

# When pain never goes away: Understanding the lived experiences of children with chronic pain and their parents in Portugal

Ana Patrícia Hilário 

Instituto de Ciências Sociais,  
Universidade de Lisboa, Lisboa, Portugal

## Correspondence

Ana Patrícia Hilário, Instituto de Ciências Sociais, Universidade de Lisboa, Av. Professor Aníbal de Bettencourt 9, 1600-189 Lisboa, Portugal.  
Email: patriciahilario@gmail.com

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## Abstract

This study intends to provide insights into the lives of children who suffer from chronic pain and of their parents. A qualitative, multi-modal approach was employed, using the draw, write and tell technique with seven children, and semi-structured interviews with parents. By illustrating that children are active social agents in the management of chronic pain (even when they are understood by parents as vulnerable), the findings support recent sociological work in the field of childhood health. Indeed, the findings show that children with a chronic condition can take autonomous decisions in relation to disease management even when supervised by parents.

## KEYWORDS

children, chronic pain, parents, risk, uncertainty

## INTRODUCTION

Worldwide around 20% to 35% of children and young people are likely to suffer from chronic pain (Friedrichsdorf et al., 2016), yet there has been a limited number of studies that have documented their lived experiences (Pate et al., 2019) as most research has focused on the accounts of health-care professionals and family members (Clemente et al., 2008; Maciver et al., 2010). Chronic pain has been operationalized as the pain which persists or recurs for more than 3 months and may have a primary or secondary origin (Friedrichsdorf et al., 2016). Most of our knowledge on the lived experience of chronic pain draws from quantitative studies (Pope et al., 2017). The scarce involvement of children and young people in research about chronic pain (Pate et al., 2019) results

in a limited understanding of their experiences, compromising the implementation of effective strategies for managing their affliction. When studying the experience of chronic pain, children should be understood as co-constructors of their social world (Brady et al., 2015), capable of making sense of their lived experiences of pain within social interaction (Jenkins, 2015).

Children have been found to be competent symptom informants in the context of paediatric chronic pain treatment. Indeed, it has been found that they may use their parents as key actors in the communication process with medical professionals while affirming their rights as experts of their affliction (Clemente, 2009). The notion of child agency is key (Valentine, 2011) and draws on the belief that children should have a say on matters affecting them such as their health and illness (Brady et al., 2015). However, despite the need to hear children on matters concerning them (Prout, 2005), research on the experiences of chronic pain have largely been limited to afflicted adults (Broom et al., 2015; Evans & Souza, 2008; Miles et al., 2005; Werner et al., 2004). Parents have been found to be key in the management of chronic illness in childhood and adolescence (Kingod & Grabowski, 2020), even though children and their parents may disagree in terms of how the chronic illness should be managed (Atkin & Ahmad, 2001). However, there is little information available on how both children and their parents experience and manage a chronic condition (Twycross et al., 2015). Further, there is a lack of knowledge about the daily lives of families of children with chronic pain. This study intends to provide insights into the lives of a small group of children and young people with sickle cell disorder who suffer from chronic pain and of their parents. I will begin by presenting an overview of the sociological literature on the experiences of children and young people with a chronic condition.

## **THE EXPERIENCE OF CHRONIC ILLNESS IN CHILDHOOD AND ADOLESCENCE**

The chronic illness/condition is likely to have an impact on the daily life and social interactions of children and young people (Vindrola-Padros, 2012). Living a ‘normal’ life may be difficult due to the uncertainty associated with the chronic condition, particularly in relation to the timing and severity of symptoms (Webster, 2019). Sickle cell disorder is a chronic illness marked by uncertainty. This is particularly due to the painful chronic crises that characterize this illness—as the ‘sickling’ of the red blood cells causes blockages in smaller blood vessels (Atkin & Ahmad, 2001, p. 616)—occurring without any warning and eventually leading to the hospitalization of children and young people. Pain is a major feature of sickle cell disorder and pain management is key for the health and well-being of children and young people who suffer from this condition (Atkin & Ahmad, 2001).

