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Children’s Experiences of Living with Cleft Lip and Palate (CLP): a qualitative study in Colombia

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Abstract

This thesis explores children’s views and experiences of living with CLP in three regions of Colombia. CLP is a birth condition resulting from a failure in the development of facial structures during the development of the embryo. CLP features visible clefts in the upper lip, the palate which often compromise speech, and in facial structures such as nose shape, dental alveoli and teeth. Colombia is a middle-income country located at the North-West of South America. It is the third largest country in this continent with a population around 50 million. Children and young people make up a third of the population (DANE, 2018). The prevalence of CLP in Colombia is high, reflecting the same pattern elsewhere in South America. Despite its economy’s growth in the last decade, social inequalities and poverty limit significantly children’s full participation in society. The negative impacts of poverty are more stringent on those with certain bodily impairments and particular healthcare needs, such as those with CLP.

Much existing literature concerning CLP focuses on exploring genetics and environmental factors involved in its aetiology, as well as assessing the quality of life of those with this condition. These mostly quantitative studies are limited in their potential to offer a more in-depth picture of what it is like to live with CLP from the child’s perspective. Given the paucity of qualitative research about this topic in the majority world, my study explores children’s understandings of CLP and their experiences of living with this condition in respect of two main dimensions: social lives and treatments; both are common aspects in the lives of those with CLP.

Findings presented in the thesis are the result of a qualitative study conducted in Colombia between March and August of 2018. Twenty children with CLP between 6 and 12 years old, from both urban and rural areas of three regions of Colombia (Bogotá, Cundinamarca and Boyacá) were interviewed on three different occasions. All participants were active attendees of Operation Smile-Bogotá (a CLP clinic). Two different approaches were used for interviews: home based (usually interviews 1 and 3) and walking interviews (interview 2) in combination with some creative tools. The interviews were designed to encourage children’s participation; creative tools (emotion body maps, life story works and pictorial cards of different types of bodies) were used
in a flexible way considering participants’ preferences and needs. Walking interviews entailed tours guided by the children to places/spaces significant to them, or simply places they wanted to visit around their homes/neighbourhoods. Data were analysed through a bespoke approach which incorporated the listening guide (Gilligan et al., 2011), disnarrated, non-narrated approach (Vindrola-Padros & Johnson, 2014) and thematic analysis (Ritchie et al., 2013). Analysis of the data drew upon literature from childhood studies, medical sociology, sociology of the body, emotions and disability studies.

The thesis puts forward three key findings: first, the children defined CLP as bodily differences but not as an illness. They understood the origin of CLP as the result of certain life circumstances and events occurring before birth and in line with God’s will. Their causation models were culturally-socially shaped and greatly influenced by narratives available to them (mainly from parents). Their agentic position in constructing meanings of their condition was not obscured by their dependency on parents’ stories; rather, this dependency facilitated the enactment of their agentic roles.

Second, CLP brought about important social costs, communication difficulties and bodily discomforts. Functional and physical differences such as speech difficulties, lip scars and nasal differences were stigmatised by school peers. This stigmatisation process affected their social relationships and interaction in significant ways. Despite the disruptive character of stigma for their social lives, children actively resisted, challenged and coped with these events. Embodiment of emotions and emotion work were key in shaping their responses of stigma resistance.

Third, although the children described their differences in non-biomedical and pathological terms, they also spoke of the need to ‘fix’ these differences through medical treatments. Embedded in a CLP health care plan, the children’s bodies and therapeutic outcomes were regulated by healthcare practitioners, thus reflecting how their bodies were part of a medical body project. The bodily transformations and improvements that came with treatments were in line with the children’s needs and desires: improving communication, displaying a more normal
body (e.g. more usual speech, an upturned nose), the alleviation of certain symptoms associated to CLP. Particularly ‘speaking well’ and a more common physical body offered them the opportunity to reduce chances of stigma. This shows that the children were not passive recipients of these medical works but that this body project was also their project.

This thesis offers a nuanced picture of how Colombian children with CLP understand their condition, the social costs of living with CLP, and their views and experiences with treatments. A shift from a binary view of children’s agency towards a more contextual and relational focus of agency reveals how children asserted their agentic positions even in the presence of potential agency constrainers. Implications of this study for practice include: the importance of incorporating children’s understandings into clinical practice in order to provide more culturally sensitive healthcare services, and the need to offer children greater emotional and social support to manage everyday difficulties such as stigma.
Lay summary

Cleft lip and palate is a birth condition common in Latin America and consists of a gap in the lip and palate which affects speech and facial appearance needing surgical correction. Disciplines such as genetics, medicine and psychology have investigated its origin and the psychological and social issues that children with this condition often experience. However, these studies have been mainly conducted in high income countries and did not explore directly children’s views and what it is like to live with this condition. For that reason, my study interviewed (at their homes and walking around their homes) twenty children with CLP from three regions in Colombia (Bogotá, Boyacá and Cundinamarca). This was in order to learn what they thought of their condition and what it was like to live with CLP from their own perspectives. Colombia is a large and middle-income country located at the North-West of South America, with children and young people representing a third of the population (DANE, 2018).

My research found that for the children CLP meant a bodily difference but not an illness and they used their own words and body language to explain their condition. CLP was something which they had been born with, a consequence of specific events which occurred to their mothers before children’s birth, but also allowed by God with a positive purpose. These views were mainly influenced by their parents’ views and did not reflect the common medical understanding of CLP.

The children’s social lives and oral communication were aspects of their lives greatly compromised by CLP. Their nose shape, lip scars and speech difficulties were frequently stigmatised by school peers. Despite these negative social responses towards their differences, the children retaliated with verbal responses, fights, and reports to teachers and parents. These actions were encouraged by feelings of anger and demonstrated their capacity to be agentic even in harsh circumstances.

With regard to their treatments, another important aspect of their lives, for the children these aimed to fix their bodies in order to make them look more common, and to improve speech and certain symptoms (associated to CLP) such as nasal breathing problems. Having a more common
body in the future was particularly important to stop mockery at school. Although their treatments were regulated by their doctors, the children did not receive these treatments passively. These were in line with their needs and desires as bodily transformations implied important benefits for their social lives.

This research offers a broader picture of how a group of children with CLP understood their condition, the social costs of living with CLP and what was important to them about their treatments. Despite children with CLP often being associated with vulnerability, given the social difficulties and medical problems they often experience, these children demonstrated a capacity to deal with these difficulties and showed an agentic self.
Declaration

In accordance with University regulations, I hereby declare that:

1. This thesis has been composed by myself;
2. This thesis is entirely my own work; and
3. This thesis has not been submitted in part or whole for any other degree or professional qualification

Liliana Arias-Urueña
June 2021
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Guide to transcriptions

Quotes from the participants are presented in italic font

‘uhmmm’, ‘mmm’, ‘ehh’ indicate participants’ verbal inflections

‘Aja’ means yes

Bold text in some quotes are used to indicate my emphasis

‘[...]’ indicates that some text is not included in the quote

‘….’ indicates a short pause less than 5 seconds

‘[LP]’ indicates a long pause (more than 5 seconds)
Chapter 1  Introduction: background and context to my research

1.1  Introduction

This thesis explores children’s experiences of living with CLP in three regions in Colombia. CLP is an umbrella term referring to a group of congenital conditions affecting orofacial structures such as the lip, palate and dental alveoli. Its congenital nature has been mainly investigated by biomedical disciplines in order to elucidate prevalence, risk factors, pathogenesis, potential treatments and preventive measures. The dominance of biomedical and quantitative research approaches in investigating CLP means that less attention has been paid to exploring children’s understandings and experiences of living with this condition. Although there is some qualitative research available, this has been mainly focused on exploring parents’ experiences of having a child with CLP (Guerriero et al., 2017; Lindberg & Berglund, 2014), decision-making processes about their children’s treatments (Nelson et al., 2012), or their roles as carers (Sischo et al., 2016). The paucity of child-centred research on their experiences with this condition represents a potential limitation for the design of healthcare services more sensitive to peoples’ beliefs, needs and the diverse trajectories which CLP can trace in people’s lives.

This introductory chapter provides context and background to the research. To do this, I first provide an overview of biomedical definitions and the aetiological model of CLP. Then, I offer an overview of the therapeutic regimes children with CLP often go through across their lives and the origin of my research idea. From this initial discussion I highlight that qualitative research exploring children’s perspectives and experiences with this condition is limited. Having defined CLP, a standard CLP healthcare plan, and areas of research which require further attention, I introduce some socio-demographic information about the Colombian context. This familiarises the reader with some geographical and socio-cultural aspects of the context from which the data were generated. Finally, I explain some particular terminology used throughout the thesis and present a broad outline of the thesis structure.

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1 Alveolus is a hollow cavity of bone containing tooth root.
1.2 What is CLP? Biomedical definition and aetiological model

Orofacial clefts of cleft lip and palate are medically defined as perceptible ‘disruptions of normal’ facial structures (Costa et al., 2021; Johansson & Ringsberg, 2004; Lindberg & Berglund, 2014) resulting from a failure in the fusion of the upper lip and/or palate shelves during the embryological development of the face (4-12 weeks). The structural ‘anomaly’ that represents this condition has led health practitioners to use terms such as dysmorphism, abnormality, birth defect and disorder. The prevalence of CLP varies according to geographic region with populations of Asian and Amerindian ancestry (e.g. Latin America region) having the highest rates (Mossey & Modell, 2012).

Clefts are divided into three groups: clefts anterior to the incisive foramen² (lip and/or alveolus), clefts posterior to the incisive foramen (palate) and a combination of both (lip and/or alveolus, and palate) (Singh et al., 2015). Physically, while cleft lip (CL) consists of a partial or complete gap on one or both sides of the upper lip, cleft palate (CP) is a complete or incomplete opening in the palate which affects the structural wall separating oral and nasal cavities (Jugessur & Murray, 2005; Mossey et al., 2009; Singh et al., 2015). Cleft lip and palate is the combination of both and often is accompanied by alveolus cleft (Mossey et al., 2009). This is a fissure in the bone that holds the teeth and is more frequent in the lateral incisor and canine (Mossey et al., 2009; Singh et al., 2015). Along these major types of CLP, there are some microforms such as submucous cleft palate, subcutaneous cleft lip and perioral muscle cleft (Jugessur & Murray, 2005; Mossey et al., 2009). These are less evident clinically and require greater expertise from the clinician for their diagnosis.

Although the aetiology of CLP is complex and not fully understood, several studies have indicated that genetics and environmental factors are involved (Dixon et al., 2011; Mossey & Modell, 2012; Wehby & Murray, 2010). For example, genome-wide association analysis has identified susceptibility regions and mutations associated with CLP (Imani et al., 2019; Lidral et al., 2008; Murray, 2002; Pengelly et al., 2016). Similarly, epidemiological studies have reported maternal

² Fossa located midline in the palate posterior to the central incisors.
malnutrition, and exposition to teratogenic substances such as alcohol as risk factors (Dixon et al., 2011; Ortega-Miller et al., 2017).

Alongside the clinical features, genetic bases are also considered in CLP classification. From this perspective, syndromic forms (30% of cases) have a stronger genetics base, follow a Mendelian patterns of inheritance and entail CLP in addition to other birth conditions (Mossey et al., 2009; Turnpenny & Ellard, 2011) (e.g. CLP and microtia). In contrast, non-syndromic forms are the most frequent and often occur as sporadic cases (Mossey & Modell, 2012). Individuals with this form only have CLP (Mossey et al., 2009; Turnpenny & Ellard, 2011).

1.3 Treatments for CLP

The faces of children with CLP, even after initial reparative surgeries of their clefts, have significant visible differences. These include asymmetrical lips, underdeveloped maxilla, lip scars, concaved mid-face, mal positioned teeth and nasal ‘deformities’ (Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Shi & Losee, 2014; Swennen et al., 2002). Although these features vary according to CLP severity, nasal ‘deformities’ are not only the most frequent but also the most complex to treat surgically (Berkowitz, 2013; Sykes et al., 2016). These ‘deformities’ are often observed as nasal septum deviation, flattering of lower latter cartilage, and under-projected and flat nasal tips (Sykes et al., 2016). In addition to the above mentioned issues, particularly CLP and cleft palate (CP) are also accompanied by important functional impairments such as speech difficulties, nasal breathing issues and feeding problems (Sykes et al., 2016; Zhang et al., 2019). Structural and functional issues make children at higher risk of presenting medical complications, the most common of which are: nasal airway obstruction; upper and lower respiratory infections; nasal regurgitation of food; malnutrition; developmental delay; hearing loss and sleeping disorders (Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Lindberg & Berglund, 2014).

3 This refers to a mechanism of inheritance in which genes and traits are passed from parent organisms to their offspring.
4 A congenital condition in which the external ear is small with absence or underdevelopment of the ear canal.
These often result from nasal ‘deformities’ and the open connection between the mouth and inside the nose (Jugessur & Murray, 2005; Lidral et al., 2008; Mossey & Modell, 2012; Wehby & Murray, 2010). Significant attention is therefore focussed on treating structural and functional issues because if they are not timely addressed, there are increased risks to children’s growth and development, nutritional status, breathing, feeding, and, oral communication; with potential life-threatening consequences (Alonso & Raposo-Amaral, 2018; Lewis et al., 2017).

A standard CLP care plan, therefore, starts very early in children’s lives and continues through adulthood. Although this plan may vary with the type of cleft, children’s co-morbidities, and nutritional status during their first months of life (1-3 months), treatments focus on stimulating palate bone growth and avoiding the collapse of dental arches (pre-surgical orthopaedics and feeding plates) (Berkowitz, 2013). These initial dental treatments are key for a successful primary cleft lip (CL) surgery (cheilorrhaphy-between 3 and 6 months) (Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Hospital de La Misericordia, 2009). After a first CL surgery, children continue with dental appliances in order to expand the palate and then facilitate the cleft palate (CP) surgery (palatorraphy- 8-12 months) (Alazmi, 2018; Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Hospital de La Misericordia, 2009).

Once lips and palate clefts have been surgically repaired, children continue to have medical and dental follow up to check facial growth and development and any potential new issues (Alazmi, 2018; Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Hospital de La Misericordia, 2009). Subsequent interventions often involve ‘revision’ surgeries when primary surgical outcomes are not satisfactory, such as hypertrophic lip scars or a persistent structural defect between nose and mouth (Berkowitz, 2013). During preschool and school years, dental care (e.g. orthodontics, removal of supernumerary teeth, bone grafting) and speech and language therapies are the core treatments (Hospital de La Misericordia, 2009; Howard & Lohmander, 2011). Rhinoplasties and orthognathic (maxilla) surgeries to correct nasal structural and functional issues and maxilla problems are often performed during transition to adulthood (Alazmi, 2018; Shi & Losee, 2014; Sykes et al., 2016).
Speech impairments are mainly experienced by those with CLP or isolated cleft palate (CP) (Howard & Lohmander, 2011). These result from the cleft palate and are characterised by hypernasal speech and compensatory articulation errors \(^5\) (Bernal-Sandoval et al., 2018; Pamplona et al., 2012). Typically these issues lead children to experience communication difficulties which often compromise their social relationships particularly with peers (Lee et al., 2017; Nyberg et al., 2020). Although speech therapies vary with protocols and languages, as indicated earlier, these often start during preschool years and go through adulthood and aim to improve children´s speech intelligibility and language pronunciation (Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Pamplona et al., 2012).

Despite initial treatments, children´s facial differences tend to be visible which lead to negative social responses such as staring, bullying and teasing (Shavel-Jessop et al., 2012). Speech difficulties are also the target of negative social responses (Nyberg et al., 2020). Children with speech impairments often report that communication difficulties lead to feelings of frustration and anger about not being understood by others (McCormack et al., 2010) but also enact negative judgements about children´s linguistic and communicative competency (Frederickson et al., 2006; Nyberg et al., 2020). These include labels such as the sick child (Lee et al., 2017). Despite the awareness that children with CLP frequently experience psychosocial issues particularly in the school years (Rumsey & Stock, 2012), the nature of their problems is not completely understood (Murray et al., 2010). This in part is due to the lack of qualitative research with children and from children’s perspectives on their experiences of living with CLP (Sharif et al., 2013).

There is awareness among health practitioners and parents of children with CLP of the potential negative impact of physical and functional differences in children´s lives. This awareness has led non-government organisations such as Operation Smile, Changing Faces-UK, CLAPA-UK and public figures (mainly celebrities) to raise awareness about the importance of offering children with CLP a timely and comprehensive healthcare plan. Central to this activism is the idea that,

\(^5\) These involve substituting one sound for another.
particularly after reparative plastic surgeries, children would be able to live happy lives (Operación Sonrisa, 2017). However, as noted in the beginning of this section, there is limited knowledge about how children understand their condition and the significance of those aesthetical, social and functional issues in their lives. Drawing on the previous discussion, I now move on to present the origin of my research idea, and the aims of my study.

1.4 The origin of my research idea

My interest in exploring this research topic was influenced by my medical training and my work in clinical genetics. My clinical role in Operation Smile- Colombia was focused on CLP genetic diagnosis and offering parents genetic counselling. Although my medical knowledge enabled me to explain to parents and children the possible origin of CLP, they did not always look at those explanations as consistent. Children´s parents occasionally counter argued my biomedical theory of genetics and environmental factors with their own theories. This led me to see the diversity and complexity of their explanations and I became interested in knowing more about them.

Parents also raised concerns about the potential negative effect of CLP in their children´s social lives. They often spoke of their children´s school issues, some of them relating to bullying, poor academic performance and poor support from teachers. To some extent I was aware of the psychosocial issues which children with CLP often experienced, but also knew that psychological and emotional support is not the backbone of a CLP healthcare plan. This led me to recognise that I had a limited (mainly biomedical) understanding of CLP and that if I wanted to contribute to improve my patients’ health and wellbeing, I needed to construct a broader picture of what it is like, as a child, to live with this condition. This implied accessing their views directly, a practice which is not frequent within biomedical disciplines, but the gold standard in childhood studies.

My research focus developed during the first year of my Ph.D. as I began to engage with key literature in medical sociology. As I discuss in Chapter 2, biomedical notions of the body, health, and illness fail to appreciate that the experience of illness is entangled in a complex web of meanings that only make sense within the socio-cultural context of a particular life (Kleinman,
and that health and illness processes follow different life trajectories (Frank, 1995; Kleinman, 1988). I was partially aware of this, as the tendency within clinical practice (except for psychiatry) is to pay less attention to elements of people’s stories that fall outside of the biomedical realm (Russell, 2013), such as patients’ own beliefs about the origin of their conditions and how their illnesses have affected broader aspects of their lives. I was aware of this narrow view during my clinical practice, but it was during the first year of my Ph.D. that I began to see biomedicine with more critical eyes.

Although this engagement with new disciplines was enriching (see Chapter 3), it also brought me into conflict with the dominant paradigm of health and disease that I had developed during my training and practice. For instance, the strong criticisms that medical sociology draws against the ‘objective’ and distanced way in which clinicians tend to look at peoples’ health problems, led me to think of the risks of adopting a less distant role for healthcare professionals’ mental health. Similarly, criticism of the narrow and biologistic nature of the developmental notion of childhood (strong in biomedicine) also made me feel that I had not always adopted good medical practice with children, given that in clinical genetics, children’s conditions are often assessed by proxy and decisions on genetics tests hardly ever ask for children’s opinions.

It was particularly difficult for me to open up to a broader understanding of the kind of evidence that can inform medical practice. I had learnt a traditional hierarchy of knowledge based on scientific methodology, which had limited space for qualitative research or for inclusion of lay knowledge. I also felt that some ideas and notions in medical sociology were solid in theoretical contexts but difficult to implement in practice. For example, despite the value and importance of seeing people’s illness experiences as unique and within the context of their lives, this might not be feasible in clinical practice given that the majority of primary care practitioners work in highly constrained settings (e.g. short time appointment, overload of work, low wages). I sometimes struggled to look at sociological theories as fluid, changing and complementing each other, as biomedical knowledge tends to be systematic, less holistic and less changing e.g. smoking is a high-risk factor for developing chronic obstructive pulmonary disease (COPD). However, the
more I engaged with sociological theories and especially both theoretical and empirical work in childhood studies, the clearer were the limitations of biomedicine for understanding health and illness experiences from individuals’ and particularly children’s perspectives. This awareness led me to identify further research lacunas in relation to what it means and entails for a child living with CLP; and thus it helped me to clarify the aims of my study, which are outlined in the following section.

1.5 Aims of the study

Given the discussions from the previous sections, my research aims to explore children’s understandings of the definition and aetiology of their condition and provide insights into their experiences of living with CLP with regard to two main dimensions of their lives: their social lives (bearing in mind the lack of characterisation of the social costs of having this condition noted earlier) and CLP treatments (a common/standard aspect in the lives of those with CLP).

This study aimed to explore:

1. Children’s understandings of the definition and aetiology of their condition
2. The significance of CLP in the context of their everyday lives with regard to two main dimensions: social lives and treatments.

After introducing biomedical definitions of CLP, how this is medically treated and the main research gap that inspired my research idea (limited qualitative research exploring children’s own accounts and experiences), I move on to give an overview of the socio-demographic context in which the fieldwork was conducted and my affiliation with the clinical site where the sample recruitment took place.

1.6 Research context

1.6.1 Colombia

Colombia is a middle-income country located at the North-West of South America. It is the third largest country in this region with a population of around 50 million (Departamento Administrativo Nacional de Estadística (DANE), 2018). Children and young people form 31.02%
of the total population (Departamento Administrativo Nacional de Estadística (DANE), 2018). Like other Latin American countries, Colombia is undergoing changing patterns in population distribution, with a decline in the prevalence of communicable diseases and increases in chronic and long term conditions, including congenital and genetic conditions (Ministerio de Salud y Protección Social, 2015). Although epidemiological data in relation to CLP is limited, congenital conditions are frequent in the children’s population and are the second cause of death among those aged under 12 months (Zarante, et al., 2010).

Over two thirds of the population live in the central area (región Andina) which is mainly urban (Departamento Administrativo Nacional de Estadística (DANE), 2018). The participants of this study lived in Cundinamarca, Boyacá and Bogotá (the capital city), three regions located in this central area. However, some of them either had migrated from other regions such as the Pacific coast (mainly rural) or lived in rural areas of Cundinamarca and Boyacá. There is a significant difference in terms of education, healthcare access and rights protection between urbanised and rural areas. While children living in the former have more opportunities to access school and healthcare services, those in remote and rural zones experience the most serious effects of poverty and armed conflict (e.g. high rates of infant mortality, forced recruitment) (García et al., 2015; United Nations International Children’s Emergency Fund (UNICEF), 2018). Although ethnic groups in Colombia are diverse, Colombians often identify with three main groups: ‘mestizo’; Afro-Colombian, and indigenous (Departamento Administrativo Nacional de Estadística (DANE), 2018). Those from minority ethnic groups (e.g. Palenquero de San Basilio, Raizal del Archipiélago, indigenous and Romani) live mainly on the borders (Amazonas, Pacífico, Orinoquia, Caribe) – areas marked by both poverty and extreme poverty (Departamento Administrativo Nacional de Estadística (DANE), 2018).

Child poverty is a significant issue in Latin America and Colombia. Over a third of children and adolescents in Colombia live in poverty with the youngest experiencing the most serious effects

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6 Colombians with European (mainly Spanish) and Amerindian ancestry.
of poverty (Estrategia de Atención Integral a la Primera Infancia de Cero a Siempre, 2015; García et al., 2015). Although Colombia has had economic growth over the last few years, it is the most inequitable country in the region (United Nations Development Programme, 2020).

Children and young people´s rights legislation in Colombia are outlined in the Children and Adolescents Code (Ley 1098: Código de Infancia y Adolescencia, 2006; Ley 1878, 2018) and the Statutory Law of Young people´s Citizenship (Ley Estatutaria 1622: Estatuto de Ciudadanía Juvenil, 2013; Ley 1885, 2018). These are legal instruments constructed in line with the UN Convention on the Rights of the Child (UNCRC) and explain the steps that society should take to uphold, promote and protect children and young people´s rights. Despite the efforts to outline social policy and public health strategies which promote children´s rights and health, particular factors including poverty, displacement, national and international migrations, armed conflict, and domestic abuse continue to affect children´s health and wellbeing (Strauch & Valoyes, 2011). Social inequalities and structural barriers tend to affect more seriously those with special healthcare needs (Strauch & Valoyes, 2011). This includes children with CLP.

1.6.2 The clinical site: Operation Smile - Colombia

A comprehensive CLP care plan often involves a multidisciplinary team (speech pathologists, social workers, psychologists, geneticists, dentists, nutritionists, plastic surgeons and paediatricians) (Lewis et al., 2017). Although these plans might vary across private and public healthcare services, main treatments such as plastic surgeries, speech therapies and dental care are not available in rural areas. This represents an important barrier for healthcare access, something that requires some children and parents from these areas to travel to the main cities (e.g. Bogotá) in search for medical treatments. However, geographical and economic barriers are even worse for those living in the most remote and poorest regions such as the Pacific (west) and Caribbean (North) coasts, Amazonas (South) and Orinoquia (East) (Departamento Administrativo Nacional de Estadística (DANE), 2018). This is problematic given that the Caribbean coast, Amazonas and Orinoquia have the largest population of indigenous people (Departamento Administrativo Nacional de Estadística (DANE), 2018), a high risk group for CLP.
Aware of these socio-economic and geographical barriers, Operation Smile-Colombia run ‘medical missions’ in order to provide reconstructive surgeries to those from remote and unprivileged areas. Operation Smile-Colombia is a non-profit organisation based in Bogotá which offers a free and comprehensive CLP care plan to children and adults regardless of their socio-economic and ethnic backgrounds. I was a medical volunteer with this organisation from 2010 to 2016, before starting my Ph.D. and this role was important in shaping my research idea. As I describe in Chapter 3, the recruitment of my participants was done through this organisation, which also provided medical treatments to the participants.

1.7 The thesis structure

This introductory chapter has provided some of the background context to this thesis. I have presented definitions of CLP, its aetiological factors and a brief summary of a standard CLP healthcare plan. I have also introduced some details of the social, cultural and geographical context in which my study was conducted. The following chapter (Chapter 2) engages more critically with some themes discussed in this introductory chapter and reviews key sociological conceptual and theoretical orientations towards the body, children, emotions and disability. Critically appraising this body of literature, I note some underdeveloped research areas and gaps which constitute the underpinnings of my research questions. This includes: minority world-centric and unproblematised notions of children’s agency; limited research with a biographical focus on children’s experiences with their health conditions; the limitations of research on the psychosocial issues experienced by children with CLP and adult-centred research on explanatory models of the origin of CLP.

In Chapter 3, I present the methodology of my study. This covers details related to research design; sample; recruitment; data generation; analysis approach; ethical considerations and a reflexive discussion of my role as a researcher.

Chapter 4 is the first findings chapter, focusing on the children’s accounts and stories about defining their condition and their views on the causes of CLP. In order to position the children’s definition of CLP within a conceptual framework of health, illness, and abnormality (these latter
two terms used frequently by biomedicine) I examine how the participants define healthy, ill and normal/abnormal bodies. Important findings emerge from this chapter including the children’s views of CLP causation as congenital but contingent, and the children’s views of their bodies with CLP in terms of difference and sameness.

After analysing children’s understandings of CLP, in Chapter 5 I focus on a theme frequently raised by the participants – their school lives. Their accounts allowed me to characterise their experiences of stigma and to shed light on the link between stigma and their socio-relational difficulties; I draw on Link & Phelan (2001) conceptualisation of stigma to characterise their stories of stigmatised events. These narratives also allow me to analyse their strategies for facing and resisting stigma.

In Chapter 6, I analyse children’s stories of views of and experiences with CLP treatments across their life course. This includes reasons for their treatments as well as physical sensations and emotions experienced before, during and after certain medical interventions. Drawing on the idea of the ‘body project’ (Shilling, 2012) I demonstrate how certain treatment outcomes are seen by the children as forms of relational works and alleviate certain bodily discomfarts associated to CLP. Children also engage with some treatments in implicit and subtle ways thus demonstrating their agentic roles.

In Chapter 7, I synthesise the findings presented in Chapters 4, 5 and 6 to develop a discussion in the light of explanatory models of health and illness, lay knowledge, agency, emotions, the body project, biographical disruption, and biographical contingency. I end by outlining some conclusions drawn from the study in relation to my research questions, highlight strengths and limitations, note potential implications for clinical practice, and identify future research areas.

**A note on terminology**

Despite the dominance of medical terminology in defining this condition, there has been an increasing awareness of the potential negative effect of using terms such as ‘disfigurement’ on individuals’ identities (Rumsey & Harcourt, 2007). Therefore more neutral expressions such as
visible facial difference (VFD) (Perella, 2013; Rumsey & Harcourt, 2007) appearance-affecting health conditions (AAHCs) (Costa et al., 2021) have started to be used by NGOs such as CLAPA and Operation Smile.

Throughout the thesis I use a variety of terms when referring to CLP and associated features. These include CLP, health/birth/congenital condition, visible facial difference, bodily difference, and bodily impairments (particularly in reference to nasal obstruction, speech difficulties and breathing issues). Despite their frequent use in biomedicine, I prefer not to use terms such as ‘deformity’, ‘abnormality’, ‘defect’, or ‘dysmorphism’ in my findings chapters and discussion, given that there are available more neutral terms such as ‘facial visible difference’, and bodily difference. However, I use some biomedical terms within the critical discussion I present in the literature review (Chapter 2) and in Chapter 7.

It is important to mention that I use the term ‘body’ instead of ‘the face’ throughout my thesis. This is because the face is part of the body and as indicated earlier, CLP also involves associated features such as communication issues which cannot be described only as being part of the face. Different terms such as medical treatments, interventions, management, and practices are used in reference to treatments carried out by health practitioners. Terms such as surgeries and surgical care refer to mainly plastic and maxillofacial surgeries. This includes cleft lip and palate reparative surgeries, rhinoplasties, surgical ‘revisions’, orthognathic surgeries and bone grafts. Speech rehabilitation entails speech therapies, and dental care involves orthodontics treatments and other types of dental interventions such as dental check-ups and dental cleaning.
Chapter 2 Literature Review

2.1 Introduction

In the previous chapter I signalled some key research gaps which this thesis contributes to bridging such as the paucity of research on children’s own perspectives and accounts about living with CLP and the lack of clarity with regard to the psychosocial difficulties which these children experience. In this chapter I engage critically with key literature in order to provide a framework of the broad context in which the research questions of my study can be understood and explored. In this review, I also further identify and expand on the research gaps which are explored throughout the thesis.

After introducing the methodology used to develop the literature review, I give an overview of current academic understandings of children and childhoods. Here I explore notions of being and becoming and emphasise debates around agency from both the minority and the majority world. With this exploration, I show how agency continues to be an ambiguous and contentious theme within childhood studies, and highlight the relevance of seeing children as ‘been’, ‘beings’, ‘becoming’. Secondly, I introduce biomedical understandings of the body and how this contrasts with the lived body—the axis of contemporary sociological research of the body. With a specific focus on children’s bodies, I review the notion of the body project and provide some examples of how bodily markers are used within peers’ culture to construct meanings around class, competence and group memberships.

Bearing in mind the relevance of notions of disability, and sociological works around bodies with differences in the context of my study, in section 2.4.4. I review three main models of disability and their key debates. Given that those bodies with differences are often subjected to biomedical practices in order to restore their functionality and anatomy, I then move on to discuss some

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7 ‘Minority World’ and ‘Majority World’ refer to the ‘Global North’ and the ‘Global South’, respectively (Punch, 2000, p. 60). The Majority World entails the most extended and populated region in which people experience less privileged lifestyles and more serious issues such as poverty.
literature around children’s experiences with medical treatments from which I note the lack of research on their embodied experiences.

In section 2.4.5. I discuss emotions, a topic closely connected to the lived experiences of the bodies. Here I highlight the role of emotions in patterning relationships and how these are often used as vehicles of power. The last section covers core themes of medical sociology from which I note how these are centred on adults. With a focus on childhood, I engage with key critical views of the notion of biographical disruption demonstrating how factors such as social structures, ethnicity and age might exacerbate or alleviate the disruptive character of an illness. I then review the notion of explanatory models and how these are important to illness and health-meaning production. With a focus on CLP, I highlight the paucity of research on explanatory models around CLP despite the strong cultural beliefs about the origin of CLP.

2.2 Literature review methodology

The literature review was constructed on an ongoing and recurrent process across my PhD and involved a variety of search strategies. Topics reviewed were selected and explored on the basis of their relevance for my research focus and recommendations from my supervisors and colleagues and the work I had already done on CLP in my masters and clinical practice.

During the initial stages of my PhD, conversations with my supervisors were key to my engagement with sociological literature and concepts. This was important given that my non-sociological background meant that I had first to understand some core sociological concepts. To do this, I reviewed mainly classic text books of the sociology of childhood; sociological perspectives of the body; emotions and social theory; theories of stigma; disability studies; the sociology of health and illness and illness narratives. From this initial review, some core concepts and citations were selected and further reviews were done in order to engage more profoundly with them. My focus at this stage continued to be on sociological and qualitative research on the body, children and health and illness; for that reason I mainly used social science data bases such as ASSIA (applied social science index and abstracts), and manual searches in the University
library. Concepts covered at this point were more specific: the lived body; the child body; children’s agency and competence; explanatory models of health and illness; the social model of disability; biographical disruption; stigma and facial visible differences; management of emotions; emotions in social life; child centred research/methodologies; participatory methods. In order to learn more about child-centred research conducted in Latin America I engaged with the work of key authors such as Samantha Punch, Irene Rizzini, and Lucía Rabello de Castro and I reviewed studies more specific to the Colombian context in CINDE (Centro Internacional de Educación y Desarrollo humano).

Once I felt more familiar with sociological concepts and qualitative research I refined my search strategy. Instead of being a broad search, this started to be more specific to CLP, children, and topics relevant to the focus of my study. To do this I sought directly in key journals (e.g. Childhood, The Cleft Palate-Craniofacial Journal, Body and Society, Social Science and Medicine, children’s geographies) and used several data bases such as ASSIA, IBSS (international Bibliography of Social Science), ProQuest Sociology, JSTOR, Scopus, MEDLINE, EBSCO, Sage Research Methods. I also used different search terms, I have included some of them as an illustration: cleft lip, cleft palate, craniofacial, child*, adolescent*, teen*, qualitative research, participatory approach*, biograph*, disruption, stigma, bullying, embodiment, body, illness, agency, etc. In order to make this search more context specific to the majority world I also used some Latin American and Caribbean region data bases such as Scielo and LILACS. This more targeted search clearly demonstrated the limited qualitative research on children’s experiences with CLP, predominantly in Latin America.

During my fieldwork and data analysis, ongoing searches were more focused on particular themes emerging from the data generation (e.g. stigma, speech impairment, emotions, agency, embodiment, vulnerability, unfinished, experience, medical intervention, body project, disability, and religion). Reviews across the last stages of the research were particularly nurtured by discussions with my supervisors, and an informal presentation of my ongoing analysis in a social science seminar. Further targeted searches were conducted when discussing my data (e.g.
biographical disruption, continuity, reinforcement, etc). I used Zotero as bibliography manager and hand-written mind maps (see an example in appendix 1) to connect concepts and develop a more structured framework of the themes studied.

2.3 Children and childhoods

2.3.1 Understanding the ontology of childhood

The ontology, or nature of childhood has been a recurrent theme of discussion within sociology and cognitive sciences. Core to this discussion is the presence of binary conceptualisations of the child – being and becoming - which are reflective of the traditional dualism between nature/biology and society/culture (James & Prout, 1997). With an emphasis on children’s biological status of immaturity, developmental sciences propose a notion of the child constructed on their status of ‘becoming’, of unfinished adults in terms of their development and growth. Embedded in this concept are expectations of how this process of becoming should unfold, and the outcomes to be fulfilled at particular stages; healthy and normal children should achieve certain developmental milestones such as motor abilities, language, and the display of socialisation skills at particular points of their lives (Marcdante & Kliegman, 2015). Fulfilment of these outcomes is considered evidence of the normality and adequacy of the growth and development of the child. An example of the prevalence of this notion within the medical realm, is the frequent focus of public health strategies on promoting healthy social contexts as the means through which children are able to have a normal development and therefore more likely to become good adults in the future (Center on the Developing Child Harvard University, 2011).

Although children had been absent from the sociological research agenda, given the dominance of developmental sciences in their theorization and empirical research (James & Prout, 1997), in the 1980s and 1990s there were important moves towards incorporating children into the sociology agenda. Partially in response to the reductionist and biological determinist character of ‘becoming’, European theorists such as James & Prout (1997), Qvortrup (1994) and Jenks (1982) contested the biological immaturity and developing character ascribed universally to children, by conceptualising children’s ontology as dependant on social, cultural and historical
contexts. This new paradigm advocated for defining children as a social group with competences, abilities, and agency, in which their present lives, their being, were privileged over their uncertain future as adults (James & Prout, 1997; Qvortrup, 1994). Other social sciences disciplines such as anthropology and geography joined this group of sociologists to consolidate a more interdisciplinary field of childhood studies. The enactment of a specialised area of childhood studies not only represented a vital point in the theorisation of childhood and children’s lives, but empirically made important contributions to enhance and protect children’s rights and participation in society (Tisdall & Punch, 2012).

However, dualistic views of which being/becoming are examples, have been seen as rather problematic within contemporary sociology (Prout, 2011; Williams, 1998). By emphasising the social construction of childhood, the notion of ‘being’ was initially presented in opposition to the somewhat essentialist, biologically driven developmental perspective. This served to accentuate a binary position towards understandings of children and childhood. Moreover, while the new paradigm provided an essential counterpoint to biological reductionism, social constructionist accounts of childhood neglected the fact that social worlds, and particularly the child’s body, have a material component (Prout, 2000, 2011). The accelerated biological change that characterises children’s bodies, was something that the ‘being’ approach failed to fully address (Prout, 2000), leaving the child’s body as an ‘absent presence’ within sociological discussions (Valentine, 2010). The child body is discussed further in a later subsection of this chapter.

Nevertheless, the wider sociological turn to the body, and its hybrid (social/biological) nature (Shilling, 2012, 2016), has also seen a foregrounding of the child’s body in sociological discussions of childhood (Prout, 2000, 2011; Uprichard, 2008). In doing so, the recognition of time, change, and the position of children’s bodies within temporal scales allowed the theoretical reconciliation of the biological, social, present and future dimensions of childhood. The work of Uprichard (2008) was fundamental in demonstrating that theoretical orientations of children as ‘beings’ and ‘becoming’ were not opposite as children could look at themselves as both beings in the here and now and future adults. Her research showed that children were aware of the changeability
of their bodies and worlds, and how this awareness enabled them to speak of their beings also in future terms. This work was key in revealing that the neglect of the ways in which children were ‘becoming’ had inadvertently led to gaps in our understanding of children’s present, ‘being’ lives (Uprichard, 2008).

While the dualist notion of children was, to a greater extent reconciled by Uprichard, both Cross (2011) and Hanson (2017) note that children’s past – ‘been’ – is a temporal dimension widely absent in both theoretical and empirical research on and with children. Although some researchers have discussed the notion of the ‘been’, this has focused on young people’s and adults’ accounts of their experiences when they were children, rather than children’s accounts about their past (Brannen, 2004; Conrad, 2012). A potential reason for the paucity of research embracing children’s past is the assumption that this is a stage of their lives difficult to explore given the shortness of the past that they have to remember, and cognitive limitations to have memories of their early lives (Hall et al., 2013).

Nevertheless, Cross (2011) and Hanson (2017) assert that embracing the three dimensions of ‘been’, ‘being’ and ‘becoming’ offers the possibility of seeing the relations and shifting sequences between these temporal orders, something important for the construction of a more holistic understanding of their lives (Hanson, 2017). My research is constructed on the awareness that ‘been’, ‘being’ and ‘becoming’ are integral to children’s lives and that recognition of all these dimensions of temporality are key to examining their experiences.

2.3.2 Agency

Agency is a core concept in theoretical debates and extensive empirical research developed within childhood studies (Abebe, 2019; Eßer, 2016; Spyrou, 2018; Tisdall & Punch, 2012). This concept is often described as an attribute of children which positions them as able, active and autonomous social actors instead of passive and dependant beings (Abebe, 2019; Moran-Ellis & Tisdall, 2019; Spyrou, 2018). These attributes which denote that children are competent and therefore agentic are often used to justify children’s rights to participate in decision-making.
processes and to legitimate their capacity to take part in the research process (Alderson (2007); Moran-Ellis & Tisdall (2019); Spyrou (2018); Tisdall & Punch (2012). The view of agency as something valued and equally prized by all children, has led childhood studies to protect and enhance this attribute across society (Tisdall & Punch, 2012). These efforts are visible in strategies which seek to enhance children’s involvement in policy making process such as the Children’s Parliament in Scotland, or the incorporation of child consent for taking part in research processes and medical treatments (Alderson, 2007; Coyne & Harder, 2011).

Similarly to the new paradigm of childhood, the theorisation of agency has been mainly developed in European countries such as UK and Norway (Edmonds, 2019; Tisdall & Punch, 2012). The minority world dominance of this concept has raised important questions about the applicability of this understanding of agency in the majority world (Abebe, 2019; Edmonds, 2019). Partially in response to this question, there has been an increasing interest in producing more theoretical and empirical research within the global south (Bordonaro, 2012; Bordonaro & Payne, 2012; Panelli et al., 2007; Tisdall & Punch, 2012). However, the majority world’s theoretical and empirical contributions have not been sufficiently incorporated into the minority world’s research (Tisdall & Punch, 2012). Despite this, research from the majority world has been key in examining and challenging dominant orientations towards agency (Punch, 2016a; Tisdall & Punch, 2012). For example, contrary to the assumption that children’s labour goes against children’s agency, the work of Punch in rural Bolivia demonstrated children’s abilities to negotiate work, play and school even in the presence of potential highly constrained settings (Punch, 2009). Similarly with a focus on collective memories, Hedrera-Manara & Álvarez-Martínez-Conde’s (2016) ethnographic work with children in Chile shows that although the process of constructing memories around key historical events of their country took place within a relationships with adults, children were active in the ownership of those memories.

Child-centred studies conducted in Africa have been important in shedding light on different types of agency. From their work with child domestic workers in Tanzania, Klocker (2007) proposed a new conceptualisation of agency as a spectrum of possibilities – ‘thin and thick
agency’ rather than agency being an attribute of the child. While ‘thin’ agency entails children’s everyday decisions within a limited pool of options, ‘thick’ agency is a more inwardly reflective agency in which children have the opportunity to decide within a broad range of alternatives. Also in Africa, the work of Honwana & Boeck (2005) demonstrated how children involved in armed conflicts and in a vulnerable constrained position, managed to make decisions strategically to ‘cope with the concrete and immediate conditions of their lives’ (Honwana & Boeck, 2005, p. 49). This type of agency is termed ‘tactical’ agency and implies that these children have an hybrid status of being innocent victims but also guilty perpetrators (Honwana & Boeck, 2005). A more recent typology of agency developed from the work of Payne (2012) with children living on their own in Zambia, concerns ‘everyday agency’. This refers to how children, embedded in highly relational and structural constrained contexts, developed capacities to face, cope and overcome their everyday life struggles.

