their role. In their work with parents of children with chronic diseases or disabilities, Woodgate and colleagues (2015) describe that, for parents, being a “good parent” meant maintaining their child’s health and safety, but also ensuring that their child had a good life. This meant constant self-sacrifice and attempting to meet the needs of their children. Wilkinson and colleagues (2020) also found that mothers expressed a blurring of roles between mother and carer, and proposed that mothering a child with complex healthcare needs extends normative ideas of motherhood. In studying parents of young people with intellectual disabilities, Almack and colleagues (2009) examined the ways in which parents negotiated risks and

described competing discourses around finding a balance between the dual imperatives to protect and empower their child.

In the specific case of adjusting to paediatric CKD and its treatment, the child and their family must obtain new skills and find new life routines (Ong et al., 2021; Park, 2019). The demands on parents of children with this condition are even greater than for other chronic conditions because of the responsibility for highly complex and specialised home-based care. Furthermore, the distinct stages of the child's CKD and its treatment call for unique actions, to which the family must respond appropriately. Understandably, these parents report lower quality of life and significant distress related to the disease, personal struggles, family functioning, and social life, as well as a lack of resources and unrealistic social expectations (Ong et al., 2021). Tong and colleagues (2010) described parents' struggle to fulfil their responsibilities as parents and healthcare providers as giving rise to fatigue, stress, and emotional pain.

In sum, the parental role in the case of a complex condition like CKD requires unrelenting care, with careful attention to signs of illness. Parents are expected to be accountable for their children's protection and wellbeing. Hence, under these circumstances, satisfying the ideals of good parenthood is more complex and challenging. Considering that good parenthood is fashioned in context, achieving a deeper understanding of the construction and negotiations of good parenthood in relation to a severe and demanding condition such as CKD may shed light on the journey of these parents and contribute to improving the support they receive.

## **The study**

According to Hanson et al., (2017), qualitative research is essential to enhance expertise and understand how to improve care and outcomes for children with CKD. Ethnographic fieldwork has the potential to examine crisis and how brutal life can be, without losing sight of people's resilience (Vigh, 2008.) This study draws upon a research project based on hospital ethnography, involving participant observations and interviews (Bruno de Sousa and Wickström, 2021). Although the unique practice of parenthood related to a child with CKD was not the primary focus, it emerged as a significant theme and an important analytical category during the research project. Therefore, it was pursued through specific questions during the interviews. Charmaz (2004) points out that studying the emerging subject is a

valuable strategy in qualitative research, because it clarifies theoretical categories that enrich the data. In our study, the concept of readiness parenting sheds light on the parents' practices when handling paediatric CKD.

Participants were the primary caregivers of children with CKD. They were recruited from the nephrology clinic of a major hospital in Portugal and the Portuguese Association of Kidney Patients. The invitation to participate was made through the paediatric specialist, the kidney association, and the parents who were recruited initially, using a snowball technique (Bruno de Sousa and Wickström, 2021). Of 59 families invited, 21 participated in the study (Table 1).

### **Table 1 here**

The caregivers (referred to as parents) were aged between 19 and 65. Fifteen interviews were conducted with mothers only, one with the legal caregiver, and five with both parents. The 21 children were aged between two and 16 years, with an average age of 10.5. Seventeen children were boys and four were girls. Fifteen of the children had kidney failure that required replacement therapy in the form of transplants and/or dialysis.

The first author made repeated visits to the nephrology clinic of a major paediatric hospital in Portugal over a period of six months, to explain the research to the prospective participants and make observations in the hospital setting. She similarly presented the research to the staff at the patient association. The association's representative gave information to families dealing with children with CKD from different parts of Portugal. The interested families subsequently contacted the researcher. Ethical approval was granted by *the Ethics Commissions of the Regional Health Administrations* (No. 33872016) and *the Portuguese Data Protection Authority* (No. 12607/2016). Prior to each interview, written consent was given by each participant. Consent forms, including information about each participant's right to withdraw at any time, were discussed. The interviews were conducted in 2017 in the caregivers' preferred place, such as their own home, workplace, university, or library (for details see Bruno de Sousa, 2018). The interviews revolved around the child's disease trajectory, the family's daily routines related to the child's CKD, and the management of the child's condition from nutrition to social life. Open-ended and follow-up questions were used to enable the parents to talk freely and narrate their experiences in dealing with their child

with CKD. The interviews lasted between one and two hours. Interviews were conducted in the participants' native language, digitally recorded, and transcribed verbatim. Data collection took place from February to July 2017.