The experience of uncertainty has been widely discussed in relation to adults who suffer from chronic back pain (Broom et al., 2015; Lillrank, 2003), chronic widespread pain (Richardson, 2005) and idiopathic chronic pain (Honkasalo, 2008), but the uncertainty of the chronic pain experienced by children and young people still needs to be fully conceptualized. Within social science research, it has been found that the chronic pain felt by children and young people is often discredited by healthcare professionals due to the uncertainty that tends to characterize the condition leading these children and their families to engage in a search for a diagnosis (Carter, 2002). Recognition is central in the experience of chronic pain in childhood (Werner et al., 2003) as historically it has been discredited by the medical community (Werner & Malterud, 2003). The waiting for a diagnosis of chronic pain has been described by parents as a negative process characterized by feelings of guilt and sadness (Le et al., 2019). Therefore, parents of children with

chronic pain pointed out that a diagnosis offer to their children the possibility for them to felt validated by others (Neville et al., 2019).

Children and young people with sickle cell disorder often are diagnosed with this chronic illness from an early age. However, the invisibility of their condition—specifically, their chronic pain—may evoke negative reactions in others and lead to stigmatization (Jackson, 2005). As a way to minimize the risk of being stigmatized, children and young people may try to manage their chronic condition through concealment (Monaghan & Gabe, 2019). As chronic pain cannot be medically resolved, taking control over uncertainty is often at the forefront of this illness experience (Broom et al., 2015). Indeed, chronically ill children—with the help of their parents—often try to discipline their body either through medication routines, physiotherapy or eating healthy (Guell, 2007). Within modern life, children have been understood as being ‘at risk’—in particular, ill children (Lee et al., 2010); whereas, parents have been seen as being responsible for the safety of their children, protecting them from harm—i.e., of risk (Lee et al., 2014). Indeed, parental constructions of risk are a contextual or situated phenomenon (Henwood et al., 2008). While dealing with risk is part and parcel of childhood (Christensen & Mikkelsen, 2008), risk exposure and its management is even more central in the daily living of children and young people who suffer from a chronic condition (Stjerna, 2015; Stjerna et al., 2014). However, limited sociological research to date has been developed on parents’ and children’s experiences of uncertainty and risk perceptions related with a chronic condition during childhood (Webster, 2020). There is also a paucity of sociological research on the everyday experience of children who suffer from chronic pain and their parents. Thereby, the current study intends to address this gap by exploring children’s and parents’ experience of uncertainty and perceptions of risk resulting from chronic pain in childhood.

## THE STUDY: CONTEXT AND METHODS

The data within which the present paper is based draws from an ongoing qualitative study on family experiences of chronic pain in childhood. A qualitative, multi-modal approach was employed, using the draw, write and tell technique (Angell et al., 2015) with children and young people who suffer from chronic pain, to gain insight on their lived experiences of pain. Also, semi-structured interviews were conducted with parents, to understand how they perceive and manage their child’s chronic pain. Seven children aged between 7 and 17 years old (4 girls and 3 boys), and their parents (6 mothers and 1 father) participated in the study. All participants were Black and lived in the same suburb area of Lisbon.

Within the context of chronic pain in childhood, one of the main challenges that researchers face is the use of effective tools to access children’s views on their lived experiences of pain. The draw, write and tell technique (Angell et al., 2015) appeared to be the most appropriate method for conducting research about pain with children and young people (Pope et al., 2018). This technique focuses on children’s own interpretations (Driessnack, 2006) by enabling them to explain their drawings and the words they have written (Pope et al., 2018). The draw, write and tell technique has been successfully applied to explore children’s perceptions of pain and pain management (Pope et al., 2018); however, this is the first time that the technique is used to study the experience of chronic pain in childhood and adolescence. The use of the draw, write and tell technique places children and young people at the centre of the research process by offering them control over the data generated (Martin, 2019) and allowing them the chance to interpret the data they have produced (Morrow & Richards, 1996). Indeed, the previous use of this

technique has proved that children and young people are able to provide detailed descriptions of their pain experiences (Pope et al., 2018).