These works started to raise awareness that agency might vary across societies and relationships, and led to a more critical scrutiny of the concept within childhood studies (Abebe, 2019; Spyrou, 2018; Tisdall & Punch, 2012). A key reflection of this critical turn was that agency is often used as a ‘mantra’ (Tisdall & Punch, 2012, p. 251) within this discipline, rather than a term conceptually clear (Abebe, 2019; Ëßer, 2016; Spyrou, 2018; Tisdall & Punch, 2012). The ambiguous and global north-centric view of this term was fundamental to further problematise this concept and recognise the importance of having a more interdisciplinary conversation between the minority and majority worlds (Punch, 2016a). A common point raised by childhood studies theorists was the limitations of seeing agency in binary terms. As mentioned earlier, the tendency has been to define children’s agency by the characteristic of their actions – active/passive, autonomous/dependant-vulnerable. This notion of agency is not only problematic for unrecognising the relational and socio-cultural influences of its enactment, but perhaps most important is that it overlooks children’s vulnerability and dependency (Bluebond-Langner & Korbin, 2007; Mizen & Ofosu-Kusi, 2013; Philo, 2011; Spyrou, 2018).
At the epicentre of the enthusiasm to promote and protect agency is the idea of autonomy as a supreme and desired value (Hammersley, 2017). Autonomy is often linked with individuals’ capacity to make informed and uncoerced choices and therefore a way to overcome dependency and vulnerability (Hammersley, 2017). However, ideas of autonomy as a supreme value and contrary to dependency and vulnerability, risk overlooking the fact that children may have some vulnerabilities and that vulnerability is not always seen as something negative (Christensen, 2000). Indeed, several authors have noted the importance of not forgetting children’s vulnerabilities and dependency when conceptualising agency (Bluebond-Langner & Korbin, 2007; Mizen & Ofosu-Kusi, 2013; Oswell, 2016; Spyrou, 2018). For example, Mizen & Ofosu-Kusi, (2013) argue that agency and vulnerability are not necessarily contrary concepts but rather coexist in childhood. Their work with children in Ghana demonstrated that some children’s decisions to live by their own even in potentially adverse contexts such as streets, were shaped by the recognition of their inabilities to live in a chaotic family context. Drawing on this, these authors conclude that children’s awareness of their vulnerabilities is key in the assertion of their agentic roles.

Works such as this and the abovementioned studies developed in the global south have adopted a more critical view of prevalent and uncritical notions of agency (in terms of children’s independency and activeness), and scrutinised children’s decisions, actions or omissions within the complexity and diversity of their everyday lives. Given the relevance of examining childhood ‘mantras’ through critical eyes (Tisdall & Punch, 2012, p. 251), I have adopted a critical orientation towards agency in the analysis and discussion of my findings. This involves paying particular attention to the embodied practices of agency and the diversity of children’s voices (Eßer, 2016; Komulainen, 2007; Spyrou, 2018). This is particularly important for moving forward research on children as health actors, which remains focused on their participation in giving consent (Alderson, 2007; Alderson & Morrow, 2011), children’s active or passive roles in making decisions on treatments (Hall et al., 2012) and their participation in the design and provision of healthcare services (Bolin, 2018). Considering this, I examine my participants’ accounts being sensitive to the temporal, socio-cultural and relational dimensions in which their actions or omissions unfold.
As mentioned in section 2.3.1, the child’s body has occupied an implicit rather than explicit position in childhood studies (Coffey et al., 2016; Valentine, 2010). Aware of its absence in childhood studies and the central position of the body in my thesis, in the following section I review key literature with a medical and sociological orientation towards the body which has been applied to the theorisation of the child bodies.

2.4 The body

In this section, I turn my attention to bodies to consider more systematically salient debates regarding how bodies are understood. To do this, I discuss biomedical and sociological views of the body and how these have been applied in relation to children’s bodies, including those with differences. Given that emotions are closely tied to the body, in this section I also engage with some theoretical perspectives of emotion in social life.

2.4.1 The biomedical perspective of the body

Biomedical\(^8\) understandings of the body are mainly constructed on a mechanistic-organic view; the body is constituted by genes, molecules, cells, tissues and organs which are selectively organised in systems with structural and functional purposes (Boron & Boulpaep, 2017; Kasper & Harrison, 2005). The body is therefore a complex system whose good or bad functioning gives way to health and disease processes. Based on the fact that these processes are dependent on the harmonious or anomalous work of bodily systems (Kumar et al., 2017), quantifiable and experimental techniques are preferred to assess and correct its structure and function (Krieger, 2011). Based on this understanding, disease is an anomalous/dysfunctional status of the body and this has a specific organic cause (Kumar et al., 2017). Notwithstanding contemporary medical perspectives of the body that advocate for a more holistic view of it such as the case of personalised medicine (Best & Swensen, 2012), diseases are still defined mainly in biological

\(^8\) Biomedicine is an umbrella term which refers to mainly biological sciences and medicine, with particular emphasis on health technologies.
terms (Gabe & Monaghan, 2013; Williams, 1998). This implies less consideration to sociological, individual and lay understandings of the body, health and illness (Conrad, 2007).

The biomedical notion of the body is at the epicentre of health policy-making, systems and institutions globally (Clarke et al., 2003). This is not only reflective of the powerful position of medicine in society but also its authority to determine what and how bodies are considered to be normal (Foucault, 2012). A common way in which biomedicine operationalises its discourse of what a normal body entails, is through the promotion of healthy practices in individuals’ lifestyles (Crawford, 2006), and the offer of pharmacological and surgical treatments to correct the erratic functioning of the body (Williams, 1998).

However, the biomedicalization of the body has not been seen with uncritical eyes (Conrad, 2007). Authors such as Coffey et al. (2016), Gabe & Monaghan (2013) and Williams (1998) have criticised this notion for seeing the body as mainly biological, and a passive site where health and illness take place rather than an active being which participates in the production and experience of health and illness. Furthermore, some medical models of disease causation cannot explain patients’ uncommon symptoms, and some terms and categories used within biomedicine to define and treat people’s health issues have the potential to impose discrediting labels on individuals’ identities (Conrad, 2007). The biomedicalization of the body is further discussed in section 2.4.4 where I discuss models of disability and the role of medical treatments in instances of bodily differences. In the section that follows I discuss how the biological determinist nature of this biomedical notion was key for the enactment of a more tangible position of the body in sociological discussion.

2.4.2 The lived body and the body as a project

Distinct from the biomedical perspective of the body, mainly focused on its organic and biological substrate, sociology has traditionally focused on the meaning and symbols constructed from and ascribed to the body (Howson, 2013; Shilling, 2012). However, the body was rather absent at theoretical and empirical levels in sociology for a long time. The prevalent naturalistic view of the
body implied that this was a matter separated from the social rational actor and therefore a topic which did not concern sociology (Williams & Bendelow, 1998). By the 1990s a greater interest in, and scrutiny of the body as a focus for sociological study had developed. The result of this was a strong social constructionist understanding of the body, something that allows the recognition of the body as a matter of sociological discussion (Williams, 1998). From this sociological stance, the body was seen as a product of knowledge and power and as such greatly shaped by society (Shilling, 2012, 2016). The potential of the body to be constructed on either individual or collective ideas meant that the body, rather than being a natural-biological entity, was a representation of particular historical and social-cultural circumstances (Shilling, 2016). While the enactment of this social constructionist approach moved forward the theoretical conceptualisation of the body, this approach was criticised for neglecting the embodied nature of human action and perpetuating the division of nature-social rather than exploring their interactions (Prout, 2000; Shilling, 2012; Williams, 1998).

With the awareness of the limitations of understanding the body in binary terms, the importance of recognising the body as both a biological and social entity was noted (Nettleton, 2013). Thus the lived body notion emerged and this embraced an understanding of the body in terms of hybridity, heterogeneity and holism which advocates for no dual positions between mind/body, reason/emotions and nature/social (Cregan, 2006; Shilling, 2016; Williams & Bendelow, 1998). Proponents of this hybrid notion argue that the materiality of the body (corporeal-physical dimension of the body) both shapes, and is shaped by society (Howson, 2013; Shilling, 2012; Williams & Bendelow, 1998). For these theorists, the body would appear inert if we do not recognise that the significance, meanings and experiences we create of our social worlds are mediated through our corporeal bodies (Coffey et al., 2016; James, 2000).

The reconciliation of the biological and social dimension of the body in this more lived understanding of it, opened up opportunities to pay greater attention to the interplay between the body and society. Influenced by the work of Bourdieu (1977), which states that our embodied dispositions and habits are greatly influenced by our historical, social and cultural backgrounds,
some sociologists of the body focused their attention on scrutinising how the material body was likely to be transformed by our social worlds (Coffey et al., 2016). This included purposes and the operationalisation of bodily transformations as well as how those desires for bodily changes were informed by society and cultural paradigms (e.g. beauty, health, normality, competence).

Acknowledging the possibility of the body being able to change according to societal and cultural norms, implies that the body is malleable and unfinished (Shilling, 2016). Key in the theorisation of this malleability of the body is Shilling (2012), who proposes a concept of the body as both an individual and collective project. From this perspective, the body has the potential to be shaped according to individuals’ desires, identities and needs. Central to this body project is that individuals also demonstrate their commitment and engagement with the process of transforming their bodies through bodily maintenance practices such as following exercise routines or certain medical treatments. This malleability means that the body is not a predestined biological organism, but an entity, unfinished and open to reconstruction. He illustrates through distinct empirical examples how this notion of the body is particularly prevalent in contemporary life in which people engage with different types of body work practices to produce a specific identity.

The concept of body work has different connotations in sociological literature. These include: ‘the work performed on one’s own body; paid labour carried out on the bodies of others; the management of embodied emotional experience and display, and the production or modification of bodies through work’ (Gimlin, 2007, p. 353). The latter most specifically refers to bodily transformations, marks and health issues that arose from the nature and demands of certain jobs. With regard to the former, ‘the work performed on one’s own body’, this is focused on transforming, shaping and fixing the appearance and function of the body.

Central to body projects is that they hold a disciplinary nature which attempts to bring individuals to normality standards (Balfe, 2009; Shilling, 2012). These standards are greatly influenced by prevalent and dominant socio-cultural normatives (Balfe, 2009; Coffey, 2016) with medicine
having a significant presence (McLaughlin & Coleman-Fountain, 2014). This disciplinary and regulatory character is more evident with regard to those bodies which show physical and functional variations. I return to this point in section 2.4.4.

However, against the idea that modifying one’s body often arises from individuals’ desires to have a body more consistent with social and cultural constructed norms or to produce a specific identity, certain bodily transformations allow bodies to be experienced in both more comfortable and functional ways. Drawing on the notion of the absent body (Leder, 1990), Gimlin (2006) analyses how plastic and cosmetic surgeries have also the potential to help people overcome the body’s dys-appearance. This dys-appearance entails physiological and social instances in which the body becomes uncomfortable. She illustrates this phenomenon drawing on several examples but a notorious one was the bodily discomforts that having big breasts caused in a woman when doing physical exercise. In the face of this discomfort, a reduction mammoplasty was promising in allowing her jogging without experiencing pain.

The bodily transformative character of particularly medical interventions such as plastic surgeries have been at the heart of important debates within disability studies. I engage with some of these debates in section 2.4.4. when discussing some key concepts in relation to different bodies and disability.

The above review has served to understand different conceptualisations of the body and how debates around them have allowed the generation of a more holistic and lived perspective of it. Given that the dominance of the embodied-lived body and the body as a project are two stances used in discussion around children’s bodies, I use in the analysis and discussion of my findings these particular two theoretical orientations.

### 2.4.3 The child body

The body holds a central role for discussing core concepts such as agency within childhood studies, however this has been left at the margin within this discipline (Coffey, et al., 2016;
Valentine, 2010). Several authors have noted that despite much of the theoretical and empirical work of childhood studies being indirectly concerned with the body, it has occupied rather a vague position in such discussions (Castañeda et al., 2002; Prout, 2000; Valentine, 2010). In particular, the ways in which children construct and develop their everydayness through and with their bodies and how these are also shaped by social and cultural norms have not received much attention (Coffey, et al., 2016).

Referencing back to the concept of ‘been’, ‘being’ and ‘becoming’ discussed in section 2.3.1 change is at the epicentre of children’s bodies and therefore a universal feature of childhood as a social category. The awareness of the mutability of children’s bodies allowed the theorisation of their bodies as an unfinished and flexible process, and with this the recognition that they are also the target of multiple interventions (Castañeda et al., 2002; Coffey et al., 2016; Coleman, 2008). These interventions have the purpose of making their bodies more consistent with social norms (Lupton, 2013), such as efforts by parents, teachers and carers to teach them to control their emotions (Harden, 2012), adopt healthy eating practices (Bhagat & Howard, 2018; Rail, 2009), acquire socialisation skills (Moriguchi et al., 2016) and learn certain principles of ethics (Collado & Hernández, 2018). However, these practices are not only about disciplining the performance of the body but also transforming its corporeality according to society and cultural norms (McLaughlin & Coleman-Fountain, 2014). Those children whose physical and functional bodies are not meeting growth and development milestones or who experience certain medical conditions, are also positioned within a network of medical interventions (James & Hockey, 2007; Lupton, 2013) in order to restore their normal functionality. I return to this point when discussing children’s bodies with differences in the next section.

Apart from the rapid change of children’s material bodies because of growth and development, the way they experience their social worlds with and through their bodies also changes. ‘Children's experience of embodiment is the experience of the embodiment of time’ (James, 2000 p. 29) and for that reason children’s experiences with their bodies should be analysed through a more embodied analytical lens (Hackett et al., 2015). This is in order to have a better
understanding of how children’s and young people’s bodies are implicated in the complexity and tensions of their lives (Coffey et al., 2016). Adopting a more embodied exploration of children’s social lives is also important because the body is the means through which children create and construct their lives and therefore an important lens though which the process of agency can be analysed (Eßer, 2017).

Although the empirical material examining children’s social worlds from an embodied-lived perspective is limited (Coffey et al., 2016), the work of James (2000), Corsaro (2018) and Kustatscher (2017a) with children in the minority world (Italy and the UK) contributed to understanding the role of children’s material bodies in the production of social categories and identities within their peer relationships. Central to this construction is the use of bodily markers such as height, appearance, shape, gender and performance as points of difference between children. For example, the ethnographic study of Kustatscher (2017a) with Scottish pupils shows the emotional and embodied aspects through which class, socio-economic status, ethnicity and gender are constructed. Her work especially illustrates the way in which children’s physical bodies and predominantly the embodiment of emotions serve to operationalise social othering and belonging.

The significant role of children’s bodies within peer culture makes them also aware that by modifying their bodies, their social identities might also change. For example, James (2000) illustrates how children who were deemed to be too short for their age, displayed certain physical abilities (e.g. such as sports) in order to be perceived as more competent. Similarly young people engage in different body work practices such as weight lifting and doing cardiovascular exercise to give off messages about their healthy identities (Coffey, 2016).

Despite the scarcity of research exploring children’s own perspectives of living with CLP, and the lack of a detailed characterisation of their psychosocial difficulties, some studies have described some socio-relational struggles which these children experience with peers because of their bodily differences. For example, Beaune’s et al. (2004) work with young people with Treacher
Collins syndrome presents the fluid and complex journey of forming an identity of sameness, difference and social competence in relation to peers; the challenges of constructing friendships, and how by excelling in academic performance young people dealt with negative social responses towards their bodily differences. Similarly, Murray et al. (2010) report that especially the school context and instances in which children with CLP interact with new people are challenging and distressing for them. These studies connect with the existing literature reporting how social othering tends to be more stringent in relation to bodies with differences and impairments (Strauss et al., 2007; Valentine, 2010). As discussed previously, peers often draw on points of difference to construct group memberships (Corsaro, 2018; James, 2000) and for that reason, some children might feel unsure about being a friend of someone with a less common physical appearance (Beaune et al., 2004).

The broad premise that children with CLP experience negative social responses because of their difference has placed them in two main registers: vulnerable and victims of negative social responses (e.g. teasing, bullying); problematic and burdensome because of their mental health problems and lack of social abilities. These pathological registers in which the children’s bodies are located with regard to their social lives alongside the significance of their bodies in peer culture, raise questions about how children use their bodies to negotiate their social relationships and socio-relational difficulties. I engage with this question in Chapter 5.

2.4.4 Different bodies

The lived and open nature of the body is a central topic of discussion within disability studies. In the first part of this next subsection I review three main models of disability and then the position and role of medical treatments with regard to children’s bodies with differences.

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9 Treacher Collins is a genetic syndrome characterised by cleft palate, underdeveloped ears, cheekbone, chin and eyes. Hearing loss and breathing problems are frequent.
2.4.4.1 Models of disability

The conceptualisation of disability has moved between two theoretical poles – biological and social determinism. The former mainly adopted by biomedicine looks at disability as a bodily status of impairment\(^{10}\) derived from certain congenital or acquired medical conditions (Scully, 2004). Clearly the fact that disability is constructed within a biomedical frame implies that it is medicine which determines when someone is experiencing disability and how it should be treated (Barnes, 2012a; Clarke et al., 2003). Therefore, rather than an individual and diverse bodily experience, disability tends to be homogenised as a bodily disturbance which can be fixed or diminished through medical interventions/practices (Garland-Thomson, 2011).

An alternative understanding of disability is proposed by the social model (Barnes, 2012b). Unlike the above discussed model, the problems which disabled people experience in their everyday lives stem from the absence of a social policy of inclusion and diversity rather than from their bodily impairments (Barnes, 2012b; Owens, 2015). This means that the experience of disability occurs when certain bodies do not find social structures and environments into which they can fit and for that reason it is society who should guarantee and protect the rights of disabled people to participate in social life without restriction (Thomas, 1999).

However, both the medical and social models had been criticised for being reductionist (Shakespeare, 2006). While the medical model fails to recognise that the absence of a policy of inclusion contributes to the experience of disability, the main problem with the social model is the assumption that disability can be overcome only by social change (Owens, 2015). A point of particular concern in relation to the social model is that it fails to consider the impact of biological impairments and vulnerabilities in people’s lives (Shakespeare, 2006). Although disabled individuals have to deal with different forms of social repression, their impairments also generate bodily discomforts and limitations that restrict their lives in society. With this in mind, medical...

\(^{10}\) Any mental, physiological or anatomical loss or dysfunction (World Health Organisation (WHO), 2011).
treatments have also the potential to improve bodily impairments and contribute to the overcoming of disability (Hamze et al., 2017; Poenaru & Poenaru, 2013).

Proponents of a more balanced approach to disability argue that this should be seen as both a biological and social phenomenon (Shakespeare, 2006) and advocate for understanding disability as a contingent phenomenon (Garland-Thomson, 2007, 2011). They recognise that restructuring social environments is important, to offer other forms of embodiment the opportunity to occupy more participative and active roles in society (Garland-Thomson, 2011). But equally important is giving them the opportunity to overcome bodily impairment and vulnerabilities through equal access to medical technologies and practices (World Health Organisation (WHO), 2011).

The redefinition of disability as mainly an equity issue gave way to the development of a human rights model. This places greater responsibility on governments to promote inclusive social environments in which people with disability can have equal access to work, health, and leisure activities (Degener, 2016). This model is operationalised through the United Nations Convention on the Rights of Persons with Disability (United Nations, 2006). This is an international human rights instrument which aims to inform governments about the measures and strategies they should incorporate into their policies in order to protect and promote the rights of those with disabilities (United Nations, 2006).

Despite the positive moves towards constructing a more holistic approach to disability, this is an area of research little developed in childhood studies (Watson et al., 2012) and particularly in the majority world (Pinilla-Roncancio, 2015). This is concerning given that the majority of the world’s disabled population is located in the majority world (Watermeyer et al., 2019; Watson et al., 2012; World Health Organisation (WHO), 2011). Particularly in relation to those with CLP, it is important to mention that they may and may not experience disability. CLP may be accompanied by significant impairments such as learning difficulties, hearing problems, and neurodevelopmental disorders (Mossey et al., 2009; Tillman et al., 2018) which may result in a disabiling condition (Bell et al., 2017). However, as mentioned earlier, disability goes beyond the
For that reason, I do not consider CLP as a disabling condition itself, but rather look at this condition as diverse and individualised. Having reviewed existing and dominant models of disability, in the next subsection I review some key concepts in relation to children’s bodies with differences.

2.4.4.2 Differences, children’s bodies and medical treatments

As indicated earlier, children’s bodies with differences are subjected to surveillance and regulation, particularly from healthcare practitioners. Certain treatments can be considered as activities through which the functionality and normal anatomy of children’s bodies with impairments is often restored (Clavering et al., 2008). These involve different techniques and practices such as pharmacological treatments, surgeries and rehabilitation regimes (Mclaughlin & Clavering, 2012).

In relation to children with CLP, I mentioned in Chapter 1 that a standard CLP healthcare plan includes dental care, corrective surgeries and speech rehabilitation. These medical interventions are seen as part of a (medical) body project of transforming children’s bodies with impairments into ones free of them or normal (Hall, 2009). A common aspect of these treatments is that they are tightly regulated by health practitioners and outcomes set and assessed within a biomedical understanding of the body (Alansari et al., 2014; Hall, 2009).

Given that decisions on early life CLP treatments are mainly made by parents and health practitioners (Nelson et al., 2012), it is a common assumption that interventions such as surgeries and dental treatments are accepted by children without question (Hall et al., 2012). However, looking at medical practices as passively impinged on children’s bodies would be neglecting their status as social actors (Hall et al., 2013; McLaughlin & Coleman-Fountain, 2014). Aware of the risks of this assumption, Hall et al. (2013) explored children’s experiences of participation in the CLP care pathway (the CLP healthcare plan in the UK). They concluded that children held both passive and active roles in making decisions about their treatments, with those who adopted a
passive role considering their parents as more expert on matters relating to treatments than them (Hall et al., 2012).

Returning briefly to the notion of the body project, a key aspect of this theory is that individuals can create their own identity through bodily modifications which they design and choose from an array of options (Shilling, 2012). Considering that CLP medical treatments are seen as part of a body project regulated by health workers, constructed on biomedical knowledge, and therefore not designed by children, it might imply that these projects were not children’s projects. However, despite the clear authority of healthcare workers in assessing and regulating these normalising body works and therefore these body projects, authors such as Hall et al. (2012) and McLaughlin & Coleman-Fountain (2014) invite us to be cautious about looking at children as passive recipients of medical body works. By these body works I mean health care practitioners’ activities of ‘assessing, diagnosing, handling, treating, manipulating, and monitoring bodies’ (Twigg et al., 2011, p. 171); in the particular case of children with CLP these include surgeries, dental care and speech rehabilitation. Being cautious about this assumption becomes more important when we consider that children may express their agentic roles in diverse and subtle ways (section 2.3.2).

Despite the valuable contribution of Hall et al. (2013) to the underdeveloped area of qualitative research on children’s experiences of living with CLP, this study did not explore how they understand the body project intended to ‘fix’ their bodies. Furthermore, their work analysed children’s agentic roles in binary terms: passive and/or active, without scrutinising the context in which these agentic practices emerged. These are gaps which I explore in Chapter 6, when discussing children’s accounts of their experiences with treatments.

Other authors exploring children’s experiences with medical treatments have noted that uncertainty in relation to therapeutic outcomes and significant bodily discomforts are commonly reported by children with long-term conditions (Bray et al., 2014; Kirk & Hinton, 2019; McLaughlin & Coleman-Fountain, 2014). These authors suggest that apart from experiencing the
usual uncertainty of a rapidly changing body during growth and development, children with certain conditions have also to deal with the uncertainty of how their bodies will appear and function after medical interventions, thus adding an extra layer of complexity to their experiences with their bodies and lives (Bray et al., 2014; Kirk & Hinton, 2019; McLaughlin & Coleman-Fountain, 2014).

For example, the work of McLaughlin & Coleman-Fountain (2014) with children with cerebral palsy shows how despite the potential benefits of medical interventions in improving bodily impairments, for these children their future lives remain uncertain. Their narratives showed that the end point of interventions was uncertain for the majority of participants as well as whether their bodily improvements would be temporary or permanent. This uncertainty seemed to increase with children’s growth as they felt they were losing rather than gaining bodily abilities over time. This, alongside the unfinished cycle of medical interventions, lead children to experience their bodies as something much more uncertain. Similarly, Alansari et al. (2014) explored adults’ memories of their childhood (with CLP) and suggested that the physical appearance in the post-surgical stage (featured by facial swelling and bruises) exacerbated instead of alleviating body image issues.

However, the uncertainty and discomforts related to children’s differences and treatments go beyond the corporeal and material dimension of the body. Bodily impairments, health conditions and treatments also bring to the life of children uncertainty with regard to their present and future social lives, especially the construction of friendships, professional careers and the creation of a family (Grinyer, 2007; Kirk & Hinton, 2019; Wedgwood et al., 2020).

A key topic frequently discussed within disability studies is to what extent medical technologies and health practices to transform bodies and make them more suitable to the world contribute in positive ways to the experience of disability (McLaughlin & Coleman-Fountain, 2014; Runswick-Cole et al., 2018). Seeking to standardize those bodies through medical practices implies looking at them as faulty entities which need to fit into the world (McLaughlin & Coleman-Fountain,
36

2014). The major problem with this view is that it not only supports ‘cultural fantasies’ in which bodies are stable and predictable (Garland-Thomson, 2007, p. 1), but also perpetuates the notion of the body with impairments as something incomplete (McLaughlin & Coleman-Fountain, 2014). However, it is also clear that the key role of medical treatments is in improving certain bodily impairments, issues that if they are not treated, might also exacerbate the experience of disability. Certain medical interventions become particularly important to address such as functional issues and potential consequences that might be life threatening, namely feeding problems, breathing issues and malnutrition in the case of CLP (Lewis et al., 2017; Sobol et al., 2016; Zhang et al., 2019).

Another important aspect regarding children’s bodies with differences (e.g. bodily impairments, visible physical differences, health conditions) concerns the terminology used to define and treat these conditions. As noted in Chapter 1, biomedicine holds a dominant role not only in treating but also in defining CLP. Although medical terminology facilitates communication within clinical settings with regards to diagnosis and treatments, these terms also have drawbacks. As mentioned earlier, biomedical categories which often define individuals’ health issues or bodies in pathological terms, tend to separate those who are healthy from unhealthy groups discrediting individuals´ identities (James & Hockey, 2007, p. 153). This was exemplified by Alansari et al. (2014) who report that adults with CLP (when they were children) felt that they belonged to a faulty group because they were categorized with other children with visible differences during clinical appointments.

The dominance of biomedicine in defining and treating CLP in pathological terms invites us to explore to what extent this tendency is consistent with children´s views and understanding of their condition and bodies. With this in mind, in Chapter 4 I explore children´s conceptualisation of health and illness, in order to construct a frame of reference as to how children understand these concepts. This would allow me to examine children´s understandings of their condition against a biomedical discourse of CLP, which defines CLP mainly in terms of illness (e.g. defect,
abnormality, pathology, disorder). Having discussed key literature in relation to those bodies with differences, in the following section I explore a concept closely related to the body – emotions.

2.4.5 Emotions

Central to an understanding of the body, is the study of emotions (James & Hockey, 2007; Lupton, 2013). Emotions are an important example of the hybridity of the body, given that they have both biological and social inputs (Bericat, 2016). For example, emotions are materially experienced in the form of sensations, feelings, bodily movements, and gestures, but they are not only biological products as they emerge from and shape our social relationships (Burkitt, 2014). Some have tried to differentiate terms related to the study of emotions such as affect, mood, emotions, and feelings, with mood and affect more frequently used within medicine (Aneshensel et al., 2013; Kohn & Keller, 2015). While mood concerns the kind of emotional dispositions someone tends to experience, affect refers to an emotional status derived from the impact of particular situations on us (Burkitt, 2014). The main difference between emotions and feelings is that the former has a social component, hardly measurable; in contrast to feelings which are more visceral, instinctive and quantifiable physical experiences such as pain (Bendelow & Williams, 1997; Burkitt, 2014).

Despite the attempts to theorise emotions and feelings as separated phenomena, they have been seen as impractical for sociological discussion given that both feelings and emotions occur in a social-relational world (Hochschild, 2012; Sheppard, 2020). As will be shown throughout this thesis, I opted for using the term emotions to refer to emotions (e.g. anger, fear), feelings (e.g. pain) and sensations (e.g. nausea).

As a bodily experience and product, emotions have a social purpose– communicating with and constructing our social worlds (Bericat, 2016; Burkitt, 2014; Williams, 2001). This is tangible in the way in which everyday actions are accompanied by different types of emotions that shape our social relationships, including the actions of others (Burkitt, 2014; Hochschild, 2012). Emotions, then, not only give us the opportunity to make our lives meaningful through the
experience of joy, pleasure or serenity, but also offer us the opportunity to express our tastes and disgusts in order to make changes in our social contexts (Burkitt, 2014, 2018). The acknowledgement that emotions are used to direct our actions and the action of others means that through emotions we can exercise power (Burkitt, 2014; Hackett et al., 2015; Shilling, 1999). At the heart of the relationship between power and emotions lies our need for emotional energy (Collins, 2004). An important reason why social interaction occurs is because within a social encounter, individuals obtain emotional rewards. This means feeling that our social selves are worthy and valued by others (as cited in King, 2019). However, alongside positive emotions, there is also the potential to experience negative emotions, particularly when there is a misfit within a social encounter. This occurs when someone does not fulfil the expectations of the other, leading the individual who has been negatively assessed to feel shame (Goffman, 1968). A common effect of the experience of shame is status loss and social exclusion (Furr, 2014; Goffman, 1968). According to Goffman (1968) the emotional experience of shame and embarrassment represents a powerful resource through which the status loss of the stigmatised is sustained and perpetuated. This means that the stigmatiser might use these emotions to maintain a powerful position (Link & Phelan, 2014).

However, according to Burkitt (2014) emotional responses within a relationship are often unpredictable, given that emotions are ambivalent, shifting and can alternate with each other and across relationships. It is this fluidity that makes patterns of relationships diverse and complex and the response of others difficult to predict (Burkitt, 2014). As discussed in Chapter 1, children with CLP are often seen as a target of stigma despite the lack of characterisation of their experiences. Several studies exploring the impact of CLP on children’s quality of life, have signalled their risk of suffering emotional and mental health issues such as anxiety, and depression resulting from bullying and teasing at school (Murray et al., 2010; Rumsey & Harcourt, 2007; Sousa et al., 2009; Strauss et al., 2007). However, the unpredictability of emotions, and how these can occupy different positions in, and shape our social interactions, leads us to question whether those who are stigmatised may also experience other types of emotions apart from shame and embarrassment – typical emotions linked with status loss. Furthermore, the
recognition of the agential character of emotions opens up opportunities to explore the ways in which children with CLP use them to resist and negotiate socio-relational struggles. This also connects with the point I make in section 2.3.2—the relevance of examining the relational context in which children’s agency unfolds. With this in mind, in Chapter 5, I analyse how children’s emotions hold different positions and purposes within their relational context of being stigmatised at school.

After examining core concepts in relation to the body and highlighting the questions and gaps the literature poses for my research, I now move on to consider key concepts of medical sociology and research on health and illness within childhood studies.

2.5 Children’s health and illness

2.5.1 Research on health and illness: an underdeveloped area in childhood studies

Health and illness experiences of children and young people have been examined from both quantitative and qualitative perspectives, with the majority of qualitative studies exploring their experiences with chronic and/or degenerative conditions (Besier & Goldbeck, 2012; Khair et al., 2015; Kirk & Hinton, 2019; Monaghan & Gabe, 2015; Williams et al., 2009). Despite the significant contribution of these studies and their emphasis on biographies, their focus is on long term conditions, which according to Abualfaraj et al. (2017) are in nature and course different to CLP. Equally important is to highlight that these studies examine mainly children’s present experiences with less explicit attention to their ‘been’ (past) and ‘becoming’ (future).

There is particularly a scarcity of childhood health research with a biographical character in relation to children’s experiences with genetic and congenital conditions (Bray et al., 2014; Wedgwood et al., 2020). Brady et al. (2015) notes that although research on prevalent diseases among children, and efforts to examine these within socio-cultural contexts, have grown, there is still the need to scrutinise how children negotiate their health conditions within an everyday context. Some potential reasons for this limited research have been identified. Bray et al. (2014)
explains that the lack of biographical research on children’s health conditions is in part because notions exploring the biographical effect of an illness (e.g. biographical disruption (Bury, 1982)) are centred on adults. Furthermore, the belief that ‘genetic and congenital impairments are stable rather than progressive’ and ‘can form an important part of a person’s identity’ (Scully, 2004, p. 651) has contributed to seeing these conditions as integral to children’s lives and therefore less likely to be disruptive (Williams et al., 2009). Another important reason some scholars have identified for this limited research is the assumption that the child is unable to give accounts about their health conditions given their young age (Bray et al., 2014; Hall et al., 2013). This is problematic given that there is evidence that children do interpret and create information about their health conditions and are able to engage actively with the decision-making process about treatments and medical practices (Alderson, 2007, 2013; Mayall, 2006).

The paucity of health and illness research with a focus on the child’s perspective (and their life) is evidence of a theoretical disconnection between childhood studies and the sociology of health and illness (Brady et al., 2015). This theoretical and empirical disjoint perpetuates multi-disciplinary rather than interdisciplinary work, something that particularly within childhood studies has been noted as problematic (Punch, 2016a). But perhaps most important is that the implicit disregard of children’s abilities to talk about their health conditions as part of their life story, means that they continue to be neglected as social actors in studies of health and illness. A key aspect of my thesis is to draw from developments in childhood studies, the sociology of the body and the sociology of health and illness, with the aim of positioning children’s bodies and their health and illness experiences more tangibly in childhood studies. In the following sections I examine some core theories in medical sociology that although centred on adults are relevant in the context of my research.

2.5.2 Biographical disruption

Central to the exploration of illness experiences in adults, particularly chronic and long term conditions, is the concept of biographical disruption (Bury, 1982). From this notion, the individual’s physical body, identity and everyday life are affected by the onset of a chronic health
issue (Bury, 1982). For example, bodily impairments, symptoms and medical treatments often generate changes in the way the body is physically experienced and socially performed (Bury, 1982). These changes are likely to affect the development of everyday activities, routines and social relationships, leading people to rethink their position as a member of society and a family, and to reorganise their plans for present and future lives (Bury, 1982).

In the light of a chronic health condition, individuals tend to mobilise personal and collective resources to cope with the illness (Bury, 1982). Among these, the normalisation process is a strategy frequently adopted (Bury, 1982; Emiliani et al., 2011). This entails a process by which the illnesses and their consequences are integrated into individuals’ lives (Emiliani et al., 2011). For example, aspects linked with the illness, such as the need for therapeutic regimes and economic changes, are seen as part of a new normality to which the individual and family dynamics need to adjust. A core element that allows this process to be effective concerns a change in the conceptualisation of illness (Deatrick et al., 1999). Traditionally, illness is conceived as contrary to health and wellbeing and therefore something undesired (Crawford, 2006; Halasz, 2018). In part, this conception has contributed to the enactment of current social tendencies in which the adoption of healthy practices are means through which we can avoid suffering (Crawford, 2006). However, in the normalisation process, illness becomes part of life and therefore something that can occur (Deatrick et al., 1999; Emiliani et al., 2011). This view of illness as a possibility allows acceptance and offers the individual the opportunity to reconstruct a new everydayness in which the condition becomes less disruptive (Bury, 1982; Emiliani et al., 2011).

The notion of biographical disruption, although widely adopted, has also been critiqued. Several authors have noted that, although the concept highlights the significance of seeing illness biographically, in connection with other dimensions of individual’s life, it overlooks the role of structural inequalities and timing in the life-troubling character of illness (Grinyer, 2007; Kirk & Hinton, 2019; Monaghan & Gabe, 2015; Williams, 2000). Against the idea that chronic conditions are by default biographically disruptive, some illnesses are understood as ‘normal crisis’ at certain life stages (Williams, 2000, p. 50). Stroke for example, can be seen more as a biographical flow
among older populations (Faircloth et al., 2004). Most recently, authors such as Grinyer (2007); Hudson et al. (2016); Kirk & Hinton (2019); Monaghan & Gabe (2015); Wedgwood et al. (2020); Wolfenden & Grace (2012) have also illustrated how timing, ethnicity, age and gender may exacerbate or minimise the disruptive effect of certain health conditions among children, young people and young adults.

Grinyer’s (2007) work for instance suggests that the life-disruptive effect of cancer tends to be more stringent at certain life stages such as during transition from adolescence to young adulthood; strong social pressures to perform a social identity of a masculine boy tends to exacerbate the experience of life disruption. Likewise, ethnicity plays an important role in the way an illness causes disruption or not. The case study of Wedgwood et al. (2020) illustrated how an Asian young adult with mobility impairment felt his life to be disrupted when he could not fulfil the Asian cultural expectation of supporting his family business. In addition to the life stage, ethnicity and gender, social structures are also important. The work of Monaghan & Gabe (2015) suggests that the negative life impact of a health condition such as asthma is exacerbated by poverty, weak social networks and loneliness.

These examples illustrate the array of factors shaping the potential biographical impact of illness and how this goes beyond the abrupt onset of a chronic illness. In particular, the role of strong social networks noted by Monaghan & Gabe (2015) in reducing the negative impact of asthma in children’s everyday lives invites us to consider whether children’s relationships, such as those with school peers, might have negative implications for how a condition is experienced. This is particularly significant to explore with children whose bodies may display a less common pattern such as those with CLP, taking into account the role of the bodily markers mentioned earlier for processes of social othering and belonging within peer culture (Corsaro, 2018; Kustatscher, 2017b). Although I do not explore the above mentioned concepts related to biographical disruption in my finding chapters, Chapter 5 provides data with which I discuss the potentially disruptive effect of stigma within the context of living with CLP in Chapter 7.
2.5.3 Constructing meanings of health conditions: Explanatory models and lay knowledge

Central to the process of rethinking the self, and life adjustment in the face of illness, is having a clear diagnosis and explanations of the origin of the condition (Bury, 1982; Kleinman, 1988). According to Bury (1982), the onset of an illness frequently leads the sufferer to question why she or he became ill. However, in the absence of a clear aetiology, the sufferer might find it more difficult to understand their past, anticipate and therefore plan for their present and future lives (Bury, 1982; Kleinman, 1988). For this reason, processes of meaning production in which an individual seeks and constructs explanatory models for the why and how their illness started, eases individuals’ adjustment to a new everydayness (Frank, 1995; Kleinman, 1988).

Frameworks of aetiology, pathophysiology, prognosis, and treatments of health conditions are traditionally constructed on a biomedical understanding of health and disease (Kleinman, 1988). Previously, I mentioned that biomedical understandings of the body, health and illness tend to privilege biology, physiology, anatomy and pathology over social and cultural factors in the models of illness causation. Despite the recognition of biopsychosocial factors in the genesis of diseases, the tendency within biomedicine (the dominant discipline studying CLP), especially in clinical disciplines, is to appreciate knowledge on their grounds of whether it is evidence-based or not. The fact that the evidence-base is generated through systematic methods and from quantifiable data has delegitimised other forms of understandings such as lay knowledge (Kleinman, 1988; Prior, 2003).

Lay knowledge entails beliefs and ideas that individuals create and use to make sense of their processes of health and illness (Gabe & Monaghan, 2013; Kleinman, 1988). In contrast to medical knowledge, this knowledge is constructed on a diverse, rich and complex cultural stock (Gabe & Monaghan, 2013; Nettleton, 2013). Apart from being culturally and socially shaped, this knowledge is key in the construction of models of causation and therefore how people respond to illness in their lives (Nettleton, 2013). Explanatory models around our health conditions are often constructed collectively (Frank, 1995; Kleinman, 1988), and for that reason discussions on
and understating of diagnosis, prognosis and aetiology within the family contribute to the production of illness meanings (Kleinman, 1978, 1988).

Although there are some studies exploring models of CLP causation in the majority world these have been developed with adults (Adeyemo et al., 2016; Daack-Hirsch & Gamboa, 2010; Gichuhi & Nduta, 2020; Mednick et al., 2013; Oginni et al., 2010). For example, Oginni et al., (2010) demonstrated that having a child with CLP was understood by parents as punishment from God or the consequence of the parents’ sins. Similarly, a child with CLP is regarded as an outcast because of the negative religious connotation of CLP among communities in Kenya (Gichuhi & Nduta, 2020). However, there are also positive connotations ascribed to this health condition in other socio-cultural contexts. For example, CLP is often understood as a gift from God among some Buddhist communities in Asia (Daack-Hirsch & Gamboa, 2010; Li-Rong, 1990). Therefore, a common theme in this research is the dominance of religion and spiritual beliefs in the global south (Bennett et al., 2016). However research has not explored children’s accounts of the origin of CLP.

As noted earlier, despite the important contribution of especially the works of Hall et al. (2012) (2013) with children in generating knowledge centred on children’s perspectives, these studies have two main limitations. First, they were developed in the minority world and may not reflect the views of children from other geographical, social and cultural contexts. This is because health and illness experiences vary across societies (Singal & Muthukrishna, 2014). Second, they do not examine children’s explanatory models of causation, something that is important to scrutinise, given the diversity of cultural beliefs that research with adults have reported about the origin of this condition (Gichuhi & Nduta, 2020; Oginni et al., 2010). Bearing in mind these research lacunas, I explore in Chapter 4 children’s understandings of CLP and its models of causation. The potential contribution of this exploration is the generation of a more contextually embedded understanding of what CLP is and its origin from the perspective of children.
2.6 Conclusion

This chapter has engaged critically with key literature of childhood studies (ontology of children and childhoods, agency), the sociology of the body (lived body, the body projects, the child body), disability, emotions and medical sociology (biographical disruption and illness meanings). Throughout this review I have highlighted some questions and research gaps that my thesis addresses. These include: the lack of qualitative research into children’s own perspectives and experiences, in general with congenital conditions and in particular with CLP in the majority world context; the lack of clarity of the social difficulties which children with CLP experience; the absence of research exploring children’s understandings and their explanatory models of their condition (CLP); the minority world dominance and narrow focus of research on children’s accounts of treatments – mainly on their participation and involvement in decisions on treatments, less on subtle forms of agency and their embodied accounts. The different areas of research and theories that inform my study, situate my thesis at the intersection of biomedicine, childhood studies, sociology of the body and medical sociology, areas that do not frequently come together in theory and practice.
Chapter 3  Methodology

3.1  Introduction

In this chapter I give details of how my research study was designed, emphasising the research methods used and the reasons for their implementation. I provide a description of the data generation process, some ethical challenges during my fieldwork, how I ensured research rigour, and the process of data analysis. The following table offers an outline of the study.