The interviews were analysed using thematic analysis (Braun and Clarke, 2006) in conjunction with the field notes to validate the themes. Using open coding and constant comparative analysis, we created a thematic map to identify any part of an interview related to the participants' endeavours regarding doing good parenthood in the context of paediatric CKD. The open coding allowed us to identify data items that were persistent throughout the data (Braun and Clarke, 2006). It was accomplished by reading and re-reading the transcribed accounts and discussing them between the authors. Using the codes and a comparative approach, we identified three main themes (protecting the child, involving the child in their treatment, and transferring responsibility) and two or three sub-themes within each theme. All the names used in the article have been anonymised, other identity markers have been excluded, and some interchanged to ensure the anonymity of the participants.

## **Analysis**

The findings illustrate that the interviewed parents worked to manage the undertakings related to their child's care and made efforts to transform the life-limiting circumstances into a life that worked well for both themselves and their child. This involved protection and engagement, as well as transferring knowledge and responsibility. To explain chronic care work in relation to parents' expectations and norms about children's independence, the concept of "readiness parenting" is coined in this article. This concept brings together the vigilance required of the carer with the task of being prepared to act when the child's own efforts do not go as expected.

### **Protecting the child**

In the following, we describe three strategies that parents use to protect their child: protecting the child from too heavy a burden of knowledge; balancing risks with the efforts to create a "normal" childhood; and protecting the child from stigma.

*Protecting the child from too heavy a burden of knowledge*



Laura was three years old when she received her diagnosis. Her treatment went from conservative measures involving daily medication and a special diet to replacement therapy requiring dialysis and a subsequent kidney transplant. The interview with Laura's father revealed that the family went through a complete life change from their habitual routines around household chores, work, and care for the child to an unusual new situation that involved constant medical care.

We had to adjust to Laura's new condition and at the same time keep moving forward with our life. We had to learn about CKD, manage Laura's treatment, and protect our daughter. We had to make constant decisions about what information about the CKD to disclose to her. It was the most difficult time.

The father explained that they had to be conscientious in explaining her condition to their daughter. First, the parents carefully discussed it between themselves and then chose to disclose the most important facts that would allow their daughter to be safe, such as diet, what she could eat or not, and the reason why she could not share food with her friends. For the participants, protecting their child sometimes meant revealing and sometimes withholding information about CKD, illness indicators, and medication. While other parents might wish to avoid discussing disease and medication with their children in order to protect them, the interviewed parents did not have that choice. However, they described how they had tried to distinguish between what was essential knowledge for the child and what could be withheld. This finding mirrors a classic study on parenting children with cystic fibrosis, which demonstrated that parents searched for knowledge and were aware of the prognosis of the illness, but also wanted to distance themselves from the disease and its future consequences (Bluebond-Langner, 1996). Protecting the child from too heavy a burden of knowledge draws attention to the reasoning and emotion that parents bring to their considerations about what to share with their child.

#### *Balancing risk-aversion with the efforts to create a normal childhood*

As they struggled to protect their child's health, parents tried to balance between risk and developmental needs (cf. Almack et al., 2009) and searched for ways to mitigate the child's restrictions and limitations related to diet, sports, and leisure activities. They found it important to focus on the child's development and socialisation alongside the tasks of disease management. Paediatric CKD imposes restrictions related to sports activities – swimming

classes, for example, bring the threat of infection, and any kind of high-impact sport, such as judo or football, risk injuring the abdomen area. Thus, in order to balance the risk of infections and injuries with the efforts to create a normal childhood, the interviewed parents sought substitute approaches to practising sports. Alice and Manoel created a special swimming suit for their five-year-old son Davi to use on beach trips to motivate him to take part in sporting activities.

We wanted Davi to engage in and learn the same activities as at school, such as swimming. We don't want him to be discriminated against as a boy who doesn't do sports, so we made a special swimming suit for him to learn and enjoy swimming.

The parents made daily efforts to normalise childhood through finding appropriate activities for their child. The parents sometimes felt that they did not do enough (cf. Almack et al., 2009; Valentine et al., 2019), or that they were failing to meet the challenge of caring for all their children. However, while siblings required their parents' attention as well, they also played an essential role in helping them to monitor the treatment or adapt entertainment activities. Involving a sibling in the care and as an active participant in leisure activities was a way for parents to be attentive to all their children. This confirms that the chronic disease responsibilities become a family undertaking (cf. Knafl et al., 2012).