The data collection and the sampling frame were drawn from a paediatric chronic pain consultation, located in a hospital in Lisbon, Portugal. This occurred during the first months of 2019 and had to be interrupted due to the COVID-19 pandemic. At the time the study was conducted all children and young people who were being followed at the consultation due to their chronic pain had been diagnosed with sickle cell disorder (a 'common' disease within the Black community). This was due to the fact that the chronic pain consultation was a new service at the hospital. Ethical approval was obtained from the Instituto de Ciências Sociais da Universidade de Lisboa, the host research centre of the project, and the hospital where fieldwork took place. Prior to the paediatric chronic pain consultation, I introduced myself and the research project to both parents and children and sought verbal permission to be present during the consultation. The consultation happened on the morning of a particular day at the week. However, as I was only interested in children and young people between 5 and 16 years of age, the medical team informed me in advance when their patients did not fit this age range. I aimed to gain a mix of age and gender. In my first conversation with children and their parents, I invited both to participate in the study. Written informed consent was then obtained from parents on the understanding that their participation and the participation of their children was voluntary, that they had the right to refuse to participate in the completion of any task and/or to answer any question. A guarantee was given to both parents and children that participation was not compulsory and if they decided to not participate or to withdraw from the study this would not have any consequences on the care of their children. Written consent was also obtained from parents in relation to the use of the drawings produced by their children for research purposes. A consent information sheet was given to parents with written information about the aims of the study, their rights and the rights of their children, as well as how the data will be used and saved. The right of privacy, confidentiality and anonymity was guaranteed to parents and children.

While my initial intention was to obtain informed written consent from children, this strategy did not appear to be the most appropriate option. Indeed, I tried to obtain written informed consent from children in my initial interviews offering them an age appropriate information sheet and a consent form but both parents and children saw this as something unusual and strange. I then decided to obtain the child's verbal assent for their participation in the study. All children and young people were very enthusiastic about their participation more so than their parents. Because some parents were suspicious about the study and what the participation of their children will actually involve (even though this was explained to them orally and in writing) as this was the first time that they and their children were being invited to participate in social science research, almost all interactions with children occurred in the presence of their parents in a private room at the hospital. Sometimes this was not possible because the mother/father of the child was having a consultation with his/her other son/daughter. When that was the case, my interaction with the child took place in a room nearby and I left the door of the room partially open. Then, after the consultation I asked the mother/father and the sibling who also suffered from chronic pain to join us. I invited children to draw about their chronic pain on an A4 blank paper using some crayons, and to write some words about it (in case they wanted). Some children asked what I would like them to draw to which I replied that maybe it would be nice if they were to draw something about their last major pain experience. Only two children added words to their drawings as a way to better express their feelings. With the exception of a boy who drew himself playing football with a friend and a girl who drew herself and her mother while being at the hospital, all the other children drew only themselves. Some children focused on the emotional aspects of pain by

expressing either through what they drew or wrote their feelings. After they finished, I asked them to explain the drawing and the words in case they had used it. Using the drawing as a background, I was able to ask children questions about their lived experiences of pain. The draw, write and tell technique provided a child-centred way to access their lived experiences of pain (Horstman et al., 2008), and helped to diminish the power differences between myself as an adult researcher and the young participants (Angell et al., 2015; Martin, 2019).

The interviews were tape-recorded with both parents' and children's permission, transcribed verbatim, anonymized and analysed using Maxqda. A thematic analysis as proposed by Braun and Clarke (2006) was developed drawing on the accounts of children and their parents. In the analysis, an equal weight was given to the experience of children and parents and their discourses were analysed independently. I first employed an open coding procedure. Then, first order themes were reduced into a family of codes. After a deep reading, the codes were reduced into core categories. Four themes emerged from data analysis: (1) the use of non-medical strategies to deal with chronic pain; (2) food as a way to deal with uncertainty; (3) (not) being different; (4) the impact of hospitalizations; and will be presented in the findings section. Drawings were used as a vehicle for engaging children in the research and were not analytical interpreted, nevertheless they will be presented as it may be interesting for readers to see what the children drew and wrote.

## FINDINGS

### **The use of non-medical strategies to deal with chronic pain**

The mother of a 14-year-old girl (Alice) pointed out that albeit they did not have any notion of the disease at the time of the diagnosis they have learned about it. Alice suffers from chronic pain. She has back pain at least three times per month and from time to time she suffers from pain in her leg. Her mother acknowledged that they have developed some strategies to deal with Alice's pain:

We've learned strategies for pain relief. The hot-water bag. The massages. Finally, I also use the option of taking an S.O.S. medication. If it's an uncontrollable situation, we go to the emergency department. But we use these three steps.