Table 1: Study synopsis

<table>
<thead>
<tr>
<th>Sample size</th>
<th>20 participants (aged 6-12) with Cleft Lip and Palate (CLP).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Clinical site: Operation Smile - Bogotá, Colombia.</td>
</tr>
<tr>
<td></td>
<td>Consultation-based approach made by healthcare practitioners.</td>
</tr>
<tr>
<td></td>
<td>Informal approach made by the researcher in the waiting room of the clinical site.</td>
</tr>
<tr>
<td>Methods</td>
<td>Qualitative interviews: walking based and home based interviews supported by creative tools.</td>
</tr>
<tr>
<td>Analysis</td>
<td>Bespoke approach based on: the listening guide (Gilligan et al., 2011), the narrated, disnarrated and non-narrated approach (Vindrola-Padros &amp; Johnson, 2014) and thematic analysis (Braun &amp; Clarke, 2006; Ritchie et al., 2013).</td>
</tr>
</tbody>
</table>

3.2  Research design

3.2.1  Research questions

As indicated in Chapter 1, this study aims to explore children’s understandings of their condition (definition and origin) and gain insights into children’s experiences of living with CLP with regard to two dimensions: their social lives and their treatments. The discussion of the literature presented in Chapter 2, highlighted research gaps and areas that need further attention and helped me to define my research questions which are outlined below.

1. **What terms and/or language do children use to define CLP?**
2. *How do children conceptualise health and illness? How is CLP understood within this conceptual framework?*

3. *What do children think causes CLP and what is the basis for those ideas?*

4. *What are the social costs and difficulties that children face as a result of their condition?*

5. *How do children understand and experience their treatments?*

6. *How do children assert their agentic roles within the context of their everyday lives?*

Given the nature of my research aims and questions (experiences, meanings, perspectives, relationships), it was important to adopt a methodological approach consistent with the sense-making nature of my research inquiry. After engaging with the foundations of qualitative research during the first year of my Ph.D., I could appreciate the value of a qualitative approach in my research. In contrast to quantitative approaches, qualitative research is complex to define given that it draws on different epistemological orientations and methodological approaches and it is implemented within distinct disciplines (Ritchie et al., 2013; Silverman, 2016). Despite this diversity, a common aspect of qualitative research is that it offers researchers the possibility of conducting a theoretically informed, interpretive, rigorous and in-depth investigation of how people make sense of their experiences, life circumstances and social worlds (Ritchie et al., 2013). The sense-making nature of qualitative research fits with the scope and aims of my research and therefore I decided to adopt this approach for my study.

### 3.2.2 Epistemological underpinnings

Planning and conducting research involves a continuous reflection on how our backgrounds, assumptions, perspectives of the world (ontology) and how we come to know the world (epistemology) shape the research process (Ritchie et al., 2013). While ontology studies the nature of our worlds, epistemology concerns how we come to know that world, and therefore the recognition that there are several ways of knowing (Blaikie, 2017). In research, defining both our epistemological and ontological position is important as it enables us to support the rationale for certain methods and approaches (Ritchie et al., 2013).
In line with my disciplinary background, my thinking was greatly influenced by a Cartesian understanding (matter separated from mind), as a result of the dominant positivistic tradition in biomedicine. A positivistic paradigm states that a single universal reality exists and that this reality can be explored through systematic and unbiased observations (Alderson, 1998; Park et al., 2020). As I indicated in the literature review, health and illness processes from a biomedical perspective have specific causes and tend to follow certain and predictable patterns. This means that as a medical doctor, I used to look at health and illness as predictable phenomena which follow certain clinical patterns, and can be explained by evidence-based models of causation. However, as indicated in Chapter 1, my engagement with the underpinnings of social and qualitative research during the first year of my Ph.D., enabled me to adopt a more critical position towards this positivist stance. I could note that looking at health and illness in biomedical and clinical terms (e.g. biomedical explanations for the origin of CLP, clinical features, prognosis and treatments) was limited in appreciating people’s own understandings and views of health and illness events. Furthermore, this positivist standpoint was not congruent with the nature of my research – exploring children’s understandings and experiences of living with a health condition. During the first year of my studies, therefore, I engaged with the underpinnings of qualitative research in order to better define the philosophical basis of my research.

During this engagement, I first examined interpretivism given that this has been a key tradition in the development of qualitative research (O’Reilly, 2012). In contrast to positivism, from an interpretivist approach reality is not universal but rather multiple and diverse and is greatly shaped by social-cultural contexts, individuals’ biographies and time (O’Reilly, 2012; Ritchie et al., 2013). The nature of knowledge is therefore socially and individually constructed (e.g. experiences, beliefs, biographies) rather than objectively determined (Ritchie et al., 2013). Studies informed by this paradigm often draw on language, meanings and experiences to examine individuals’ worlds (Ritchie et al., 2013). Although this epistemological stance is frequently used in sociological research and is congruent with the nature of my research, it fits partially with my beliefs; I also recognise that there is a world beyond our understandings of it.
The challenge of adopting this position in my research led me to explore further other paradigms such as critical realism and its application in research with children.

Critical realism proposes to adopt a critical position towards reality in order to enhance our capacity to understand it (Archer, 1998). For critical realists there is a reality beyond our experiences and understandings and we come to know this reality through the facts and events that we experience, examine and interpret (Bunt, 2018). For example, from this philosophical stance, models of illness causation are not seen merely in biological terms, but rather there is a recognition that complex social structures and contingencies are involved in illness causation. Critical realism therefore foregrounds the hybrid and complex nature of our reality and therefore the intersection of the biological/natural and social dimensions of the world.

Alderson (2013) discusses critical realism as a useful paradigm through which researchers can study children and childhood. For her, this epistemological position allows the researcher to recognise the existence of ‘real children’ independent from theoretical paradigms, divisions of the world (minority and majority) and the researcher’s ontological positions.

In the same vein as and closely connected with critical realism, subtle realism also acknowledges the existence of an independent reality, stating that: ‘all research involves subjective perceptions and observations and concedes that different methods will produce different pictures of the participant(s) being studied’ (Duncan & Nicol, 2004, p. 455). This stance recognises that some world phenomena are independent of the social and individual meanings given to them, but the way we come to know the world is greatly shaped by our personal experiences and social-cultural contexts (Hammersley, 1990). Subtle realists suggest that research is not able to reproduce world phenomena, but rather through research we can formulate questions about the world and to some extent answer them (Hammersley, 1990). The above-discussed epistemological positions seem to reconcile both approaches – positivism and interpretivism - and offer the opportunity to see the world as a natural/biological phenomenon but also as socially constructed. However, subtle realism acknowledges that: ‘there is no manner in which the researcher can claim to have
absolute certainty regarding the findings of his or her research’ (Duncan & Nicol, 2004, p. 455), ‘but rather the objective should be the search for knowledge about which we can be reasonably confident. Such confidence will be based upon judgements about the credibility and plausibility of knowledge claims’ (Murphy et al., 1998, p. 69). This point is particularly important as it fits with a key premise of qualitative research: we can provide rigour to our research through the pillars of qualitative research (reflexivity, validity, credibility, and reliability), however, our accounts and interpretations are greatly shaped by our backgrounds, research contexts, and preconceptions and therefore cannot be value-free (Ritchie et al., 2013).

My thesis is therefore informed ontologically and epistemologically by subtle realism. This stance enables me to see CLP as a condition on its own (a congenital condition with biological and bodily features), but also to recognise that the meanings and understandings around this condition are shaped by our personal beliefs, lives, experiences and socio-cultural contexts.

3.2.3 Why qualitative research with children?

In line with The United Nations Convention on the Rights of the Child (UNCRC), a plethora of empirical and theoretical works in childhood studies foreground children’s rights to participate in research. This means offering children a research context in which they can adopt an active rather than a passive position. This impetus for foregrounding children’s participation rights has given rise to doing research with children instead of on children. This study is therefore informed by the new paradigm of childhood (children as social actors and agents, and childhood as socially, culturally and historically constructed), and its subsequent debates and re-orientations (e.g. recognising children’s past, present, future; agency as a relational process rather an attribute of the child). The methodology was constructed, bearing in mind that children are social agents and are able to participate actively in a research process. This ontological and epistemological position then foregrounds children’s capacities and rights to provide their accounts and make sense of their own experiences by themselves.
Despite the acknowledgment of the active position which children might adopt in research, there have been concerns about their ‘competence’ to engage with a research process. These concerns are founded on developmental notions that see children as not having the linguistic and cognitive skills to speak of their experiences in a coherent and systematic way (Christensen & James, 2017; Greene & Hogan, 2005; Moran-Ellis & Tisdall, 2019; Tisdall et al., 2009). However, children’s engagement with a research process does not depend on their linguistic and cognitive skills or ‘competence’, but rather on the researcher’s abilities and methodological approaches (Punch, 2002). Several empirical examples have demonstrated that children’s success in taking part in research depends on their expertise and familiarity with the research topic and on the researcher’s skills in communicating with them at their level of understanding (e.g. when explaining consent forms and formulating questions) (Alderson, 2007; Alderson & Morrow, 2011; Eiser et al., 1990; Punch, 2001, 2002) rather than on their cognitive or communicative skills. For that reason, my methods were designed to be flexible in response to children’s preferences, styles and their socio-cultural backgrounds, and also I ensured that my communication with them was at their level of understanding. Throughout this chapter I offer distinct examples of how the design and implementation of my methodology reflects this ontological orientation (e.g. seeking consent, creative tools).

3.2.4 Outline of methods

Informed by the ontological and epistemological reflection which I provided in the above section and the aims and research questions of my study, I decided to conduct qualitative research using two interview approaches (home-based interview and walking-based interview) in combination with some creative tools (emotion-body maps, pictorial cards and life-story works). In this section I discuss the rationale for incorporating a qualitative interview and creative methods in my research. Further details of the interview approaches and creative tools used with my participants are included in section 3.4.1.
3.2.4.1 Interviews

A view of children as actors and agents implies that approaches often used with adults, such as the qualitative interview, might be also used with children. The qualitative interview is a widely-used format of data generation in qualitative research (Ritchie et al., 2013). It entails a conversational and interactional process in which two or more people can participate. Its interactional nature and structural flexibility makes this approach particularly useful for exploring opinions, perspectives and experiences in real time (Kvale & Brinkmann, 2008).

I noted earlier in this chapter, the long-held concern about children’s competence to engage with the research process. However, there is considerable evidence that qualitative interviews can be successfully incorporated into research with children. Doing qualitative interviews with children has multiple benefits: it generates in-depth insights into children’s understandings of and experiences with certain life events (Greene & Hogan, 2005); engages with the participants directly, thus contributes to constructing rapport; checks children’s understandings of questions, and observes children’s verbal and non-verbal language, something that often enriches the data generation and allows the interviewer to detect potentially sensitive topics (O’Reilly, 2020). Apart from these benefits, qualitative interviewing is also a flexible and versatile approach. Two key points flagged by several authors are that interviews can be adjusted according to researchers’ and participants’ needs (Mooney, 2014; Stevens et al., 2010) and can be used in combination with other methods such as creative tools (Fraser & Open University, 2004; Greene & Hogan, 2005; Punch, 2002). Bearing this in mind, a semi-structured interview in the particular context of my research allowed me to explore children’s definition of CLP and their experiences within an interactional context and offered children opportunities to either expand on their accounts, or introduce topics of interest and relevant to them in the conversation. In addition, the interaction that involved a one-to-one encounter facilitated the creation of empathic relationships with the participants, which is a fundamental aspect when exploring children’s experiences of a potentially sensitive topic (Dickson-Swift et al., 2008; O’Reilly, 2020) such as CLP. Perhaps of most significance is that its versatility allowed me to incorporate different approaches.
of interviews and creative tools. In the data generation section, I provide details of interview approaches and numbers of interview.

### 3.2.4.2 Creative methods

Much of the literature about research with children has focused on determining the barriers for children´s engagement with research and whether some methods might facilitate this engagement (Darbyshire et al., 2005; Spratling et al., 2012). An important theme within this discussion is whether and to what extent researchers should incorporate ‘child-friendly’ techniques into their studies with children (Harden et al., 2000; Punch, 2002). This is because some researchers tend to assume that these techniques are likely to fit better with children’s interests and competences (Harden et al., 2000; Punch, 2002). Drawing on this belief, some researchers tend to privilege these tools over more standard methods such as the qualitative interview (Deacon, 2000; Punch, 2002).

This set of methods is commonly known as ‘creative methods’. A common feature of these methods is that they seek to promote children´s participation in research with positive impacts on potential power imbalances between children and researchers (Coyne & Carter, 2018). For example in narrative research, photo-narrative is a creative way in which children can construct and speak of their stories (Böök & Mykkänen, 2014; Drew et al., 2010; Thomson, 2009; Zartler, 2014). An important advantage of these creative tools is their versatility, given that many of them can be adapted to or re-designed with regards to the research socio-cultural contexts, research aims, and participants´ age, language, and cognitive-linguistic skills (Christensen & James, 2017; Greene & Hogan, 2005). However, these methods should not be incorporated randomly into research with children. Before making decisions on whether and how to use these tools it is important to reflect on their rationale and potential drawbacks (Punch, 2001, 2002).

The first point to reflect on is whether the incorporation of these tools is equal to being participatory (Coyne & Carter, 2018). Using creative tools does not mean that a research is participatory (Gibson et al., 2018; Punch, 2002). This is because children might engage with a
range of participatory activities within the research process which are not necessarily innovative or creative (Coyne & Carter, 2018). This includes the qualitative interview (Gibson et al., 2018; O’Reilly, 2020). Secondly, fun and creative methods are not always congruent with children’s competences and likes (Harden et al., 2000; Punch, 2002). For example, drawing on her ethnographic work with rural children, Punch (2002) illustrated how some children might struggle with ‘child-friendly’ tasks such as drawing. She concluded that rather than incorporating standard ‘child-friendly’ tools into our methodologies, we need to reflect on the reasons for using certain tools. This includes being flexible about our toolbox when generating data and not ruling out adult-centred methods such as the qualitative interview. Informed by the above-discussed literature, the backbone of my research was the qualitative interview. In line with the importance of offering children methodological approaches flexible and sensitive to their preferences and competences, the interview was combined with some creative tools which offered children alternative ways to speak of their experiences.

The use of creative tools during the interviews allowed for sensitivity to children’s preferences and responses during the interview. For example, I invited some children to have a look at some pictorial cards when I felt that they were struggling to explain their concepts of health and illness or it was difficult to find an opportunity to introduce this topic in the conversation. To do this I asked the child if they wanted to have a look at some cards ‘as I wanted to know more about their thoughts in relation to the people in the cards’. The youngest children in particular engaged very well with this tool; they used the cards to exemplify what for them entailed a healthy and ill body. This clearly helped me to further explore their own concepts of health and illness, and their experiences with past illness episodes. At the end of the third interview, I also asked the children if they wanted to do a ‘a kind of life story book’ in which they could include anything they wanted about their lives. As I explained later in this chapter, these life works, in combination with interviews accounts enabled the children to expand on and build up a picture of those aspects of their lives that were significant for them. In all instances, it was the child’s decision whether or not to use any particular creative tool.
Having discussed the design and planning of my research, in the following section I discuss how the project was conducted. To do this I give details of the sample, recruitment process and data generation.

3.3 Participants

In this section I present details of the sample and the recruitment process. I was interested to find a group of children with CLP between 6 and 12 years of age who were involved in a CLP healthcare plan. Children at these ages are commonly at school and this was an important feature in terms of allowing me to explore their social relationships – something important for exploring one of my research questions. While methodological and ethical aspects of my research were sensitive to children’s age differences and preferences (for example the use of pictorial cards facilitated the exploration of health and illness concepts with some younger children) age was not considered for the analysis of data. Interviews with children took place at their homes and in surrounding areas across three different times. Although I expand on interview details in the data generation section, the number of interviews is important to bear in mind at this point in order to better understand the recruitment process.

3.3.1.1 Sample

An important aspect to ensure validity and reliability relates to sampling adequacy and sufficiency (Morse et al., 2002; Ritchie et al., 2013). A benefit of purposive sampling is that it enables the researcher to select the population who best ‘represent or have knowledge’ of the research phenomenon under study (Morse et al., 2002 p. 18). For that reason, purposive sampling was adopted to ensure that participants had CLP and met the age criteria. Although exploring the role of socio-economic factors in shaping children’s accounts or experiences was not part of my research questions, I attempted to ensure diversity in the participants’ socio-economic backgrounds. This was in order to reflect partially the socio-economic diversity of the Colombian population (Departamento Administrativo Nacional de Estadística (DANE), 2018). However, this was not entirely possible as upper class children and families do not often attend NGOs such as
Operation Smile but rather private or another type of services. The majority of the participants lived in urban areas from strata 1-2 and 3-4 according to the socio-economic stratification system in Colombia\textsuperscript{11}. Table 2 summarises the socio-demographic features, ages and types of CLP of my sample.

Qualitative research does not seek to ensure epidemiological representativeness (Barbour, 2001); as such a small sample was considered sufficient to generate and explore in-depth qualitative data. A sample size of 10-15 children was initially proposed on my study protocol with acknowledgement that this could be increased up to 20, depending on the quantity of data generated across the three research encounters with each child. Agreement to participate was gained from 23 children, however parents of two children declined to participate and one child was excluded for ethical reasons (see section 3.5.2).

\textbf{Table 2: Sample overview}

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Type of CLP</th>
<th>Sociodemographic features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeronimo</td>
<td>6</td>
<td>CLPB</td>
<td>3-4 Urban</td>
</tr>
<tr>
<td>Carlos</td>
<td>10</td>
<td>CLPB syndromic</td>
<td>3-4 Urban</td>
</tr>
<tr>
<td>Camilo</td>
<td>9</td>
<td>CLU</td>
<td>3-4 Urban</td>
</tr>
<tr>
<td>Lina</td>
<td>11</td>
<td>CLPB syndromic</td>
<td>1-2 Rural</td>
</tr>
<tr>
<td>Juliana</td>
<td>6</td>
<td>CLU</td>
<td>1-2 Urban</td>
</tr>
<tr>
<td>Coni</td>
<td>8</td>
<td>CLPB</td>
<td>1-2 Urban</td>
</tr>
<tr>
<td>Beto</td>
<td>8</td>
<td>CLPU</td>
<td>1-2 Rural</td>
</tr>
<tr>
<td>Carolina</td>
<td>7</td>
<td>CLPB</td>
<td>1-2 Urban</td>
</tr>
<tr>
<td>Natalia</td>
<td>8</td>
<td>CLPU</td>
<td>1-2 Urban</td>
</tr>
<tr>
<td>Javier</td>
<td>6</td>
<td>CLPU</td>
<td>1-2 Urban</td>
</tr>
<tr>
<td>Santiago (Santi)</td>
<td>12</td>
<td>CLPB-familiar</td>
<td>1-2 Rural</td>
</tr>
<tr>
<td>Mica</td>
<td>7</td>
<td>CLPB-familiar</td>
<td>1-2 Rural</td>
</tr>
</tbody>
</table>

\textsuperscript{11} This is a system which classifies neighbourhoods in Colombia from one to six, those in strata one being the most socio-economic deprived areas. Middle-class is equivalent to strata four while the most affluent population lives in strata six.
As the table shows there were no children from high strata as the main population involved in a free or low-costs CLP healthcare programme belongs to strata 1-4.

### 3.3.2 Recruitment

Recruitment consisted of four steps. I explain each one in the following subsections.

#### 3.3.2.1 Step 1: introduction of the study to parents and children

The first step entailed the introduction of the study to potential participants. This step was carried out by some staff of the Operation Smile clinical site (a social worker, a speech therapist and a clinical genetics consultant) who agreed to get involved in this phase of the study and by me. I made the decision to invite these particular health professionals as I knew that children who attended their consultation were within the age range of my eligibility criteria. Before starting this step, I met with all health professionals in a one-to-one encounter to make sure that the nature of the study and eligibility criteria were clear. During this meeting I explained briefly the objectives of the study and the eligibility criteria and I gave specific instructions on how the study should be broached (see appendix 2).
The clinical genetics consultant (CGT), the speech therapist (ST) and the social worker (SW) gave a brief outline of the study to those who met the eligibility criteria at the end of their consultations. Families who expressed an interest in knowing more about the study were given a recruitment package with information sheets for both children and parents (see appendix 3) and a contact form (see appendix 4). Consultants encouraged potential participants to read the information provided (at a convenient place and time e.g. waiting room\textsuperscript{12}, home, bus, etc) and fill in the contact forms if they were interested in further information about the study and/or meeting with me. Those with potential interest in having a talk with me and discussing the details of the study further, filled in the contact form and handed it back to their consultant who then handed it back to me.

I visited the clinical site at least three times each week in order to be available for those families who might be interested in knowing further about the study and talking to me. I spent most of the time in the waiting room during my visits, considering that it was a convenient meeting point with those families interested in talking to me. My presence in the waiting room was also an opportunity to have informal chats with other families who were waiting for their appointments. From those informal talks, I could identify some children with eligibility criteria to whom I briefly broached the study and gave recruitment packages to those families with an interest in knowing further about the study and being contacted later. Many of those families (both parents and children) filled in the contact form and handed it to me on the same day. Although the contact forms were usually completed by parents, on some occasions children participated by helping their parents remember phone numbers, with some of the oldest completing the forms by themselves. Others left the contact form with the receptionist in a sealed envelope which was later handed back to me.

\subsection*{3.3.2.2 \textit{Step 2: making contact and meeting with me}}

As mentioned earlier it was common for children to have multiple appointments during their

\footnote{\textsuperscript{12} It was frequent that children and parents spent several hours in the waiting room as they usually had multiple appointments in one visit to the clinic.}
visits to the clinic. This was particularly normal for those families coming from rural regions who had their appointments during several consecutive days in order to reduce the costs and complexities of travelling. Multiple appointments in either a single day or consecutive days allowed me to facilitate contact (in person) with families and talk to them during their visits to the clinic. However, in other cases, families were contacted by phone. Email was never selected by families as a contact method.

Meetings with families consisted of a brief discussion about the study, in person or by phone. Although some of the families that I approached in step 1 had already chatted with me, this meeting gave room for further discussing the study, and resolving questions. I drew on the information sheets (given in the recruitment package) to guide the conversation. For example, I often started by introducing myself again and asking them if they had had the opportunity to have a look at the information sheets. This was often followed by both parents and children asking me particular questions. For instance, children often asked whether they can ‘really’ choose the route of the walks and said that they had already in mind what places to visit. The mothers were more interested in knowing further about my background; some of them asked whether I was a doctor of Operation Smile and the reasons for doing this research. I explained that I used to be a medical volunteer (clinical genetics) but because of my Ph.D. I was no longer involved in clinical consultations. I also said that this study was part of a Ph.D. research and referenced back to the aims of the research discussed when I first introduced the study (step 1).

3.3.2.3 Step 3: agreement to participate

Following the above meeting (step 2) I waited one week to allow children and parents to read the information sheets again and think carefully about their possible participation. After that time, I contacted the children’s parents by phone to ask whether their children had agreed or not, to participate. In cases of agreement, the date and time for the first interview was arranged, usually between one to 10 days after such a phone call. I did not implement any strategy to confirm the children’s agreement at this point, given that I preferred to check this in private during our first meeting.
I contacted 23 children’s parents (predominately mothers) in total, out of which two declined to participate. In one case, agreement was gained from the child’s mother, but not from the father who argued that the child was ‘too little and restless’ to go for a walk. Although I explained that a walk was just an option and there was also the alternative to have all interviews at home, he still said no. In the other case, contact details had been initially given by the child’s grandmother (who was the initial point of contact at step 1 because she had come along with the child to the clinic), however, when talking to the child’s mother in a phone call there was no interest shown in participation. One child was excluded for ethical reasons and are discussed in section 3.5.2.

My role as a clinician and my affiliation with the clinical site (Operation Smile- Colombia) facilitated both the process of recruitment and the construction of trust relationships with parents. For instance, during the recruitment process a mother of one of my participants told me that she was very pleased to know that I was the researcher, as she had met me during a clinical appointment in 2012 and found the fact of knowing me already reassuring for her.

3.3.2.4 Timing of recruitment and interviewing

Recruitment and interviewing took place in three phases. During the first phase, between late February and late April 2018, seven children were recruited. In late April I asked health professionals to stop recruitment (step 1) for two weeks in order to complete interviews with these seven children. These two weeks off were important, as suspending my visits to the clinic enabled me to concentrate further on interviewing and starting transcription. This was also an essential point during my data generation as I could share some transcripts with my supervisors and receive feedback from them. Furthermore, I could reflect more deeply on my position as a researcher and gauge my interviewing skills. For example I could restructure the way in which I was asking some questions and inviting the participants to construct their life story works. In early May 2018, I resumed the recruitment and completed it in early July. Interviewing continued until the middle of August. The final stage of recruitment and interviewing (early July- middle August 2018) was particularly intense. Given the strict timeframe in which a Ph.D. should be completed, it was important to me to complete my fieldwork within the dates agreed. This made
this last phase the most demanding as the day of my return to Edinburgh came closer (late August).

3.4 Data generation

This subsection is divided into two. In the first part, I provide a more detailed overview of approaches for interviews and the set of creative tools used. In the second part, I present a reflexive discussion of the data generation process.

3.4.1 Interviews and creative tools

As indicated earlier I decided to develop interviews with the participants across three different encounters in combination with some creative tools. These interviews were conducted in Spanish and drawing on two different approaches: home-based interviews and walking interviews. In the discussion that follows I explain the underpinnings of each approach and how they were incorporated into my research.

3.4.1.1 Number of interviews

Early on in the planning process of my research I decided that interviews would be conducted throughout three encounters. This decision was greatly influenced by my engagement with key literature about doing research with children. Much existing research on qualitative methodology highlighted the potential benefits of multiple encounters in the construction of relationships of trust with the research subjects (Evans & Holt, 2017; Kvale & Brinkmann, 2008; Ritchie et al., 2013; Spratling et al., 2012). Research participants who feel comfortable with their interviewers tend to express their opinions and stories with less apprehension or fears about being negatively judged, thus contributing positively to the richness and quality of the data (Kvale & Brinkmann, 2008; Ritchie et al., 2013). Particularly in relation to doing research with children, relationships of trust also tend to minimise potential power imbalances between participants and researchers (Spratling et al., 2012). Constructing rapport and ensuring that my participants felt comfortable with me was an essential point in the context of my research and for that reason I interviewed
children at three different times with 2-4 weeks between each interview. I expand on this point in the second part of this section when I reflect on how multiple encounters contributed positively to the data generation.

3.4.1.2 Home-based interview

Home is generally perceived as a safe and familiar place where the research participants may feel less nervous about engaging in the research process (Moyson & Roeyers, 2012). The informal research environment that home offers, allows children to feel more comfortable with the researcher, something that might contribute to rapport (Punch, 2017). However, researchers should not make an assumption about homes being convenient and comfortable places for all children (Bushin, 2007), particularly among low income families, where children often share their rooms with other family members (Punch, 2001, 2002). This means that some children might look at their homes as places less private and comfortable for talking about their experiences (Bushin, 2007; Gorin et al., 2008). Similarly, the presence of siblings or parents at home also might increase risks of interruptions while conducting the interview (MacDonald & Greggans, 2008). The main problem of interruptions is that they can hamper participants’ confidentiality as personal information of the participant is likely to be recorded, while audio recording is on (MacDonald & Greggans, 2008). The awareness of downsides of conducting interviews at home has led researchers to propose strategies to ensure particularly privacy and rapport. For example, sitting on children’s bedroom floors allowed Punch, (2007) to ensure a more relaxed atmosphere where children could talk about their stories. Also, conducting interviews in a relaxed environment and wearing casual outfits allowed Phelan & Kinsella, (2013) to reduce power imbalances with their participants.

I considered potential benefits and drawbacks from conducting a home-based interview when planning my research. I was aware that risks of interruption were high given that some of my participants were likely to live in challenging home circumstances. However, I perceived that an initial interview at home (a place familiar to them and where significant others might be also present) might be positive in minimising children’s concerns about talking to a stranger.
Furthermore, being in my participants’ homes meant that I could get familiar with some of their home routines, roles and family relationships. This was important as it might also contribute to the data analysis. Proponents and developers of the listening guide- an analytic approach - argue that researchers need to familiarise themselves with the plot of their participants’ stories in order to better engage with the data (Gilligan et al., 2011; Mauthner, 2017; Woodcock, 2016). This involves getting familiar with the spatial and relational context in which the events narrated take place (Gilligan et al., 2011). For that reason, being familiar with some places or actors that the participants were likely to include in their stories (e.g. homes, neighbourhoods, parents, siblings) had the potential to facilitate the process of data analysis. I decided to incorporate a home-based interview into the methodology of my research. However, being aware that interviews at home might be difficult to conduct in certain cases, and that children might also have different preferences about the context in which these interview take place, I decided to offer the participants the option of an alternative context and format for developing these interviews, namely a walking-based interview.

3.4.1.3 Walking-based interview (WI)

The walking interview is a type of qualitative interview approach mainly used within geography studies (Anderson, 2004; Evans & Jones, 2011). These interviews often entail participants and researchers walking together, and where the spatial context is used as a prompt for discussion (Sheller & Urry, 2006). This method seeks to understand the relationships between individuals’ accounts and the contexts where those experiences are narrated (Dubé et al., 2014). Proponents of these mobile methods argue that social science has overlooked the role of physical movement in people’s lives, namely their work, family relationships, migration, and leisure activities (Sheller & Urry, 2006). For these authors, engaging with mobile methods is important for generating more live data, something equally relevant for a sociology that has been rather ‘a-mobile’ (Sheller & Urry, 2006 p. 208). Mobile methods include different types of interviews ranging from structured walk routes to more flexible and non-planned walks (Evans & Jones, 2011; Sheller & Urry, 2006). I searched theoretical and empirical materials which discussed the implementation of this mobility paradigm in doing research with children. However, no studies were found, suggesting
that this was an approach little used with this population. This explains why the literature I drew on to provide rationale for the use of walking tours in my research is adult-centred research.

This approach offered several advantages in the context of my research. The dynamic nature of the WI (non-spatially-fixed setting and physical movement) allowed participants to connect with significant places and landscapes, facilitating the process of remembering and evoking memories (Sheller & Urry, 2006). This was particularly valuable as those memories had the potential to help me examine some significant experiences and life events of my participants. In addition, doing an activity together such as walking, usually allows for feelings of empathy between participants and researchers (Dubé et al., 2014; Evans & Jones, 2011), contributing then to rapport and relationships of trust – as mentioned earlier, a fundamental point in my research. Perhaps of greater significance was that a WI allowed me to get familiar with the socio-cultural contexts of my participants as well as to adopt a more participative role in some of their routines. I hoped that this would help me construct a more nuanced picture of their everyday lives especially relevant for exploring my research questions. However, some concerns were raised by my supervisors in relation to the feasibility of using this approach with children.

Predominately in the minority world, children’s lives are tightly regulated and supervised by adults (Punch, 2003, 2016b). This regulation raised concerns from my supervisors about the possibility of gaining children’s parents consent to have an interview outdoors (public space) with their children. However, bearing in mind that there is no an universal definition of childhood and that childhoods vary with socio-cultural and historical contexts, children in contexts of the majority world often have greater control over their everyday lives, and develop most of their routines without the supervision of adults (Powell et al., 2008; Punch, 2003, 2016b). I was confident that in the Colombian context obtaining consent from parents would not be problematic as my potential participants were likely to have greater independency and autonomy over their routines, including being on their own in public spaces.
3.4.1.4 Creative tools

The creative tools implemented in this research (pictorial cards, emotion-body maps, life-story work) were inspired by four main methods: visual vignettes (Coyne & Carter, 2018; Drew et al., 2010; Fargas-Malet et al., 2010; Greene & Hogan, 2005), emotion maps (Gabb & Singh, 2015), body maps (Devine, 2008; Gastaldo et al., 2012; Macgregor, 2009), and life story work (timelines, scrapbooks and photo elicitation) (Böök & Mykkänen, 2014; Clark-Ibáñez, 2012; Hewitt, 2000; Hooley et al., 2016; Rose, 2012). I offer a brief overview of each one below.

Pictorial cards
Visual vignettes such as short graphic stories and drawings are useful to prompt children to talk about topics that can be difficult to conceptualize and express (Drew et al., 2010), such as those relating to adversity and life stressor events (Costantino et al., 2014; Fargas-Malet et al., 2010). The use of images allows respondents to reflect on associations that hardly might be done without a visual pattern (Zartler, 2014), engage in a more reflective thinking and therefore expand on their accounts (Clark-Ibáñez, 2004; Harper, 2002). In the particular context of my research, pictorial cards were promising as they facilitated the exploration of children’s perspectives towards different types of bodies (research question 1). I decided to use drawings and images of different types of bodies to spark conversations about concepts such as normality, health and illness (see appendix 5). These images were downloaded from different websites and represented different types of bodies and parts of the body such as bodies with visible differences, from minority ethnic groups and different age groups. In the second part of this section I explain how these were incorporated into the research.

Emotion-body maps
Emotion maps were developed by Gabb & Singh (2015) to examine the dynamics of emotions within family relationships. The main value of this method is that it does not rely on literacy or language skills and so it may be convenient for populations with communication difficulties such as my participants. Drawing on the same visual nature of pictorial cards, body maps have been used to enable individuals to narrate their lives and experiences through a visual representation...
of their bodies (Devine, 2008; Macgregor, 2009), enabling participants to tell their stories in a more lived and embodied form.

Inspired by the use of emotion maps and body maps, I designed a tool (emotion-body map) combining both approaches to explore from a more embodied perspective how the participants looked at and felt about their bodies (appendix 6). Through the emotion-body maps the children described and talked about their emotions in relation to each part of their bodies. I provide further details on how this tool was used with my participants in section 3.4.2.

**Life-story work: timelines, life-books, posters and photo-elicitation**

Life story work (LSW) entails an exploratory and therapeutic strategy mainly used by social workers to help children going through a process of adoption to make sense of their lives (Cook-Cottone & Beck, 2007; Rose, 2005). With this tool, children can speak of their memories, uncertain life events, everyday activities and also communicate their perspectives towards their future lives (Hooley et al., 2016). This is important as children who are adopted often come into their adoptive families with an incomplete picture of their early lives, adverse experiences such as domestic abuse and with certain expectations about their future families (Cook-Cottone & Beck, 2007).

Although there is no clear definition of what elements are entailed in life story work, several different formats can be used (Hooley et al., 2016). These include life books in which children make a chronicle of their lives (Rose, 2012); diaries; album of photos with some text; drawings and timelines (Cook-Cottone & Beck, 2007; Fargas-Malet et al., 2010). Its application also goes beyond social work and children. For example, Hewitt (2000) drew on LSW to assist children with learning difficulties to construct meanings around different aspects of their lives. Similarly McKeown et al. (2010) used this tool with patients with dementia in order to raise awareness about the importance of offering more person-centred health care services to this population.
Although the use of LSW has been little used within childhood studies, given the scarcity of research with a biographical focus noted in Chapter 2, incorporating this tool into my toolbox had some potential benefits. First, it offered children the option to make a non-verbal/oral representation of their lives with chances to explain or/and expand on their accounts. Second, visualising key life episodes and stories recounted in the interviews helped me to explore the position and significance of CLP in the children’s lives. Third, the fact that they made a summary of their lives gave me the opportunity to check whether aspects of their stories or experiences I have understood as significant were or were not included into their works. I therefore decided to offer the children the option to make their LSW according to their preferences and in formats they found most appropriate. To do this, at the last interview I brought a variety of stationery materials which the children could use to make their works. I also found it useful to ask their parents to collect some family photos in order to use them as a prompt during this exercise, given that photos are commonly used as a stimulus that might help children to talk about their experiences (Clark-Ibáñez, 2012; Thomson, 2009).

After having presented an outline of the creative tools used in the interviews, I now offer a more reflexive discussion on the process of data generation.

### 3.4.2 The data generation process

I visited my participants’ homes on three different occasions between late February and mid-August 2018. During these visits, I used the home-base and walking interviews in combination with the set of creative tools discussed above which I adjusted for my research. In the following section I provided details of these visits and interviews and how the creative tools were used.

#### 3.4.2.1 Number of visits and interviews

The second and third visits took place within 2-4 and 5-7 weeks respectively of the initial visit. Home-based interviews with the children lasted approximately 45-60 min, while walking tours took longer (1.5-2 hours). On average, each visit took between 2-3 hours, given that some parents
had some food and coffee to share with me at the end of the interviews. The time spent in each location also varied depending on geographical and environmental factors. The total duration of all interviews per participant ranged from 120 to 180 minutes. When visiting the children’s home in rural areas, on some occasions I had to stay overnight at the child’s town (in a hotel) as travelling times or environmental conditions made it difficult to return to Bogotá (my home city) on the same day.

Multiple encounters with my participants offered several advantages. Conversations with the participants across three different encounters meant greater interaction between us and therefore greater chances to construct relationships of trust. This was evident in how some children seemed more open and relaxed in the second and third interviews. For example, Juliana seemed nervous in our first encounter (there is further discussion of this in section 3.5). However, it was fascinating to see how this changed in our second and third encounters where she was more relaxed about talking. This was particularly evident in our second encounter where she guided me through the walking tour. But it was in our final encounter that she explicitly expressed feeling more relaxed as she already knew that she can ‘trust me’:

[…]’Liliana: Hey! we’ve told about many things today, super! 
Juliana 3: Yeah!
Liliana: We both were a bit shy the first time we chatted, weren’t we? 
Juliana 3: mmm Yeah... but now I’m not shy anymore... because now I trust you’

Three meetings offered us (the participants and me) opportunities to explore more deeply certain themes raised in previous interviews, or complement some of their accounts in subsequent encounters. For example, Lina in the first encounter mentioned feeling ‘sometimes sad’ about her best friend, with no details given of reasons for her feelings. However, in our second encounter while we walked together she opened up more and explained reasons for her feelings. Multiple visits also were helpful for following changes in children’s experiences across time, something that helped me to note the fluidity of their relational struggles. For example, girls such as Isa and Lina reported some changes in their social interaction at school between our first and subsequent encounters. In the first interview, both had reported spending the
breaktime mostly by themselves, given that they did not have ‘so many’ friends. But this situation changed in the second and third interviews where both reported having made ‘a new friend’.

3.4.2.2 Home-based interviews

The first interview was conducted in the child’s home, given the benefits of doing a home-based interview in the context of my research, discussed earlier in this section. Once in the participant’s home, after greetings and prior to starting each interview, I held a brief chat with the child and parents to recall the purposes of the study and to check the children’s understandings and agreement to participate. I discuss the consent process in section 3.5.1. The child’s preferences for being interviewed alone or with the parent/caregiver, as well as the space where interviews would be conducted, were also checked at this point. The spatial context in which home-based interviews took place varied with each visit and type of house. For example, with Dilan interview 1 and 2 took place in his grandmother’s home (in the sitting room) as this was the place where he was after school. However, this spatial context changed when our last encounter, on a Saturday, took place at his home (in his bedroom) because he spent weekends at home. The children’s houses and neighbourhoods were diverse, ranging from studio flats located in busy urban areas (mainly in Bogota), to houses in rural areas surrounded by nature and therefore plenty of space.

Privacy was an important aspect to ensure for the children and many of them felt that this was something achievable in their bedrooms. Many of them selected their bedrooms for our conversations, even when these were shared with a sibling or parents (Marcos, Natalia and Coni). For example, Marcos decided that interview 1 would be conducted in his bedroom which was shared with his mother. Privacy was particularly important for him, given that the limited space of the studio flat where he lived with his mother (who was at home during the interview), meant that she could overhear our conversation. For that reason, he made sure that the door of his bedroom was completely shut, before starting speaking. This according to him, prevented his mother getting into the room without permission or overhearing our conversation.
Despite the potential spatial limitations of small flats or houses, or the potentially negative effect on the privacy of interviews that was implied by the presence of family members in their homes, the children drew on different strategies to ensure privacy during our conversations. For example, Natalia who also lived in a studio flat with her parents (present during my visits), asked them to stay outside in the terrace while we chatted in the sitting room, which was also her bedroom. Ricardo and Fabian also preferred to have the three interviews outdoors in the walking format. A quiet conversation with Ricardo was possible when he decided that we should move from his bedroom (where interruptions from siblings and cousins were frequent) onto a little green space in front of his home. Similarly, Fabian had already decided before our first encounter, that all interviews would be walking-tours, this in order to avoid ‘gossip’ interruptions from his siblings. Referencing back to the drawbacks of conducting home-based interviews mentioned earlier, these examples demonstrated how children drew on different strategies to ensure privacy in the interviews. It is also relevant to note that walking interviews offered children an alternative context for interviews, something that also contributed to ensuring privacy.

Being at the children’s home also served as a prompt during our conversations. The spatial and material features of their home facilitated the exploration of their daily routines, roles and relationships with family. For example, being with Isabel in her bedroom in the first interview allowed me to examine some of her night routines and relationship with her sister:

*Fieldwork-diary- interview 1 with Isa.*

*We are in her bedroom and she is showing me her bedroom and some of her dolls.*

*She shows me her bed and her sister’s bed (we are sitting on her sister’s bed)*

*She says that she never sleeps in her bed as her sister always asks her to move on to her bed in the middle of night… because her sister’s afraid of darkness.*

Knowing some of the children’s routines helped me construct a more nuanced picture of the context of their everyday lives. Sharing time with my participants in their homes also enabled me to observe some of their eating practices and food choices. These observations were important in helping me to understand the impact of some medical and dental treatments in their everyday lives. For instance, Valeria struggled to chew a chocolate bar that I had brought for her in our
second encounter. This was because according to her she had ‘no longer teeth’. She said that in her last surgery, two weeks before our first encounter, the majority of her teeth had been removed. Despite these eating limitations, her sister often helped her. While she tried to chew her chocolate bar, her older sister present in the interview helped her by first removing the nuts from the chocolate bar and then passing it onto her. From this episode I learnt that children’s feeding problems went beyond early life and that some treatments might exacerbate eating problems. As indicated in the introductory chapter, feeding issues are common during children’s early lives.

As planned, in the majority of cases interview 2 was conducted in the form of a walking tour. All children set out a route for their walking interview based on their preferences (e.g. places they like to spend time, or which are part of their daily routines) and accessibility. The walk was planned by the child in agreement with their parents/caregivers during the first or in the time between our first and second encounters. The tour consisted of a route visiting significant places to the children as long as they were located nearby their homes (e.g. the park, the court, school surroundings, the corner shop, grandmother’s home, etc). Some children proposed tours which included long journeys to locations, such as their mother’s workplace, hometowns, which it was not feasible to visit. In these cases, I explained that visits to these places were not possible, and they set out a new route around places closer to their homes. No parent(s) caregiver(s) disagreed with the walking routes proposed by the children and in most of the cases they came along with us. A significant aspect to highlight about this interview approach is that all walking tours entailed visits to places unknown to me. This meant that it was the child who guided the tour and explained to me the places visited. This clearly encouraged the child to adopt a leading and active role in the research process which minimised the control I could have over our encounters.