In order to protect the child, and at the same time normalise childhood, parents also tried to make intake of food appropriate to the social situations the child would inevitably encounter. As an example, the mother of one 13-year-old boy explained:

I had to teach my son to eat real food after his transplant. It's very difficult as he doesn't want to eat anything because he doesn't know the taste of real food.

Because the boy had been fed through a feeding tube since he was a baby (he could start eating solid food only after the kidney transplant), he did not know the taste of food or how to chew. In order to strengthen her son's facial muscles, and allow him to experience tastes and textures, the mother had to stop feeding him through the feeding tube when he was four years old. Educating the child to eat was an important strategy to make his childhood as normal as possible. The parents were attentive to the risks and requirements involved in school days and

leisure activities and searched out ways for the sick child to participate and socialise, simultaneously trying to protect and empower the child (cf. Almack et al., 2009).

### *Protecting the child from stigma*

In the process of protecting the child, parents and children chose when and to whom they would release information about the CKD. Bluebond-Lagner (1996) attributed this to parents' avoidance of reminders of the illness and its consequences. In our study, parents found that the best way to protect their child was to restrict the number of people to whom the information was given. Three families with older children with CKD reported that the children themselves refused any kind of special treatment at school in order to avoid being singled out as "special" or "sick". The mother of a 10-year-old boy, commented:

My son wanted to stop going to doctor's appointments and his frequent check-ups because his friends at school were calling him sick because on the day of the appointments he missed school or got to school very late.

Social norms usually dictate that parents should disclose their child's health condition and treatment to school staff, but some parents respected their child's choice not to reveal the disease. One could argue that these parents were reacting to a double bind in which, on the one hand, society can offer people marked as "special" accommodations that can be appropriate, but on the other hand, these accommodations often come with some degree of stigma. This leaves the families facing the predicament of whether or not to accept the label along with the accommodations.

To sum up, parents' efforts to protect their child are interconnected with the desire to normalise their child's experiences of childhood and adapt to the societal norms and expectations of being good parents. Doing good parenthood for these parents meant protecting their child from bearing too heavy a burden due to their CKD when choosing what to disclose to their child about the condition, its treatment and the consequent limitations. Wherever possible, they found ways to overcome risks and allow activities and socialisation that they found essential for their child to have a normal childhood. And, finally, they protected the child from stigma by carefully choosing when and to whom to disclose the child's condition. While intensity and vigilance regarding risks are general to many forms of

parenting, the above demonstrates the specificities in the case of child CKD. The readiness required involves recognising the need to change and being ready to act.

### **Involving the child in their treatment**

The process of involving the child in the chronic homework begins in the hospital environment, and parents described how they had to be innovative to find good ways to do so. The following focuses on how parents involve their child through sharing knowledge and responsibility, and how they balance between trust and surveillance.

#### *Sharing knowledge and responsibility: signs and processes*

The process of sharing knowledge about the CKD treatment is essential in developing interdependence between parents and child. When describing the child's involvement, the parents disclosed that acceptance of the disease was essential for both themselves and the child, and that it came one day at a time. To achieve the child's acceptance, parents emphasised the importance of including the child in their own treatment (cf. Kalantar et al., 2021). Since children's and adults' abilities and skills differ, children may experience tensions in their attempts to learn CKD-related tasks. Consequently, parents had to adopt methods to share the responsibility for treatment with their child.

Angel, mother of a five-year-old boy, explained that she had taught her son about his condition and treatment since he was a baby, as he was born with CKD. She remarked that, since he had spent his first year of life in hospital, hearing the health professionals' conversations, observing the medical surroundings, and going through constant treatments, he had learnt much from the environment. She noted:

He knows everything, and he understands about his condition. I would never have thought he was learning so much through his experience in the hospital.

Angel's statement demonstrates how the environment teaches a child (cf. Dermott, 2016). It also illustrates the significance of being open to the child, which enables parents to move on to the next step: allowing the child to gradually become involved in their own treatment. The interviewed parents were inventive when involving their child in the treatment, as described by the mother of a five-year-old girl:

My daughter spent a big part of her childhood in hospital. I had to learn how to play with dolls to play with her because she could not be around other children. To explain to her about her condition in a playful way, I played with toy medical instruments.