This account is very interesting in that it shows that both medical and non-medical strategies were used to relieve pain. These strategies were also spoken about by Alice and became evident in her drawing (Figure 1) description:

I'm in my room. This is my bed. I'm in pain and here's the hot water bag.

Alice, 14-year-old girl

### **Food as a way to deal with uncertainty**

Alice's mother suggested that food was a strategy employed to deal with the uncertainty of her daughter's condition:



FIGURE 1 Pain by Alice a 14-year-old girl

Nowadays we understand, and we try to be more careful with food. It's one of the things we do about the disease. This is important to us even if it is not so important to her. Well, I understand she is young. It's adolescence. Drinking water, is one of the things. Also, eating green stuff. There are also the traditional remedies we have learnt to do. I use a mother's radar so when I look at her I can have some notion of how she is doing. I make a 'mum' diagnosis. If her eyes are yellow, she's not well. I don't know if this is real because I don't have much contact with other mothers but one of the things I use is parsley juice. In the morning when I see that she's weak I always do it.

This mother attributed a medicinal value to certain foods and understood it in functional terms. The mother also stressed that although the disease is complicated her daughter has not had many hospitalizations (her last hospitalization took place in 2017 due to a flu episode), unlike other children with sickle cell disorder. She questioned if this was due to the care that she provided to her daughter.

In a similar way, the mother of a 7-year-old girl (Ariel) and an 11-year-old girl (Aurora) stated that she has been careful with her daughters' food. Although she tries to adapt the food so that all the family can eat the same, she also said that sometimes it was difficult as the food for her daughters is more specific, as they eat more fruit and green vegetables. The mother acknowledged that she treated her daughters differently from her sons in the sense that the girls have access to certain foods unlike the boys. Food was to a certain extent a symbol of Ariel and Aurora's difference.

## (Not) being different

Peter a 10-year-old boy felt discriminated against by his peers because he was unable to actively participate in sport activities. He already suffered from physical bullying at school. Peter only told his best friend that he could not play football because of his chronic condition. Once his best friend protected him from other children who had punched Peter in the belly (the place where he often has pain). Peter does not like school and has some learning problems. In the drawing he wrote “mouth when I am not happy”. Peter described his drawing (Figure 2) as follows:

This is when I'm playing with my friends and they want to run. They say: 'Come on, come running, don't be afraid.' I say, 'I can't because my tummy will hurt soon.' If I run too much, my stomach hurts. I really like to play football. I wanted to play football, but I can't because my tummy hurts due to my health problems'.

Peter, 10-year-old boy

When asked about the impact that her illness and in particular pain has had on her life Alice indicated that she could not do much that required physical effort, namely running. However, she also told me that she tried to do her best at sports in school as she did not want to be different from other colleagues. Because of the physical exercise at school, Alice suffered from pain from time to time. The fear of being understood by peers as different and therefore stigmatized due to their chronic condition was more important than the risk of the physical hazards of engaging in activities that are considered normal for their age but could put at risk their health ending up in a pain crisis.

Aurora also indicated that she did not like the fact that her mother reminded her of the illness, particularly in front of other children:

**Me:** Does Mom often remind you of your illness?

**Aurora:** Yes.

**Me:** And do you like her to do that?

**Aurora:** Hmm.

**Me:** And she reminds you around the other kids?

**Aurora:** Yes.

**Me:** And do you like it?

**Aurora:** No.

**Me:** Why?

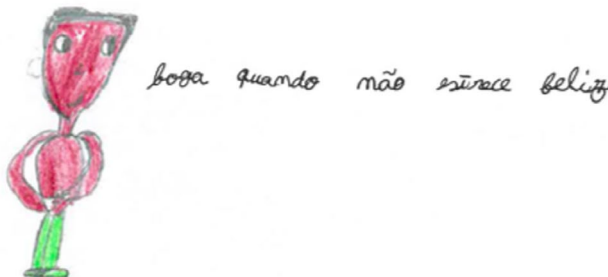


FIGURE 2 Pain by Peter a 10-year-old boy

**Aurora:** Because sometimes I feel bad.

**Me:** Why? Do you feel different?

**Aurora:** Yes.

**Me:** Do you want to be the same as the others?

**Aurora:** Yes.

Aurora, 11-year-old girl

## The impact of hospitalizations

Peter disclosed that he often suffers from pain but does not tell this to anyone:

**Peter:** When my tummy hurts, I just go home and take the medicine by myself.

**Me:** And you don't tell anyone you're taking the medicine?

**Peter:** No. I take that yellow thing (ibuprofen).

**Me:** And you don't tell your mum or dad?

**Peter:** No, I only tell them sometimes.

**Me:** And you do it often?

**Peter:** Just sometimes. When it gets worse, I tell my mum.

**Me:** And why don't you just tell mum?

**Peter:** I don't know...

**Me:** Are you afraid of something?

**Peter:** It's because I don't want to stay in the hospital.

Peter, 10-year-old boy

Peter has been hospitalized several times while living in Brazil and in Portugal. The hospitalizations are also very difficult for his mother. She disclosed that once Peter saw her crying while he was at the hospital and asked her to accept his apologies for being at the hospital. When asked why Peter did not like to be at the hospital, he replied that he was afraid of the injections.

Ariel (7) and Aurora (11) had to be hospitalized several times due to the intensity of their pain. They live with their parents and two brothers, 9 and 15 years old. The two boys do not suffer from sickle cell disorder. When their sisters are hospitalized, they usually help their parents at home preparing the meals and washing their clothes. The condition, and in particular the hospitalizations, has had a detrimental impact on family life. The mother spoke about this as follows:

It's no good, in particular hospitalizations. It's often the father who spends the night here. Because I have 15-year-old and 9-year-old boys. So, he comes. He spends the night and goes to work. Then I come during the day because I'm not working. Because of this I can't get a fixed job.

Hospitalizations are a problem because they had an impact on the girl's mother's ability to find a job. Also, it is difficult to care for all the family equally when one or the two girls are hospitalized. Coming

to the hospital is also a problem because the family does not have a car. When asked to draw about their pain, both Ariel and Aurora drew their hospitalizations (Figures 3 and 4). Ariel drew broken hearts as a symbol of her sadness when being in pain. She also drew the doctor taking her to the hospital.

Ariel commented that she did not like to stay at the hospital:

**Ariel:** I don't like being in the hospital because they have to put a catheter in me.

**Me:** And does the catheter hurt?

**Ariel::** Sort of.

Ariel, 7-year-old girl

Aurora also expressed her discontent with staying at the hospital, albeit for different reasons:

**Aurora:** I don't like being admitted.

**Me:** Why?

**Aurora:** Because then mum has to go home and take care of my brothers and I'll be alone.

**Me:** Are you afraid to be alone at the hospital?

**Aurora:** No.

**Me:** But what do you feel?

**Aurora:** I feel lonely.



FIGURE 3 Pain by Ariel a 7-year-old girl

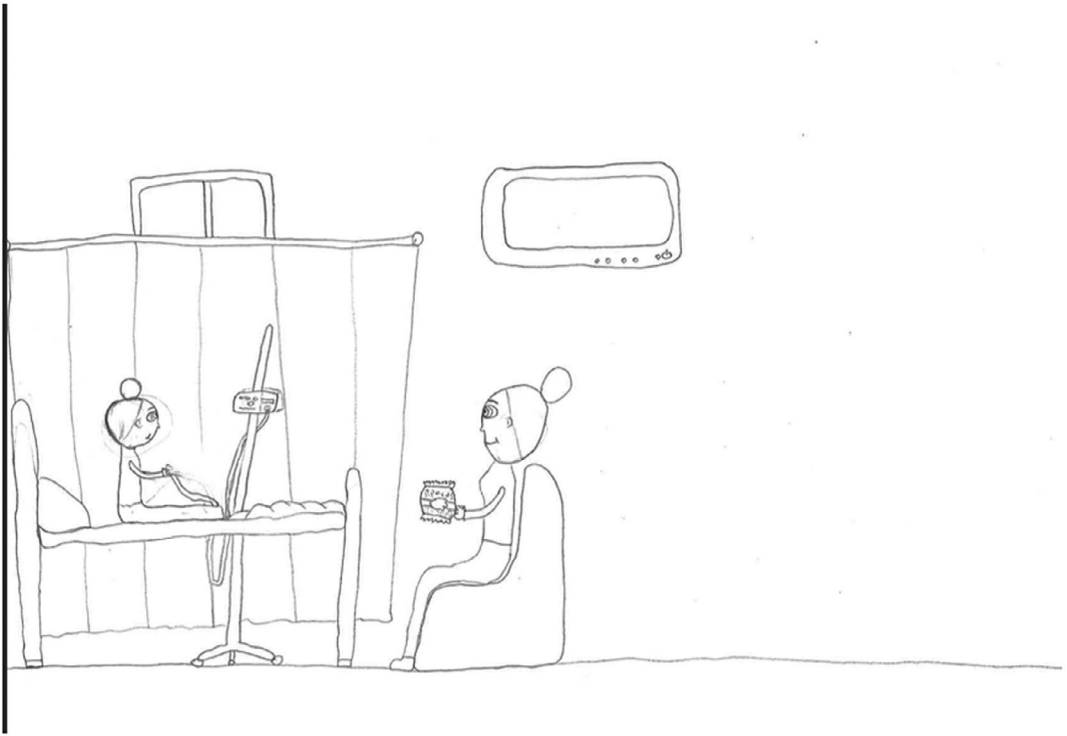


FIGURE 4 Pain by Aurora a 14-year-old

Aurora, 14-year-old

## DISCUSSION

This study offers insights into the lives of children and young people with sickle cell disorder who suffer from chronic pain and of their parents. The findings of this study show that children and young people are capable of managing their chronic condition whether in the family setting, at school or within other social environments. While having in mind the physical limitations imposed by their chronic condition such as their inability to play certain sports like their colleagues and friends, they engage in efforts to live as normal a life as possible as children of their age (Atkin & Ahmad, 2001). That is, these children desire to be seen as a normal child rather than someone with a chronic condition (Bagge-Petersen et al., 2020). The wish to be normal has been similarly experienced by children and young people who suffered from other chronic conditions (Guell, 2007; Meah et al., 2010). This sense of normalcy may be to a certain extent challenged by others' reactions towards their condition (Monaghan & Gabe, 2015) and, therefore, these children and young people tried to conceal it from colleagues and friends (Dyson et al., 2010). What appears to be at the heart of this was their fear (real or imagined) of being seen as 'inferior' by their peers (Monaghan & Gabe, 2019). Children and young people would rather engage in physical activity that was detrimental to their health and, thereby, risky than be stigmatized by their peers. Christensen and Mikkelsen (2008) have previously argued that often children manage risk in their everyday activities', and this is an important part of their collective learning. The authors go further by stating that not running risk may exclude children from activities and connections

with their peers. Childhood culture appears to influence the way in which children and young people understand their chronic condition (Webster, 2020).

The study's findings are also in accord with those of Webster (2020), who claims that children and young people are more likely to feel that their chronic condition is stigmatized in their interaction with friends and colleagues rather than in the family setting. These children and young people indicated that they only disclosed their condition to their closest friends and, thereby, they defined it as a private matter. In addition, they indicated their embarrassment of being reminded about their condition by their parents in public as they were afraid that this would spoil their identity (Monaghan & Gabe, 2019), while parents struggle to find a balance between protecting them from hazards due to their condition and letting them do things that are 'normal' for their age (Dyson et al., 2011). Parents are worried with the safety of their child, but they also try the best they can to correspond to the ideal of being a responsible parent (Stjerna et al., 2014). In a similar way to parents in Webster's study, the parents of these children and young people (re)conceptualized physical risks taking into account their child's condition in the sense that they evaluated the consequences that engaging in certain physical activities may have for the child, leading to pain. What appears to be at the heart of parents' perceptions of risk is the societal construction of children and young people as vulnerable (Lee et al., 2010). These perceptions also appeared to be framed by the child's age. In line with the findings of Backett-Milburn and Harden (2004) study of the family context and everyday negotiations of risk, our findings suggest that teenage years tend to be understood by the parents of children with chronic pain as particularly risky.