It was common that certain places evoked memories and then prompted the children to speak of certain life events and feelings. For example, a visit to the ‘waterfall’ in the walking tour with Lina, prompted her to speak of her feelings of loneliness and how she dealt with them:
Liliana: Mmm... By the way, what do you like about this route/path? Tell me why did you pick this particular route for our walking-tour?
Lina 2: uhmm I just like it (Shy laughter)
Liliana: ok. could you tell me, why you like it?
Lina 2: Because when I want to be in peace I go on a walk over here (shy laughter)
Liliana: What do you mean by being in peace?
Lina 2: mmm, I get rid of bad thoughts. I go on a walk to get rid of bad thoughts [...] uhmm, at times I get stressed, or feel sad... so... that's the reason why I go on a walk [...] yeah, sometimes I felt alone and... that makes me feel sad... for example when Juanita moved to Bogotá, do you remember that?'

In other cases, the walking tour enabled me to observe the participants interacting with other people. In a similar way to the eating limitations noted above, these observations enriched the data. For example, visiting the park in the walking tour with Santi, I could observe that despite wanting to join a group of children playing football, he felt ‘shame’ about asking if he could join them. After making several attempts to overcome his ‘shame’, he did not approach them and it was his mum who asked if Santi could join the play. From this episode I could gain some first-hand information on the interactional context in which my participants experienced some of their socio-relational struggles.

As planned, creative tools such as pictorial prompt cards, emotion-body maps and life story works were used, depending on contextual factors of the interviews (topics, needs/issues raised as interviewing proceeded) and the children’s preferences. Pictorial cards were used with those who expressed interest in looking at drawings and images (particularly the youngest participants) and during home-based interviews. As I showed the cards, I asked the child what image caught their attention, in order to prompt the child to express their thoughts. As the conversation followed, I asked questions such as: do you think she/he could be healthy? do you think he/she might he be ill?, why? These prompts served to spark conversations around concepts such as health, illness, normality and abnormality and how the children understood their CLP within this conceptual framework.

What the children thought of their bodies and how they felt with them was often explored in the first or third encounters through the use of emotions body maps, but not limited to them.
some children, body image and how they felt about their bodies, were themes that emerged spontaneously in our conversations. For example, speaking of their treatments and school lives, both Marcos and Dilan mentioned feeling happy with their bodies just as they were, with Marcos voicing some concerns about his nose shape as this was target of criticism by some school peers. When using emotion-body maps, the participants were asked to select a sticker from a set of feeling faces congruent with how they felt with a particular part of their bodies and then paste it on their maps. This enabled me to visualise how they felt about their bodies, but also was a form in which the children constructed more embodied accounts of their experiences. For example, using their emotion-body maps, the children spoke of how their physical bodies (e.g. senses, motor abilities) enabled them to interact with, experience and know their world. These maps also helped them to expand on their accounts about bodily discomforts related to their health condition. To illustrate, Ricardo pasted a sad face on his nose (in the emotion-body map), indicating that bleeding through his nose when playing made him feel sad. This was important in giving me a more embodied understanding of the potential impact of CLP and associated features for the children’s social interaction.

The children made their life-story works in the last interview. I felt that being familiarised with the participants’ main accounts and stories and transcribing some of the interviews at this point would help me to engage with these works. As previously indicated, incorporating this tool into my set of creative methods had several benefits. I highlight two of them: offering children a non-oral alternative to expand on their accounts or include new stories, and having a more visual picture of whether CLP held a position in their lives and what position it occupied. This visual representation of their lives particularly assisted me in the process of data analysis. For example, the contrasts I made between the interview transcripts and these visual representations of the children’s lives helped me to identify some themes in the data and reinforce some of my interpretations. To illustrate, in the first interview with Isa she mentioned keeping the fact of wearing a dental appliance as a secret, given that this could be a target for stigma by her school peers. The private character of CLP and treatments which Isa flagged in her interview, was reinforced by Marcos who decided not to include his ‘surgeries’ in his life story book given that
they were part of his ‘private life’. These kinds of contrasts were possible thanks to the combinations of approaches and were important in giving shape to my analysis.

Before doing these life story works, I asked the children whether they wanted to write or draw a short book or a timeline with those aspects of their lives which they find important for them. All children found the task interesting as they could use pencil colours, stickers, stamps, paper and other materials. In order to help the children to start their works, I first asked them what kind of work they wanted to make, namely a book, poster, little story or timeline in which they could include aspects of their lives they considered most important and relevant to them. While some children engaged very well with these instructions, some of the participants interviewed at the initial stages of my fieldwork in particular (e.g. Carlos, Jeronimo) expressed difficulties in finding what to write or draw about their lives. Children such as Jeronimo explicitly described feeling ‘bored’ as he did not know what to write or draw in his timeline. These difficulties led me to identify potential issues with the way in which I was introducing this tool to the children. I realised that asking my participants to write or draw about what they considered relevant about their lives, or would want to include in their life works, was an ambiguous instruction, as even if somebody asked me to do this, I would not know what to include. I then considered it helpful to hand write or print some of their quotes (from the first and second interviews) in the form of stickers and use them as a stimulus for the children to remember some events/experiences they had spoken of during our previous encounters. The implementation of this strategy had a positive impact on the children’s engagement with life story works. Many children not only remembered much of their accounts (from interviews 1 and 2), but also confirmed, expanded on those stories, and included new ones. The idea of using stickers was also positive in terms of making the process of constructing a ‘life-work’ less time consuming. Having stickers facilitated the production of their works as many pasted the quotes directly on the materials they had selected for their works (blank paper, coloured paper, cardboard) thus speeding up the process. However, some participants decided to write or draw some of their quotes without using these stickers (see Figure 1).
Photo elicitation also helped the children to remember and speak about some significant life events. The availability of photos depended on the children’s parents, who although asked in the first and second interview to collect some photos of their children for the third interview, frequently forgot or chose not to do it. However, when available, the children engaged with photos very well by using them in a variety of ways; going through old photos the participants remembered events such as holidays, birthdays, and past initial surgeries and prompted them to speak of, write or draw about these events in their works. Others preferred to incorporate photos directly into their life story works by pasting some of them. The children drew on different materials, ideas and styles to create their works. These included posters, life story books, drawings and ‘autobiographies’.¹³

¹³ This was the term used by Beto to refer to his life story work.
Figure 1: Life Story Work
3.4.2.3  Being reflexive in the fieldwork

During my fieldwork I kept a diary inspired by the experience of Punch (2012) doing research in rural Bolivia. She invites researchers to use field diaries to record particularly their emotional struggles and then facilitate the process of reflexivity. A diary helped me to record details of my journeys to the children’s houses, observations of their households and neighbourhoods, details of their families, friends and in some cases the body language of some participants. Keeping a diary also helped me to reflect on fieldwork challenges (e.g. emotional and ethical challenges) and facilitated the development of strategies to address them. Below I provide some of my initial reflexive accounts during the fieldwork.

Being a local researcher

It is acknowledged that researchers conducting a study within a familiar setting are more likely to share social and cultural commonalities with their participants, facilitating both data generation and analysis (Atkinson, 2003). Certainly, the fact of being a local researcher meant that I was familiar with the historical, social, geographical and cultural features of the research context, but also being at home allowed me to be accompanied by my family and close friends. Such company was positive as it helped to mitigate the loneliness of the researcher (Punch, 2012), and also represented an opportunity to share with them my research concerns and emotional struggles. My familiarity with the research context resulted not only from the fact that my participants and I shared the same nationality, but also from a sense of closeness to those with CLP derived from my previous work with children with this condition. From the ‘insider’ and ‘outsider’ notion, my position could fit with the ‘insider’ (Gair 2012).

However, this familiarity with the research context was problematized when my position as an ‘insider’ shifted to that of an ‘outsider’ in several contexts. As a researcher of the majority world, I was aware of the serious social and economic inequalities I could find during my visits to the children’s homes. Yet, such an awareness did not prevent me from being concerned about the precarious living conditions of my participants. Reflection on how the social and cultural conditions of many of my participants shaped their life-chances led me to experience some
emotional struggles. For example, I judged myself for having been to Soacha (a deprived area in Bogotá) just once, in spite of living in the same city. Similarly, I looked at my complaints about busy public transport and long journeys to the children’s homes as irrelevant when noting that they had to go on even longer journeys to attend their appointments in the clinical site. The poverty conditions of some of my participants also raised questions about my role as a researcher and the contribution of my study, after being aware that some of their basic needs were not even satisfied. Although these concerns and emotions were always present during my fieldwork, I often dealt with them by stressing the potential implications of my findings for practice, especially delivering healthcare services more sensitive to children’s needs. Furthermore, I also maintained at the fore the reasons for following a career in research and academia instead of doing a residency in a clinical discipline. After finishing medical school, I felt that my contribution to people’s health was limited from a clinical position as I was addressing people’s health problems from a narrow perspective of health and illness (see Chapter 1 and 2) rather than understanding their issues more holistically. Furthermore, I felt that I could make more substantial contributions to people’s health through the generation of new knowledge with potentially positive impacts on their lives.

**Parents’ contribution to the research process**

Given the child-focused nature of my research, parents were not interviewed. However, it was a decision of the participants whether their parents were in the interviews or not. Authors have signalled that parents’ presence in interviews might inhibit children from speaking of their experiences in a free and open way (Gardner & Randall, 2012). Some children might feel that their parents’ views are more important than their own and defer to adults (Gardner & Randall, 2012; O’Reilly, 2020). However, the absence of parents might mean missing important information about children’s lives and experiences that can only be obtained by involving parents (Gardner & Randall, 2012). Given these concerns, it is relevant to reflect on their influence in the data generation in my study.
The contribution of parents who were present in the interviews was mixed. Some of them encouraged the children to give further details of their accounts by helping them to remember about their experiences and events. For example, Jeronimo’s mother helped him to remember details of one of his CLP surgeries and how scary one of these had been for him. However, in some cases I felt that their presence made children’s engagement with some activities more difficult and inhibited some of my participants from talking. For example, in our second interview with Juliana, the presence of her father who came to us to say hello, made her stop talking. This was also noticed by her father and he left the room after he recognised the effect of his presence on Juliana.

These examples are reflective of how parents’ presence might either enrich or limit the expression of the children’s views. For that reason, researchers need to reflect carefully on the role of parents in the data generation and make decisions considering advantages and disadvantages of their involvement. In the particular case of my research I was interested in children’s own accounts, given the extensive body of research focused on investigating parents’ experiences of having a child with CLP. For that reason, I decided not to involve parents in my research. However, aware of the potential benefits of their presence in making children feel comfortable in the research process or complementing their accounts, I felt it was important that the participants could decide whether their parents were present or not in the interviews.

3.5 Ethical considerations

With the increase of children’s participation in research, there has been also a greater awareness among researchers of the importance of ensuring an ethical research practice when doing research with this population (Alderson & Morrow, 2011; Mitchell et al., 2016). This has led researchers to reflect on a number of ethical considerations when doing research with children. In this section, I discuss how I ensured an ethical research practice within the context of my research, some ethical challenges, and the strategies used to ensure my own safety and wellbeing during the fieldwork.
3.5.1 Seeking consent

The broad premise of seeking consent is that it should be a continuous process rather than a stand-alone event (Alderson, 2007; Alderson & Morrow, 2011; Tisdall et al., 2009). This entails not only ensuring that children have made the decision to take part in research without coercion, but also that the information delivered or explained has been fully understood. Furthermore, it is also important to bear in mind that participants’ agreement to participate can change as the research develops and for that reason their agreement should be reassessed at different points of the research process. A core aspect throughout my fieldwork was to ensure that children’s consent to participate was both an active and ongoing process.

Although the process of consent started with the children’s and parents’ agreement to participate (see step 3 of recruitment), written consent from the children and their parents was sought after a brief recap of the aims and voluntary nature of the study in the first interview. In order to ensure the children’s understandings of the consent, I designed a two-section consent form (see appendix 7) to be read out and explained to the child line by line by me before starting the first interview. Sitting, usually in the living room, I handed out copies of the consent form to the children and their parents (see appendix 8) respectively. While the parents read the consent on their own, I read it together with the child. While doing this I reminded them of some information given during the recruitment process such as who I was, what I did and the purposes of my research (‘do you remember I told you that I was a student in a university in Scotland, a country far away from here?... and that I was interested in talking to children who go to Operation Smile about their lives... for example their lives at school, their friends, what they like to do, what they think of CLP?’). I also emphasised that they could change their minds about their participation at any point during my visits (‘if you say: “yes, I want to talk to you and participate in your research”, but then you change your mind and you find the conversations or the activities boring or simply you don’t want to do this anymore, you can tell me that at any time, for example you can say something like- “look Liliana I don’t want to continue with this” and there would be no problem at all!’).
I checked the children’s understanding of information explained throughout the first section of the consent before signing the second part of the consent form. I present below a summary of each section.

**Section 1 - children’s understanding assessment:** this section of the form consisted of five statements checking the participants’ understanding of the voluntary nature of their participation and their rights to opt out and stop talking at any point. Using the three response options (Yes/Tick symbol; Unsure/Question mark; Not/Cross symbol), the children were asked to choose one option. Those children who reported Not or Unsure responses were invited to discuss unclear points, their questions, and doubts with me. This was an opportunity for me to explain unclear points, clarify their doubts and then re-assess their understanding using the same form. With Coni, for instance after reading the first section she was unsure about the first statement, whether my research was on children’s experiences with CLP. After explaining this in other words: ‘do you remember I told you that I was interested in knowing what children who attend Operation Smile think is CLP and what it is like to live with CLP from their point of view? I also told you that I was looking for children who wanted to talk about their experiences and what they think of CLP with me, do you remember that?’ Coni confirmed her understanding and then signed the second part of the consent which is explained below.

**Step 2 - consent form:** This second part was completed only by either the children with full understanding at the first place (Yes to all statements-section 1) or those who after discussing unclear points/questions understood all section 1-statements. Affirmation of consent was recorded via two response options (Yes/Tick; Not/Cross symbol).

During the interviews, the children were also encouraged to assert their capability of giving consent through the use of a non-talkative object. This was a small foam ball (placed next to the child) which the participant might take every time she/he did not want to answer a question or wanted to stop discussing a particular topic. This strategy was particularly effective for those children who might feel shame or concern about communicating that they did not want to talk
about a particular topic, as well as allowing me to identify potential sensitive issues. For example, in my first encounter with Valeria, I asked about her father, but she preferred to grab the ball and for that reason I changed the topic of our conversation. However, later in the walking tour (second interview) she mentioned that her father used to take her to the park, but that was no longer happening and that made her feel sad. In the same interview, on the way back to her home, she commented that her father did not live with her anymore as her parents had divorced recently. This example shows how the non-talkative object contributed to balancing the power relationship, as grabbing this object means changing the topic of our conversation and therefore provides a way in which they were also leading the process of interviewing.

The non-talkative object not only allowed the identification of sensitive topics, but also indicated instances in which some children might want to draw upon other methods to express their thoughts. While talking about surgeries with Jeronimo, he grabbed the ball when I asked what part of his body had been operated on recently. After doing this, I intervened to ask if he did not want to talk about that topic and preferred that we talked about another theme. He answered that he felt embarrassed about ‘that part of the body’. I then said that if he felt shame about talking, he could write down or draw on my notebook instead. He then decided to use my notebook to write that his surgery had been done on his penis. The above examples served to illustrate how this non-talkative object not only enabled me to seek ongoing consent during interviews, but also flagged sensitive topics and instances in which children might want a non-verbal way of giving their accounts.

It is also important to mention that the data generation process was permeated by an ongoing ethos of consent that went beyond my research participants. As mentioned earlier, although parents were not interviewed, they also gave consent to participate. In those instances in which parents were present and/or took part in the interviews, I also checked with them their understanding that their accounts and interventions were part of the research process and therefore these would be used as data.
Although ensuring active and continuous consent was an ethical research practice, this process was not always free of concerns or challenges. Some issues were experienced with a young girl (Juliana) who had expressed agreement to take part in the study in our discussion meeting (step 2), but did not engage with the consent form before starting the first interview. When I read the consent out and explained the two-section form, she did not express agreement or disagreement to participate; she instead remained quiet, looking at her grandmother and me. Her grandmother intervened to say that she was too shy to talk at times and encouraged her to talk if she wanted. In view of the fact that she affirmed wanting to talk to me when I asked if she preferred not to do the interview, I considered that an initial informal chat might help to minimise her nervousness before engaging with the actual process of consent again. We therefore had a long ice-break chat and did some drawing activities together, both helping her to relax and interact with me. After doing this, I checked again if she wanted to do the interview or preferred not to do it. She confirmed her agreement to participate and after reading and explaining the consent again she engaged with the form very well.

This episode gave me the opportunity to look at my ethical research practice more critically. The fact that until the above mentioned episode with Juliana, all children had engaged successfully with the consent, made me assume that the rest of my participants would engage too. However, as noted in my ontological and epistemological reflection, children have different competences and preferences and their successful engagement with a research process depends on how effective the researcher is in communicating with them. Clearly the issue that prevented Juliana from engaging with the consent form was not related to her cognitive or linguistic abilities, but rather my anxiety of gaining consent before starting talking. My concerns about ensuring the children’s consent before starting the interviews, led me to overlook that I needed to make them feel comfortable before seeking their consent. This episode reinforces the concept that constructing a connection with the child before and during interviews is critical to a successful research process, and that this largely depends on the opportunities they have to talk about anything they feel interesting or important (Spratling et al., 2012).
I also experienced other types of ethical challenges when conducting my research. In dealing with these, I drew on several resources – support of professionals at Operation Smile- Colombia, my knowledge of procedures to report child abuse in Colombia, and discussions with my supervisors. I present a reflective discussion on these challenges and how I addressed them in the following subsection.

3.5.2 Ethical challenges

Ensuring children’s confidentiality, protecting children from harm or abuse and balancing power relationships are three pillars of an ethical research (Alderson & Morrow, 2011). I presented above some examples of how walking tours and the non-talkative object contributed to levelling power imbalances between my participants and me. With regards to confidentiality, I drew on different strategies to ensure my participants’ confidentiality including the anonymization of their names, no sharing details of their places of living, encryption of transcripts and the children’s work with creative tools, but also by maintaining the content of our conversations as confidential. However, confidentiality is problematised in cases in which children are at high risk of harm or abuse (Tisdall et al., 2009). This includes explicit or implicit reports from the participants or researcher’s observations of episodes of abuse, neglect and unfulfilling of children’s rights. For that reason, the complete confidentiality of my participants and our conversations was not assured. During the consent process I explained to my participants that although our conversations would be private and I will not share their opinions or reports to anybody, if from their stories I perceived that they or somebody else could be at risk of harm or danger, I would have to report this to the social workers of Operation Smile or their parents.

Despite my efforts to ensure an ethical and good research practice, I experienced some ethical challenges during my fieldwork. During the early stages of the data generation, a child disclosed a long term history of domestic abuse (from her father towards her mother) in our first interview. Following procedures set out in the study protocol, the case was reported to the social worker of Operation Smile and discussed with my supervisors. Legislation in Colombia is clear in saying that any action to protect children from abuse or any other form or violence takes precedence over
children’s confidentiality and professional codes. This, along with the caveat given during the consent process, meant that reporting this case to the social worker did not represent unethical conduct or a breach of confidentiality.

Inadvertent disclosure might represent a criterion for excluding participants (Ritchie et al., 2013). However, there is no agreement on this and decisions should be made according to individual cases (Alderson & Morrow, 2011). After discussing this case with the social worker and my supervisors, I decided to not exclude this participant but to continue with the remaining interviews. Several reasons helped me to make this decision. First, the social worker confirmed being already aware of the situation of domestic abuse and explained that this case was already under strict supervision by both institutional (social worker in Operation Smile) and local authorities (ICBF 14). The child always showed great enthusiasm for participating and communication with her mother was always good and respectful, which made me think that excluding the child from the study might have an emotionally negative impact on the child. In addition, I observed a close and warm relationship between the participant and her mother which reassured me that there was little risk of her being reprimanded for her disclosure. In relation to my own safety, I did not feel that it was compromised by continuing with my visits. The child’s mother and siblings (her father never was at home during my visits) always showed great hospitality which led me to think that my safety was not at risk in case of knowing that I had reported the case. However, as a preventive measure I decided to always go into the field with a non-researcher colleague, whom I met up with after each visit.

In contrast to this case, serious ethical and safety concerns were reasons for excluding another child after the first interview. During our first encounter (interview 1), the child reported physical abuse from her mother. Verbal and emotional abuse towards the child was also observed during an informal conversation with her mother at the end of this visit. I reported the case to professionals namely the social worker in Operation Smile and made the decision to stop interviews with this participant. This decision was made in consideration to several factors. First,

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reporting this case was congruent with an ethical and legal research practice which prioritises children’s safety over research subjects’ confidentiality. Second, when the social worker contacted the child’s mother to notify the report of abuse, it was likely that this report would be linked with my visit. The fact that the mother knew or suspected that the child had informed me about the abuse meant that the child could be reprimanded for her disclosure. This risk could be greater if I continued with the visits, as chances for further disclosure were high in the remaining encounters.

Another important reason for stopping my visits was related to my safety. As noted earlier, I could observe the way in which the mother verbally demeaned the child. After observing this aggressive behaviour, I felt that she could confront me on my next visit for having reported the abuse. Furthermore, features of the household such as the presence of an aggressive dog also made me feel that this environment was not safe for me. This case was carefully discussed with my supervisors, who were also concerned about my safety and advised me to stop the remaining interviews. In fact making contact with the mother to inform her of my decision was not necessary as she phoned me some days after my visit to reschedule the second interview. She said that her working days had been changed and once she knew her days off, she would get back to me to set up a date for the next visit. I said that a reschedule was no longer necessary as some issues had risen recently with my study and I could not continue with the visits. Although I felt that excluding this child from the study was an ethical decision, this did not stop me from feeling powerless and guilty. Stopping my visits means that I could not have any contact with the child and that in some way I was leaving her alone in a context of abuse. I shared these concerns with my supervisors who invited me to reflect on what else I could do for her if I continued with my visits. I felt that I could not offer her anything apart from my company but this implied serious risks of harm to me. I then kept in touch with the social worker in order to be updated on the case and to know if I could contribute to anything.
3.5.3 Ensuring my own safety and wellbeing

During my stay in Colombia, I attended monthly counselling appointments. Such encounters were helpful to share some of my concerns and to supervise the emotional impact of interviewing. As mentioned earlier, being at home also meant that I could share my concerns with my family and close friends. Despite being geographically distant from my supervisors, we arranged on-line meetings frequently. These encounters with my supervisors and their willingness and availability to discuss challenges and emotional struggles were always reassuring. I went to the majority of my visits with a non-researcher colleague, who waited for me in a nearby coffee shop until I finished my visits. This was essential to make me feel safe, in particular when going on long journeys or visiting unsafe areas. Having a colleague along on the journeys also contributed to better addressing the difficulties and discomfort of public transport, and deal with tiredness after some visits.

3.6 Data Analysis

3.6.1 Transcription

The process of transcription was the most time consuming part of the analysis stage, perhaps due to my limited experience. Acknowledging the centrality of actively listening and transcription to initial analysis, I decided not to use a transcription service. This decision was also made on the grounds that by transcribing myself I could evoke key memories and therefore have greater insights into the data (Given, 2008). Interviews were transcribed and analysed in Spanish. Some initial transcripts were fully translated into English and shared with my supervisors for feedback on my initial analytical thoughts. However, full translation of these transcripts was a time consuming process which impacted negatively on meeting deadlines for completion of my thesis. For that reason I decided to analyse data in its original language and translate into English only those sections of the transcripts that would be used in the thesis. This was mainly done when writing up the thesis.
I paid special attention to preventing loss of meaning when translating quotes, probably contributing to making the transcription process slower. Translations need to be checked by a second reader in order to ensure clarity and accuracy (Alderson & Morrow, 2011). For that reason, I asked the same colleague who accompanied me on my visits to check the style and tone of my translations (from anonymised transcripts).

3.6.2 My analytic approach

My analysis was informed by three analytic approaches: the listening guide (LG)/voice-centred method (Gilligan et al., 2011); the narrated, disnarrated and non-narrated approach (Vindrola-Padros & Johnson, 2014) and thematic analysis (Ritchie et al., 2013). Acknowledging that analysis methods are ‘dynamic and open-ended practices’ (Mauthner, 2017 p.1), I chose to merge these methods to best address my research aims and questions. Below I present a brief overview of each method and rationale for their use.

3.6.2.1 The Listening/Reading guide

In recent years, the growing interest of social researchers in narratives has led to the development of analytic approaches to better understand people’s stories (Riessman, 2012). Analysing narratives implies understanding both the factual content of individuals’ stories and what the story is telling about the narrated subjects (Doucet & Mauthner, 2008). According to Doucet & Mauthner (2008) (2003) the listening guide helps researchers to become familiar with the plot of interviews but also sheds light on how narrators are embedded in the complexity of their social relationships and networks. Originally developed by Brown & Gilligan (1992), this feminist method of narrative analysis seeks to analyse individuals’ stories and narratives through a layered listening or reading guide. Mainly focused on the interviewee’s voice, the researcher reads interview transcripts or listens to the audio-records a number of times (Doucet & Mauthner, 2008; Gilligan et al., 2011; Jankowska, 2014; Petrovic et al., 2015; Woodcock, 2016). Although number and types of reading or listening are flexible depending upon research aims and questions (Doucet & Mauthner, 2008), some guidance is provided as follows:
1. **Reading or listening 1**: the main purpose of this first listening or reading is to become familiar with the content of the interview. Through this first listening, the researcher constructs an overview of the participant’s stories, experiences and accounts. Key to do this is paying attention to the participant’s voice, silences, omissions, contradictions and the reader responses. This includes keeping a record of ideas and comments that emerge as we read transcripts or listen to the interview (Woodcock, 2016).

2. **Reading or listening 2**: during this stage, the researcher is focused on the active ‘I’, this is who is telling the story (the narrated subject) (Doucet & Mauthner, 2008; Jankowska, 2014; Petrovic et al., 2015). To do this, the researcher pays particular attention to how the participant speaks of him or herself, which often includes their thoughts, desires, points of conflicts and needs (Woodcock, 2016). By focusing on the participant’s voice, the researcher can construct a more detailed picture of who the participant is, with the potential to gain insights into their experiences.

3. **Reading or listening 3 and 4**: these are focused on the ways themes and/or subjects interact with each other (Doucet & Mauthner, 2008; Jankowska, 2014; Petrovic et al., 2015). Here the researcher is focused on how the interviewee speaks of themselves in relation to others, namely people, materials, and social structures. At this stage it is also common to be ‘listening for contrapuntal voices’ (Gilligan et al., 2011, p. 10). This entails identifying themes that overlap, or are in tension with each other. Once themes are extracted Gilligan et al. (2011) suggest returning to the transcript or recording and underlining phrases that relate to the themes in question. To facilitate the analysis of the selected extracts, the researcher can ask themselves in what ways this relationship or tension is pertinent to the research. An important aspect throughout readings or listening is keeping a record of analytic ideas and comments either manually or digitally.

Gilligan et al. (2011) recognise that the development of the listening guide was inspired by the limitations of the coding schemes traditionally used to analyse the substantive content of qualitative data. Although the systematic nature of approaches such as thematic analysis enables
the researcher to have pieces of more manageable data, breaking down the data also risks losing sight of the individuality of each participant and their narratives (Gilligan et al., 2011).

Some components of the listening-reading guide offered me several advantages. First, it enabled me to look out for the unexpected (Mauthner, 2017), something that had the potential to reduce the impact of my preconceptions and anticipations on the analysis process particularly preconceptions related to my medical knowledge and positivist background. For example, coming from a biomedical discipline meant that I often analysed data looking for causality relationships. The listening guide implied that I had to concentrate on the child’s voice in the transcripts and how their voice was embedded in a complex socio-relational context. This allowed me to see each participant and their stories as something individual and unique instead of using categories to group their accounts and find causal relationships. Second, the idea of identifying points of tension in the last reading was valuable as it helped me to problematise the data and therefore force me to go deep in my analysis.

I tried the four-step listening guide with some of my participants’ transcripts, in order to know whether this approach fitted with the purposes of my study. The first reading –getting familiar with the plot - was a straightforward process, as after transcribing the interviews I was to some extent already familiar with the plot. However, when I moved on to the second reading (tracing the ‘I’ voice), I noted that my participants were always speaking about themselves within and from the interaction with others, namely peers, friends, parents, siblings, other family members, and doctors. To illustrate, the following extract from the first interview with Carlos (I highlight in red colour Carlos’ voice often expressed in the form of ‘I’, ‘me’ and ‘my’):

‘L: Well… mmm tell me what do you often do over the weekend?
Camilo 1: on Saturday… well I used to play football but I can’t go anymore,
L: really? why you can’t?
Camilo 1: Because my mum is on debt, she owes the school (a football academy) some money (voice down) so I can’t go anymore….
L: mmm ok, but can you play here at home with friends may be?
Camilo 1: No, I can’t because my brother plays football on Saturdays (long pause) and I’m also grounded (he looks embarrassed -moves pages of a book)
L: mmm and can I ask why?
Camilo 1: Because I brought a note from the teacher
L: why a note?
Camilo 1: well, the thing is I’m intelligent and do well at school with grades and stuff (voice up) but I’m not good at discipline...that’s what makes me get into trouble ...as I’m friend of everyone...I’m kind of chatty so I talk to everybody at all times...

From the above excerpt is possible to see how Carlos´ voice intersects in his account with other people such his mother, brother, teacher and friends. However, here it is important to make a caveat. During this pilot analysis, I did not include some components of the four layers of the listening guide as this entailed the construction of ‘I’ poems in which the researcher pays attention to tone of voices, resonance and counterpoints. Although these elements are valuable for narrative research particularly in psychology (Mauthner, 2017), I felt that these did not fit with the nature and purposes of my research. Having said this, after implementing a modified version of the listening guide with some of my transcripts, I concluded that having three separate readings in which I paid attention to how the child spoke of themselves, in relationships with others and in relationships with social structures, was not useful for me, as the voice of my participants was never isolated. I therefore decided to merge readings two, three and four into one only reading and combine this approach with other analysis methods that also offered some advantages.

3.6.2.2 The narrated, non-narrated and disnarrated approach

Foregrounding the value of illness narratives for people to make sense of their conditions, and the curative nature that involves sharing these stories Vindrola-Padros & Johnson (2014) proposed an approach for analysing illness narratives based on three main components: the narrated, non-narrated, and the disnarrated for social research in health. This method seeks to go beyond what is found explicitly in the transcripts. They therefore propose examining the content of interviews in relation to what is explicitly narrated, but also identify those elements of participants’ accounts and stories that are ‘missing, silenced or purposely deleted’ – the non-narrated (Vindrola-Padros & Brage, 2017, p. 17). In addition to exploring the narrated and non-narrated elements of the participants’ stories, it is also important to pay attention to the
disnarrated. These are stories that recount past, present or future events embedded in hypothetical situations or imaginary scenarios and often shed light on participants’ emotions and feelings regarding certain aspects of their lives (Vindrola-Padros & Johnson, 2014). To illustrate, the authors of this approach showed how a sense of guilt about the economic burden of oncological treatments is visible in the following disnarrated extract:

‘Sometimes I feel like stopping all of this (in reference to an oncological treatment) [...] I mean, look at my family, we get 150 pesos from Plan Jefas [a government assistance program] and we have to spend all this money so that I can come here to get the treatment. I have two brothers and they have kids, my mom, and my dad and we are paying for the bus ticket for me, and the hotel. We put in the papers for a pension like 8 months ago and haven’t gotten anything (Vindrola-Padros & Johnson, 2014, p. 1608).

In order to facilitate the identification of non-narrated and disnarrated elements the researcher might ask themselves: is there any element that individuals choose not to incorporate into their accounts? Do they mention some points in their stories that were not developed completely? (Vindrola-Padros & Johnson, 2014). Furthermore, particular attention should be paid to those episodes narrated in the form of hypothetical situations or signalling regrets. In these instances researchers should ask themselves: if these events have not happened why are they part of the story? (Vindrola-Padros & Johnson, 2014).

Although this analytical approach is predominately used in narrative research, it was promising in illuminating alternative narrative styles in which my participants tell their stories, something also positive for gaining greater insights into their accounts and experiences of living with CLP. Similarly with the listening guide, I then decided to incorporate some elements of this approach into my analysis in a flexible way. I felt that paying attention to the non-narrated and disnarrated aspects of my participants’ accounts might help me address the research questions concerning what language children use to define CLP, and the social costs of being a child with CLP. This is because some children were likely to talk about their understandings and experiences of living with CLP in less explicit ways given that CLP is often seen as a sensitive topic due to the stigma linked with CLP and other bodily visible differences.
I used this approach initially with some participants I considered to be more likely to present disnarrated and non-narrated episodes in the interviews. This selection was made on the grounds of my fieldwork diary notes and after having read some transcripts. My fieldwork diary was important in this selection as some of my notes indicated which children had seemed rather shy in the interviews, those topics I felt more sensitive or difficult to address, as well as encounters in which there were frequent pauses or silences. I also made this selection after having familiarised myself with the plot (first reading) as this allowed me to have a rough picture of what events were more likely to be narrated in these forms.

When looking for the non-narrated in some of the transcripts, I felt I was judging stories in relation to what I was expecting to be narrated and therefore to what I want to hear from the children. This was problematic as it meant that in some way I was superimposing my preconceptions over children’s accounts with the risk of compromising the validity and rigor of my research. For that reason, I decided not to ask myself what was missing from the story but rather to draw attention to instances in which the participants explicitly said that they did not want to talk about particular topics, to silences, and to the times when they took hold of the non-talkative object. This helped me to identify potentially sensitive aspects of their stories and potential non-narrated events. To illustrate here is an excerpt from the first interview with Santi in which I identified a non-narrated element in his account:

‘[...]L: can I ask why do you go to Operation Smile?
Santi 1: mmm I don’t know [...] to speak well and to fix my mouth
L: how is that?
Santi 1: they put on me some “aparatos”¹⁵ [...] they push my teeth back [...]
L: ok, you said something about fixing your mouth, didn’t you?
Santi 1: mmm (LP) I don’t want to talk about it’

I interpreted not wanting to talk about CLP in Santi’s statement as indicative of a non-narrated element in his account and the sensitive nature of CLP for him. Similar to Santi, some of my participants decided not to include some events related to their CLP, such as surgeries and

¹⁵ Dental appliances.
treatments narrated during interviews in their life story book (see Chapter 5). Paying attention to non-narrated elements in the children’s accounts enabled me to gain insights into the sensitive and private nature of CLP for some children. I further discuss this in my findings chapters.

I used the listening guide and dis/non-narrated approaches to focus on each child’s story, but I also wanted to look across their accounts and experiences thematically, so I decided to incorporate some aspects of the thematic analysis into my approach. In the subsection that follows I present a brief discussion on how I combined this analytic approach with the above discussed approaches in my analysis.

3.6.3 Thematic analysis

There is a strong tradition of using thematic analysis within the field of medical sociology (Ritchie et al., 2013; Vaismoradi et al., 2013). Central to this approach is the development of coding frames, which might facilitate the generation of finding patterns across the data set in relation to research questions (Ritchie et al., 2013). Broadly, the thematic analysis entails breaking the data into small analytic units of content and then subjecting them to the researcher’s interpretation (Braun & Clarke, 2006; Ritchie et al., 2013; Vaismoradi et al., 2013). The fact that thematic analysis entails a systematic management of the data, in some way means that it provides qualitative research with reliability and rigour (Vaismoradi et al., 2013). However, despite the step-by-step character of this approach, it is important to bear in mind that analysis of qualitative research is mainly an interpretative process and that reliability and rigour depend on transparency and reflexivity (Ritchie et al., 2013) rather that managing the data in a systemic way.

Although analysis phases might vary with disciplines and type of research, this approach often entails the following steps: becoming familiar with the data (having an overview of the content of interviews and identifying topic and subjects of interest, record initial ideas); generating initial codes (coding interest features of the data); constructing an initial thematic framework (developing a potential set of themes into which the extracted coded might fit); indexing and
sorting (grouping coded extracts in the above thematic framework); reviewing data extracts and themes (checking consistency of the link between the coded extracts and the theme with which were labelled); data summary and display (constructing a summary of the content of themes and each participant) (Braun & Clarke, 2006; Ritchie et al., 2013). The data are subjected to the researcher’s interpretation; the researcher identifies, contrasts and explains patterns in the data and links the findings back to their research questions and broader literature (Braun & Clarke, 2006; Ritchie et al., 2013).

The main benefit of this approach is that it offered me the option to look at the data in a more conceptual and contrasting way, in comparison to the main individual focus of the above mentioned methods. Managing the data into codes and themes was also positive in that I could look across the data, helping me to identify similarities and contrasts in my participants’ accounts and experiences, and examine underlying ideas and conceptualisation. The fact of having a set of themes contributed to looking at the findings more clearly in relation to my research questions and guided me towards exploring theoretical orientations and literature which I could use to interpret and discuss my research findings.

During the multiple readings of the transcripts (getting familiar with the plot, paying attention to the ‘I’ voice, disnarrated and non-narrated elements) alongside the children’s works (emotions body maps, life story works), I recorded analytical thoughts, perceptions and initial themes and concepts using NVivo. I used these analytical notes to guide the generation of initial codes and construct an initial thematic framework. It is worth mentioning that I also coded the data according to whether it had a disnarration or non-narrated style. Having a thematic framework enabled me to start indexing and sorting the data according to themes in nodes and child nodes (sub-themes). This gave me a more organised view of the data.

Once I had ‘piles of data’ (Ritchie et al., 2013, p. 283) that had been categorised according to themes, I started to look at the data with more conceptual and interpretative eyes. To do this, I constructed mind maps of relevant themes guided by my research questions (see an example in
Figure 2) where I also included some coded extracts from the transcripts, emotions body maps and life story works. This helped me to think more theoretically, contrast findings, and link the data with key literature. When I felt that I was struggling with the data in this form, I went back to the raw data to re-read and explore further particular aspects to make sure that I had not overlooked valuable data. For example, in relation to the body (a node) there were tensions between two sub-nodes – fixing the body (mainly accounts of treatments) and competent body (children’s accounts of their bodies in terms of capacities and abilities). Tensions such as these had been also previously noted during the multiple readings I made of the transcripts and creative tools. These tensions as well as some gaps in my analytic framework made me go back to the raw data on many occasions, forcing me to reflect on my analysis.

Analysing the data, and writing my findings chapters, was a concurrent and ongoing process. Writing allowed me to look at the findings from different stances, identify points of tension, areas in need of further analysis (e.g. such as children’s accounts of their treatments), and look at my data in the light of key concepts and literature. I had regular meetings with, and feedback from, my supervisors across the process of analysing and writing. Their feedback served to uncover areas of underdeveloped analysis, and engage with key theoretical orientations and literature.
3.7 Summary

This chapter has presented a reflective discussion of my research design, approaches used during the data generation and analysis, and ethical considerations of my study. Informed by my research questions, epistemological and ontological reflections, I developed a qualitative research project, based on two interview approaches and some creative tools across three different encounters. The data were generated from home-based and walking-based interviews with 20 children with CLP who were also active attendees of Operation Smile - Colombia. Three creative tools (pictorial cards, emotion body maps and life story works) were used across the interviews in a flexible way in order to complement the data generated through the interviews. A bespoke analytic approach was developed drawing on three methods: the listening guide (Gilligan et al., 2011), the narrated, disnarrated and non-narrated approach (Vindrola-Padros &
Johnson, 2014) and thematic analysis (Braun & Clarke, 2006; Ritchie et al., 2013). I incorporated into my analysis only those elements of the above mentioned approaches which I felt fitted with the nature of my research. Having provided a discussion on the methodological aspects of my study, in Chapters 4, 5, and 6 I analyse the data generated with the children, drawing on some key theoretical orientations and key concepts which helped me structure my findings.
Chapter 4 Children´s understandings of CLP: a congenital and non-pathological condition

4.1 Introduction

In this Chapter I present the children´s understandings of CLP and the explanatory models they constructed around the origin of their condition. Before providing an outline of the chapter structure I give a brief summary of key concepts and research gaps discussed in the literature review that shaped the research questions addressed in this chapter.

In parallel to biomedical definitions of CLP and its origin, lay explanatory models are often used by people to make sense of congenital conditions. In Chapter 2, I provided examples of these models, for example associating congenital conditions with natural forces on pregnancy, God’s will or destiny (Cassibba et al., 2014; Li-Rong, 1990; Mednick et al., 2013). The diversity of lay orientations towards the origin of CLP and other congenital conditions reflects how cultural and social backgrounds give shape to the production of meanings of health and illness processes. The construction of explanatory models of illness are closely tied to the way individuals experience an illness or a medical condition (Kleinman, 1988). In Chapter 2, I also noted that limited empirical research has explored individuals’ perspectives towards the origin of this condition (Abualfaraj, 2016; Beaune et al., 2004; Hall et al., 2013; Oginni et al., 2010), however these studies have been focused on adults, outside of the Latin-American region (Asia and Africa). This identifies a gap in knowledge as children´s views differ from adults and there are important socio-cultural differences between regions, even when they belong to the majority world (Punch, 2001).

In the first section of this chapter I discuss how the children named, described and defined CLP in their own words, as well as the way they made sense of the origin of this condition. I aim to address the following research questions: what do children think causes CLP, what is the basis for these ideas and what language do they use to define CLP? This section of the chapter makes two key contributions: providing an examination of children’s understandings of CLP and its origin; and focusing on the particular cultural context of Colombia/Latin America.
Section two of this chapter addresses the third question of my research: how do children conceptualise illness, health and normality, and how do they define their condition within this conceptual framework? A central aspect in the process of meaning production of illness and health conditions is the language we use in reference to them (Kleinman, 1988; Nettleton, 2013). As discussed in Chapter 2, the tendency within biomedical disciplines is to define people’s symptoms, experiences and issues with their bodies in pathological terms (Conrad, 2007). However, this process through which individuals’ problems become medical problems (medicalisation), has been criticised for defining and treating people’s experiences with their bodies in terms of pathology, deviance and abnormality (Clarke et al., 2003). A key point in these discussions is to what extent the medicalisation of the body has transformed expected and common difficulties of life into disease, contracting not only the range of what is considered normal (Conrad, 2007) but also demanding people to conform with certain patterns of bodily normality (Crawford, 2006; Rose, 2009). A significant negative effect of this process of medicalisation is that categories such as ill or abnormal might disaccredit the individual’s identity (James & Hockey, 2007; Rumsey & Harcourt, 2004).