This mother discussed the complexity of sharing knowledge about health and illness, which is a requirement for involving a child in the treatment of their chronic illness. It is not something palpable, like teaching a child about the importance of brushing their teeth or combing their hair. Nevertheless, the information and practicalities of the condition and its treatment were part of everyday life from the moment of diagnosis. The parents emphasised, however, that the information needed to be consciously considered according to the child's age and the stage of the condition. Furthermore, involving the child in their treatment was an evolving process, which followed the trajectory of the disease and its treatment, as well as the signs of willingness demonstrated by the child. In sum, the process of sharing knowledge and responsibility is a tactful process of attention and negotiation.

#### *Balancing between trust and surveillance*

The participants recounted that they had to balance confidence in their child with close monitoring (cf. Tong et al., 2008). However, teaching their child and involving them in the treatment was a way of employing the child's capacity to make the chronic disease part of their everyday routine and keeping it as ordinary as possible amid the many necessary adaptations (cf. Park, 2019; Kalantar et al., 2021). Parents revealed that they reminded their child about their medical condition and medication every day. They would check the lunch box and water bottle to make sure the child had followed their instructions when they returned home from school, demonstrating the feature of readiness parenting and the parents' dual role of supporting their child's independence while at the same time making sure that no serious problems are likely to arise. As the child became conscious of and responsible for their condition, the parents allowed additional steps in their autonomy, stepping back from permanent surveillance. The father of a six-year-old girl clarified:

She knows how to explain to her friends when they offer food like crisps or crackers to her, that she can't eat them, as it makes her sick.

While this father found it sad that his daughter could not share food with her friends, it made him proud that she understood how to stick to her diet. Another family explained that their son had found it challenging to follow the recommended diet at the beginning, because he was diagnosed when he was already 11-year-old and was not used to restricting his diet. However, after a time he learned about the importance of following the treatment and accepted his condition. This released both him and his parents from their constant supervision, allowing him to travel, attend events on his own, and be more independent. In summary, in order to involve their child in the treatment, parents sought to have confidence in the child and share their knowledge and responsibility. This meant that they had to attend to the child's signs of willingness and ability, balance trust with surveillance, retain control over ordinary everyday things that for most parents can pass unnoticed, and be constantly ready to intervene.

### **Transferring responsibility**

The process of transferring responsibility to the child regarding their treatment is built up over years. The interviews demonstrate that it is a step-by-step transfer, and that parents must promote their child's independence during the process.

#### *Step by step transfer*

The parents' stories demonstrate that they hand over more and more of the treatment to the child, until they can see that it is possible to allow the child to be independent. First of all, the parents sought to provide the child with autonomy and freedom, through allowing them daily experiences that are typical for healthy children, such as attending pre-school and birthday parties. Parents engaged the child in practical actions and, step by step and through small changes, gave the child space to manage the condition on their own.

They began the process in a controlled environment and with a time limit, allowing the child to attend a birthday party or participate in a school field trip. Parents had to be confident that the child could follow instructions without close guardianship, helping the child to understand their circumstances and gradually becoming accountable for their treatment as they grew up, which illustrates a shift from a directive role to a more collaborative one.

In the progressive transfer of responsibility, the father of one 15-year-old boy declared: "He takes his own medicine because he knows the importance of it". Because of their son's

conscientiousness, the parents had authorised him to go by himself to spend a vacation with his grandparents in a distant town. The parents' expectations and desires for the child's well-being were related to the ability of the child to self-manage their condition and to succeed as an independent individual (cf. Bluebond-Langner, 1996).

Parents sought ways to attain freedom for both themselves and their child through being open with the child about the condition, including the treatment demands and the unavoidable limitations and restrictions. Parents also encouraged their child to self-educate about CKD. The internet became a valuable resource in this regard. The caregiver of 15-year-old Felicidade narrated:

As she grew up, it became much easier to teach her. She also started to research about CKD on the internet. It was very helpful to us because she became conscious about her condition and even taught us about it. She could ask her doctor questions and we could share the treatment management with her.

Nevertheless, being the caregiver of a child with CKD raised questions about when to release the child. For example, the mother of a 12-year-old girl explained that they had to step back from the previous arrangement with their daughter in order to protect her:

My husband and I had to stop giving her money because she started to buy snacks at school. Only when she had a health checkup did we realise that she was eating foods not allowed to her because the blood analysis showed the inconsistency.