The study's findings also reveal that parents (particularly, mothers) tend to act as alert assistants in the sense that they try to identify, or at least anticipate, and meet their child's needs regarding their chronic condition (Williams, 2000a). These findings are similar to the findings of Kingod and Grabowski (2020), who in their study of parents of children with a chronic illness stressed that they are often positioned in a surrogate self-care role which ends up placing them in a stage of vigilance to secure their child's health. This was illustrated by the story of Alice's mother, who disclosed that she was able to identify when her daughter was unwell. As a result, she prepared for her daughter certain foods that have, according to her beliefs, a medicinal value. As with parents in Webster and Gabe (2016) study, these parents understood food functionally. This contributed to the maintenance or development of the 'good parent ideal', as it enabled parents to feel that they had exert some kind of control over their child's illness avoiding, to a certain extent, the development of a crisis (Gunnarsson & Hydén, 2009; Webster & Gabe, 2016). What also became apparent in the findings is that it is not always possible for the whole family to adjust their food consumption to the child's need. This was the case for Aurora and Ariel's family who were not able to provide green vegetables and fruits to their brothers as well as to them. This could be due to economic reasons, namely the cost of such foods. Aurora and Ariel's family does not appear to have a comfortable socioeconomic condition: they were not able to afford a private car and the mother was unemployed. The mother disclosed that due to the unpredictability of her daughters' condition, as it was not possible to predict when the next crisis will happen, she has not been able to find a permanent job. This finding is in accord with previous research by Hill and Zimmerman (1995), who demonstrated that extensive caregiving by mothers of chronically ill children (such as those who suffer from sickle-cell disorder) is strongly associated with lower rates of employment. What the study shows, also in align with Webster's (2019) research, is that the uncertainties surrounding the child's chronic condition affect not only the life of the afflicted child, but also the life of their parents.

What also became evident in the study's findings is that children and young people are well aware of the impact that a pain crisis may have on their family. This was the case of Peter who

once apologized to his mother for his need to stay at the hospital. Peter did not like to be hospitalized and in order to avoid it he often takes S.O.S medication when he is in pain without his mother's supervision. Whereas the self-medication of antipyretic analgesics (e.g. paracetamol and ibuprofen) may have some risks when used improperly and, therefore, may put in danger Peter's health and well-being (Du & Knopf, 2009), this practice also shows that children are capable agents in modifying care practices in accord to their own needs and interests (Bagge-Petersen et al., 2020). Like Peter, Ariel and Aurora also indicated that they did not like to stay at the hospital. The girls indicated that this was mainly due to the fact that they were separated from their mum who was not able to sleep at the hospital. The limited research conducted with children with a chronic condition about hospital care suggests that for children it was important for them that their parents could stay with them and were always present (Aldiss et al., 2009). The emotional support offered by parents, in particular by mothers, was an aspect spoken about by these children. The support given by siblings either to children or to parents were also made apparent in the discourse of some of the children interviewed. The research available suggests that not only parents, but also siblings are important sources of support for children who suffer from chronic conditions (Pals et al., 2020; Williams, 2000b; Webster, 2018).

These parents prepared the best as they could to manage their child's pain at home and employed both pharmacological and non-pharmacological strategies (e.g. use of a bottle of hot water, massages, 'etc'). This study did not support previous findings that suggest that little attention is paid by parents of children with a chronic illness to non-pharmacological strategies in order to control the outset of a crisis (Prout et al., 1999). Unlike other research on parents of children with chronic pain (Maciver et al., 2010), the findings of the current study suggest that although parenting a child with chronic pain is a challenging experience most parents in this study appear to have the expertise and the knowledge to manage and control their child's pain at home. The findings also demonstrate that children with a chronic condition can take autonomous decisions in relation to disease management, in particular medical regimens. This is very interesting in that it confirms Bagge-Petersen et al. (2020) finding that children are capable agents in their own treatment. In a similar way to previous research on pain in everyday life (Jenkins, 2015), the findings of the current study demonstrate that the experience and management of chronic pain in childhood is influenced by contributions from children and their parents. It is interesting to note that health care professionals seemed to be more aware than parents of children's ability of self-care practices. Indeed, I observed that during medical consultations healthcare professionals tried to empower not only parents, but also children with chronic pain with the knowledge and tools to minimize the experience of pain at home.