As stated in Chapters 1 and 2, CLP is defined and treated as a biomedical problem with terms such as birth anomaly, defect and disorder being frequently used. I also mentioned that the use of these terms has the potential to impose on children’s identities with labels such as sick or abnormal. This section examines how the children understand CLP against a backdrop of biomedicalization that often defines their condition in terms of pathology and abnormality.

It is important to be clear about the terminology used in this chapter. Despite the variety of terms and non-verbal resources the children drew on to describe and explain their CLP, I use the term ‘CLP’ and associated features throughout the text, in order to use a unique term which facilitates the flow and understanding of the chapter.
4.2 Children’s understandings of CLP and explanatory models of causation

4.2.1 What is CLP? Physical and functional bodily differences

The term Cleft Lip and Palate and its Spanish translation ‘Labio y Paladar Hendido’ and ‘Fisura Labio Palatina’, is frequently used in health care settings and biomedical research. Despite the common use of these terms among clinicians, they were rarely used by the interviewees in their accounts. Rather, the children drew on their own words and non-verbal resources, such as gestures to describe the physical and functional traits of their condition.

A frequent manner in which the participants spoke of CLP and associated features, for example, nose shape, teeth position, speech, was by giving details of the physical appearance of their lips before surgical reparation. Many of the children mentioned being born without a portion of their upper lips, linking that characteristic with words such as ‘hole’ (Marcos), ‘nothing’ (Dilan), ‘wide apart lip’ (Camilo) and ‘a cross’ (Javier). It was also frequent that these verbal descriptions were accompanied by gestures in which they depicted more visually what their lips and noses looked like. These bodily descriptions are illustrated by Dilan and Marcos:

(Dilan was explaining a story told by his mum about the pre-orthodontics care)
‘[...] Dilan 1: They (doctors) put me a tape and “aparato” here (points out upper lip) Liliana: What for?
Dilan 1: To close this (points out a side of his upper lip and folds a portion of his upper lip to the opposite side- mimicking closing a gap) Liliana: Ahh ok you had this part, kind of, a bit lifted, right?
Dilan: No, no, no, I just had nothing in this part (points out a side of his upper lip)’

‘[...] Marcos 1: I was born with my nose, like, a bit droopy (put his nose tip down) Liliana: so.. you were born with your nose turned down 16, right?
Marcos 1: yeah Liliana: Any other features apart from the nose?
Marcos 1: Yeah, with .... hang on I ask my mum cause I’m not sure what it was Liliana: But before asking your mum, what do you think?
Marcos 1: I think I was born with “labio hondito or porino”17 ... right? mmm I’m not sure...

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16 ‘Nariz agachada’.
17 ‘Harelip’. 
Liliana: mmm don’t know… just tell me what you think
Marcos 1: what ...what do you call that hole you have here (points out mouth) ... yeah that hole... I couldn’t eat when I was a baby... it was the lip... I couldn’t eat, the food went through my nose...anyway! I don’t know’

There was a sense of uncertainty in Marcos’ description about the clinical term to name his condition. As his account shows he tried to incorporate the term harelip into his explanation but potentially this term in Spanish (‘leporino’) was a complex word to use. Similar to Marcos, Carlos seemed to be confused when I used the term cleft lip and palate in our first encounter. Examining what he thought caused CLP, he said not being sure whether CLP referred to his ‘mouth problem’. The above examples suggest that CLP, despite being used in clinical settings and therefore potentially by healthcare professionals in the clinical site, was a distant and non-familiar term to the children.

The absence of a portion of their upper lips was also described as compromising the asymmetry of other facial structures such as nose, teeth and the nasolabial fold\(^{18}\). Natalia and Coni for example, described how being born with an absent portion of their lips also affected the shape of their nose and lips:

‘Coni 1: because of my lip and nose ... I was born with both sides opened (she points out her upper lip and the area between her upper lip and nose)’

‘Natalia 1: mmm... mmm... mmm (LP) when I was a baby I didn’t have this (points out her nasolabial line)... I didn’t have this fold\(^{19}\) (points out her nasolabial line) this was loose ... I had nothing here... just loose like this (lifts up a side of her lip)’

However, holes and gaps were not only present in the children’s lips. Other children commented that their palates had been also born with a missing portion. For instance, Mariana and Manuel reported being born with a ‘problem’ in her palate and ‘no palate’ respectively:

‘L: ok... tell me why do you have to wear that “aparato”, your sister doesn’t have one, does she?’

\(^{18}\) A furrow between the nose and the lip.
\(^{19}\) ‘Gestico’.
Manuel 2: because she was born with teeth
L: and you?
Manuel 2: with no the roof of my mouth
L: she was born with teeth and you without palate, right?
Manuel 2: she was born with teeth and palate
L: can I see your teeth and palate?
Manuel 2: Look (opens his mouth and shows me his “aparato”)

For a group of children CLP was more of a bodily discomfort or a physical sensation. Although aware of a hole in his palate, Ricardo described his cleft palate by stressing how this hole made some food pass from his mouth through his nose, something that caused him to feel his nose ‘stuffy’ everyday. Similar to Ricardo, Carolina described her hypertrophied upper lip (a potential sequelae of a lip corrective surgery) as a sensation of having ‘some extra flesh’ in her upper lip:

‘Carolina 2: well ehhhh mmmm well in my lip I have uhhmm ... I feel that ... I have some extra flesh here (lip)... my mum always says that I have some extra flesh ... here’.

Carolina’s account illustrates how children’s parents helped the children navigate and understand these sensations. This is worth noting as later in this chapter I discuss how parents were important sources of information for the construction of the children’s explanatory models.

Carolina’s and Ricardo’s accounts were marked by a more sensorial description of what CLP feels like – an enlargement of the upper lip for Carolina, and food going through his nose for Ricardo. The embodied accounts of Ricardo and Carolina have some similarities with the narratives of other children who also spoke of bodily sensations related to their CLP (see Chapter 6). The emphasis which some children placed on the sensorial and proprioceptive character of their CLP and associated features, invites us to consider the relevance of the material dimension of the body in the experience of this condition. This is a point which is discussed more deeply in the light of the children’s accounts about treatments (Chapter 6).

In parallel to the above physical and sensorial descriptions, other participants understood their CLP as a speech issue. Although some linked their speech difficulties with cleft palate (Beto, Mariana), others associated this with problems in other structures of their mouths. For example, both Lina and Mica said that their speech difficulties were secondary to tongue problems, rather
than an issue related to their palate. While for Mica an erratic movement of her tongue was the reason why she could not ‘speak well’, for Lina the little size of her tongue was the origin of her speech problems:

´[...]Liliana: Why do you have to have those checks-ups? Mica1: ‘cause I’ve got a little problem here (points out mouth) Liliana: Ok Mica1: The thing is I can speak well... and that’s it [...]Liliana: What is that little problem? Mica1: the problem is that (LP) I can’t speak very well... my tongue always rolls back... here (opens her mouth) and that’s why I can’t speak well’

´Lina2: The thing is my tongue is too tiny [...] I think I can’t pronounce some words well because of my tongue´

Despite the presence of a cleft palate in these participants, there were no clear links between speech difficulties and palate issues in both Lina’s and Mica’s accounts. For these girls their speech problems emerged from their tongues rather than their palates. The absence of a causation relationship between a palate issue and their speech problems might be related to the fact that for some children the meaning and location of the palate was unclear. For instance, talking about her speech therapies, Carolina pointed to her throat when I asked her where her palate was located. Potentially the fact that the palate was a less visible feature of their mouths, made some participants relate their speech issues to other more visible structures, such as tongues and throat which are also implied in the voice production.

We can see from the above stories that CLP was described by the children as physical and functional differences with which they had been born. These comprised tangible and visible bodily features such holes in lips and palates, and nostrils; or speech difficulties and altered sensations such as the discomfort of having an opening between their mouth and nose. Speech difficulties were mainly viewed in association with the malfunctioning of structures involved in the voice production such as tongue, throat and palate.

An important aspect to highlight from this section, is that despite the dominance of the biomedical term CLP within clinical practice and therefore its frequent use by doctors involved in
the participants’ healthcare plan, the children drew on their own terms and language to construct their descriptions. This is indicative of their agentic roles in the production of knowledge about their condition. Closely related to the above accounts, I discuss in Chapter 6 how the children looked at these bodily differences as features that can be medically ‘fixed’ or ‘improved’. Having addressed how the participants defined their CLP, in the subsection that follows I explore how they make meaning of the origins of their condition.

4.2.2 Explanatory models of causation: religious, environmental and inheritance notions

Three main explanatory models for the origin of their condition were identified and are discussed in this subsection: religious, environmental and inheritance. A common aspect of these explanatory models was that CLP was a bodily trait with which they had been born.

4.2.2.1 Religious notion

As discussed in Chapter 2, causal attributions to CLP are culturally rich and varied. A common lay view is that traumatic events during a pregnancy, such as falls and natural forces, such eclipses, can result in malformations in the foetus (Castro, 1995). These lay conceptions have been described as strongly historical and contextually dependant. For example, while the hazardous effect of eclipses on pregnancy seems to be a prevalent belief within Hispanic culture (Case et al., 2014; Castro, 1995), a child with CLP is seen as a gift from God among some Buddhist communities (Li-Rong, 1990).

In the context of my research, there was an array of diverse and rich accounts explaining the origin of CLP. One of the most prevalent among the participants was the religious notion. These explanatory models were clearly influenced by parents’ and teachers’ previous stories and potentially also their religious beliefs:

‘[…]Liliana: Let’s imagine… I had a little friend who was born with a hole in his lip and he wants to know why he was born like this, so he asks you: “hey Jeronimo, do you know why some children are born like this?” What would you say?
Jeronimo 1: Uhmm mmm mmm (long pause) I would say that children are born with a hole in their lips because they were created by God in that way
L: Ok, and what do you think about that?
Jeronimo 1: I think... that God wants to see how other children (without CLP) treat us (children with CLP)
L: That’s interesting
Jeronimo 1: My teacher told me that the other day’

Here Jeronimo illustrates the influence of his teacher’s religious discourse of the origin of CLP in his own model. The phrase ‘God wants to see how other children (without CLP) treat us’ in the above story denotes that being born with CLP in some way followed God’s will. His account also interwove God’s will with a sense of life purpose—to know how other children treat children with CLP. This tendency to find a purpose or objective in what was described as God’s will, was also evident in other participants’ accounts. Similar to Jeronimo, Carlos described being created by God, just as he was, in order to demonstrate his determination and capacity to deal with difficult life situations such as CLP surgeries. However, he clarified that such an explanation only made sense to those sharing his same religious beliefs:

‘[…] Liliana: If Lucas (a boy from hypothetical situation) would ask you: “Carlos, why and how did your mouth problem happen?” what would you say to him?
Carlos 1: Ehhh I would say, we’ve been born like this and that’s it… God created us in this way and that’s it… if he believes in God obviously […]’
(Walking interview)
[…’]Liliana: mmm I remember you said that children were born with mouth problems because they had been created by God in that way... but why does that happen? Do you have any idea?
Carlos 2: I think God wants to know how children endure these things like surgeries and then show they can do it and go forward’

Later on, during our walking tour, Carlos mentioned feeling proud about the way he had overcome some difficult situations related to his CLP across his life, reinforcing this sense of purpose that he had described earlier:

(Walking interview)
‘[…]Carlos 2: look... if that guy (a boy which used to mock him at school for his visible facial difference) had to go through a surgery like mine, he wouldn’t be able to get through... not

20 ‘Dios quiere conocer como los niños resisten estas cosas y salen adelante’.
even one! [...] if I could decide ... I would be born again with my mouth problem... now I know what it is like to going through surgeries and I know that I’m able to get through them’

Some children perceived that the loss or absence of a bodily structure associated with CLP had a divine purpose and would be compensated by God with an alternative capacity. – Dilan for example, commented that despite being born with a missing part in his lip, he had been compensated with extra intelligence:

‘[...] Liliana: ok... so people with CLP are not sick, is that what you mean? 
Dilan 1: ... yeah! For some reason God took something away but in return gave us something extra, in my case brain! 
Liliana: ok... so people... hmmm ok so if someone has a missing part in their lip... God gives them something else in return? 
Dilan 1: yeah, isn’t it mummy? 
Mum: (shy laughter) 
Dilan 1: my mum said that 
Liliana: ok she said so 
Mum: and what did God give you in return? 
Dilan 1: my brain! 
Mum: (laughter) 
Liliana: Brain! (laughter) ok, cool 
Dilan 1: I’ve always been the 12th in my class... I don’t know I just like being the 12th, don’t like being the first’

Something similar was mentioned when walking and talking with Manuel and his family (younger sister, uncle and mum). When asked for the reason for being born with no palate, something that he had mentioned earlier, Manuel asked his mum, apparently for the first time, why he was born with his birth condition. His mum explained to him that despite the challenges associated with CLP, this was an event allowed by God with a clear life purpose – being a ‘great boy’:

‘Liliana: ohhh! Ok I’ve got it... so you were born without palate 
Manuel 2: nodding 
Liliana: and why? 
Manuel 2: because I was born without palate 
Liliana: why were you born without palate? 
Manuel 2: ehh... because I had no palate 
Liliana: and why? 
Manuel 2: ehh... mmmm
Liliana: can you imagine any reason? Have you ever been told about the reason for being born without palate?
Manuel 2: I´m told to wear the ´paladar´... yeah I should wear it
Liliana: ok... but have you been told about why you were born without palate?
Manuel 2: “Ma” (mum)! Why was I born without palate?
Mum: why? hmmm because... my God created you in that way for some reason “papi”... one has a purpose here in life and my God maybe created you like this with a purpose... maybe to be a great boy... yeah growing up intelligent’

This episode in the walking tour allowed me to observe how Manuel adopted his mother’s explanation into his own account. When, further in our conversation, the topic of being born with CLP emerged again, he drew on his mother’s explanation to make sense of the origin of his CLP:

‘Liliana: hey and mmm... have you ever seen a child without palate?
Sister: yeah I have! One day I saw a girl with a pink “paladar”
Liliana: ok... so they have a “paladar” because they were born without palate, right?
Manuel 2: ehh they were born without palate... they were born with only teeth, ´cause God created them without palate’

Natalia also talked about the origin of her CLP, as an event related to God’s will, being clear that being born like this was not a negative life event, or something affecting her physical beauty:

‘Liliana: ok and why do you think you didn’t have that lip fold (nasolabial fold) when you were born?
Natalia 1: I just was born like this... yeah my mum told me
Liliana: mmm and why do you think that happens? can you imagine any reason maybe?
Natalia 1: don’t know... I can’t imagine anything... what I can say is I was born like this... God made me in this way and that’s it (LP) my mum every time says to me that although I had a surgery in my mouth... I’m very pretty... and if a child tells me something rude or just makes me feel bad.... I should report that to the teacher’

The above stories demonstrate the way in which religious models, mainly from their parents, are incorporated into the participants’ models of causation. Religious notions of the origin of congenital conditions have been largely described as prevalent among some communities in Africa and Asia (Li-Rong, 1990; Oginni et al., 2010). A common element of these models is that

21 ‘Paladar’ is a colloquial term referring to a palate retainer – a dental appliance for orthodontics treatment.
22 Dear.
Congenital conditions are seen as a consequence of divine punishment and/or karma, causing feelings of self-blame and contempt in parents, with negative impacts on children’s wellbeing and mental health (Adeyemo et al., 2016; Case et al., 2014; Gichuhi & Nduta, 2020; Mednick et al., 2013). In contrast, my participants’ religious models have a more positive connotation: CLP had a positive effect on, and gave a special purpose to their lives. This in some way echoes previous research showing the positive impact of religious beliefs and spirituality on coping mechanisms of individuals experiencing certain health conditions (Abraído-Lanza et al., 2004; Gomes et al., 2015; van Laarhoven et al., 2010). Several authors have studied how people draw on religion to make meanings of adverse life events, including the onset of an illness (Abraído-Lanza et al., 2004; Bryant-Davis et al., 2012; Cassibba et al., 2014; Gomes et al., 2015). Religion appears to ease the way in which we face and make sense of those events happening in our bodies that are often out of our control (Boddy & Lambek, 2013). According to Shilling (2012), events happening in the body, such as those related to the end of life, are in some way more accepted when these are interpreted on cultural and religious grounds. Shilling’s argument can be also applied to those events occurring before birth or early life, such as the origin of congenital conditions.

In the children’s explanatory models, the fact that the origin of CLP depended upon God’s will denotes that neither parents nor children had control over this event. This indicates that the occurrence of CLP was somehow unpredictable. As mentioned in Chapter 2, the origin of CLP involves genetics and environmental factors, which means that a specific causal factor can be difficult to identify. The unpredictable nature of CLP, alongside the fact that clinicians might not deliver the information about the cause of their children’s condition (Kuttenberger et al., 2010; Young et al., 2001), might suggest that children and parents seek answers from other sources, such as religion, in order to construct meaning around the origin of their condition. Although religious notions were expected to be found, given the strength of religious beliefs in a predominantly Catholic country (Beltran Cely, 2013), other children constructed causation models drawing on environmental events such as exposition to pesticides, infections, smoking and traumatic events during pregnancy. These are discussed in the next subsection.
4.2.2.2  Environmental factors: pesticides, smoking, alcohol, trauma and parasitic infections

As noted in Chapter 2, health conditions and behaviours such as malnutrition, smoking, alcohol consumption during pregnancy as well as the use of teratogenic drugs are involved in the pathogenesis of CLP. Some of these factors were included in the models of causations of participants, with some stressing the potential negative effect of toxic substances in the development of the foetus. Beto, for instance explained how parents’ lifestyle and health status might increase the risk of having a child with CLP:

‘[...]Beto 3: it’s when you were born with a hole... that happens because your dad smokes or drinks too much, also because you mum is ill [...]’

Here, Beto spoke of two risk factors associated with CLP: smoking and alcohol consumption. Maternal consumption of alcohol and smoking have been associated with an increased risk for orofacial clefts in epidemiological studies (Mossey & Modell, 2012; Watkins et al., 2014). However, the emphasis Beto made on both paternal (smoking and alcohol consumption) and maternal (being ‘ill’) factors as potential causes of CLP, indicates that for him not only maternal factors contributed to the origin of CLP but also paternal. This is significant to note as the origin of congenital conditions as well as difficulties with conception are predominately attributed to the mother (Palomba, 2018; Spohr, 2018).

Models of causation which involved the deleterious effect of maternal exposition to toxic substances, such as pesticides in the foetus, were also discussed by some of the children. When asking about the reason for being born with ‘a droopy nose’, Marcos explained that the occupational exposure of his mother to insecticides during her pregnancy, could be the reason for his nose shape:

‘[...] there is a theory... “poresin” (an insecticide), she might have breathed it when she was pregnant with me’

The teratogenic effect of insecticides is both a common lay and medical belief despite limited scientific evidence of its role in the genesis of CLP (Ortega-Miller et al., 2017). This belief is perhaps more prevalent among rural communities and those working in floriculture. It was
frequent during my clinical practice that parents working in flower plantations associated their chronic contact with insecticides during their work lives with their children’s CLP. This might explain why Marcos included this environmental factor into his model, given that he and his mother were originally from a rural area.

Traumatic events during pregnancy and delivery were also described as potential causes of CLP. Camilo and Coni explained that, either accidental and intentional injuries on the pregnant woman, had the potential to affect the facial anatomy of the foetus and/or newborn. Despite not knowing a specific cause, for him an accidental blow with the umbilical cord during delivery might be the reason why some babies were born with CLP:

‘[…]L: do you know why some children are born with CLP?
Camilo 1: (Long pause) uhmmm no really...
L: hmmm and… your parents … maybe… have explained something to you?
Camilo 1: mmm no, they haven’t...
L: hmmm could you think of any reason?
Camilo 1: …yeah I imagine … they’re moved violently during the delivery and might be beaten too… let’s say with the umbilical cord… but too violently, so babies left with that’

Here Camilo constructed an explanatory model drawing on his own imagination. Different to the majority of my participants, his model seemed not to be informed by others’ stories. Although the availability of parents’ stories facilitated the children’s construction of their models, Camilo’s example shows that the children could also make meaning of their condition, despite the potential absence of parents’ stories.

Slightly different to Camilo who created a model drawing on his imagination, Coni incorporated a trauma-based theory in her model, informed by a story recounted by her mother. She explained that her brother’s speech and dental problems (he had CP, Coni had CLP) were the result of a traumatic event suffered by her mother during her pregnancy:

‘[…] when… my mum was pregnant… with Sergio (brother) … my mum said that when she told my dad that she was pregnant, he got very angry with her… and started fighting… and he threw some hot water from a pan to her belly…that’s why Sergio can’t pronounce the “R” well and has crooked teeth too’.
Interestingly she had a different model for explaining the origin of her own condition. Again, drawing on a story of her mum, Coni went on to say that her CLP had been caused by an infection acquired during her mum’s pregnancy:

‘My mum told me that a bug was eating my mouth when I was a baby. Then, in “Sonrisa” (refers to Operation Smile) I was rid of it’

This notion of an infection was also mentioned by a few of my patients when I used to work in clinical genetics. Central in this idea is that cleft lip (CL) is secondary to an infection in which the foetus lip is ‘eaten’ by a parasite. This infection seems to be understood as an in-utero and silent condition which is only manifested at birth. Similar to the religious model, this model might be also shaped by socio-cultural features of the research context. Parasitic infections are common in tropical and subtropical countries such as Colombia and as such, communities are frequently aware of this group of diseases. Potentially this awareness of the frequent links between parasitic infections and tissue damage (e.g. gastrointestinal parasites might cause extensive intestinal damage) might have important influences in the construction of this model.

The above two subsections have discussed two main models: religious and environmental. While in the former, the origin of CLP was linked with God’s will, in the latter, CLP had a rather circumstantial and contingent cause. In both models CLP was understood as a congenital rather than a condition acquired de novo in children’s lives. The children’s understandings of the origin of their condition were clearly shaped by their parents’ accounts and were greatly influenced by the cultural and social characteristics of their contexts as many of them incorporated religious beliefs, endemic infections, and life circumstances into their explanations.

4.2.2.3 Genetics and inheritance

Only one boy talked about inheritance and genetics when explaining the potential causes of his CLP. The concept of inheritance and genetics was explained in the light of other family members with the same condition. Drawing on the fact that a relative of Beto had CLP, he explained how CLP followed an inheritance pattern in his family:
‘Beto1: ... it’s (CLP) also like something that happens, because someone else in the past was like that
L: When you say something like that what do you mean? Can you explain that more for me?
Beto1: for example, someone who was born like that in your family
L: Ok... is it like something that is passed through generations
Beto1: Yeah it’s like something that someone else in your family also had
Liliana: and is there anybody in your family like this?
Beto1: yeah, I think ... I’m not sure if it’s my dad’s cousin or my dad’s uncle, one of them has CLP too’

Although Beto had also explained the potential contribution of parents’ alcohol consumption and smoking in the genesis of CLP, he was clear in saying that his CLP was a trait inherited from his father side:

‘[…] but in my case, I was born like this because my dad had a nephew who was born like me too... but he died when he was only seven months, he had a lot of health issues and just couldn’t overcome them, he was so tiny’

Beto’s model denotes that he was familiar with biomedical explanations for the origin of CLP such as the role of inheritance and parental lifestyles (e.g. alcohol consumption). This familiarity might be related to the fact that he seemed to have greater contact with staff of the clinical site. As indicated in Chapter 3, the participants of this study were involved in a health care plan which meant that they had frequent contact with clinicians. But unlike other participants, Beto seemed to have a more participative role with Operation Smile. He commented on having been interviewed by Operation Smile staff in which he had shared his experience with treatments. He also mentioned that some ‘gringos’23 (potentially people from Operation Smile International) had come to his home to talk to and take photos of him and his family. Having greater contact with clinical staff might imply that he had more opportunities to learn about the role of factors such as parents’ lifestyles and genetics (both biomedical models) in the genesis of CLP.

It is likely that during visits to Operation Smile, children and parents would have had genetic counselling, including discussion of the aetiology of CLP. However, it is notable, that even in the cases that followed an evident inheritance pattern, the inheritance transmission of CLP was not

23 Coloquial term used in reference to foreigners.
discussed by the children. Mica and Santi, two siblings with CLP, and Coni a girl with three first-degree relatives with the same condition (mum and two siblings), never mentioned the idea of inheritance or family transmission. While Mica and Santi said that God had created them in this way, Coni, as mentioned earlier, spoke of a parasitic infection and traumatic event on her mother. Indeed, this potential overlooking of the family pattern of CLP in Coni’s family was reinforced by her mum who also did not mention this, despite being present in the interview when discussing the origin of CLP with Coni. The absence of inheritance factors in Mica, Santi and Coni’s models might be related to the complexity of theories of inheritance and genetics that explain the origins of CLP. Within genetics counselling, it is common to use complex terms and theories to explain inheritance patterns of CLP syndromes to patients; terms and theories that might be difficult to understand by non-medical audiences. This finding might also suggest that the children’s non biomedical models (a religious one in Mica and Santi’s cases and an infection in Coni’s) resonated more strongly with their wider beliefs and ways of understanding their lives.

Having discussed the children’s explanatory models, I now move on to examine their views towards concepts of health, illness and normality. As indicated in the introduction of this chapter, this discussion offers insights into how children framed their bodily differences, in relation to categories such as illness, disorder, defect and abnormality – terms frequently used within biomedicine.

4.3 Exploring CLP in relation to biomedicalization

This section addresses the research question: how do children understand concepts of health, and illness, and how is CLP defined within this conceptual framework? It is important to explore how children define their conditions against a conceptual framework of health and illness, given the dominant biomedical definitions of CLP in pathological term (e.g. anomaly, dysmorphism, defect, anatomical disruption). All of these terms are pejorative and denote problems or issues with health and the body.

The first part of this section is a descriptive exploration of the participants’ understandings of health and illness. This description is important for examining how they define their CLP within
this conceptual framework in section 4.3.2. These concepts were explored with the participants across the three interviews, in some instances assisted by pictorial cards. As I mentioned in Chapter 3, these pictorial cards were images that represented several different types of bodies which aimed to facilitate conversations about these concepts with the children. Although these cards were used with the majority of the children, their understandings were also examined without the use of this creative tool. Walking tours to the park, where other people were often doing exercise also prompted conversations about the body, health and illness.

4.3.1 Conceptualising Health and Illness

4.3.1.1 Bodily markers of health and illness

The majority of children talked about health and normality in terms of being physically in shape. This status entailed being ‘not too fat neither too slim’, and having enough muscular mass:

‘Beto 1: a healthy body should have some muscles... it’s not too fat neither too slim... it’s like me (laughter)[...] like... with this part (shows me his gastrocnemius muscles- the superior and posterior portion of the leg) like a bit strong ... also with six pack abs’[...]

In the above story, it is evident how Beto perceived the health of his body; his physical body fitted with his concept of health, which consisted of having some muscular mass and a healthy weight. The maintenance of a healthy physical status implied following healthy diets, such as eating fruits, vegetables, avoiding ‘fatty things’ (Mariana) and doing regular physical exercise. To illustrate, Camilo’s and Coní’s accounts of healthy bodies:

(Walking tour)
‘[...]Camilo 2: I like those “maquinitas”24 (points out to exercise machines in the park)
Liliana: really? why do you like them?
Camilo 2: ‘cause I can do exercise... in that way you feel ... you feel... like... what was I saying? Ahh you feel you’re doing exercise and then when you look at yourself... you’re in good shape
Liliana: ohhh ok what does doing exercise mean for you?
Camilo 2: doing exercise is to improve your health... and your physical condition’

24 Equipment to do physical exercise placed in some public parks.
In similar way to Beto, Camilo spoke of his body as being in good shape. For him, the key for maintaining a good shape was doing physical activity, something that he did frequently. The accounts of these participants show how health represented a visible and physical marker (body shape, muscular mass) that could be achieved and maintained through certain behaviours and habits—regular physical activity and balanced diets. Like these children, many other participants spoke of their bodies in positive ways, particularly highlighting their physical attributes such as being in good shape.

Although the notion of health in terms of body fitness and healthy practices has been also reported in previous research with children and young people (Bhagat & Howard, 2018; Monaghan & Gabe, 2016; Rail, 2009; Thomas et al., 2014); the youngest participants drew on other visible and physical variables to conceptualise healthy and ill bodies. For Juliana and Javier, two of the youngest interviewees, being ‘clean and tidy’ were also corporeal markers of a healthy status:

‘Liliana: I would like to know what someone healthy looks like to you? can you tell me how do you imagine someone who is healthy?
Juliana 1: ... you should take a shower... to be clean and tidy... brush your hair and so [...]

‘[...] Liliana: have you ever been ill?
Javier 2: no, I’m well
Liliana: are you? I wonder what does being well mean?
Javier 2: ok... it’s being clean, taking a long shower everyday, I took one today
Liliana: really? Tell me more about that!
Javier 2: ok, I didn’t use too much water, I just soaped myself 3 times and washed my hair 3 times’

For Javier and Juliana, being healthy meant being bodily clean and tidy. Similar to being in shape, being clean and tidy could be maintained through self-care and hygiene practices such as everyday bathing and brushing their hair. Unlike cleanliness and hygiene in the above concepts
of health, in the following example we can see a more emotional and sensorial description. For Manuel health meant being well, something that he linked with being happy and the absence of physical pain:

‘Manuel 1: let’s have a look at this (pictorial card 15)
L: this one? ok... what do you think? Is he healthy, non-healthy, normal... I mean what do you think?
Manuel 1: he´s happy
L: is he? Why?
Manuel 1: ’cause ehhhh uhhmm he´s smiling
L: why do you think he is smiling?
Manuel 1: he´s well he doesn’t have any pain’

Manuel enables us to see a different form of understanding health. In contrast to the accounts of Coni, Beto, Camilo, Juliana and Javier who described health mainly on the grounds of physical and visible variables and healthy practices, for Manuel other forms of embodiment such feelings and sensations were also indicative of an individual’s health status.

Indeed, physical sensations were indicative of illness and could be physically manifested in the form of embodiment of sadness and pale skin. For example, symptoms such as pain, tiredness, headache and fever were frequent sensations linked with illness according to Dilan, Fabian, Manuel, Mariana, Mica and Santi. To illustrate two extracts from Dilan and Manuel:

‘[...]Dilan 1: someone ill looks like... pale... pale skin, mmm with bags under their eye, fever [...] (referring to pictorial card 13) he might feel pain... he might be sad for that reason... she might be ill ... headache or stomach-ache’

‘[...]L: what does somebody ill look like?
Manuel 1: it’s when you feel pain in your head (makes sad face and grabs her head), your feet, your legs, your hands, your wrists, your hands in your whole body!’

These examples illustrate how illness and health were status that had an effect on emotions.

4.3.1.2 Illness, socio-economic status and social support

Some of these physical markers of illness, such as being untidy, non-clean or sad, were linked
with people’s socio-economic status. Physical visible signs such as slimness (Coni), uncleanness (Javier) and ‘lying/sitting on the street’ (Camilo-Javier) represented an ill and vulnerable status associated with the lack of basic necessities, such as food and shelter:

‘Coni 1: somebody ill… mmm they don’t eat at all… you can see their bones under their skin… if you don’t eat at all, you won’t have muscles in your body… I mean… they can’t stay warm and well wrapped up … because they don’t have a roof over their head’

‘[…]Camilo 1: I’ve seen many people like them (pictorial card 9)... and that makes me feel sad
L: And why do you say he is not healthy?
Camilo 1: He’s drunk a lot…my dad drinks too…sometimes… and…mmm he’s homeless too
L: Why does that make you feel sad?
Camilo 1: …they just have a little blanket, sitting on that cold street floor, they don’t have a family and sometimes have some signs of abuse too’

Here Camilo linked physical signs of poverty and little social support (both associated with illness) with alcohol consumption. This behaviour was described as an unhealthy practice given that it may affect the functioning of organs such as the liver:

‘[…]Dilan 1: ok this guy seems drunk…lying on the street, looking really bad. It’s possible to say that… he’s ill’
Liliana: ok…It’s possible to say he’s ill … why?
Dilan 1: he drinks too much […] probably he’s got damage in his liver, because he drinks too much[…]’

Signs of physical deterioration in the body and alcohol consumption for some children were also indicative of mental health problems. This is exemplified by Lina’s description in reference to the pictorial card of a homeless person:

‘[…]Lina1: he’s ill, he must have something working bad in his mind, because he’s drinking too much[…]’

The association the children made between socio-economic disadvantage and illness might be influenced by the socio-cultural context of the research. That this study was conducted within a country of the majority world, and with the majority of participants belonging to strata 1-2 (living
mainly in poverty) and 3-4 (low and middle class) may mean that the children were more likely to be aware of the living conditions of those in poverty, and so to reflect on how these factors affected people’s wellbeing and health.

So far, we have observed how the participants as a whole conceptualised health and illness in bodily terms. Many of these participants drew on their own healthy bodies and healthy practices to support their definitions of health. Some participants emphasised physical variables such as body size and shape in describing health and illness (Beto and Coni). Other descriptions focused on individuals’ behaviours and practices, such as hygiene, diet, physical exercise, and alcohol consumption (Coni, Javier, Camilo), or bodily sensations and emotions, such as feeling well, pain and fever (Manuel, Dilan). These descriptions are reflective of three main dimensions of the body: corporeal or material (e.g. weight, sensations such as pain, embodiment of emotions) (Crossley, 2001; Williams & Bendelow, 1998), performative (e.g. embodiment of emotions, healthy practices, behaviours) (Burkitt, 2014; Williams & Bendelow, 1998; Williams, 2001) and mind (e.g. mental health problems linked with alcohol consumption) (Nettleton, 2013; Williams & Bendelow, 1998).

4.3.1.3 Biomedical understanding of disease

A few, mainly the oldest children, talked about illness in more biomedical terms. These accounts featured descriptions of risk factors, pathogenesis and clinical manifestations of certain diseases. For instance, both Dilan and Camilo spoke of the pathogenesis of cancer and risk factors of cardiovascular disease respectively in their own words:

‘[...]Liliana: do you know any other type of diseases? Dilan 1: Cancer Liliana: What is cancer? Dilan 1: It’s when a cell ehhhh touches other cells and they start to grow too quickly ... others.... And then those bad cells spread over the body and affect the whole body and then you lose your hair and that’s it’

‘[...]Camilo2: if you´re overweight... you can suffer from a heart attack Liliana: a heart attack? Why? How?’
Camilo2: it’s like… the body… too much food, the body accumulates too much fat inside…
Liliana: ok…
Camilo2: …and if you don’t do exercise to burn calories
Liliana: yeah
Camilo2: … you can have a heart attack... ‘cause if you eat too much and then there is too much fat in the body that can make the heart stop beating’

Camilo spoke of risk factors such as unhealthy diets and obesity in the aetiology of cardiovascular diseases, and Dilan described the uncontrolled growth of cells in cancer. Both of these accounts reflect a biomedical explanation of these conditions.

Other children also spoke of clinical features of certain diseases and the importance of medical tests for diagnosis. For example, Lina explained how flu (a short-term condition) and cancer (a long-term condition) were different in their course and how medical tests were important to confirm the diagnosis of cancer:

‘ […] ok… well … for example when you think you caught a cold… you know you caught a cold because you start feeling you have a sore throat …right? your voice sounds husky and all that stuff… but… say with other diseases… like cancer and [unintelligible] you don’t know when they come […] you need run some tests first to know if you have cancer’

In the same vein, the oldest children described conditions such as problems in the nervous system (Dilan), mobility, memory and skin problems such as those with ‘discoloured skin’ (vitiligo\(^\text{25}\)) (Beto):

‘ […]Beto 1: I have a neighbour for example… he has a disease since he was born, he can’t walk, not even to take a shower by his own, he’s lying on the floor at all times […]’

Here Beto linked a disease with a permanent mobility impairment that affected the development of everyday activities such as bathing. He also described sudden memory loss as a disease which impeded an individual’s memory. For him memory loss was expected in the elderly, but abnormal

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\(^{25}\) This is long-term skin hypopigmentary condition characterized by progressive loss of pigment-melanocytes.
if it its onset was sudden in young people, highlighting the importance of age in understanding disease and illness.

This section has provided a descriptive analysis of children`s concepts of health and illness. For the children health meant functioning well or looking good physically, following certain behaviours (e.g. healthy diets), practices (hygiene) and the absence of physical pain. In contrast, illness was coupled with bodily markers such as pale skin, being overweight, physical sensations such as pain, poor social support, the lack of basic necessities, and practices such as alcohol consumption and unhealthy diets. The children also used examples of chronic and long-term conditions such as cancer, mobility impairments and permanent changes in the physical appearance (‘discoloured skin’) to explain what an illness entailed. As mentioned in the introduction of this chapter, having this conceptual framework is important as it allowed me to explore children`s understandings of their condition with regard to the term illness – a term that is explicitly (pathology, disorder) and implicitly (e.g. dysmorphism, defect) used to define CLP by biomedicine.

4.3.2 Exploring CLP in relation to biomedical terms

4.3.2.1 CLP: ‘Normal but less common’, ‘different but the same’

The general conversation around health and illness concepts, discussed in the previous section, enabled me to ask the participants about their own health and illness experiences. This often sparked talks about their own experiences of acute illness such as chicken pox (Mariana), and amoebiasis (Dilan). In other cases, this question resulted in conversations around their CLP. In these instances, the tendency of the children was to refer to CLP as a bodily difference instead of illness or abnormality:

‘[…]Beto 1: well I´m kind of different, the thing is I have like… (a non-narrated element) and… but it´s not an illness
L: ok… what do you have?’
Here, Beto illustrated how CLP meant a point of bodily difference but made clear that this did not mean an illness. Similar to him, other children spoke of their CLP as differences that made them non-normal, ill or different from others in fundamental ways. For example, Lina referred to her CLP (speech problems) as something less common but still normal:

‘[…]Liliana: I’ve heard that some people say that speech and listening difficulties can be a kind of illness …what do you think?
Lina 3: I think it’s something normal… ok …I don’t speak perfectly and obviously something must have happened to me… but… I think it (speech impairment) isn’t a disease…
Liliana: hmm ok how is something normal? Tell me more about that
Lina 3: well… it (speech impairment) is normal because any person in the world could have the difficulty I have; I mean speaking like I do. But it is not normal too because… the other way round… the majority of people don’t speak like I do’

Here Lina described her speech difficulties as a common and normal condition which anybody could have. Like Beto, her CLP was marked by a functional difference which made her distinct from the most common speech patterns. Similar to Lina’s concept of CLP as something normal but at the same time less common, Natalia and Camilo explained how, despite their differences, having CLP did not make them different from others:

‘[…]L: do you think we are all the same or different?
Natalia 1: we’re all the same… no matter our differences… like me here (points out her lip)… like those in a wheelchair and things like that’

‘Camilo 1: all of us are the same but also different
L: why?
Camilo 1: we’re the same ‘cause we’re all sons of God, and we’re all human beings. We’re also different because each of us has a characteristic feature
L: give me an example?
Camilo 1: for example, me and my lip. You and your hair like this… like shorty. A friend of mine Lucas, mmm no Lucas, no sorry, it’s Simon, his eyes are like Chinese eyes’

26 ‘ehhh labio paladar y labio fisurado ehhh ah si, labio fisurado y paladar hendido’.
We can observe from Camilo’s account how he considers himself the same as everyone. His view is greatly influenced by his religious belief that all humans were equally created by God. Even with his ‘lip’, the fact of being a son of God made him equal to other individuals. This was a common way in which other children explained why many children, despite their bodily differences, were not fundamentally different to other people.

The children’s views towards CLP in terms of difference but sameness and normality appeared to be influenced by their parents’ views. Talking about types of bodies with Jeronimo, his mother intervened to give an example to his son of how people, despite their bodily differences were still normal:

‘[…] For me a normal body is a complete body, created by God… for example a female or male body… they have some particular physical features that make them different from each other, but they are still normal despite their differences’

There seems to be an implicit normalisation discourse in Jeronimo’s mother intervention. Drawing on an example of the physical differences between female and male bodies, she explained to her child how bodies could be normal despite their differences. It is likely that this was intended to make her child aware that bodies, such as Jeronimo’s, were still normal, despite their apparent differences. A normalisation discourse seemed also to be implicit in a recurrent phrase Natalia’s mother said to her child, when she reported mockery at school. Natalia mentioned that according to her mum she was ‘beautiful even with her surgery scar’.

Like Beto in his earlier account, the majority of children explicitly said that CLP was not an illness. They drew on their own concepts of illness to support their views. Dilan for instance, explained that people with CLP had no physical signs of illness such as pale skin or sensations such as fever or pain. They did not suffer from a serious health condition such as ‘something in the nervous system’:

‘[…] Liliana: and what about people with CLP…might they be ill too? Dilan 1: no (shaking head)
Liliana: no? Why?
Dilan 1: well, `cause... for example, they are not pale, they don’t have a fever and they don’t have any serious illness [...] Dilan 1: like something in the nervous system or something like that’

A serious illness, as mentioned in section 4.1.1.3, involved permanent and disabling conditions such as mobility impairment, memory loss and vitiligo. Like Dilan, Beto drew on his concept and examples of illness to explain why CLP was not an illness:

‘Beto 1: it (CLP) is very different to illnesses such as... that one of the discoloured skin (vitiligo- he had explained) or when people lose their memory
L: in what ways is it different?
Beto 1: mmm `cause for example, if you are born like this (CLP) that doesn’t mean that you’re gonna lose your memory or your skin is gonna change, like those with the skin discolouration (referring to people with vitiligo) [...] uhmmm the only thing is you sometimes don’t speak very great and when you’re a baby you can’t eat very well [...] for example...my mum fed me with a dropper’

For Beto, CLP did not fit with his concept of illness as this did not mean permanent change in the physical appearance as it was the case with those with discoloured skin (vitiligo), nor was it a progressive functional impairment such as memory loss. For him, those with CLP experienced some intermittent speech issues and transitory eating difficulties. Similarly, Javier and Carolina, two of the youngest children, explained that people with CLP were or felt well (which meant for them being healthy), as long as their cleft was surgically repaired. For example, Carolina in reference to other children attending Operation Smile said:

‘[...]Carolina2: they’re well
Liliana: and why?
Carolina 2: their lips were already operated, so they’re well
Liliana: how’s that being well, can you explain that to me?
Carolina2: mmmm how I can explain it to you (LP) mmm ...mmm
Liliana: mmm ...mmm
Carolina2: for example, I feel well, normal...without pain but I was operated’

It is possible to see how the surgical reparability of CLP was something that allowed children to ‘feel well’, an important indicator, according to them, of being healthy.
These stories demonstrate that the children understood CLP mainly in non-pathological terms. Despite acknowledging the physical and functional differences associated with CLP, the participants talked about their bodies and their differences in terms of sameness and normality. In many ways CLP did not fit with their wider definitions of illness and disease and the surgical reparability of their condition seemed to be an important reason for not seeing CLP as an illness.