This quote illustrates how difficult it can be for parents to decide when they should give their child responsibility. Sometimes things were not successful and parents had to step back, reconsider their decisions and seek new ways to negotiate with their child. Parents had to deal with dominant norms of parenthood and the idea that parents "are wholly responsible for their children's outcomes" (Faircloth, 2014:31). They struggled to determine the appropriate decisions regarding the step-by-step transfer of aspects of responsibility to the child, looking for a balance between protecting and empowering (cf. Lee et al., 2014).

*Promoting independence and decision-making*

Parents found it important to let their child make their own decisions and take over responsibility at their own pace in the process of managing the disease. Felicidade's caregiver said that Felicidade did not participate in the summer camp for children and teenagers with CKD when she was first invited because she was not aware of the community and its activities. However, when she saw the photos and comments from the participants on social media, she realised that the camp was a fun and educational event where she could engage in "normal" activities such as dancing, playing games with peers, and learning more about CKD, and she decided to participate the following year. This particular case represents the parents' emphasis on promoting independence and decision-making.

Parents also sought signs that the child was ready to internalise the family routines. Only thereafter did they deem it appropriate to begin gradually transferring the treatment to the child. The mother of nine-year-old Pedro explained that he helped her to remember his medication: "Pedro sits at the table and if he doesn't see his medicine, he immediately asks for it." The mother's comments reveal how even small demonstrations of the child's awareness and responsibility for their CKD condition are a valuable achievement. Another case related to a girl who tried to protect her parents regarding the suffering and limitations relating to her condition. The mother reported:

Maria is always very conscientious and understanding about her situation. She never complains about it. She tries to protect me by hiding her symptoms of pain.

This shows that, as well as taking on her chronic homework responsibilities, Maria had developed a protective approach and made decisions about what to reveal to her parents about her suffering.

To conclude, the course of the disease and the necessary life readjustments compelled parents to engage their child and transfer the responsibility for treatment step by step to the child. They had to ensure that the child became knowledgeable about their condition as early as possible, and learned to make their own decisions, take care of their medicine, and participate in social activities or travel. The transference of responsibility was a shared interest between parents and children. In some cases, the child even tried to lighten the parents' burden, as though they were already independent adults. Nevertheless, the process included experiences of setbacks and the need to draw back and find new paths to independence. The parents'



considerations and negotiations were based on specific situations as well as on contemplations of parenting and the broader cultural context, even though their situation differed from general parenting experiences and involved an extra layer of responsibility and readiness. This included some level of risk consciousness intertwined with social norms regarding protection, expectations of normative development, and leisure activities.

## **Readiness parenting**

Parenting has become an intensified task over the last decade in several ways, whether through parents' classes and workshops, "how-to" manuals, or expert advice. It has been the object of moralisation throughout history and has spawned conflicting discourses around the ideal approach to childrearing (Faircloth et al., 2013; Wilkinson et al., 2021). In the context of children's chronic disease, where we position our contribution, the extra efforts that parents of children with complex care needs have to make has been theorised as "intense parenting" (Woodgate et al., 2015). Care-giving engulfs the parents' time and requires their constant attention. Our article contributes to past research in that we focus on how parents raise a child with CKD and how they practise parenthood. Their everyday experiences of interacting with their child, to both protect and involve the child, which we have analysed, expand the field of knowledge concerning parental perspectives on raising children with complex care needs such as, in this case, a severe and life-threatening chronic disease. This specific form of parenting is characterised by readiness. The transformation of life-limiting circumstances into a life that works well, for both parents and their child, represents readiness parenting. Assessing risks while at the same time supporting the child's autonomy requires constant vigilance and readjustments (cf. Stjerna et al., 2014). Many factors, including family support, type of treatment, parents' understanding of dependence, interdependence, and independence, as well as the individual characteristics of the child, are combined in the construction of the parenting experience. It is a dynamic process that develops according to each individual family. In line with the literature, our findings also suggest that the parenting approach evolves according to the emergent needs of the child (cf. Lee et al., 2014; Trnka, 2017; Wilkinson, et al., 2021), which, in the case of chronic disease, requires parents to be fully prepared for whatever emerges, and always ready to act.