Understanding pain from the point of view of children and young people is important to comprehend the meaning and impact of chronic pain in their lives and of their family. This may be useful to inform clinical practice of paediatric chronic pain and stimulate the emergency of healthcare services for children and young people who suffer from chronic pain as well as their families in Portugal and elsewhere. Indeed, support should be offered to parents on how to involve their children in decision-making about the management of their chronic condition. This kind of knowledge could not only be useful to families who face similar issues, and teachers who wish to help children with chronic pain. Therefore, guidelines should be provided to teachers on strategies to manage chronic pain in the school setting. The study may also stimulate the development of social and healthcare policies in accord with the needs of these children. Indeed, the study confirms that a child-centred perspective is fundamental in order to deal with paediatric chronic pain and that children's agentic capabilities to deal with their chronic condition should be taken into consideration (Bagge-Petersen et al., 2020). With the insights of this article, I hope

that more attention should be given in the medical setting to the listening of children's voices regarding their pain management needs and pain experience more broadly. Nevertheless, the current study has some limitations. First, the sample size as due the small number of children, young people and their parents who participate it is not possible to transfer the study findings to other settings. Secondly, all participants were Black and therefore the views and experiences of other groups of the population are not represented. Thirdly, because all children and young people suffered from sickle cell disorder the study does not allow insights on the chronic pain experienced by primary or other secondary causes. Finally, it was not possible that all the themes described in the findings sections equally presented the accounts of both children and their parents. This was because either children or their parents did not openly talk about some of the issues discussed in the different themes found in the analysis.

## CONCLUSION

The purpose of this article was to highlight the experiences of parents, children and young people with sickle cell disorder who suffer from chronic pain. Similar to previous research on chronic illness (Stjerna, 2015), the study confirms that the strategies developed by children and young people to deal with their condition can be understood, on the one hand, as a response to the uncertainty that their condition entails, and on the other hand, as a manifestation of their agency. In illustrating that children and young people are active social agents in the management of their chronic pain (even when they are understood by their parents to be vulnerable), the findings of the current study support recent sociological work in the field of childhood health (Brady et al., 2015; Jenkins, 2015). Although I did not ask children and young people about their perceptions of being at risk, and in accord with Webster (2020) work, their accounts revealed that risk was a key concept in their understanding of their chronic condition. Indeed, the findings demonstrated that not only uncertainty but also risk shapes the experience of chronic pain in childhood and adolescence.

Previous research has shown children's agency and ability to exert control in the context of paediatric chronic pain treatment, namely as symptom informants in medical interactions (Clemente, 2009). Nevertheless, chronic pain in childhood and adolescence is still overlooked in the sociological field. This study intends to contribute to the limited qualitative literature on chronic pain in childhood and adolescence by showing the lived experiences of chronic pain by children and their families. I hope that this article will encourage the discussion about chronic pain in childhood and adolescence among both academic and non-academics. Knowing more about how chronic pain is experienced and managed by children, young people and their families in their day-to-day life in Portugal and elsewhere will help to improve the quality of the care provided. Through adequate care, children, young people and their parents will have a better quality of life and be able to actively participate in a social life. Further work is needed on how social aspects such as class, age, gender and ethnic differences may produce an impact on the experience of chronic pain in childhood and adolescence and how these differences may be taken into consideration by health care professionals in the management of chronic paediatric pain.

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## CONFLICT OF INTEREST

No potential conflict of interest was reported by the author.

## ETHICS APPROVAL STATEMENT

Ethical approval was obtained from the Instituto de Ciências Sociais, Universidade de Lisboa with the reference number 2019/09 and the hospital where fieldwork took place with the reference number 58/2019.

## PATIENT CONSENT STATEMENT

All participants gave their consent to participate in the study.

## PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

All participants gave their permission for the material to be reproduced.

## DATA AVAILABILITY STATEMENT

Research data are not shared due to privacy and ethical restrictions.

## ORCID

Ana Patrícia Hilário  <https://orcid.org/0000-0001-7396-5127>

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## AUTHOR BIOGRAPHY

**Ana Patrícia Hilário** is a sociologist and a Research Fellow at the Instituto de Ciências Sociais, Universidade de Lisboa (ICS-ULisboa). She had been involved in several national and international projects in the fields of gender, health and the life course. Her current main research interests focus on the sociology of health and illness, the sociology of gender and the sociology of childhood and youth.

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