4.4 Summary

For the children, CLP meant the physical and functional differences of their bodies. These differences were congenital and were described using children’s own language (e.g. a problem, a difficulty) instead of biomedical terms (e.g. cleft lip and palate; orofacial clefts; disorder; defect; pathology). There were three prevalent models of causation in the accounts of the participants: religious, environmental and genetics-inheritance (although only one child presented this mode of understanding causation). The presence of parents’ stories facilitated the children’s construction of these models, but this construction was not limited by the availability of parents’ stories.

The children’s views towards the origin of their condition were greatly influenced by parents’ lay beliefs, and to lesser extent, by biomedical knowledge. Despite being diverse, the explanatory models all associated the origin of CLP to events and circumstances occurring before or during birth, indicating that CLP was understood as having a congenital but contingent/circumstantial nature. Also of note, is how those contingencies had clear links with children’s social and cultural contexts. Religious beliefs, ideas such as the occupational exposure to insecticides, and traumatic events during pregnancy were interpreted in particular ways framed by the socio-cultural circumstances of my participants and their families. This supports the idea that the described models were socio-culturally informed.

The participants conceptualised health and illness in several different forms: drawing on physical and visible features such as weight, muscular mass, being clean; physical manifestations of individuals’ emotional status (e.g. bodily signs of sadness and pain were markers of illness); physical signs of poverty (malnutrition- being in the street) and behaviours and practices such as
alcohol consumption, doing exercise and healthy diets. Examples of chronic and long term conditions and a more biomedical understanding of disease (e.g. risk factors for cardiovascular diseases in Camilo’s account, the importance of diagnosis test for cancer in Lina’s) were also used to explain their concepts of illness.

Despite CLP being considered a bodily difference, it was not understood as a pathological condition or abnormality. Several reasons supported their view of CLP in non-pathological terms. First, CLP was a difference but also something of common occurrence. Second, their bodily differences did not alter their status of being the same as others; this idea was influenced by religious beliefs and by parental normalisation discourses. Third, their differences did not fit with certain bodily markers of illness, such as pain, or a progressive pattern or a permanent disability, such as memory loss. Instead, their differences could be treated through medical treatments.
Chapter 5  The social costs of CLP: stigma, emotions and agency

5.1  Introduction

Several studies have suggested that children with visible, facial differences are frequently the object of stigmatised behaviours (Alderson, 2011; Beaune et al., 2004; Sharif et al., 2013; Strauss et al., 2007; Tiemens et al., 2013) including teasing, bullying and staring (Feragen et al., 2009; Sharif et al., 2013; Sousa et al., 2009; Strauss et al., 2007; Tiemens et al., 2013). It is also pointed out that negative social responses towards their differences make children spend more time alone, have limited interaction with groups, and experience greater anxiety particularly during new social encounters (Hunt et al., 2005; Murray et al., 2010; Sousa et al., 2009; Strauss et al., 2007). The risk of emotional distress and social disruption among this population has led healthcare CLP services to pay more attention to socio-relational issues and to offer greater emotional support to parents and children (Kelton, 2001; Krueckeberg & Kapp-Simon, 1993; Rankin & Borah, 2003; Wehby & Cassell, 2010; Wong Riff et al., 2018).

Despite the awareness among researchers and healthcare practitioners that individuals with CLP are frequently stigmatised, with serious social and emotional consequences, I noted in Chapter 2 that little is known about their experiences of stigma (Murray et al., 2010; Tiemens et al., 2013), their link with the presence of a difference (Sousa et al., 2009) and the mechanisms which children use to cope (Feragen et al., 2009; Murray et al., 2010). This is a research lacuna, identified in Chapter 2, which this chapter will address. The chapter seeks to provide a greater understanding of the nature of stigma among my participants. To do this, in the first section (5.2) of this chapter I conceptualise children’s experiences of stigma within the school context according to the model proposed by Link & Phelan (2001): labelling, stereotyping, status loss, social discrimination and psychosocial stigma. The focus on experiences of stigma within the school context reflects the children’s perception of school as the environment where they reported the majority of episodes of stigmatisation and socio-relational difficulties. In the second section, I examine the way the participants respond to, and resist the different forms of stigma, as well as how they negotiate their social interaction and interpersonal relationships. This
chapter therefore explores the following research questions: what are the social costs and difficulties that children face as a result of their condition? How do children assert their agentic roles within the context of their everyday lives?

5.2 Forms of Stigma

In the section that follows I characterise the children’s experiences of stigma according to components of the stigmatisation process proposed by Link & Phelan (2001). These are: labelling; stereotyping; group separations (‘us’ from ‘them’); status loss and discrimination. I chose this model given that it pays particularly attention to the broader social effects of stigma, something particularly relevant for exploring the social costs of having CLP.

5.2.1 Labelling, stereotyping, status loss around facial features and speech issues

As discussed in the literature review, human differences are frequently assessed according to social and body norms set up within a specific socio-cultural context (Link & Phelan, 2001; Rose, 2009). Those attributes that are identified as being outside of concepts of social and bodily normality (labelling) tend to be seen as undesirable and associated with negative social meanings (stereotyping) (Link & Phelan, 2001). The process of labelling and stereotyping involves a reduction of the individual’s status as those attributes marked as undesirable are connected to deviance, abnormality, and incompetence. This status loss has important impacts on individuals’ social identities and socio-relational lives as those in a lower position in the hierarchical scale are often socially rejected and excluded.

Almost half of the participants reported events where features of their faces, or their speech were the object of labelling and stereotyping. The shape of their nose, the tone and the intelligibility of their speech were the features more frequently labelled and stereotyped, giving way to mockery – the most frequent form of devaluation. Mockery entailed negative comments, rude gestures and the use of pejorative terms about CLP and its associated features. This is exemplified by Marcos and Natalia who reported name-calling by school peers in relation to their nose shapes:
’Marcos 1: there’re children kinda cruel you know... when they are mad on me they call me smashed nose [...]’

’[...]Natalia 1: ehhh a boy, he’s no longer in the school... we were in 1 grade and he mocked me
Liliana: what was his name?
Natalia 1: ehhh Samuel
Liliana: why did he mock you?
Natalia 1: because of my surgery
Liliana: what did he do? ...
Natalia 1: he ... called me big nose’

In addition to the nose, features of the children’s mouths were also targets of mockery. Missing teeth, gum protuberances, upper lip asymmetry and upper lip scars were the attributes most frequently labelled. For example, Jeronimo and Coni recounted episodes of their school lives where dental issues (congenital missing teeth and secondary gum protuberance) led to name-calling by peers:

’Coni 1: well, one day, we all were in the cafeteria and I was eating... and Mateo came to me, and Sergio (brother) and Julian too... and Julian was like: hi! Brain-shaped mouth... I just remember that and I feel like I’m gonna cry’

’Jeronimo 1: Uhhmmm one day a boy told me I was a fool
L: aja
Jeronimo 1: And he also told me I was an ugly and dirty pig [...]’
[...]L: why do you think he told you those things?
Jeronimo 1: Mmm, ’cause of my mouth’

Similar to Jeronimo and Coni, Valeria, Carlos and Isa also experienced negative comments in relation to their mouth. However, in these cases such comments were directed at less visible facial features such as post-lip surgery scars. Here, it is important to mention that I use the word ‘scar(s)’ for clarity purposes; the children instead used terms such as ‘a line’ or simply pointed to their upper lip region. While Carlos commented that a peer repeatedly lifted up a side of his own

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27 Lips, perioral region, teeth, gums.
28 ‘¡hola boca de cerebro!’.
29 ‘Me acuerdo de eso y ya se me ponen los ojos llorosos’.
lip with the aim of mimicking Carlos’ lip asymmetry, Valeria and Isa reported more ambiguous comments such as being called ‘ugly’:

‘Carlos 1: He (annoying peer) did like this (gesture: lifts up his upper lip) and was pointing to me at all times ...and saying things that I really don’t remember (LP) […]’

‘Valeria 1: yeah... a girl from my class... she’s like: you’re ugly! but I don’t pay attention to her
L: ... who says you’re ugly?
Valeria 1: Sara, she’s really rude
[…L: what do you think they call you ugly?
Valeria 1: don’t know I think because of my mouth or nose
L: what’s wrong with your mouth or nose?
Valeria 1: with my mouth... because of this (points out her scar – a birth scar)’

These stories reveal how labelling and stereotyping entailed pejorative verbal language such as name calling, the use of negative adjectives and rude gestures in reference to some of the participants’ attributes. Although the participants’ experiences with mockery seemed to take the form of explicit actions, comments or gestures, in other cases these devaluing actions were less explicit. Santi, for instance reported not to know the meaning of the term ‘ñeco’ that he was called by some peers, nor the reasons for being called that:

‘Santi 1: Yeah, he (referring to pictorial card 13) might be sad because he feels bad ’cause he can’t walk or maybe he doesn’t like something... or...maybe somebody mocks at him
L: mmm ok... mmm by the way... mmm I wonder if you have ever felt bad like this child (pictorial card 13)?
Santi 1: yeah, when they call “ñeco”
L: what???
Santi 1: “ñeco”
Mum: hum... at school... children call him “ñeco”, but I have no idea what it means
L: who says that?
Mum: children
Santi 1: ... everybody in the classroom... 7, 6, 5 (grades), everybody
L: how’s that? tell me...
Santi 1: the thing is ... they used to call me crazy ... first...when I was little...but now they call me “ñeco”
L: but... what does “ñeco” mean?
Santi 1: ha! I don’t know’
There is a clear disnarration style in the way Santi introduced mockery into his story (a hypothetical situation in which the child in the pictorial card is sad because of mockery at school). This disnarrated element in Santi’s account allowed a conversation about his own experience of mockery. ‘Ñeco’, similar to other Spanish words such as ‘manco’, and ‘tuerto’, are pejorative terms used in reference to people with missing fingers, arms or eyes. Although the meaning of this term was unclear for Santi, potentially such a term was used in reference to his microtia (congenital little ear) an associated feature of his CLP. This label and stereotype of Santi’s microtia as ‘ñeco’, clearly illustrates how the congenital attribute of a little ear denotes a negative meaning for some other children of bodily incompleteness.

However, perhaps even more significant from Santi’s story is that, for him, the name-calling had a negative emotional impact; Santi said that it made him ‘feel bad’. Stigma often comes with emotional consequences, particularly evoking emotions such as shame and anxiety (Gichuhi & Nduta, 2020). Indeed, several children spoke of their emotions when experiencing stigma. I discuss this point later in this chapter.

Apart from discrediting some of their physical differences, negative comments were also directed towards the children’s speech. Dilan, Valeria and Mariana reported being mimicked frequently for their pronunciation and voice tone. To illustrate, here are two excerpts from Dilan and Mariana:

‘Dilan 1: there’s a boy and a girl ehhh they’re like always annoying me and they’re like: … hummm hum hummm (mimicking mockery towards Dilan’s speech)’

‘Mariana 3: say... I’m talking and maybe I say something incorrect... so...some boys at school... some boys start mimicking me (LP) [...]’

School was the context in which speech mockery occurred most frequently. Activities in which the children had to speak in public, such as reading aloud or oral presentations, were particularly perceived as provoking mockery. These episodes became more recurrent as school activities demanded further use of oral language. Dilan, for instance, explained that episodes of mockery
in relation to his speech, started to be more frequent when oral presentations in class started to be more often in fourth grade:

‘[...] Dilan 1: in 4th grade... that school (his past school) was extremely boring, all the time from “transición”\textsuperscript{30} to 4th grade was always boring
Liliana: was it boring? And that (speech mockery) happened since “transición”?  
Dilan 1: No, it was only in 4th grade
Liliana: only in 4th grade... in 3rd grade?
Dilan 1: No, ‘cause in 3rd grade we didn’t have so many oral presentation... neither in 2 grade’

It was common that the labelling and stereotyping of the children’s facial differences and speech difficulties gave rise to status loss. When individuals’ attributes are marked and defined as undesirable, their status is also devalued (Link & Phelan, 2001). Mariana provided an explicit example of how her speech difficulties, and associated treatments, were used by her peers to devalue her health status and to categorise her as ill:

‘[...] I had a surgery, right?... so they start saying that I’m ill...and I need the doctor and so on... but that’s not true, ‘cause I’m not ill or things like that, I just go to the speech doctor (speech therapies) and that’s it’

Comments devaluing their health status were not the only form through which the children reported lost status. In some cases, physical attributes such as downward nose tip were also linked with the stereotype of bodily imperfection and abnormality. Marcos, for instance was explicit in saying that apart from being mocked for his facial difference (nose shape), according to his peers his nose made him not ‘perfect’ like them:

‘[...] The thing is... I feel this (nose shape) like a weight on me, ‘cause at times they (peers) mock you and criticise you too much [...] they say: “we were born perfect and you weren’t” and that hurts me’

The social label of (im)perfection ascribed to Marcos in the above excerpt, connotes a separation between groups – those with a most common body (perfect) vis-à-vis those with CLP (imperfect).

\textsuperscript{30} Pre-school grade.
This is reflective of the division between ‘us’ (the stigmatiser) and ‘them’ (stigmatised) described by Link & Phelan (2001). In this component of the stigmatisation process, the labelled person (them) is deemed to be less valuable or inferior than ‘us’ (the stigmatiser) in the social scale. At the epicentre of status loss is that the bodies of those in the stigmatised group are considered to be deficient (Scambler, 2009) and less than complete (Strauss et al., 2007). This idea of deficiency could be also be present within peer culture, given that children often draw on bodily markers such as height, physical appearance and skills (e.g. sport skills) to make meaning around bodily competence (Corsaro, 2018; Prout, 2000). In relation to children with CLP, peers often assess others’ competence drawing on their speech intelligibility (Lee et al., 2017). It is possible that facial visible differences and speech difficulties of the participants were perceived as signs of bodily incompetence by peers. Indeed, this notion of bodily incompetence was implicit in the labelling of Mariana as ‘ill’ because of her need to attend speech therapy, and Marcos as imperfect because of his facial difference.

So far we have seen how the children´s physical and functional differences related to CLP were the target of labelling and stereotyping, which compromised their status and were the source from which lines of division between groups (‘us’ from ‘them’) were drawn. In addition to understanding the process of marking an attribute as deviant (labelling), and linking it to negative meanings (stereotyping, status loss), it is equally important to scrutinise the social consequences of these. This is important as one of the major limitations of social science studies of stigma is that they rarely offer a nuanced picture of the social costs of being stigmatised (Link & Phelan, 2001; Scambler, 2018). Specifically in relation to children with CLP, there is also a need to further conceptualise how these negative social responses impact on children´s social lives. The following two subsections are focused on analysing the social cost of the stigma process in the participants’ social lives. To do this, I draw on two core social outcomes of the stigmatisation process described by Link and Phelan: discrimination and psychosocial stigma (stigma self-awareness).
5.2.2 Discrimination: strong and subtle forms

Discrimination is an expected outcome of the processes of labelling, stereotyping, separation of groups, and status loss (Link & Phelan, 2001). This entails actions and omissions which denote social rejection and exclusion and that are often difficult to detect (Link & Phelan, 2001; Scambler, 2018). In this subsection, I discuss some of the participants’ accounts, in which both subtle and obvious forms of discrimination were observed. The contexts where these discriminatory episodes occurred most frequently were breaktimes, group play and class activities. This analysis allows me to better understand the children’s potential self-awareness of their stigmatised attributes, and the social cost to them.

The majority of the interviewees who reported the previously mentioned components of stigma (labelling, stereotyping, group separation, and status loss), also reported experiencing discriminatory actions from peers. These stories of discrimination and social rejection were marked by both explicit and less clear links with the labelling and stereotyping of their differences. A clear experience of discrimination was reported by Jeronimo in our second interview. He said that his peers did not accept him in football matches because of his ‘mouth’ referring to his visible lip differences. In other cases, the link between exclusion or rejection and the children’s visible differences was less explicit. Many of those who reported mockery about their visible differences and speech difficulties also experienced restrictions on participating in social activities, such as group plays. However, those constraints were often explained by the children as linked to the complexity of their peers’ culture practices, instead of an explicit connection to their stereotyped attributes. This reflects that discrimination often follows subtle patterns can be difficult to detect (Jones et al., 2017; Van Laer & Janssens, 2011). For example, Isa who was called ‘ugly’ by a peer in reference to her lip scar, mentioned that her difficulties in making friends were related to the complexity of managing her peers’ emotions:

‘Liliana: ok, tell me how do you make friends?
Isabel 1: it’s difficult
Liliana: oh really? why?
Isabel 1: (LP)
Liliana: what’s the most difficult part of making friends?
Isabel 1: (massive pause) someone gets angry with someone else and... then they can’t become friends [...] I don’t play with anybody... I just go up, ‘cause my classroom is upstairs... and I take my lunch sitting on the floor next to my classroom door’

‘Becoming friends’ was a phrase frequently used by the participants in reference to having someone to play with in the breaktime. From Isa’s account it is possible to see that in the absence of friends, she had to spend the breaktime on her own. Like Isa, Mica and Carolina also reported spending the breaktime alone. For instance, Mica connected her difficulties for social interaction in the breaktime to her peers’ rude behaviour towards her:

(we are sitting on the floor corridor next to the playground, it is a rural school so it is an open campus)

‘[...] Mica 2: children are too rude... I don’t know but... say... a boy is here (points out the corridor where we are) and there’s another boy over there (points out the playground) ... and one of them is gonna hit the other one but I’m near by... so I come to them and try to save him (the child in danger). But the other boys start saying to him: “she’s gonna hit you, let’s go, she’s a stupid girl”... but I’m not stupid!’

Having no friends and spending the breaktime on her own was a persistent pattern throughout the three interviews with Mica; she was the participant who reported most experiences of social isolation at school, but she did not explicitly link this to CLP. It is worth mentioning that Mica and Santi had a syndromic and bilateral form of CLP. This means that some of their facial differences such as lip scars and in Santi’s case his microtia were particularly visible. In a similar way to Carolina, despite the absence of an explicit link, discrimination often takes the form of subtle actions which are difficult to identity. As indicated in the above account, Mica’s chances to interact with others were limited by her peers’ rude and devaluing responses towards her, a potential stigmatised response towards her differences.

The social difficulties experienced by Carolina at school were slightly different. Her loneliness during the breaktime was described by her as due to a strict hierarchical system of play, in which ‘the boss’ determined whether Carolina could or could not take part in a group play:
‘[…] Liliana: how is that? So you say to them if you can play with them and they say: no, you can’t?
Carolina 2: well, yeah at times… yeah at times… I say: “hey, can I play?” Sometimes, they say yeah, you can… but sometimes I say: “hey can I play?” And they say: “no you can’t!” Liliana: Mmmm and… why do you think that happens?
Carolina 2: I don’t know…(SL) I hadn’t thought about that
Liliana: but, can you think of any reason?
Carolina 2: what you mean?
Liliana: mmm if you could say to them: “hey why can’t I play?” What do you think they would say?
Carolina 2: ohhh yeah, I have asked them
Liliana: oh yeah? What did they say?
Carolina 2: well, sometimes they make a circle and talk between them… and then… when they have a decision… someone says to me: “no, you can’t play ’cause I’m the boss and I decide who can play” ’

Although the stories of Isa, Mica, Carolina did not reveal an obvious form of discrimination, (as it was in Jeronino’s case), their accounts were marked by peer exclusionary practices. The absence of an explicit link between these experiences and CLP, makes it difficult to conclude definitively that exclusion was related to their condition. However, discrimination rarely follows a clear pattern and can therefore be overlooked in studies of stigma (Link & Phelan, 2001). This means that obvious discriminatory actions, or omission towards those who have been labelled and stereotyped, are not frequent. Rather, discrimination takes the form of ambiguous and difficult to detect exclusionary acts (Jones et al., 2017; Van Laer & Janssens, 2011). The accounts of Isa, Mica and Carolina demonstrate a shared experience of social exclusion. This commonality across these cases, alongside the recognition that discrimination often follows a subtle pattern, might suggest that these reports of exclusion were subtle forms of discrimination.

5.2.3 Psychosocial stigma- ‘Stigma Self- awareness’

The social cost of the stigmatisation process goes beyond rejection and exclusion. It is also common that stigmatised individuals incorporate labels and stereotypes as real aspects of themselves (Link & Phelan, 2001; Scambler, 2009). Within this act of self-consciousness or awareness, beliefs about the devalued character of their attributes lead to feelings of fear, shame, loss of self-esteem and subsequently avoidance of socio-relational encounters. This is known as psychosocial stigma (Endriga & Kapp-Simon, 1999; Sousa et al., 2009; Strauss et al.,
In this subsection, I analyse some of my participants’ accounts in which some elements of the psychosocial effect of stigma were observed.

5.2.3.1 Feelings and concerns about new social encounter: shame about speaking

Many of the participants were aware of labels and stereotypes around their visible differences and speech. This awareness in some cases gave rise to feelings of shame and negative anticipations about potential social responses towards their differences. Marcos, Coni and Dilan spoke of feeling nervous during their first school days, given that their bodily differences could enact negative social responses. In Marcos’ case such a feeling was linked to a sense of uncertainty about his peers’ responses when seeing his nose shape and hearing his speech difficulties: ‘I was nervous... about... how they were going to react ... to my problem.... I was expecting to see how they reacted to my problem’.

Dilan and Coni also reported feeling nervous and embarrassed on their first school days. Although Coni left reasons for her emotions as a non-narrated aspect of her story, Dilan did assert to feel embarrassed about speaking:

‘Coni 2: mmm I was kinda nervous... afraid of... (non-narrated)
L: And nervous why?
Coni 2: mmm I don’t know (shy laughter)’

‘L: do you remember your first day at school?
Dilan 2: mmm I didn’t know anybody
Liliana: how did you feel?
Dilan 2: mmm
Liliana: mmm happy, sad, bored? Scared? Normal?
Dilan 2: mmm weird
Liliana: weird? How weird?
Dilan 2: don’t know I just felt weird [...] I don’t know... mmm I just felt kinda embarrassed about speaking’

Negative social appraisals towards the children’s differences had significant negative emotional impact. As noted in section 5.2.1 Coni reported feeling sad when remembering having been called ‘brain-shaped mouth’ by her school peer. This might indicate that, for Coni, actual or potential
stigmatising events were sensitive topics to speak of, and for that reason she decided not to expand on this in her account. Despite this non-narrated element in Coni’s account, stigma self-awareness is evident in Marcos and Dilan’s narratives. For them, the public display of physical and functional differences seemed to raise concerns about either negative social reactions or the performance of a stereotype-relevant task (unintelligible speech in the case of Dilan).

In our last interview, Dilan expanded on his experiences on his first school day. Seeing photos of past times in the nursery, he said that feeling ‘embarrassed’ about speaking led him to avoid speaking with peers and spend much of the time alone:

(\textit{doing his life story book and seeing family photos})
\textit{’[...Liliana: you just told me that when you went to the pool (he had showed a photo of him in a pool) that was a nice time... What about less nice times, do you remember any one? 
Dilan 3: ehhh when ehhhh this one (points out a nursery photo-he is dressed up for the nursery graduation ceremony) when I was a baby... 
Liliana: ok, why?
Dilan 3: well, mmm ‘cause ... I mean I did like that time, but mmm I felt shame 
Liliana: why?
Dilan 3: don’t know, I just felt shame 
Liliana: mmm perhaps is there a reason?
Dilan 3: well, because I didn’t... I didn’t speak to anyone 
Liliana: didn’t you?
Dilan 3: I didn’t, I just played by my own’}

Shame commonly emerges when our social selves are likely to be evaluated negatively by others and therefore frequently experienced in first social encounters (Goffman, 1968). However, Dilan was aware of the stigma associated with his speech and expressed feeling shame about speaking, suggesting that, although not explicitly portrayed in his account, Dilan’s awareness that his speech was likely to be a target of stigma, given that this was an attribute previously reported as enacting mockery, could be the reason why he did not interact verbally with new peers.

Dilan’s account could be reflective of the negative effect of stigma awareness on individuals’ interpersonal lives (Brown & Pinel, 2003; Pinel, 2002). These authors note that individuals who are aware of their stigmatized status tend to be more sensitive to the ‘stereotype threat’ effects
This refers to how individuals’ awareness that they might be judged negatively when conducting a task in which they are stereotyped, leads individuals to feel less confident about developing such a task, in some cases showing the stereotyped behaviour for which they are judged (Steele, 1997). Dilan was aware of the stigma associated with his speech and potentially that was the reason he did not speak. On a social interactional level, this potential stigma threat effect impacted negatively on his social life as not approaching new peers meant that he had to play by his own. This might indicate that speech intelligibility (something that reduces chances of stigma as Beto mentioned earlier) could make some children feel confident about speaking and therefore interacting.

5.2.3.2 Feeling loved and supported ‘being special’

As discussed in Chapter 4, the children drew on different terms and language to name and refer to their CLP (e.g. a little problem, difficulty, body language). These bodily differences were linked with a common lay concept/meaning of disability –‘being special’ in the case of Lina. ‘Being special’ apparently held a positive meaning for Lina. She explained that her difficulty made her a special girl, a category that generated positive social responses such as the care and affection she received from her mother’s boss:

*(during the last encounter, Lina constructed her life book and at the same time Lina, her mum and me were seeing some family photos)*

‘Mum: this is her (Lina’s mum boss) … “doña Elisa” … she loved so much Lina… yeah… indeed she didn’t like children too much but she loved (cross talk) Lina 3:’cause I’m the only one! Liliana: how’s that?
Lina 3: mmmmm don’t know (shy laughter)
Mum: don’t know… she found something special in Lina, something nice
Liliana: what do you think Lina?
Lina 3: mmm don’t know …I was special
Liliana: how special?
Lina 3: may be… ‘cause she realised that… I had a difficulty and all these things. Ehhh and she just loved me’
Indeed, this social tag of ‘being special’ was also perceived by Lina as beneficial in the school context. According to Lina, her school peers’ awareness that she was special made them help her when she had communication difficulties with teachers:

‘Lina 3: sometimes... well mmm... when they (teachers) don´t understand ...say... if they (teachers) don´t know me very well ... then they (peers) repeat to her what [unintelligible] Liliana: ok...can you say it again... what you ...?
Lina 3: what I xxxx, what the teacher didn´t understand about what I said
Mum: she means if the teacher doesn’t understand what Lina says, then a child tells the teacher what Lina said’

Lina’s account seems to reveal a positive effect of the stereotype implicit in being ‘special’. For Lina, apparently, her status of being ‘special’ encouraged positive social responses and this was something that made her feel confident about her communication abilities:

‘[...] Liliana: ooohh ok, and do you like that? (having help from peers when the teacher does not understand her speech)
Lina 3: Yeah! I do... that means they (peers) are listening to me and they understand me when I speak’

The term ‘special’ is often seen as ‘a sentimental way of portraying disabled children’ (Connors & Stalker, 2007, p. 28). These authors argued that despite the positive connotation of this stereotype (being ‘special’) which is often used by parents to highlight their children’s value despite their differences, this could also work as a form of discrimination. Considering someone to be special often implies a process of othering in which a line of division is drawn between them (special) and us (non-special) (Connors & Stalker, 2007; Rutherford & MacArthur, 2018).

However, for Lina, being treated as someone ‘special’ had some benefits. This label served as a social sign which encouraged her peers to help her, an action Lina described as positive. Apart from easing her communication with teachers, something important within the school context, her peers’ help was also evidence for Lina that they were both able to understand her speech and interested in her opinion, the latter potentially making her feel more socially included.
This section has provided a characterisation of the participants’ experiences of stigma drawing on the components of the stigmatisation process proposed by Link & Phelan, (2001). This characterisation has shed light on how physical and functional differences were the target of labels and linked with negative meanings which in many occasions implied status loss. They were both a component and an outcome of the stigmatisation process. I also provided some examples of subtle forms of discrimination which affected the children’s chances of interacting with peers within school breaktimes and playing settings. I also presented some examples in which the children’s stigma awareness of potential negative social appraisals towards their differences (stigma self-awareness) gave way to emotions such as shame and nervousness, limiting their social interaction. However, the children’s awareness of labels and stereotypes related to their CLP had also a positive side for one child (Lina). Stereotypes such as being ‘special’ conveyed their need of help, something that Lina perceived as beneficial.

In the following section, I analyse how my participants responded, resisted, and coped with the stigmatisation process. To do this, I start by examining how they managed both initial social encounters (the context where the stigmatisation process often began) and the risk of being stigmatised within the school context. This is followed by a discussion of how some children responded to, resisted and dealt with actual stigmatised events (e.g. labels, stereotypes, and discrimination).

5.3 Stigma response and resistance

As discussed in the previous section, the majority of the children experienced labelling, stereotyping (rude gestures, negative comments, pejorative words) and predominately subtle forms of discrimination within everyday life at school. A common way in which the interviewees narrated these experiences was to address how they resisted and responded to these events. Patterns of responses towards different components of the stigmatisation process were identified and are discussed in this section.
5.3.1 Approaching new people: the importance of speech

As seen in the previous section, new social encounters, such as those that occurred on the first day of school, raised concerns in some of the participants about social responses towards their visible and functional differences. Although some participants reported feeling nervous about their peers’ reactions or embarrassed about speaking, there were also children who narrated how they dealt with those feelings and concerns, and started interacting. The temporal and spatial context in which a first encounter took place, was an important factor for reducing embarrassment about speaking to new peers. This is exemplified by Carlos. He explained that finding ‘the perfect’ time and space to talk to someone, was something that made him feel confident to interact with new people. These ‘perfect’ contexts included breaktimes, and instances in which there was less supervision from teachers such as being outside the classroom:

‘Carlos 1: Making new friends is not too difficult, it’s just you have to find the perfect time to make them [...] it’s like mmm if you feel kinda embarrassed to talk when you’re in the classroom, ok so go and do it in the breaktime! There you don’t feel embarrassed’

The emotion reported by Carlos was expected given that embarrassment (as mentioned earlier) alongside pride are frequently experienced in new social encounters. These emotions arise when our social selves are exposed to the judgements of others (Goffman, 1968; Scheff, 2003) something that occurs frequently in social encounters. Despite feeling shame, an emotion that could be accentuated by the negative connotation of their visible and functional differences (stigma self-awareness), Carlos seemed to act confidently when approaching new peers while playing in an adult-free context. This could be related to the fact that despite speech difficulties his speech was very clear.

Activities developed during those initial encounters consisted of brief talks where some children introduced themselves and asked others’ names, invitations to play, offers of help with school work and sharing things. For example, Beto and Camilo who did not report events of mockery explained that they often approached new peers by asking their names and with invitation to playing:
‘Beto 3: well you first have to say hello... for example when a new child comes to my school I came to them and say hello and asked their name I also offer them my help [...]’

‘Camilo 1: when I was little... I was there... and felt kind of bored, ‘cause I was there alone, so a boy was there and I said: hey you wanna play? And he said: yeah and then the more we play, the more we became friends’

Like Carlos, Coni who also felt nervous in her first day at school, said that being kind and supportive with others was the way in which she started interacting. She explained that playing, sharing her things such as stationery items with others and offering them her help with the homework were important within a new social encounter:

‘L: how do you make friends?
Coni 2: Uhmmm I talked to them, I share my things, if someone borrows you something so you lend it too
Brother: playing!
Coni 2: Yeah playing...helping them do the homework for example’

Regardless of the context in, and the activities through which the children started interacting with others, these initial social approaches entailed the use of verbal language. As the previous examples show, these approaches involved brief talks and the intelligibility of children’s speech was a key aspect for the success of these initial approaches. This was evident in the way children such as Lina and Ricardo found difficulties interacting with peers because the peers did not understand them. Lina for instance, narrated how her attempt to approach a new girl at school was unsuccessful given that Lina’s speech was not understood:

(walking interview)
‘[...] Lina 2: there is no one like me at school... that makes me feel bad... I wish there were more children like me in the school
Mum: I’ve seen some children like you at school
Lina2: at school?
M: yeah, there was a girl, the last year...wasn’t there?
Lina2: ohhh but she’s no longer at school
(We get at home, we are soaked. We sit down in the dining room. Mum brings some hot drinks and food)
L: can you tell me about that girl?
Lina 2: well, it was the last year, there was a little girl... she had the same scar on the lip... and I asked her if she had the same problem as me... but she didn’t understand what I said’

As the above story shows, communication difficulties between Lina and her peers limited her social interaction. Speech difficulties not only make her initial social encounters more difficult, but also impact on her regular everyday interaction, such as school class activities. Further on in our conversation, Lina illustrated how her speech impairment affected team work activities:

‘Lina 2: We were doing a workshop in class, we have to read aloud... it was my turn to read... I read and some minutes later some girls next to me were like: “Lina, honestly we didn’t understand what you said”.
L: what happened then?
Lina 2: well, I had to read if I wanted to get the workshop done... so I wouldn’t stay there... doing nothing, so I carried on, I continued reading’

Social interaction with peers were also affected by speech difficulties in the case of Ricardo. Talking about his past days in the nursery, Ricardo explained how his peers’ inabilities to understand his speech led him to spend much of the time at his nursery alone:

(we were sitting on the doorstep of his home main entrance).
‘[...] Ricardo 2: when I was little I didn’t have friends... I was alone... I just walked around the schoolyard
Liliana: why?
Ricardo 2: ‘cause... ‘cause.... Ehhl (LP) they didn’t understand what I said ... because of my palate’

The accounts of Lina and Ricardo have exemplified the negative impact of communication difficulties on social interaction, particularly for initial social encounters. This finding suggests that contrary to existing research reporting facial appearance as a key aspect for being accepted in social groups (Amodeo, 2007; Samizadeh & Samizadeh, 2019), speech difficulties of the children have also a heightened importance in shaping their chances to interact with peers. This finding is particularly relevant as there is less known about how communication difficulties of children with CLP impact on children’s social lives (McCormack et al., 2010).

It is significant to note that although Carlos and Coni were objects of labels and stereotypes, both were confident in interacting. A potential explanation for this is that their speech was clearer in
comparison to children such as Ricardo and Lina (particularly Lina who had a significant speech impairment) who reported difficulties with approaching new people. Having intelligible speech seems to be a factor making some children feel more confident to interact. This could be related to the fact that children without speech difficulties are often positively appraised by peers (Lee et al., 2017). Indeed, this was illustrated by one of the participants who said that ‘speaking well’ was a protective factor for mockery, something achievable through speech therapies:

‘Beto 3: if I hadn’t gone to OS, well first of all I wouldn’t be speaking in this way, other children wouldn’t understand me and might mock me, because in some schools there are some children mocking others when they don’t speak well. If I hadn’t gone to OS, I wouldn’t be here speaking well with you and wouldn’t have made such big steps’.

it is important to note that although all participants except for Juliana who had only cleft lip had speech difficulties, some children showed greater difficulties than others. These differences could be related to the severity of CP and associated features, the frequency and quality of speech therapies (at the clinic and home) and age.

5.3.2 Managing information about CLP: Openness vs Privacy

Link & Phelan (2001) argue that for stigma to be operationalised there should be power imbalances within the stigmatiser-stigmatised relationship. This means that when stigmatised individuals manage to minimise these power differences through resistance or showing an empowered self, the stigmatiser is likely to lose power. For that reason, it is inappropriate to look at stigmatised groups as passive recipients of stigma. Some of the children demonstrated different forms of resistance such as strategies to prevent stigma as well actions in which they actively and/or subtly challenged their stigmatisers.

Apart from speaking well, addressing their functional and physical differences openly with peers, could also serve to reduce stigma risk. This openness implied answering questions about their physical differences, even allowing others to touch their lip scars. This is exemplified by Beto who talking about the reasons for not being annoyed by peers explained:
‘[...] because I become friends of them first. When I was in Fomeque (a town) in my first school (baby brother interrupts), when I came for the first time to that school, some children were like: “what did you have there (mouth)? Open your mouth”, so they asked me: “why did you have that (lip scar)?”. So the first days they were like... asking me many things, why my nose like this and so on. But as time passed by, we became friends. Liliana: mmm ok, so it’s like... having a good attitude or something like that?, in that way children don’t bother you? Beto 3: yeah it’s about being friendly, ’cause they might not like you for being like this (CLP), but if you become friend of them first, ... the thing is you have to make friend of them’

From the above account it is evident that Beto was aware of the risk of mockery that having bodily differences implied. His openness to talk about his CLP, and even allow peers to physically explore it (‘being friendly’), was something that, according to him, minimised the risk of being stereotyped and discriminated for his condition. This finding reveals how stigma awareness can also have a positive effect on how people respond to being stigmatised. Individuals who perceive that some attributes might cause discriminatory actions can also actively mobilise resources to resist the stigmatising tendencies (as cited in Brown & Pinel, 2003; Pinel, 2002). As the above account shows, Beto was aware of the potential stigma he could experience because of his differences and presented his openness to talk about his differences with peers as a strategy to navigate social life with peers (and prevent mockery) in the light of his bodily differences. This example connects with existing literature highlighting the importance of educational anti-stigma interventions in reducing stigmatised behaviours. These strategies involve discussing myths and misconceptions of stigmatized conditions such as mental health problems in order to provide evidence that these are common and do not mean a risk for society (Wei et al., 2013).

Despite the positive effect of Beto’s openness on his social live, this was not a common pattern among the participants. Around a quarter of the interviewees preferred to keep information about their condition, including treatments as something private. By privacy I refer to how and what information is accessible to others (Anthony et al., 2017; Baghai, 2012). Camilo, for

31 ‘Los niños me preguntaban que qué era lo que tenía ahí entonces que abra la boca entonces me decían usted porque tiene eso ahí. Los primeros días así como preguntarle a uno muchas cosas y después le cogían la amistad a uno’.
instance, explained that he preferred not to give much information on the origin of his lip scar when other children asked about it:

‘Liliana: hey and mmm at school, have you ever been asked about the reason for your unique lip (upper lip scar)?
Camilo 3: yeah! at all times
Liliana: really?
Camilo 3: say...when a new child comes to the school... like in the second term, he was like: “why do you have that?” (annoyed)
Liliana: and what did you say then?
Camilo 3: ...I say: “ehh it’s a scar”
Liliana: mmm ok and if he’d said: “and why do you have a scar?” What would you have said?
Camilo3: I’d have say: “it was a surgery”
Liliana: and- (cross talk) Camilo 3: and would have walked away [...]
Liliana: why would you have walked away? Don’t you like to talk about that?
Camilo: ...well...with you I feel safe. But with other people.. mmm no at all [...] ‘cause talking about this with them (peers) mmm... they’re too gossipy! (grabs his face like indignant) [...]’

Camilo’s narrative illustrates how, by regulating information about his CLP with his peers, he protected himself from potential negative comments. In a similar way, Isa and Marcos reported keeping features of their CLP and treatments as secret and private aspects of their lives. When doing their life books in the last interview, both left out events related to their CLP and treatments. While Marcos explained that his surgeries ‘simply were part of his private life’, Isa was explicit in saying that her dental appliance was an aspect she preferred to keep out of her life book, because if her peers knew such information she might be mocked:

‘Liliana: hey, mmm I can’t remember what is that “aparat” for?
Isabel 3: it’s to get my tooth fixed
Liliana: ohh yeah, and would you like to include that in your life poster, or rather no?
Isabe l3: Ehmmmm no
Liliana: can I ask why?
Isabel 3: Mmm yeah (LP) ’cause the thing is they could laugh at me
Liliana: could they laugh at you?
Isabel 3: humhi (yes)
Liliana: why? How´s that?
Isabel 3: (LP)
It appeared that Isa and Marcos were attempting to protect themselves from labels, stereotypes and potential discrimination, by limiting peers’ access to information about their condition. However, some children not only restricted access to narrative information about their CLP, but also limited peers’ physical interaction with their condition. Valeria commented how she restricted the physical contact from curious peers to her lip and nose:

‘[...]’ L: ok... what do you think she (a peer) said to you ugly?  
Valeria 1: don’t know, I think is because of my nose and my mouth  
L: and how’s that? What do you have in your mouth and nose?  
Valeria 1: well, my mouth, because something happened here (points out her mouth), look, there’s a girl in my classroom, she was bothering me and wanted to touch my mouth, she wanted to know what happened with my mouth... but I didn’t say anything to the teacher, and then when the teacher realised that the girl was bothering me, she said to the girl to stop doing that  
L: tell me more, how was that? What did you do then?  
Valeria 1: nothing, I just dodged her and walked forward. She was about to touch me! (sounds worried)... asking me what I had in my mouth and my nose and asking me why I had my nose like this, like flat’

Valeria’s case shows an alternative dimension of the management of stigma. In contrast to Camilo, Santi, Marcos and Isa who preferred not to disclose some information about their CLP and treatments, Valeria avoided intrusive physical contact from her peers. These stories shed light on how some children drew on privacy to create physical and information boundaries around their condition to protect themselves from stigma.

5.3.3 Embodiment of anger

In addition to managing stigma risks, the children also narrated how they resisted and responded to actual forms of stigma. Core to these responses was the embodiment of emotions, such as anger. This was a frequent emotion reported by the participants in relation to their experiences
of stigma and many of them used it to retaliate verbally or physically against their peers’ insults. While boys more often challenged their stigmatisers by engaging in physical fights, the tendency of girls was to verbally counter their peers’ comments. For example, talking about his experience of being called ‘ñeco’ by some peers, Santi’s mum (present in the interview) said that Santi engaged frequently in school fights for being called that:

‘Mum: the thing is when he first got at school… that wasn’t easy to him at all... all those...children mmm were surprised to see his... mmm it’s like... I tell him... I’ve tried to explain to him that... with that advert about carrots 32, have you seen it?
LA: yeah, yeah I have
Mum: I told him that we all are the same, but we have some differences too... just a few differences... but those children didn’t understand that and started bullied him [...] so... thanks God the situation is getting a little bit better now... since 2016...... yeah ‘cause before that he was just fighting, fighting and fighting... I was practically studying with him... the teacher used to phoned me everyday and was like: “please come to school as soon as possible mum, because your child is just not tolerant” ...I can understand that ...he couldn’t deal with that... you know... it is difficult to be in those shoes’

Like Jeronimo’s mother (Chapter 4), a normalisation discourse is evident in Santi’s mother’s intervention, in which Santi’s sameness is emphasised despite his bodily differences. From this account it is also possible to see how, despite not knowing the meaning of this word, Santi resisted the stigma implicit in this name-calling by engaging in physical fights with his stigmatisers. Although Santi did not explain the potential reasons for the mockery and his fights (a non-narrated element in the story below), he did speak of how he engaged in verbal confrontations every time his sister was mocked for her physical differences:

‘L: Santi... why do you think children annoyed you? Can you think of any reason?
Santi 1: I don’t know... they didn’t like... (LP) (a non-narrated element)... and then Mica came to school... and the little girls were mocking her too [...] She didn’t say anything to you (Mum)[...] I always defended her... I just couldn’t tolerate that...so I came to them (girls) and shouted at them: hey! Stop mocking my sister!