At the same time, parenting occurs in context. According to Bööck and Perälä-Littunen (2008), parents' accountability can be comprehensive because of the powerful cultural norm

that parents should act in the best interests of their child. Parents feel responsible for their child's life and happiness, not only for their child's needs. According to Dermott (2016), who writes about the pre-established standards of good parenting practices, it is widely recognised that doing good parenthood requires the presentation of oneself as a parent, including explaining to relevant others why they act in a specific way. Thus, the question of interdependence does not only concern the dyadic relationship between a parent and their child. Considering the social and medical contexts that encompass the daily life of the child and their family, both the parent and child are influenced by social norms and cultural expectations (cf. Knafl et al., 2012; Trnka, 2017). These expectations concern, for example, the social labelling of disabilities, how to eat and having meals together, and ideas about good parenthood and a normal childhood. The social norms are seen in parents' practices of adapting themselves to the situation and the everyday activities related to the child's health condition. For example, parents were keen to find ways of enabling their child to participate in the kind of leisure activities that are seen as normal parts of childhood. Due to the risk of infections and injuries, it was challenging to create opportunities for the child to participate and then hand over responsibility to the child. This shows that the parenting of children with a chronic disease represents normative standards of parental responsibility, additionally guided by medical knowledge and risk considerations. Parents must be willing to satisfy the child's desire for challenging activities without appearing either overprotective or foolhardy to other parents or the child's physician. The parents' actions are constantly being examined and perhaps criticised, and this puts pressure on parents to be always on their toes. As another example, a child's travelling alone to their grandparents or to a summer camp was seen as an important ingredient in the child's maturing and taking over responsibility. This required parents' aptitude in balancing surveillance with trust, without losing sight of their responsibility to keep the child healthy.

The strategy of balancing trust and surveillance involves negotiation. When a child has been given responsibility and failed, the parents must be ready to recognise the need for change and negotiate how to hand over the responsibility in a new way. Another example of negotiation concerns the norm of being open and revealing the child's condition to their school and other institutions. The parents often decided to follow their own judgement or the child's desire to hide information about the chronic disease because of the stigma that might follow from their openness. Almack and colleagues (2009) demonstrate the ambiguous moral position of parents of young people with intellectual disabilities, who need to ensure the

safety of their child while at the same time relating to public and professional discourses of young people's rights to exercise autonomy, and how they find a balance between these positions. For parents of children with chronic diseases or severe neuropsychiatric disabilities that require special care, we argue that the moral obligation to allow the child to take responsibility and act autonomously comes together with the need for prolonged, constant, and intense – but unobtrusive – attention and readiness to support. Our analysis addresses how the parents appropriated norms regarding the child's independence and made great efforts to increase their autonomy while negotiating certain aspects of everyday life, such as norms about openness, in order to protect both their child and themselves. These negotiations represent personal and social resistance, creativity, and struggle.

Good parenthood was represented by the three topics discussed above. The dialectic of protecting, involving, and transferring represents readiness parenting and adaptation to child CKD over time, requiring a constant balancing act between the child's development, family circumstances, the dynamic challenges of the disease, and the surrounding environment, including social norms. When children were hospitalised, or their condition required advanced medical treatment in the form of dialysis, the children depended totally on their parents. Throughout the next phase of interdependence, parents were able to negotiate treatment tasks, such as dietary options, with the child. The demystification of CKD at an early age was vital since the child must grow up dealing with the challenges involved. Parents involved the child and shared know-how and skills in order to create space for the child's increasing autonomy. Gradually, this phase changed until parents could transfer the responsibility for their own treatment to the child, allowing the child to participate in events and go on vacations on their own, thereby allowing space for the child to be independent. The situation required them to help their children become accountable for the chronic homework, while always being ready to step in. This results in a significant extension and intensification of parenthood. The diversity of family context, illness experiences, and the idiosyncrasies of normalisation mean that each family overcomes these phases using unique approaches and at their own pace (cf. Bruno de Sousa and Wickström, 2021; Knafl et al., 2012). Also, this process might shift back and forth according to the specific circumstances. The trust the parents had in their children was essential for the transfer of responsibility for their treatment. Nevertheless, our findings indicate that the child's independence, for which both parties strive, might have a flip side. The pressure on the child to be independent could result in efforts to protect their parents. Here we see a need for future research, to examine the

perspective on responsibility and independence from the perspectives of children with CKD themselves. Understanding the lived experiences of children themselves would create knowledge based on the concerns of children that risk not being noticed in clinical settings (Hanson et al., 2017).

Our findings contribute to knowledge about the complex and intensive care associated with paediatric CKD and the expectations on and desire of parents to do good parenthood in this context. The findings can inform social policies and encourage 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 them into their programmes.

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