The way in which Santi described the situation of seeing other girls mocking his little sister as intolerable, alongside the contentious actions he put in place to stop the mockery, denote a sense

32 TV advert promoting respect towards individuals with physical differences.
of anger in Santi´s responses. Santi expanded on what anger made him do in the following extract:

‘L: when they are mocking you...mmm do you say anything to them?
Santi 1: I got angry... like in the cartoons ... I got angry like this (make an angry face-frowning, fixed look) then they stop moving... it´s like that cartoon “binki”... ‘cause... one day he ate a green potato and became green...so everybody was mocking him and he got very angry, looking at them like this (fixed look) and then they stopped bothering him
L: good strategy!!... so your strategy is...(cross talk) Santi 1: I get angry’

Santi´s description reveals how anger was not only enacted from a stigmatising event (mockery), but also how the embodiment of this emotion (fixed look and frowning) served to challenge his stigmatisers. Like Santi, older boys such as Carlos and Marcos reported physical fights which involved punches and throwing objects against their peers:

(Carlos was talking about his peer- who made a rude gesture in relation to his lip scar)
‘[...] Carlos 1: but one day... it was a kind of accident...it was in third grade, he was doing that again (rude gesture) (long pause- grabs his face- very angry) huuuy! it makes my blood boil! I then faced him with a chair! And I won! ... ha... it was a tough fight but I won! [...]’

‘[...]Marcos 3: ehhh they mocked me, and I got very angry and I tried to punch them, but they didn’t feel pain [...]’

A common aspect of the above stories is that stigmatising events gave rise to anger, an emotion that was embodied by the participants in the form of gestures and actions against their stigmatisers. The way in which these children narrated feeling angry, as result of their experiences with stigma, is reflective of how emotions and their embodiment are intense bodily phenomena and vehicles through which we give shape to our social relationships (Burkitt, 2014), including power-imbalanced relationships such as being stigmatised. I return to this point later after providing other examples of the role of emotions in the children´s responses. It is also noteworthy that these are accounts presenting a self to the interviewer. There may be elements of a desire to appear tough and strong; to draw on emotion talk in the interview to enact power

33 Manner to say that it was not the ideal, just happened.
through the narratives when discussing situations that could be experienced or interpreted as disempowering.

Contentious responses against stigmatiser groups not only included physical fights or angry faces, but also verbal retaliations and stigmatising comments towards their stigmatisers. This form of verbal retaliation was more common among girls. For example, Coni called her peer Julio (who had called her ‘brain-shaped mouth’), ‘negro’ and linked his ethnicity with expected rudeness:

(Talking about her peer who used to call her ‘brain-shaped mouth’)

‘Coni 1: And I…huyyy (angry face) I got very angry ... and said to him: “I can’t understand why black people like you are always rude and enjoy annoying those who are like me”’

Liliana: those who are like you? What do you mean?

Coni 1: yeah, you know... all of us with this little ball with some folds on it (points out her gum)...’

From Coni’s story is possible to see how she uses a marker of cultural and social power – her non-black ethnicity (drawing on my observation of her skin colour she could be mixed-race) to stigmatise her Afro-Colombian peer. Apparently, Coni is attempting to lower her peer’s status by an implicit separation between them through a stigmatising comment in which his peer ethnicity holds a negative meaning – ‘black people are rude’. Coni’s stigmatising comment could be seen as a strategy to recover her status after being called ‘brain-shaped mouth’ by Julio. Apart from demonstrating the richness and complexity of the stigmatisation process and how it can play out in unexpected ways, this example shows how those who are stigmatised are also able to use and reverse stigma to resist devaluation and status loss. Those who are stigmatised can draw on distinct markers of power to reverse and resist stigma (Kusow, 2004; B. Link & Phelan, 2001; Tyler & Slater, 2018).

Talking further with Coni about her experience with Julio, she also reported having told her mum and older brother about the incident:

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34 ‘Y yo me puse brava, y le dije: yo no se porque a los negros les gusta fastidiar a los que son como yo’.
‘[...] So I told my mum that a boy was bothering me at all times... and she said: “look, if he annoys you again, you will tell him: Julio! look at yourself in the mirror, then you will realize how ugly you are”. And then Mauricio (older brother) told me I should say: “ha! If you (Julio) look at yourself in the mirror, you break it! (laughter)” 35 [...] So, one day he was annoying me... again... and I said to him: “ok, I’m ugly, but why don’t you go and look yourself in the mirror first”? That day he was taken to the head office and then he asked me to forgive him for all that mess and now we’re friends’

The previous extract enables us to see how her mother and older brother encouraged Coni to retaliate by making discrediting comments on her peer’s physical appearance. Like Coni, Isa also mentioned that her father often advised her to hit her aggressor back if she experienced physical aggression at school. This finding along with the fact that parents were the primary information sources the children used to make sense of the origin of their condition (Chapter 4), reinforces my argument that they were key in helping them to navigate through the experience of living with CLP, although this influence may not always have been entirely positive. Although parents’ advice gave the children ideas of how to challenge their stigmatisers, I also provided important examples of how the participants drew on emotions to resist stigma without reference to parental influence.

Moreover, the children also showed self-reflection when discussing their anger responses. For example, although Carlos and Marcos reported feelings of anger and episodes of fights in the previous accounts, both looked at their actions as something potentially negative. Both agreed that fighting with their peers did not correspond to an ideal behaviour. This was evident in the way Carlos named the event where he faced a peer mocking him with a chair ‘an accident’ and less explicitly, when Marcos clarified that ‘he was not an aggressive person’ despite the fact that he had punched his peers when he was a little boy. Both comments suggest that anger might be perceived as a negative feeling and responses derived from it as something socially inappropriate.

35 ‘Entonces yo le dije a mi mama y ella me dijo: si él le vuelve a decir algo digale, Julian mirese en el espejo pa’que se de cuenta como es. Y entonces Ivan me dijo: digale si usted se ve en el espejo lo rompe’.
5.3.4 Emotion management

5.3.4.1 Ignoring

Ignoring the discrediting actions of others, such as mockery, is a strategy individuals often use to manage stigma (Goffman, 1968; Link & Phelan, 2001; Runswick-Cole et al., 2018). For those who apply it, the purpose is to overlook the insult or pretend that actions do not affect them (Fettich & Chen, 2012). Some of my participants (Santi, Dilan and Valeria) reported ignoring their peers when mocking or making bad comments. In some way some children looked at ignoring as a more convenient strategy as it implied spending less physical energy and had fewer risks of getting into trouble with teachers, in comparison to more contentious anger-led responses. For example, Santi explained that he now preferred ignoring his and his sister’s peers’ insults as he had ‘got tired about fighting’:

‘[…] and then I got tired about fighting at all times... mmm she (sister) should ... she has to do it (defending) by herself; she can do it!... not looking to anybody (stigmatiser)... just walking forward ... like me, I don’t look to anybody, finally they’re not my friends
LA: ok...so you ignore them...
Santi1: yeah... I don’t care anything... it’s like... they were not there […]’

A common way in which these children ignored their peers was by continuing with their activities (e.g. walking) or drawing their attention to other tasks (e.g. talking to someone else, playing). To illustrate here are Valeria’s and Dilan’s examples:

‘Liliana: tell me more about that (episodes in which his speech was mimicked by peers), how did you feel when that happened?
Dilan 1: Well...I felt bad, but I didn’t pay attention to them (stigmatisers)
Liliana: and... how could you do that? I mean not paying attention to someone? Give me some advice because when something bothers me, I can’t stop paying attention to it
Dilan 1: just ignoring them, I talk to someone else for example’

‘[…] Sister: there is a boy in 3rd grade, he says to me: “your sister is so ugly!”
Valeria 1: ohh yeah
Sister: I don’t pay attention to him
Valeria 1: me neither, I just keep walking forward […]’
Although ignoring had the purpose of reducing the power of the stigmatisers as their actions are in some way overlooked, those children who pretended to ignore their peers’ discrediting comments or actions still felt anger towards their stigmatisers:

‘[...]Valeria 1: ... sometimes uhmmm (angry voice)... I really want to hit him (peer who says Valeria is ugly) for saying that I’m ugly! That should be right, isn’t it?’ 36

‘[...]Liliana: when they laughed at you in the presentations, you felt bad, right? But how bad? May be sad? Angry? uhmmm what?
Dilan 1: angry!
Liliana: angry?
Dilan 1: yeah, my nerves got on like this (face gesture of being stressed)
Liliana: how? like...uhmmm... your face got red?
Dilan 1: no, it didn’t, they (peers) just got me nerves on and I just wanted to (LP) (non-narrated)
Liliana: what did you just want to...? May be shouting, hitting someone else? Or uhmmm what?
Dilan 1: no (sounds like stressed) I got stressed
Liliana: you got stressed, ok. I can imagine, that should be stressful, I think I would get stressed too
Dilan 1: uhmmm but I didn’t do anything, I just continued playing with my friends and then the stress started to go off’

Although ignoring was perceived as a convenient, and potentially effective strategy by children such as Santi, ignoring their peers’ actions did not prevent them from experiencing anger. The way in which Valeria, Dilan and to some extent Santi also reported anger, but somehow preferred to control their feelings and ignore their peers (avoiding eye contact, keeping walking or talking to someone else) are reflective of ‘surface acting’ (Hochschild, 2012, p. 36). This entails conveying through our body language, certain emotions that do not correspond with our authentic emotions. This form of emotion work is frequently done with anger. Despite experiencing it, individuals prefer to hide anger because of its negative and uncivilised social connotation of inappropriate or non-rational emotional behaviour (Lupton, 1998). Apparently the way we control the bodily presentation of our emotions in public (embodiment) and our ‘authentic’

36 ‘Sigo derecho... y a veces le quiero pegar por las cosas que él dice. ¿Cierto que está bien?’.
emotions (how we feel) help us to present a civil behaviour consistent with social norms (Elias, 1994; Hochschild, 2012; Lupton, 1998). Emotional control is often seen as an outcome of the civilising process in which the most instinctive and primitive emotions such as anger are disciplined by the power of reason and mind (Elias, 1994).

5.3.4.2 Seeking social support: Reporting to parents/teachers

Other participants preferred to report their peers’ insults to teachers and parents instead of ignoring them. This form of stigma resistance was also marked by emotion work. Some of these children had initially engaged in contentious responses that involved physical fights and verbal retaliations, however in view of the ineffectiveness of their strategies in making stigma stop, or the social perceptions of fights as inappropriate in a school context, they changed their resistance strategies.

For example, the poor effectiveness of Marcos’ fights in addition to the perception that retaliating physically against his stigmatisers was something socially incorrect, led him to change his strategy and to prefer reporting incidents to his teachers:

‘[…] L: What did they (peers) say (when Marcos punched them)? Do you remember?
Marcos 3: they were like: “you can’t hit us, you can’t hit us (LP) you can’t!”
L: so, couldn’t you beat them?
Marcos 3: I couldn’t because my little punches were too weak
L: uhhmm did you say bad words to them, perhaps?
Marcos 3: Noooo! How can you think that? (raises his voice)
L: no?
Marcos 3: noo!! I’m not an aggressive person
L: ok, and now what do you do if that (mockery) happens again?
Marcos 3: I say everything to the teacher, now my defender is the teacher’

Similarly to other children, Natalia described feeling anger when her peer called her ‘big nose’37.

Although Natalia confronted her stigmatisers verbally by asking them to be respectful, the limited

37 ‘narizota’.
effectiveness of her strategy to make the mockery stop, led her to change her strategy and ask her mother for support:

(talking about the episode where a boy said to her ‘big nose’)
‘Natalia 1: …. And one day I said to him: (raises her voice and angry) ‘You please respect me!’… I said that to him 38[...]
[...][...]
‘[...][...]
Liliana: did you do anything else apart from asking him to be respectful?
Natalia 1: no...well... he still went saying me ‘big nose’ and one day I told to my mum and... and... (mum brings food- brief interruption) and... then she talked to my teacher... and then the teacher, one day in class said: “who is the boy annoying Natalia”? so, I said: “it’s David teacher” ... and then she told him off’

However, the limited effectiveness of anger and fights in making mockery stop was not the only factor that led some children to report incidents to parents or teachers. By adopting what might be considered a more emotionally controlled response, they were also less likely to get into trouble. For instance, in the story of Mariana it was evident how she controlled her emotions and preferred to report incidents to teachers. The uncontentious nature of her strategy was in line with school rules, and therefore her actions will not incur punishment such as a ‘note’ being sent to parents. This is clearly illustrated by Mariana:

‘[...] Mariana 3: look... I don’t have to dare to fight with them
L3: of course
Mariana 3: ‘cause then, the situation might get worse... ‘cause, teachers get confused easily... actually, something like that happened the other day
L3: really, how was that?
Mariana 3: David was annoying--... oh no, it was Andrea, yeah Andrea was annoying David, they started fighting
L3: aha
Mariana 3: all of us were doing some school work in the classroom... but teacher wasn’t in, so... when teacher came back, David ...mmm as Andrea was annoying David... David pulled her back and a chair fell down and Andrea too! and she got a bump on her head (LP) I can’t remember well but when the teacher came back, Andrea was on the floor... crying [...] then teacher didn’t know who parents she should send “a note” to... David’s or Andrea’s... so they both got a note’

38 ‘me respeta por favor ... así le dije’.
Nevertheless, the strategy of reporting incidents to teachers was not always effective. Although Mariana’s peer was told off for mimicking her speech after she reported this episode to her teacher, some of the younger participants indicated that they did not always get support from their teachers and therefore their peers were not reprimanded for their actions. For example, Jeronimo and Valeria said that despite reporting incidents to their teachers none of them had support from them. While Jeronimo said that her teacher ‘didn’t do anything’ when he reported name calling (‘dirty pig’), Valeria said that her teacher ‘didn’t believe’ that a peer had called her ‘ugly’ in reference to her lip. Despite the clear structural stigma in the way that, according to these children, there were no actions against their stigmatisers, the children continued finding ways to resist stigmatising behaviour. Both Jeronimo and Valeria asserted that if the mockery continued, they would talk to the Head Teacher, who had a more powerful position at school. This is important to note as it shows how the children mobilised further resources to resist stigma and ensure that their peers were reprimanded for their actions. This is reflective of their agentic position even in situations of structural stigma and how they use their narratives in the interviews as a way to make these episodes visible.

The above examples show several forms of emotional work. The children, in some instances, had to draw on emotion work to look for a more effective and convenient strategy to respond to, and resist stigma, particularly mockery. Reporting peers’ stigmatising behaviour with those in a more powerful position, such as parents and teachers allowed for more effective reprimands towards stigmatising groups. Actions such as ‘scolding’ and bad behaviour reports (visits to the Head Teacher) from someone in a higher position and therefore with greater power, had the potential to reduce the stigmatiser’s power and make their actions more costly to maintain. It is worth noting that the acknowledgement of wrong-doing and potentially a punishment to these events were the main outcomes that the children reported seeking. The participants did not mention strategies in their school context to educate peers about CLP or measures to prevent stigmatised responses towards those with differences.
5.4 Summary

This aim of this chapter was to explore whether, and how CLP affected the children’s social lives and how the participants negotiated their social interactions. Drawing on the concept of the stigmatisation process (Link & Phelan, 2001) I presented how facial differences such as nose shape, lip scars and speech difficulties were labelled and stereotyped by the children’s peers. The undesirable meaning ascribed to CLP attributes gave way to negative views of the status of their bodies (unhealthy and imperfect), subtle forms of discrimination, and the construction of a self-awareness that their differences, particularly their speech, had a negative social connotation (stigma self-awareness). Subtle acts of discrimination and stigma self-awareness were factors limiting their participation in socio-relational contexts at school. Although stigma self-awareness is mainly studied in relation to their negative psychological (e.g. evoking shame) and socio-relational effects (e.g. social isolation); this seemed to have a positive effect in one of the participants. Lina associated being ‘special’ to kindness and peers’ support, something that made her feel confident that in case of communication breakdowns her peers could help her.

Despite the negative social connotation of their bodily differences, the children actively managed instances prone to stigma, and challenged their stigmatisers. Speech intelligibility was key for making children feel confident about interacting in a new social encounter such as first day at school – a context in which stigma-related events often started. Some children showed clear agentic roles in controlling information related to their CLP, either informing their peers about their condition or restricting their access to it.

Emotions, their embodiment (Bendelow & Williams, 1997) and emotion work (Hochschild, 2012) were key resources that the children used to resist stigma. Driven predominately by anger, some participants retaliated physically and verbally against their stigmatisers. Although feeling anger, other children opted for less contentious responses in order to challenge their peers. Although the children were often stigmatised by peers, and so in some respects their school lives represented adverse socio-relational contexts, the participants demonstrated a clear agentic role
in the way they resisted stigmatised events. This is important to note as adversity is often seen as a constrainer of children’s agentic position.
Chapter 6 Children’s views and experiences with CLP treatments

6.1 Introduction

As stated in Chapters 1 and 2, children with CLP are often involved in a CLP healthcare plan from very early on in their lives. This is in order to restore, structurally and functionally, those aspects of their physical bodies affected by CLP. To do this, children will undergo reparative surgeries of CLP and associated features (e.g. cheiloplasty, palatoplasty, rhinoplasty, etc), dental treatments (e.g. orthodontic treatment, alveolar bone grafting), and speech therapies, at different stages of their lives. Given the complexity of treatments, this plan involves multiple healthcare professionals, with dentists, speech pathologists and particularly plastic surgeons having a central role.

The bodily changes and improvements that come with treatments are seen as part of a medical body project which implicitly and explicitly seeks to normalise children’s bodies. As noted in Chapter 2, children’s agentic roles with regard to these treatments and therefore (medical) body projects have been examined through a binary view of agency – the extent to which children are active or passive in making decisions about treatments. This chapter responds to the need to go beyond the premise that children are active or passive with regard to their treatments as noted in Chapter 2, to scrutinise the subtle ways, contexts and circumstances in which their agency (in this Chapter with regard to their CLP health care plan) is asserted. To do this I examine the participants’ accounts of their experiences with, and expectations of past, present and future treatments, paying particular attention to their embodied stories and accounts. By embodied I refer to the physical sensations, perceptions, emotions and actions that speak of the bodies ‘as sites of experiences’ (Coffey, 2016, p. 196), experiences that allow us to better understand how bodies (including their materiality) are socially mediated and informed. Exploring the children’s embodied experiences with treatments focuses attention on the materiality of the body; this addresses the gap in childhood studies identified in Chapter 2 (Coffey et al., 2016).
I present the findings in this chapter chronologically (past, present and future) because; the CLP health care plan follows a temporal pattern and I also wanted to explore the temporal aspects of agency (‘been’, ‘being’, ‘becoming’) in the participants’ accounts. I start by discussing the children’s stories of their experiences with early life treatments (‘been’); to follow with their more recent treatments (‘being’); and end with their expectations of their future medical treatments (‘becoming’). This chapter addresses the following research questions: how do children understand and experience their treatments? How do children assert their agentic roles within the context of their everyday lives? This latter research question was also explored in Chapter 5.

6.2 Children’s awareness of initial treatments: the role of parents’ stories

A common event in the children’s life stories, both in their visual works and in the interviews, was their previous CLP treatments, including those that occurred earlier in their lives. These initial treatments had a clear reparative purpose: to close the gap in their lips. The tendency of the children was to describe these interventions as procedures in which ‘a hole’ (Marcos, Beto), ‘a gap’ (Camilo) and ‘a missing portion’ (Dilan) in their lips had been ‘filled in’ (Dilan), ‘closed’ (Camilo, Marcos) and ‘fixed’ (Beto):

('[...]Liliana: and how was that surgery, why were you operated, do you know?
Camilo: ...‘cause I had my lip wide apart[^39] [...] they (parents) told me that I was born with that and... they (parents) took me to there (OS) to get an operation to get closed that gap

‘[...]Dilan 1: my mum told me that a mass was placed over here (points out to his upper lip)
Liliana: tell me ...tell me more... really? A mass? How was it?
Dilan 1: they (drs) put a tape and a mass on my lip to shape my lip and start aligning my teeth... but they are out of square now... I’ve got like a teeth party
Mum: laughter
Liliana: ohh really, and what did that mass look like?
Dilan 1: I didn’t see it, my mum told me [...] 
Liliana: ok so you had a mass on your lip...but...why did they put a mass on your lip?'

[^39] ‘porque tenia el labio separado’.
Dilan 1: the mass... filled in the missing portion in my lip... to make the lip not to look like this... to not to look this part like opened (point to his upper lip)’

The above descriptions illustrate the children’s understanding of the structural reparative nature of initial treatments. In both cases an initial surgery\textsuperscript{40} (Camilo) and ‘a mass’\textsuperscript{41} (Dilan) aimed to resolve the (congenital and visible) gaps in their lips which generated not only a less common facial appearance but also feeding issues, problems which Beto explicitly mentioned that he had experienced when he was ‘a baby’ before his first corrective surgery.

Both Camilo and Dilan referenced back to their parents when speaking of their first surgery and ‘a mass’. Clearly the fact that these interventions had been performed when they were babies meant that the awareness of these procedures were formed through the stories told by their parents (Hall et al., 2013). Like Camilo and Dilan, other children such as Beto, Valeria, Fabian and Coni, in both implicit or explicit forms, also narrated stories of early life treatments which had been informed by stories recounted by their parents:

‘Fabian 1: My mum told me that I was born with a hole here (points out his mouth)...and in Operation Smile they fixed it [...] to not to look like this... with this (lip) opened[...]’

In a few instances, the influence of parents’ stories in this process of making meaning around initial treatments was observed during some interviews and key for this was photo elicitation. As mentioned in Chapter 3, photo elicitation was incorporated as a methodological tool to prompt the participants to talk about past, and perhaps non-remembered events. The participants and their parents at the end of the second interview were asked to collect (if possible) some photos of the children when they were babies. These photos were commonly presented, and served to spark and expand conversations of early life treatments. Some mothers remained with us while we looked at the photos, telling their children stories about some particular events.

\textsuperscript{40} This entails a cheiloplasty. This is often performed at three months of age and has the purpose of closing a cleft lip in order to improve the shape and symmetry of the nose and upper lip, but also facilitating sucking and feeding (Berkowitz, 2013; Hospital de La Misericordia, 2009).

\textsuperscript{41} ‘A mass’ resonates with a pre-surgical treatment in which a device is fitted to shape the nose and gums before the first corrective lip surgery. This pre-surgical naso-alveolar moulding is often performed in cases of CLP bilateral and aims to improve surgical outcomes (Bennun, 2016; Shetye, 2016).
For instance, Camilo’s mother was present at the beginning of our final interview. When looking at photos of Camilo when he was a baby, she told Camilo that his first surgery had been performed some months after his christening, an event that Camilo was not aware of:

‘[…]Mum: Look at this Cami (points out to a photo of Camilo- baby with stiches) this was after your Christening… yeah, you were baptised before getting the first surgery
L: uhmm really?
Mum: Yeah for me it was important… I wanted Camilo to go to surgery baptised… just in case […]’

The phrase ‘just in case’ in Camilo’s mother account refers to the potential risk of complications during Camilo’s first surgery. She explained that having her child baptised before this initial surgery made her feel confident, as in the case of death, her son could go to heaven. This example alongside the religious explanatory models discussed in Chapter 4 show how children and their families use religion to make sense of their conditions and make decisions about treatments.

This information about Camilo’s early life enriched his story of initial treatments, as he decided to incorporate the date of his baptism into the section on ‘surgeries’ in his life story book:

‘I was born with my lip wide apart and when I was 6 months I had my surgery and my christening… when I was 3 months and 2 days’

From these accounts therefore, we can see how the children construct meanings around initial CLP surgeries, based on the stories available to them - mainly from parents. This shows how despite these being events not remembered as these had occurred early in their lives, the children make sense of these episodes of their past drawing on the stories of others, reflecting their agentic ‘been’. However, the parents’ stories were not passively adopted by the children.
Despite the presence of her mother’s story about her surgeries, for Isa, her early lip and palate surgeries remained unclear and uncertain events of her life. Isa reported not being sure whether she had had a surgery, despite her mother, present in the interview saying to her that she did:

(we are seeing some photos of her just after her first surgery)
‘Liliana: have you ever been operated?
Isa 3: uhmmm nooo…. I have not yet ... I haven´t had my surgery yet
Liliana: and uhmmm maybe then you were a baby?
Isa 3: uhmmm don’t know […]
[...]Mum: look Isa... in that photo you were just operated...this was your first surgery look... some stiches were still there (lip) 42
Liliana: uhmmm but I’m not sure about something... did you have a surgery then?
Isa 3: (LP)
Mum: talk dear, I have talked to you about that
Isa l: I don´t know’

The previous account shows how despite the visual evidence of a past surgery that offered a photo of Isa with stiches, and her mum’s story affirming that she had been operated, for Isa a previous surgery in her life remained uncertain. When seeing further photos of her with stiches on her lip, she continued asking her mum whether that ‘baby in the photo’ was her. This sense of uncertainty experienced by Isa with regard to a photograph of her when she was baby is not unusual. According to Hall et al. (2013) pre-surgical photographs may not be recognised by children, given the obvious physical differences between their past and present faces, but also due to their cleft being no longer visible. However, contrary to the potential contribution of peri-operative photographs in making children aware of treatments, Isa did not incorporate into her account either the photograph or her mother’s story. Although the case of Isa was unique in explicitly rejecting the mother’s account, this finding could be related to the fact that memories, while socially constructed, are also individually negotiated (Elias, 2007).

For Hall et al. (2013) children become aware of their condition and initial treatments through their parents’ stories. For these authors, through the retelling of their parents’ stories, children make sense of non-remembered events, thus reflecting how parents’ stories are transferred to children and become part of the ‘collective fabric of the family’ (Hall et al., 2013 p.23). Although

42 ‘... tenía punticos’.
memories have a ‘collective’ nature, as they are often constructed and shared by groups (Olick, 1999) as the work of Hall et al. (2013) illustrates, social actors have also the option to incorporate or reject those memories into their own stories (de Carvalho, 2018; Elias, 2007). The way in which Isa decides not to incorporate her mother’s story into her own story is reflective of her capacity to select whether the memories of others become part of her own memories.

The way in which these stories are based on parents’ versions of the participants’ early lives is expected, given the already mentioned (cognitive) limitation to remember those events. However, the children’s agentic roles are visible in the way they constructed stories of their past and how they decided or not to incorporate parents’ stories into their own versions. Their capacity to position themselves in the past and speak of events happening in their early life is reflective of their agentic ‘been’. It is worth noting that my data is limited in saying whether the children’s stories were the retelling of their parents’ stories or whether these were indeed modified in substantial ways by the participants. As mentioned in Chapter 3, my research was focused on the children’s views not those of their parents, and I do not have data from parents with which to contrast the children’s stories.

This section has shown how the participants became aware of early life treatments mainly through the presence and incorporation of their parents’ stories. These initial treatments had a clear reparative purpose in which their cleft lips were closed through pre-surgical devices and surgeries. Although Isa was a unique case, her narrative revealed that parents’ stories informing children about their treatments were not passively incorporated. Having discussed the children’s stories of early life treatments (‘been’), the first stage of a CLP healthcare plan, in the next section I analyse their accounts of their experiences with current and most recent treatments.

6.3 Present treatments: dental care, speech therapies and surgeries

In comparison with the stories of early life treatments, constructed mainly on the incorporation of their parents’ stories, the children’s narratives about their current and most recent treatments were built on their own memories of their experiences, reflecting their position as ‘beings’. The
participants spoke of three main treatments performed on their present bodies: dental and orthodontic treatments (‘aparatos’), speech therapies, and surgeries (bone grafting and lip revisions). While some children talked about their dental treatments and speech therapies in terms of aesthetical and functional purposes, the focus of their stories of the most recent and upcoming surgeries was on the sensations and emotions experienced before and after these procedures. In this section, I discuss the children’s accounts of each of the three treatments – dental, speech, and surgeries in turn. In doing so, I use the term ‘feelings’ to refer to both physical sensations (e.g. pain, dizziness), and emotions (e.g. sadness, fear, anxiety, happiness) (Burkitt, 2014; Lupton, 1998).

6.3.1 Healthy teeth: its relevance for the presentation of the social self

Dental care and speech therapies (see section 6.3.2) marked two predominant interventions in the stories of my participants about their current treatments. Talks about these treatments were expected, given that these are core aspects of CLP management plans during children’s school age (Alonso & Raposo-Amaral, 2018; Bennun, 2016), the age of my participants.

In contrast to the main aesthetic component of early life treatments discussed in the previous section (improving the appearance of the lip), treatments at this stage had both aesthetic and functional purposes (Lewis et al., 2017; Rankin & Borah, 2003; Wehby & Cassell, 2010). However, it was the potential for aesthetic change that was the dominant feature of the children’s accounts. The aesthetic component of dental treatments was described by most of the participants as dental ‘aparatos’ placed in their mouths by ‘doctors’, with the aim of moving their teeth back and forward. These were devices which transformed the appearance of their teeth from ‘crooked’ (Juliana, Coni) and ‘sunken’ (Isa) teeth into ‘straight’ (Coni, Juliana, Beto, Dilan) and ‘normal’ (Juliana) ones. To illustrate here are two extracts from the first interview with Isa and Dilan:

‘Dilan 1: they (drs) put an “aparato” right here (points to his mouth)
L: what is that for?
Dilan 1: to get my teeth straight’
‘Liliana: why do you go to Operation Smile?
Isa 1: the thing is I’ve got a sunken tooth... but it is already moving forward
Liliana: ohhh really? Could you show me
Isa 1: (shows me)
Liliana: how does your tooth move forward?
Isa 1: I wear an “aparato “[…]’

For these children their ‘aparatos’ changed, but also improved the appearance of their teeth, an improvement marked by teeth alignment. However, these dental adjustments were also reported by the children as causing pain and limitations with eating. Eating problems were reported mainly with regard to hard and grainy foods, given that these often go into their ‘aparato’. Pain was commonly linked with the force of the dental tools used by their dentists to tighten and remove their appliances. These bodily discomforts were experienced mainly at initial phases of their orthodontics treatments and during regular dental check-ups.

Despite these discomforts, the dental treatments seemed to be accepted and very well tolerated by the participants. Talking further with Beto and Isa about their ‘aparatos’, both explained that although they caused them dental pain, they were ‘strong’ and ‘don’t complain about the pain’:

‘Liliana: I heard that those “aparatos” cause pain, is that true?
Isabel 1: yeah ...but I don’t complain about that
Liliana: don’t you? And your “aparato” is the one you have to wear at all times and you can’t remove it or it is rather those you can put on and off ?
Isabel 1: I can’t remove it’

There is a sense of emotional and pain control in Beto and Isa’s reports. The phases ‘not complaining’ and ‘being strong’ show how Beto and Isa were presenting themselves in a positive light: a sense of pride about their ability to cope with dental discomforts. Despite the pain experienced with their non-removable dental appliances (pain especially exacerbated by dental check-ups) both children decided to accept these discomforts and to wear them.

Returning to the notion of the body project discussed in Chapter 2, a key aspect of this notion is that individuals engage with and contribute to the body works and practices through which their bodies are transformed or shaped (e.g. follow workout routines, strict diets, tolerate pain of
plastic and cosmetics interventions). This element of the body project notion is apparent in the way some children showed adherence to orthodontics treatments, an adherence that is indicative of their commitment to their dental improvements. Like Beto and Isa, Manuel, Natalia, Isa and Coni also reported wearing dental appliances everyday (in some instances I could observe they were wearing their appliances in the interviews) because of the bodily improvements that they perceived came with them. Beto for instance explained that he wore his removable ‘aparato’, although painful sometimes, in order to maximise its potential for change:

‘[…]L: how are you strong? I wonder how do you wear it (‘aparato’) if it is sometimes uncomfortable, right?
Beto 3: well I just have faith that it (‘aparato’) is helping me […]
if I didn’t wear it, then the process (straightening his teeth) would be too slow, but as I am now wearing it so often, my teeth are getting better quickly’

Dental status, including appearance (something that improved with dental treatments) seemed to be important for the children as this was a bodily marker that could be evaluated positively or negatively within social-interactional contexts. Talking about her mouth and teeth, Mariana spoke of the significance of her teeth’s appearance within a socio-relational context. Drawing on a hypothetical situation in which someone would take a photo of her, she mentioned how embarrassing it would be to not have a good dental appearance:

‘L: I wonder why do you like having your teeth white?
Mariana 1: well because if someone says to you “let’s take a photo” but you have your teeth yellowish or something like that… that’s not nice, it’s embarrassing!’

Embarrassment is often experienced when our social selves are likely to be appraised negatively within a socio-relational context (Goffman, 1968; Shilling, 1999); negative appraisals that were illustrated in Chapter 5 in the form of stigma. Although the link between Mariana’s feeling of embarrassment and a potential social negative response to her dental appearance as a result of CLP, is not explicit in her account, the fact that the social display of a non-ideal dental appearance might make her feel embarrassed, suggests that she was aware that this body marker could give rise to negative social responses.
Like Mariana, Beto also spoke of the importance of having healthy teeth for social interactional contexts. Beto explained that white, straight and shiny teeth were markers of a healthy mouth that allowed him to ‘smell good’ when talking to someone else:

‘[…]Beto 1: ok ehh uhhmm if you want to keep yourself healthy you need to brush your teeth everyday […] yeah you should brush your teeth and also use “Listerine” to get your mouth smelling well when you speak to someone
L: ohh ok, and what do healthy teeth look like?
Beto 1: Ehhh “parejitos”⁴³, shiny, white, well white and ehhh your teeth look like a mirror!’

Beto’s narrative indicates that smelling good, a marker of a healthy mouth was important when talking to someone else. Clearly talking implies social interaction, which indicates that having healthy teeth (clean white teeth and smelling good) for Beto was important when interacting. The dental care component of CLP healthcare plan is also focused on teaching children oral hygiene practices and performing periodic teeth cleaning. Therefore Beto’s status of healthy teeth was something that he could also achieve through his visits to Operation Smile. Although he did not expand on the reasons why ‘smelling good’ was important when verbally interacting, this could be related to the fact that poor oral hygiene is a bodily marker often labelled as undesirable within peer culture (Al-Bitar et al., 2013). It is worth bearing in mind that children naturally choose to have little body space between each other when playing/talking together and therefore ‘smelling good’ could be something important to ensure when verbally interacting.

Dental appearance brings harmony to the face and therefore is often considered a key for attractiveness (Schmidt et al., 2012; Samizadeh & Samizadeh, 2019; Perella, 2013). But apart from making faces more attractive, dental appearance is an important marker of our social status (Horton & Barker, 2010; Magno et al., 2019; Moeller et al., 2015; Vettore et al., 2019). Several scholars have reported that dental diseases such as malocclusion and decays are bodily markers of socio economic disadvantage, poverty and poor social support (Hobdell, 2001; Horton & Barker, 2010; Magno et al., 2019; Vettore et al., 2019).

⁴³ Straight.
Within children’s peer culture, dental appearance also shapes children’s social relationships. Several studies have reported that children and young people with poor oral health and bad hygiene practices (features associated with poverty) are often segregated from groups and bullied by school peers (Al-Bitar et al., 2013; Barasuol et al., 2017; Seehra et al., 2011). Bearing in mind that dental status and appearance are markers that shape our social relationships, ‘smelling good’ and having a good dental appearance (white and straight teeth) which are attainable through hygiene practices and dental care, gave Beto and Mariana the possibility of displaying a safer social self.

Despite the tendency of the participants to stress the aesthetic component of their dental treatments, a few children also spoke of their ‘aparatos’ in functional terms. Manuel and Santi highlighted from their dental treatments that these devices helped them to speak better:

‘[…]: ...by the way why do you go to OS (Operation Smile)?
Santi 1: I go to get my mouth fixed ...to speak better
LA: how’s that of fixing your mouth?
Santi 1: yeah... they (Drs) put me those “aparatos”... to speak better[...]

‘Liliana: Why do you wear those “aparatos”?
Manuel 2: Hmmm I have to speak well (LP) I take it off, wash it and then put it back
Liliana: ok... what are those “aparatos” for?
Manuel 2: they’re to speak well’

For both children the end result of their treatments was the improvement of their speech difficulties. ‘Fixing’ in Santi’s account, reflects the reparative character of certain medical treatments, a point that raises important debates within disability studies (Chapter 2). Clearly these functional repairs meant improvements in the communication with others and therefore benefits for their social relationships. I expand on this point in the following subsection.
Although speech difficulties are mainly dealt with by speech pathologists, there are some structural issues such as palate fistulas and velopharyngeal insufficiency (VFI) which compromise speech and are addressed also by dentists and plastic surgeons. These structural and therefore functional issues are more common among those with bilateral CLP and particularly those who had a late surgical reparation of their cleft palate (De Agostino Biella Passos et al., 2014; Pollard et al., 2021). Santi and Manuel both had bilateral CLP and potentially their dental appliances worked as occlusion plaques on their palates, which minimised the hypernasality of their speech and therefore improved it. These stories reveal that dental treatments were also seen by some participants in functional terms.

The previous stories have illustrated how some children understood the purpose of their dental treatments as primarily bringing about a change, described as an improvement, in their appearance but also fixing a key function – their speech and then oral verbal communication. Dental appearance seemed to be a bodily marker that gave messages about children’s social selves. The following subsection is focused on another treatment carried out in the participants’ present lives: speech rehabilitation and it expands on the functional aspect of the CLP healthcare plan.

6.3.2 Speech therapies: improving communication and the social safety of ‘speaking well’

Speech therapies were a dominant theme in the participants’ accounts of their present and most recent treatments. A relevant point of contrast of children’s experiences with their speech therapies in relation to dental and surgical care was that they did not cause bodily discomforts. Instead, the children tended to refer to these therapies as nice encounters with ‘speech doctors’ in which they often sang and read alongside their consultants. Likewise, they described their therapies in terms of purposes – helping them to ‘speak well’. For example, for Carolina speech

44 A non-physiological communication between nasal cavity and mouth, often a sequelae of primary cleft palate surgery (palatoplasty).
45 It is a common complication after primary palatoplasty and entails an incomplete closure of a valvule (palate and throat) that allows the production of a non-nasal speech.
therapies were encounters with doctors in which they taught her how to ‘speak well’ given that she did not know ‘how to pronounce some words well yet’:

‘[…]
Carolina 1: sometimes she (a speech pathologist) looks at me, sometimes she says hello to me, sometimes says hello to my mum too and sometimes she weighs me anddd...mmmm [...] 
Mum: what does she teach you?
Carolina 1: she teaches me to speak well
Mum: yeah... to pronounce words well
Liliana: cool... and mmm why do you have to learn to pronounce words well?
Carolina 1: because I don’t know how to pronounce some words well yet […]’

As with many other medical treatments, therapeutic outcomes such as dental alignment and nasal symmetry are defined and assessed according to biomedical knowledge (Pausch et al., 2011; Sykes et al., 2016); speech improvement was assessed and regulated by healthcare professionals. Speech therapies seemed to be an ongoing process that children could return to at any time if their doctors advised, rather than something that finished at a certain point. Beto and Isa explained that according to their doctors they should ‘go back’ to speech therapies as extra work on the pronunciation of some syllables was still needed:

‘[…]
Beto1: that day... when we met each other, do you remember?
Liliana: ohhh yeah yeah
Beto 1: so... that day, the doctor said to me that I should go back to therapies... with the speech doctor... to improve “la eRRe” (RR)... ’cause I pronounce “la eRRe” with my throat and it should sound like: “eRRRe…”

‘[…]
Isabel 1: (LP) the thing is I speak some words kinda badly
Liliana: ahhh...for example?
Isabel 1: “la eRRe” and “La eRe”
Liliana: Awww and why?
Isabel 1: ...I say “eRe” (R) and it should be “eRRe” (R) ...
Liliana: how do you know that “eRRe” is the correct way to say it?
Isabel 1: ’cause the doc says so’

The children’s desires for speech improvement were clearly related to the social benefits of displaying more common speech. Referencing back to Chapter 5, Beto spoke of his speech abilities (something that protected him from stigmatised responses at school) as something he
had gained through speech therapies at Operation Smile. Talking further about the role of ‘speaking well’ in reducing chances of stigma and therefore the benefits for his social life at school, he explained:

‘[...]Beto 2: they (peers) look at me like a normal child, they look at me like a child without CLP, they looked at me like a friend and not the cleft
L: Ok, so that means that there’re two forms of looking at children?... does that mean that I could look at you like a boy without CLP but I could also look at you like a boy with CLP?
Beto 2: Well in fact there’re three ways: looking at me like a normal child...and obviously like a friend, looking at me like a child with CLP but still like a friend and looking at me in a funny way, like... if I had a metal (referring to his dental appliance) in my mouth’

For Lina, speech therapies contributed to improving her communication, something that had the potential to minimise communication breakdowns during school activities (see Chapter 5), but also helped her in being understood by family and friends. However, in the following story, Lina illustrates that it was not straightforward for some children to engage with speech therapy. Here Lina is aware that a way in which her speech could be improved is through home speech practice, an activity in which her father seemed not to be sufficiently involved.

‘[...]Lina 2: uhmm...at times my dad gets angry at me when I pronounce some words wrong... that makes me feel sad... but he doesn’t help me with home speech therapy, he doesn’t correct me when I say something wrong, he just says “speak well!” [...]’

Home speech practice is a key activity for children’s speech rehabilitation, with parents playing a significant role in this process. Speech pathologists often instructed parents to develop activities at home alongside their children such as reading aloud, singing and specific exercises which aim to help children to develop particular linguistic skills. Despite the benefits of these practices for children’s speech improvement, both therapies at the clinical site and home practice are not always attainable for some children and families, especially for those living in rural regions.

Speech therapies as well as other treatments are offered in the clinical site (in person), which means that those participants and their families from rural areas have to travel to Bogotá to attend their appointments. This implies significant travel and accommodation costs that, particularly low-income families (such as Lina’s), frequently struggle to afford. Likewise, parents’
employment and time constraints might add an extra layer of complexity to the development of home speech practices, factors that Lina’s mother (present in the interviews) explicitly linked to her inability to support her child’s home practice.

The above mentioned geographical and economic barriers alongside the limited support Lina had from her parents were factors that encouraged Lina to look for alternatives to practice her speech by herself. At the end of our second encounter, she asked me whether I knew activities she could engage with, to practice her speech on her own. Lina’s search for alternatives resources to practice her speech provides a useful example through which we can go beyond the ‘mantra’ that children are social actors (Tisdall & Punch, 2012, p. 251) to scrutinise the structural and relational contexts in which this agency unfolds (see Chapter 2). Her account revealed a clear agentic position (her active and autonomous search for alternative resources for speech self-practice) within a context of limited support and healthcare access barriers, but also showed her clear commitment to the improvement of her speech (an outcome of the CLP healthcare plan which as mentioned in Chapter 2 is often seen as part of a body project). Her active search for ways to practice her speech at home could be seen as a demonstration of her commitment to the improvement of her speech (an outcome of the medical body project of fixing/normalising children’s bodies), something that reflects a key element of the body project notion discussed in Chapter 2.

The narratives discussed in this subsection have demonstrated how speech therapy was perceived by the children to bring about change to their speech that resulted in important social effects: improving communication (Lina) and being perceived as an ordinary child (Beto). I return to this point in section 6.4. when I discuss how future treatments also offered the participants the opportunity to improve their speech. In the following subsection I discuss another medical intervention which the children spoke of in their accounts of current and most recent treatments – surgeries.
6.3.3 Embodied experiences of recent surgeries: pain and fears

In relation to current surgical care, the majority of the interviewees spoke of two main surgeries – alveolar bone grafting (Beto, Javier, Coni, Dilan) and lip revisions (Carolina). The focus on these two surgeries was anticipated, given that surgical care at school age (6-12 years old, the age of my participants) usually comprises alveolar bone grafts and lip and/or palate revisions. Other surgeries such as rhinoplasties and pharyngoplasty\(^{46}\) are also likely to be performed at school age. However decisions on whether, and when, to perform these surgeries are made according to the type of CLP, the needs and particularities of each child (Alonso & Raposo-Amaral, 2018; Berkowitz, 2013; Shetye, 2016).

Beto, Javier and Coni described their upcoming alveolar bone grafting as a surgery in which a piece of their hip or ribs bone would be taken out and then transferred to their mouths. The purpose of this surgery was to fill in a ‘gap’ in their gums as the following excerpt illustrates:

‘[...]Beto 1: Ehh ok well they´re (Drs) going to put me on a last “aparato” and then it is time for the … I say the graft because you call it in that way mum [...] [...] they´re going to take out a bit from here (points out his ribs) and then put that little bone in here (points out his gum)
Liliana: ohhh ok, and uhmmm what is that graft for?
Beto 1: it is for ehhh uhhmmmm I don´t know why they take a bone from here, could be taken from here (ribs) or there (hips) ehhh they do that to fill in the gap
Liliana: do you have a gap?
Beto 1: yeah here (points to his teeth and gum), uhhmm so they are going to put it (a little bone) in here and “fiushhh” that´s it’

Lip and palate revisions are also frequently performed at this stage in children’s lives. Surgical correction of the lip is a multiple stage process that is performed throughout a child’s life and often involves lip revision surgeries (Papathanasiou et al., 2017). These are surgeries performed after the initial lip corrective surgery and are focused on correcting structural issues of the lip, often a sequelae of the first lip surgery (Papathanasiou et al., 2017).

\(^{46}\) A surgery that shapes the soft palate and pharynx (throat).
Carolina spoke of a potential lip revision in our second interview. She explained that a surgery performed some weeks before our second encounter had the purpose of taking out ‘some extra flesh’ from her lip:

‘[… ] L: why did they (Drs) do that surgery? Carolina 2: they took some extra flesh from the lip’

Carolina’s reference to her lip in terms of having ‘extra flesh’ might be related to a ‘secondary cleft lip deformity’ (Garland & Matic, 2019). These ‘deformities’ include imbalances in the tissue volume between the upper and lower lip, hypertrophic scars and whistling deformity, secondary to initial lip surgeries (Garland & Matic, 2019; Sykes et al., 2016). Although she did not link this surgery explicitly with specific bodily improvements, these lip revisions, as other medical interventions in the CLP health care plan, have both aesthetic and functional purposes. Apart from improving lip aesthetics, these revisions also aim to restore lip movement and to facilitate normal facial growth (Soltani et al., 2012).

Different to dental treatments and speech treatments discussed in earlier sections, mainly focused on purposes, the accounts of those participants who spoke of alveolar bone grafts (Javier, Beto, Mica, Marcos) and lip revisions (Carolina) were on the more embodied and physical sensations experienced with their surgeries. Potentially the fact that current surgeries were very immediate and then felt, meant that these accounts were more nuanced than the early life surgeries which were distant and almost as though having happened to someone else (Isa).

Pain was a salient concern for some children about their most recent and upcoming surgeries. Apparently the use of medical devices and needles described as ‘injections’ during surgeries was linked with potential physical pain and then fear about being physically hurt during these procedures. This is exemplified by Carolina’s account about her experience with her most recent surgery (lip revision):

‘[… ] L: can you tell me about that surgery (3 weeks before our second encounter)? how was that surgery?’
Carolina 2: I was scared
Liliana: mmm... why? why were you scared?
Carolina 2: the thing is... ehhh my sister said ... that... you were given an injection during surgeries
Liliana: oh and how did that make you feel afraid?
Carolina 2: well, I was afraid of that... I was afraid that they (drs) do something bad to me [...]'

Like Carolina, Mica voiced concerns about the potential to feel pain during her upcoming alveolar bone grafting. Talking about reasons for her most recent visits to Operation Smile, she expressed feeling afraid of the potential pain with her next surgery, an intervention that had already been performed on her brother (Santi):

‘...Mica 1: I have a surgery soon...the same that they (drs) did on Santi, just here (points out her hip)... there in Bogotá...I need it (surgery) too...they take out a... a little bone over here (touches her hip) and... I don´t want them (drs) to do that on me... I´m afraid of that... it´s better if they put on your face that thing ...like this (covers her mouth and nose mimicking a mask) and then you get asleep
[...]L: ok, so you prefer the mask before the surgery, right?
Mica 1: yeah, to not to feel pain’

Uncertainty and fears about risks and complications of elective surgeries are often reported by adults who often articulate concerns about anaesthesia risks and intraoperative awareness (Aust et al., 2016; Eberhart et al., 2020). Like adults, the above stories have exemplified how children also raised concerns about medical interventions performed on their bodies, experiences that have been largely overlooked in clinical research (Behrman & Field, 2004). It is interesting to see from Mica´s passage, the emphasis she placed on anaesthesia as the means through which pain could be avoided. Like Mica, other participants such as Valeria, Marcos, Carlos and Natalia also described the fact of putting ‘masks’ on their faces as the means through which they fell asleep and then did not feel pain. This contrasts starkly with adults´ experiences with surgeries who, as noted earlier, tend to be specially concerned about anaesthesia risks (Aust et al., 2016; Eberhart et al., 2020).
But concerns about pain and the unknown were not only experienced before surgeries. Some children also reported being ‘scared’ when they woke up from their surgeries, indeed describing this experience as ‘horrible’ (Jeronimo):

‘[...] Valeria: I was there (recovery postoperative room) and my mum started to wake me up and I was scared and wanted to cry but my mum calmed me down and I didn’t cry’ [...]

‘[...] Jeronimo 2: Ohhhh yeah yeah!!! (shouting), I remember...it was horrible, horrible, horrible!!! (shouting)
L: what? ...How was that? I never had heard about that before!
Jeronimo 2: I remember, it was horrible!!! I had my tongue tied up with stitches, it looked horrible!
Mum: ... he was just kicking off and I had to calm him down [...]’

Although I did not explore the reasons why Valeria was afraid in the recovery room after her most recent surgery, this is a common feeling reported by adults in the postoperative period (Wei et al., 2016). Valeria might have felt unfamiliar with the cold and bright setting of a recovery room, this being the potential reason for feeling scared. Jeronimo’s experience also echoes adults’ reports of feeling dissatisfied with the facial appearance of their faces after CLP surgeries when they were children. The facial appearance after surgeries is featured by swelling, bandages and stitches, something that has the risk to exacerbate children’s dissatisfaction with their bodies (Alansari et al., 2014). The way in which Jeronimo describes the experience of waking up from his most recent surgery as ‘horrible’ might indicate that seeing the postoperative appearance of his tongue (with stitches) was in some way shocking. This experience could also relate to the expectation that surgeries will improve rather that worsen appearance.

Other interviewees also reported physical discomforts in this postoperative period. Dilan and Natalia reported pain and numbness in their mouths after their most recent surgeries, although these discomforts were rather transitory as they ‘just lasted a while’ (Dilan).

This subsection has shown that some children narrated stories of their experiences with surgeries, emphasising their more embodied experiences. These procedures raised important
concerns about the potential to feel pain, fears about the unknown and unfamiliar (Valeria) and potentially also anxiety about facial appearance (stiches) in the postoperative period. These findings shed light on children’s (embodied) experiences with CLP surgeries from their own perspectives, experiences that to date have been mainly examined retrospectively with adults (Alansari et al., 2014). Having discussed the children’s stories about their current and most recent treatments (‘being’) the following section explores their accounts about their future treatments.

6.4 Future treatments: reconstructive surgeries

Once children have reached maturity and full development of their facial structures (usually before transition to adulthood, around 18 years old), the clinical intention of the CLP care plan changes slightly in meaning and focus. Although still with significant functional purposes, surgical works at this stage are more concerned with improving facial aesthetics with rhinoplasties (nasal surgeries) being a central surgery (Berkowitz, 2013; Hospital de La Misericordia, 2009).

As mentioned in Chapter 2, certain treatments to ‘fix’ bodies have been viewed critically by some within disability studies; the normalising purposes either implicit or explicit in certain medical interventions risk imposing ideal standards of normality on disabled children, and framing their bodies as not only different, but also as lesser. In this subsection I discuss the children’s accounts of their future treatments in which was more explicitly recounted the normalising character of medical interventions. This subsection is divided into two parts. The first part is focused on discussing their accounts about the aesthetic and communication improvements of their future medical treatments, while the second part is particularly concerned with analyzing the functional improvements that future nasal surgeries would bring to some children’s lives.

6.4.1 Reconstructive surgeries: normalising the nose and speech

The children commonly discussed treatments of their noses (nasal surgeries and appliances) as procedures which would take place when children ‘turn 18’. These interventions had the purpose
of transforming ‘droopy’ noses into ‘normal’ ones, a transformation which offers them the possibility to be perceived by peers in terms of bodily normality:

‘[...]Marcos 1: My nose is a bit droopy but it can be fixed when I turn 18! [...]I’m a bit afraid that they (doctors) do a surgery on my nose, but after that I would be a normal boy
L: What does being a normal child mean?
Marcos1: I want to be free from this weight!
L: Which one?
Marcos1: My difficulty [...]they (peers) criticise me too much and mocked about my nose’

For Marcos being a ‘normal boy’ implied not being mocked by his peers for the shape of his nose, (as seen in Chapter 5, this was a frequent situation he experienced at school). For Marcos, the physical transformation of his nose had the potential to bring significant social benefits to his life. This links back to Beto’s story in section 6.3.2 of how ‘speaking well’ (an outcome of speech therapies) allowed him to be perceived by peers as a ‘friend’ (an ordinary boy), something that also minimised the risk of stigma (section 5.3.1).

Like Marcos, other children also emphasized how some future medical and dental treatments gave them the opportunity to transform their body into something more ‘normal’. With a focus on the aesthetic benefits of future treatment, Coni spoke of how an ‘aparato’ that would be placed in her face when she was older, would normalize her teeth and nose:

‘[...]Coni 3: when I become older they are going to close this (point out his teeth)
L: What do you mean by close this?
Coni 3: uhhmm that’s when the dentist puts that appliance on your face to get your nose lifted and push your teeth back... to get normal... Then I’ll get my nose normal
L: ahh ok I think I’ve seen that “aparato”...what does a normal nose look like?
Coni 3: A normal nose is mmm like yours [...]’

Coni’s narrative seems to reflect a face mask or headgear. This is an orthodontic appliance which aims to treat malocclusion and issues with position and growth of the maxilla (Shetye, 2016). Although with important functional purposes, as it aims to align teeth, bite and restore the physiological position of the maxilla, this therapy also significantly improves facial symmetry and
therefore appearance (Shi & Losee, 2014). Coni did not mention whether the normalisation of her nose and her teeth could bring social benefits, as Marcos did. However, given the fact that her gum was an attribute commonly stigmatised (Chapter 5), the normalisation of her teeth (and potentially also the protuberance in her gum, the attribute that was stigmatised) might mean an opportunity to reduce mockery.

Apart from visible physical bodily transformation that would come with future treatments, these bodily changes also had the potential to improve the children’s speech, with significant social benefits. Talking about what Lina liked about her visits to Operation Smile, she explained that a future reconstructive surgery of her ear and tongue had the potential to improve her listening and speaking, skills important to communicate with others. Lina had unilateral microtia and a little tongue, both of them features associated with a syndromic form of CLP. Apart from the frequent and expected speech difficulties that most of the children with CLP and/or CP experienced, Lina’s microtia implied that she had also listening difficulties. For her this surgery might open her ear up and putting something ‘like a tongue’ in her tongue, something that could improve her listening and speaking skills:

‘Lina 2: I like when doctors say to me I can be a better girl
L: ok… when she says that you can be a better girl… or get better, what does that mean?
Lina 2: I can get better because I could hear better… with my two ears… and… speak better too, you know… there is a problem with my tongue […]
[… and I like when the surgeon tells me I will hear better and speak too […] she (plastic surgeon) says that all in my inner ear is complete and working well, then I just need a kind of surgical procedure to get my ear open… regarding my tongue… something looking like a tongue can be put on my tongue […]’

Lina’s account is reflective of a medical normalising discourse (clearly, I do not know what her doctors actually said as I did not interview healthcare professionals). Here it is apparent how becoming a better girl implied having an ear opened and the enlargement of her tongue, bodily changes that speak of the surgical normalisation of these structures. Clearly these bodily changes meant for Lina the possibility to improve her communication difficulties, issues that as discussed in Chapter 5 affected her social interaction (e.g. initial encounters, talking to the teacher). Lina
expanded on why speaking and listening well, something possible through speech therapies and this future reconstructive surgery (tongue and ear), were important:

‘[…] surgeries are painful but good because I can have a better future […] Surgeries can help me with my speech […] ‘cause hearing and speaking are very important … you know, ears and tongue are some of the 5 sensory organs in human beings, so in order to have all those 5 organs complete, we need to speak and hear very well ’

There is a sense of wanting to achieve the completeness (potentially the normalisation) of her five sense organs in Lina’s account. Despite framing this change in terms of completeness, she was clear in saying that her body was not incomplete. Nevertheless, this completeness that the surgery would bring was significant to Lina in representing the potential to improve her communication abilities, something that was very important to her in terms of social interaction (see Chapter 5 and section 6.3.2).

Despite the potential benefits of this future surgery for Lina’s oral communication, her mother was aware that this procedure was ‘too idealistic’. After Lina’s account of how ear and tongue reconstructive surgery could make her become a ‘better girl’, Lina’s mother who was present in the interview, intervened to say that the complexity of this surgery implied risks to Lina’s health, risks that seemed to be higher than its benefits. Lina also voiced concerns in case ‘something bad happened’ to her, as this surgery involved ‘drilling’ her skull:

‘[…]Mum: the doctor says that… but that surgery is too risky, the doctor says that something could be place in her tongue something like …what is that called? (asking herself) L: hmmm a graft may be? Mum: yeah, something like that… but she (doctor) says that if they (drs) put in something like a graft, her tongue couldn’t move well, even with that (graft), because of the veins or something like that… she said that… it (tongue) would be bigger but it wouldn’t work well, I don’t know, I say to Lina, that (performing or not a surgery) is finally your decision, but that’s tricky… besides to get her ear opened up, Lina’s skull would be drilled … L: …hmmm ok…Lina, what do you think? Lina 2: Hmmm don’t know… I’m a bit afraid that something bad happen to me…’
Lina’s desire for becoming a ‘better girl’, something possible through a future surgery, is complicated by her fears about the risks of this procedure. In contrast to Lina, her mum seems to be unconvinced about the feasibility of this reconstructive surgery, apparently leaving the decision whether or not to have this surgery on Lina. This example is reflective of the potential challenges children may experience when they are involved in decisions around treatments, particularly when there are differences of opinion between adults (e.g. parents and doctors).

Like Lina, Marcos and Carlos also mentioned being afraid and worried about certain aspects of their future surgeries. While Carlos’s main concerns about his foot surgery were losing weight and school absences, given that from past experiences, he had to ‘eat just liquids’ and stay at home from some days after surgeries, Marcos said that he was worried about ‘hobbling’ for some days after his future nose surgery:

‘[...]Carlos 3: I don’t like surgeries because I can’t eat anything... after a surgery you can just eat liquids... soups, pureed food, just liquids [...] that’s so bad ... I always lose weight after my surgeries’

‘[...]L: would you like to have that surgery (nose surgery)?
Marcos 1: yeah, I’m a bit afraid of it, ‘cause I would be hobbling for some days, but after that my hip would heal and I would be able to run again ... be more athletic, ‘cause I’m good at running!’

Marcos’ reference to taking out a piece of bone from his hip, something important to ‘fix’ his nose, was potentially related to a cartilage graft for his future rhinoplasty. Particularly from Marcos’s narrative it is possible to see a sense of optimism in the way that despite surgical downsides he highlighted his capacity for recovery. This indicates that although discomforting, he continued looking with hope towards his future nasal surgery. Carlos and Marcos’ stories also show how their concerns about surgeries were grounded in what is important to them, and the potential disruption these procedures may cause them, even temporarily.

This sense of managing the balance between risks and benefits, that would be involved in future decisions about surgery, was also evident in Dilan’s account. However unlike the other children, the drawback of the surgery was the change in appearance to his nose. He mentioned that
although the fact of having a ‘pointy nose’ after a future nasal surgery was not something he liked, given that he was satisfied with his ‘squared nose’, he would accept this nasal transformation because of the improvement to his speech that it would bring:

(He was doing his emotion body map and he mentioned that he did not like ‘pointy noses’)

‘Liliana: ok so you don’t want to have a pointy nose right?
Dilan 2: uhhmm no, I don’t, but I have to
Liliana: do you? How’s that? tell me!
Dilan 2: ok the thing is a part of me says: yeah the surgery is fine but another part says no, it’s not
Liliana: how’s that? … A part of you is saying: yeah a surgery is fine? can you tell me more about that?
Dilan 2: uhhmm... in part yeah, I kind of want...because ehhh with that surgery I could speak better
Liliana: ok and what about that part of you saying no?
Dilan 2: well, because (knocking the table) I wouldn’t have my nose as it is’

This example shows how the functional and the aesthetic improvements that came with bodily change after reconstructive and plastic surgeries, could be in tension for some children, albeit in this study it was only Dilan that expressed such concerns.

The above accounts have revealed that although there were some concerns about the risk and possible discomfort of surgeries, and potential tension with the children’s preferences, the treatments’ downsides were evaluated by the participants in the light of the social benefits that bodily improvements (through future surgeries) would bring to their lives, including being perceived as a normal child (Marcos), something that might reduce stigma and improve communication abilities (Dilan and Lina). This connects with earlier sections in which I argued that speech and dental improvement resulting from the CLP treatment plan offered the children the possibility of becoming a more typical and therefore socially safer body.

In the final section, I explore the children’s accounts of future treatments in relation to the alleviation of bodily discomforts associated to their CLP.
6.4.2 Future surgeries: working on body dys-appearance

As seen in Chapter 2, the body is often experienced as a silent, absent and undisturbing entity (Leder, 1990). The body dys-appears when we start to feel it in discomforting ways either for pathological or physiological conditions (Leder, 1990). In line with this, plastic surgeries and other medical interventions have the potential to shift our explicit awareness of the body, by alleviating these discomforts (Gimlin, 2006). This notion of body dys-appearance and how treatments may alleviate these discomforts, is evident in some participants’ accounts; their future surgeries also meant the way in which certain bodily discomforts would be overcome.

As indicated in Chapters 1 and 2, individuals with CLP often experience some biological vulnerabilities associated with their clefts including upper respiratory issues such as ear infections, chronic nasal obstruction, breathing problems, sleep problems and oronasal reflux, this latter mainly related to nasal deformities and palate fistulas (communication between nose and mouth) (Bennun, 2016; Berkowitz, 2013; Dixon et al., 2011; Lewis et al., 2017). Most of the participants reported some of these conditions.

Participants such as Dilan and Carolina said that they often experienced infections in their nose and ears respectively. Indeed, in our second encounter, Dilan was on a short course of antibiotics to treat a nasal infection:

(Mum comes to us and gave Dilan a medicine)

‘Dilan 2: hmmm yummy!  
L: What is that?  
Mum: antibiotics  
Dilan 2: a medicine that the doctor gave me to clear my nose... he said that I have my boogers too yellowish’

Similar to Dilan, Carolina also reported frequent ear infections. This was something she included in her emotion body map as the recurrent episodes made her feel sad about her ears:
These frequent, but transitory respiratory infections of Dilan and Carolina contrasted with the rather permanent and everyday discomforts which Marcos and Ricardo experienced with their noses. These boys, both with CLP bilateral, reported everyday nasal symptoms that affected biological functions such as breathing, eating, and sleeping, but also their social lives. Their experiences with nasal symptoms were embedded in narratives about their future nasal surgeries. Both mentioned that these future surgeries would help to reduce these nasal discomforts. To illustrate here is an excerpt from Ricardo in which he explained how a future nasal surgery might improve some nasal symptoms experienced when eating:

‘[…] Ricardo 1: I need a surgery because I’m always stuffy nosed, I can’t breathe well through my nose …nose is too stuffy
L: why is your nose stuffy, do you know?
Ricardo 1: hmmm …some food goes from my mouth to my nose…I’m all day long with boogers’

Ricardo’s nasal symptoms might be associated to oronasal reflux potentially caused by a palate fistula. As mentioned in Chapter 1 and 2, corrective surgery of cleft palate seeks to close the non-physiological connection between the mouth and the nasal cavity, as keeping these cavities separated is important for feeding, breathing and speech. However, a common complication of cleft palate surgeries, particularly in cases of CLP bilateral, is palate fistula. This is a communication between nasal and oral cavities which causes nasal regurgitation of food, hypernasal speech and eating problems which often impact negatively on individuals’ lives (De Agostino Biella Passos et al., 2014).

Marcos also reported nasal issues when talking about purposes of his future nasal surgery. Apart from being the target of stigmatised responses, Marcos explained that his ‘droopy nose’ also caused breathing problems, issues that would be ‘fixed’ through the same nasal surgery that
would allow him to become a ‘normal child’ (earlier section). Marcos’ chronic nasal obstruction caused significant sleeping troubles which were narrated as episodes in which he ‘woke up suddenly in the night’ feeling like he was ‘suffocating’:

‘Marcos 2: at times I’m sleeping so well and dream that I’m breathing so nice... but then, I feel like... I can’t breathe... like I was suffocating and then I wake up’

Marcos’ account is reflective of breathing and sleeping troubles frequently experienced with nasal ‘deformities’ (Zhang et al., 2019, p. 177). Although sleeping problems such as snoring and sleep apnea are frequently experienced by children with severe forms of CLP (Fernandes et al., 2019; Zhang et al., 2019), only recently has some research investigated the functional issues of nasal ‘deformities’ (Zhang et al., 2019). Marcos’ story illustrates the impact of nasal breathing issues on sleep quality. This is significant to note as poor sleep quality among children and young people has been associated with adverse health outcomes (e.g. mental health problems, delayed growth, obesity) (Beebe, 2011; Wong et al., 2004) and life dissatisfaction (Blackwell et al., 2020)

With a more social focus, Ricardo narrated how his nasal problems affected his playing times at school. Although Ricardo’s nasal obstruction also caused breathing problems, the main issue with his nose was that this was prone to bleed when playing football. He explained that when accidentally his ‘nose was hit by the ball’, this ‘started bleeding’, something that frequently forced him to withdraw from matches. Indeed recurrent nasal bleeding was depicted in his emotion-body map as something that made him feel sad:
Nasal bleeding is expected to occur when there is chronic inflammation of the nasal mucosa, this being a common consequence of oronasal reflux (Pollard et al., 2021). Although Ricardo and Marcos’ nasal problems had a different origin, both looked with hope towards future surgeries in which these discomforts would be alleviated.

This section has discussed the children’s perspectives towards the last stage (future) of their CLP treatments. As with their accounts of previous and current treatments (particularly speech therapies), there was an emphasis on the improvements that treatment could bring, in both aesthetic and functional terms. The functional benefits of treatments were considered important by the children in alleviating bodily discomforts associated with CLP and symptoms that affected fundamental activities of their lives (breathing, sleeping and eating), and improving their ability to communicate more easily, this being key for their social interaction. The aesthetic improvement of surgery was seen by the children as offering them the possibility of displaying a more ordinary body, something that might reduce their experiences of stigma. Children’s agentic roles are visible in the way participants such as Marcos and Dilan start to navigate the difficulties in making decisions about treatments, thinking of both therapeutic benefits but also surgical risk and discomforts.

6.5 Summary

This chapter has drawn out four themes: first, the process of the children’s becoming ‘normal’ in appearance and function across three timespans: the children’s past, present and future lives; second, their abilities to make sense of these past, present and future treatments, reflecting their positions as ‘been’, ‘being’ and ‘becoming’; third, their views of treatments influenced by key adults (e.g. early life treatments influenced by parents and the purposes of present and future treatments influenced by doctors) but also by what was important to them (improving communication, display a more common body to reduce stigma, bodily discomforts alleviation); and fourth, the ways in which they navigate the difficulties of involvement in decisions about future surgeries, in relation to their weighing up of the risks and benefits.
The children’s awareness of their initial treatments (primary surgeries and presurgical treatments) were constructed mainly through their parents´ stories. This reinforces the role of parents in helping them to navigate through the experience of living with their condition. Although hers was a unique case, Isa showed that parents´ stories were not incorporated passively. Her case demonstrated that decisions were also made on whether and what part of those parents´ stories and memories were incorporated into the children´s own stories. This illustrates a clear and active agentic position of Isa.

Outcomes of dental care included having healthy teeth (straight, white) and a nice smelling mouth. Although implicit in some children´s narratives, the dental appearance might mean a marker of their bodies that gave messages of themselves. This is because having yellowish teeth was linked with embarrassment, a feeling that often emerges when our social selves are appraised negatively. Speaking well and having a more typical nose, both outcomes of speech therapies and future reconstructive surgeries respectively, enabled the participants to display a more typical body, something that reduced and had the potential to reduce chances of stigma. This spoke of the socio-relational safety of showing and performing such a body.

Although the CLP healthcare plan was regulated by healthcare professionals, these bodily improvements and transformations were not passively adopted by the children. The participants negotiated drawbacks of treatments in the light of benefits and looked at some of these interventions as forms of relational work and to overcome bodily dys-appearence. This suggests that a CLP health care plan, often seen as a medical body project, was also in line with children´s needs and desires. Clearly these desires for bodily transformations were informed by dominant societal notions of normality, beauty and bodily competence. This is because explicit and implicit in the above accounts is that their experiences or awareness of risk of stigma shaped their desires for a more typical body.
Chapter 7  Discussion

7.1  Introduction

This chapter aims to discuss the key findings of the study, drawing on the literature and concepts discussed in Chapter 2, and to consider how the findings address the research questions. This discussion seeks to reflect on the theoretical, empirical and methodological contributions of my research. In section 7.2, I provide a summary of the findings and how these answer my research questions. Following that, I unpack the findings further. In section 7.3 the participants´ definition of CLP and explanatory models of the origin of their condition are discussed in relation to health and illness narratives, lay knowledge, biomedicalization and the biomedical model of CLP. In section 7.4, I consider evidence of the social costs and bodily discomforts that living with CLP involves, in the light of stigma, and theories which deal with the biographical effect of certain health conditions. This section is followed by a discussion of the children´s views and experiences with treatments in relation to the body project notion and some key critiques raised by disability studies about the normalising nature of medical interventions (section 7.5). In section 7.6, I discuss concepts of agency in connection with emotions with regard to three main findings: the children´s stories of early life treatments and explanatory models, stigma resistance, and their engagement with CLP treatments. The biographical focus of the data generation is a significant contribution of my study which I discuss in section 7.7 and in section 7.8, I offer an outline of the strengths and limitations of my research.

7.2  Summary of key finding and research questions

Based on the research gaps identified in Chapters 1 and 2, as well as the formulation of the research questions that guided the data generation, analysis and discussion of the findings, this study explored children´s experiences of living with CLP in three regions in Colombia. The findings are overlapping, and complement each other to address the research questions and construct an in-depth picture of what it is like to live with CLP, from children´s perspectives. In this section I summarise the main findings and how these answered each research question.
What terms and/or language do children use to define CLP? In Chapter 4 I analysed how the participants named, described and defined CLP, what they thought caused this condition and the basis for these ideas. We saw that CLP and associated features such as dental issues and speech difficulties were understood as congenital bodily differences (physical and functional). These were described by the children in their own words and body language, instead of using biomedical terms such as cleft lip and palate (‘labio hendido’, ‘paladar hendido’, ‘labio fisurado’). Although CLP implied bodily differences, these were reported by the participants as a normal and common occurrence, and not making them different in fundamental ways to others. Two potentially related factors were identified as contributors to this notion of sameness: an implicit parental normalisation discourse and the Christian belief that all human beings are the same.

How do children conceptualise health and illness? How is CLP understood within this conceptual framework? The participants understood health as being in shape (weight and muscular mass), and following certain practices such as healthy diets and physical exercises. In contrast, illness was linked with the absence of the above markers of health, certain physical signs such as pale skin, a permanent change in the physical appearance (vitiligo), and cognitive and mobility impairment. The presence of bodily signs of sadness and pain, poverty and poor social support, and behaviours such as alcohol consumption, were also markers of illness. Older children also supported their concepts of illness with a biomedical understanding of disease (e.g. pathogenesis of cancer and risk factors for cardiovascular diseases).

The tendency of the children was to frame their condition within a non-pathological picture. Indeed their bodies were used as examples of what a healthy body implied (e.g. enough muscular mass, normal weight, being clean, feeling well and free of pain). CLP did not mean an ‘illness’ for the children for two main reasons: i) CLP did not fit with their definition of illness (e.g. CLP did not cause a pale skin, neither did it involve a mobility or cognitive impairment); ii) It was a condition that improved with treatments and time.
What do children think causes CLP and what is the basis for those ideas? There were three prevalent explanatory models: religious, environmental and genetics-inheritance. For the participants, CLP was a consequence of God’s will (religious model), and certain events that occurred during pregnancy and delivery (environmental), but also could be an inherited trait (genetic and inheritance). The two former were the predominant models, in comparison to the genetic/inheritance which was only constructed by one child (Beto). The religious explanations and the diverse family circumstances, that formed the two dominant models, reflect a lay understanding of the origin of CLP rather than a biomedical and evidence-based knowledge. The presence of parents’ stories facilitated the children’s construction of these models, but this construction was not limited by the availability of these stories; Camilo used his own imagination to make sense of the origin of CLP.

What are the social costs and difficulties that children face as a result of their condition? Having CLP implied two main social costs: being stigmatised for their differences, and difficulties for social interaction within the school context. These difficulties included restrictions in taking part in play groups, in interacting with other children during the breaktime, and friendships constructions. These led to some of the participants spending a lot of their school time on their own. These socio-relational issues were, in part, outcomes of the stigmatisation process which I characterised in Chapter 5, but also were derived from their speech-related communication issues.

How do children understand and experience their treatments? Treatments marked a significant and common aspect of their lives and took place throughout their life course. In Chapter 6 I demonstrated that as a result of their differences, my participants’ bodies were the focus of different types of medical and dental interventions which seek to normalise their bodies physically and functionally. These involved dental care, plastic and reconstructive surgeries, and speech rehabilitation, treatments that started early on in their lives and would go on through adulthood.
This process of bodily improvement (becoming functionally and physically normal) started early in life with lip and palate reparative surgeries. During pre-school and school lives (children’s present) treatments were focused on improving functionally and aesthetically their teeth and their speech. Before transition to adulthood (their future lives), treatments would be mainly secondary surgical interventions that aimed to shape their nose and lips; these have aesthetical and functional outcomes including normalising the nasal appearance, speech improvement, and improving nasal breathing and eating issues (Ricardo, Marcos). Closely connected to their experiences of stigma and communication difficulties, these treatments were seen as forms of overcoming these relational and communication difficulties, these treatments were seen as forms of improving communication, displaying a more common body in order to reduce stigma).

*How do children assert their agentic roles within the context of their everyday lives?* The children asserted their agentic position in subtle but clear ways in three main dimensions and circumstances of their lives: 1) the meaning production around CLP, its origin and early life treatments; 2) their actions and decisions to resist stigma at school; 3) their engagement with CLP treatments. The children showed their capacity to give meaning to their condition when explaining their views and understanding of CLP and its origin. Although explanatory models were shaped by the presence and content of their parents´ stories, they made implicit decisions on what and whether to incorporate those stories into their own versions, reflecting their agentic contributions. They also narrated how they resisted and challenged their peers´ negative appraisals towards their differences. The children challenged views and actions that situated them at a lower position in the social scale, revealing diversity in their stigma management and resistance. Their responses were preluded by intense emotions such as anger, and ranged from less confrontational actions and avoidance such as ignoring and reporting to, and seeking support from, parents and teachers, to more verbal retaliations and physical fights. Some of their responses showed emotional work which shaped their actions and avoidance of resistance.

Children’s agentic contributions were also visible through their implicit, but clear involvement with treatments. Although the CLP health care plan was regulated and designed by health practitioners, the children engaged implicitly and explicitly with these bodily improvements. This
was apparent in how they started to navigate the difficulties of decisions about future surgeries, in relation to weighing up the risks and benefits of those interventions. Their agentic contributions were also visible in the way that bodily transformations, and improvements were not passively received; these transformations were consistent with their needs and desires. This means an implicit agreement with and acceptance of treatments in order to reduce stigma, and to improve communication and bodily discomforts.

Having summarised the key findings of my study I move on to discuss these in the light of some key theories and concepts.

7.3 Children’s understandings of CLP: challenging biomedical knowledge

This study has explored children’s understandings of CLP, including the language they used to define and describe CLP and their explanatory models around the origin of their condition. In this section I discuss how my participants’ understanding of their condition (terms used to define their condition and explanatory models) challenged the biomedical view of CLP as a pathological condition/abnormality and biomedical etiological models of CLP.

As noted in Chapter 4 and earlier in section 7.2, the children drew on their own words and language to speak of their condition. Their descriptions in non-biomedical terms is a key point of contrast in relation to some previous studies exploring children’s experiences with impairment and long-term conditions. For example, Connors & Stalker (2007) report that the majority of their participants tended to understand their impairment in medical terms. Similarly, in Monaghan & Gabe’s study (2016) about young people's experiences of asthma, the majority of children included the medical term ‘asthma’ when defining their condition and severity. Connors & Stalker (2007) indicate that it is common among children involved in health care services to incorporate medical terms into their explanations of their conditions, given the high contact with health practitioners and medical practice they often have. However, this was not the case in my study. While the participants of my research were active attendees of a CLP care plan which implied a
high level of contact with medical vocabulary, the tendency of the children was rather to define and describe their bodily differences (CLP) in their own non-pathological terms.

There are some possible explanations for this. First, as indicated in Chapter 4, the Spanish translation of the clinical term CLP is long and difficult to pronounce. This linguistic complexity might have represented a barrier for the children’s use of biomedical language in their accounts. Second, the fact that CLP and associated features were visible attributes of the children’s faces and bodies meant that they had the option to show or point out those regions of their bodies affected by the cleft (e.g. lips, mouths, teeth, noses). This might have been perceived as a more convenient way of explaining their condition instead of using verbal descriptions or perhaps clinically appropriate but distant jargon (LeFrancois, 2007) in their explanations.

It is important to note that I tried to avoid the use of medical words, including the term CLP, when asking questions or referring to their condition in the interviews. Early in the data generation I felt that the use of medical jargon had the risk of limiting children’s opportunities to speak of their conditions in their own words/forms. The fact that I did not use CLP in my interventions might have encouraged my participants to draw on their own expressions and language to give explanations about their condition.

As noted in Chapter 2, CLP is defined in pathological terms, with words such as abnormality, diseases, and illness, being frequently used within both biomedical settings and research. I argued in Chapter 4 that the children explicitly challenged medical descriptions of CLP as an illness; rather, they described their bodies as healthy. The children’s views about their differences in non-pathological terms also have some similarities with the work of Monaghan & Gabe (2016). They noted that despite children’s awareness of their diagnosis of asthma they often presented themselves as healthy children. Like my participants’ concepts of health analysed in Chapter 4, these children with asthma constructed concepts of health on the grounds of their physical appearance, how they felt, and the incorporation of health practices such as balanced diets and physical exercise into their routines. Furthermore, my participants’ accounts also challenged
biomedical descriptions of CLP by emphasising their ‘sameness’ rather than ‘abnormality’. This
will be discussed in more detail in section 7.4.2.

Nevertheless, despite challenges to biomedical understandings of CLP by embracing a picture of
themselves as healthy and the same as others, the children still also wanted to change their
bodies, in order to fit into the world (Garland-Thomson, 2011). I explore this idea of ‘fixing’ the
body, and the ways in which this reflected children’s agreement with, or challenges to medical
perspectives in sections 7.5.1 and 7.6.

The children’s construction of explanatory models of the origin of their condition was another
aspect examined in this study. The construction of knowledge around the origin of CLP was
dominated by lay beliefs, thus reinforcing my argument that children understand CLP mainly in
non-biomedical terms, therefore challenging the biomedical notions of CLP origin. This is a key
finding of my study as it provides evidence that lay knowledge which is often unrecognised by
biomedicine (Chapter 2) is the main source which the children and also potentially their families
draw on to make sense of the origin of CLP.

As noted in Chapter 4, the religious and circumstantial nature of the two predominant models
(religious and environmental respectively) was influenced by the socio-cultural and life contexts
of my participants. It was stated earlier, and in Chapter 4, that religion is a dominant element in
Colombian society, and that dominance was evident in some aspects of the children’s stories
(e.g. origin, notion of sameness). However, in contrast to the predominantly negative
connotations of religious models, in which CLP is the product of a divine punishment or karma
(Adeyemo et al., 2016; Li-Rong, 1990; Oginni et al., 2010), my study has shown that religious
beliefs allowed the children to see their condition within a positive framework. Not only did the
participants look at CLP in line with a benevolent God’s will (according to the children), but these
beliefs also gave them a sense of purpose in life, for example being more self-determined and
resilient. The role of religion in these models not only reflects a religious dominance that prevails
despite the secularization trends seen in Colombia in recent decades (Beltran Cely, 2013), but
also reinforces the idea that religious beliefs might help people cope with, and make sense of their health conditions (Abraído-Lanza et al., 2004; Cassibba et al., 2014). This religious anchor may be more relevant when it comes to make sense of unclear and complex health conditions such as CLP.

However, it is important to note the limited ethnic diversity of my sample. Apart from one boy (Afro-Colombian), my participants did not belong to minority ethnic groups. This means that children from indigenous communities, where CLP has a high prevalence (Watkins et al., 2014), and among whom negative fatalistic views tend to be more frequent (Adeyemo et al., 2016; Folayan et al., 2020; Oginni et al., 2010), were not interviewed. This homogeneity in the sample might have contributed also to the dominant presence of these positive religious understandings of CLP.

As seen in Chapter 4, particular socio-cultural and life contexts circumstances of the participants’ families gave shape to their environmental models. This was apparent in how circumstances to which the participants’ mothers were exposed during pregnancy, were seen as contributors to the occurrence of CLP (e.g. domestic abuse, infections, exposition to pesticides). This reflects how people make sense of health practices, illness risks and causation drawing on those ideas which are consistent with their realities (Gabe & Monaghan, 2013; Kleinman, 1988). Social and life realities such as domestic abuse in Colombia (Duque & Peña, 2004; Fajardo-Gonzalez, 2021; Rengifo Arias et al., 2019) in Coní’s story, and the use of pesticides and unsafe working conditions in floriculture (Jiménez-Quintero et al., 2016; Varona et al., 2005) in Marcos´ model, featured in their explanatory accounts.

The absence of a biomedical explanatory model based on inheritance genetics (other than Beto) suggests that these biomedical ideas were less relevant to the children and their families. Two main factors might explain this result: i) risk factors such as malnutrition, alcohol consumption (Mbuyi-musanzayi et al., 2018; Mossey & Modell, 2012; Vanrooij, 2004; Wehby & Murray, 2010) and genetic mutations (Imani et al., 2019; Lidral et al., 2008; Murray, 2002; Pengelly et al., 2015)
might not fit with the socio-cultural and biographical contexts of the participants; ii) the complex and unclear aetiology of CLP in a biomedical model (Jugessur & Murray, 2005; Watkins et al., 2014) means that consultants are not always able to answer the questions from families and children as to the why of CLP. It is acknowledged that effective public health strategies need to be sensitive to the cultural and social particularities of the communities (Erves et al., 2017; McCalman et al., 2017). This means that despite the presence of biomedical explanations, these might not be provided by consultants in social and culturally sensitive ways. This is perhaps more likely to occur in instances in which biomedical theories are complex and incompletely understood such as the origin of certain birth and genetic conditions (Jugessur & Murray, 2005; Stock et al., 2019; Turnpenny & Ellard, 2011).

7.4 The effect of CLP in children’s lives: integral but biographically contingent

In Chapters 1 and 2 I mentioned that biographical research on children’s health conditions has been underexamined both empirically and theoretically. In this section I discuss in what ways my study contributes theoretical and empirically to an area which has been underattended in childhood studies.

As noted in Chapter 2, the adult-centric character of theories about the effect of a health condition in people’s lives is a salient contributor to the paucity of biographical research within childhood studies. Despite this paucity, birth and genetic conditions are traditionally seen as not being biographically disruptive given that the presence of a condition since birth means that there is no previous normality which has been altered by the onset of an illness (Williams et al., 2009).

I mentioned in Chapter 4 and in section 7.2 that CLP was described as a congenital condition – ‘I was born like this’. The presence of CLP since birth speaks of its integral character to children’s lives and therefore it may not be considered as biographically disruptive from Bury's (1982) perspective. However, the idea that non-acquired conditions are integral within a person’s life has been problematised by several scholars who have demonstrated that those with congenital and genetic conditions can also experience biographical disruptions (Bray et al., 2014). The link
between biographical disruption and chronic diseases has been also troubled by evidence showing that the disruptive character of chronic conditions can be permanent, fluctuant and intermittent (Monaghan & Gabe, 2015; Wedgwood et al., 2020), and experienced in more stringent forms at certain ages when an individual’s identity and social relationships are more ‘fragile’ (Grinyer, 2007 p. 275) or when there are particular social demands to meet (Wedgwood et al., 2020).

Bearing in mind these more flexible perspectives towards the biographical effect of a health condition (including birth conditions) in children’s lives, it is possible to see four main aspects of my participants’ lives that speak of the potential biographical disruption effect of CLP: the presentation of themselves in terms of sameness, their experiences of stigma and social difficulties (Chapter 5), the temporal but bodily discomfiting effects of certain treatments (Chapter 6) and the presence of symptoms that affected basic bodily functions such as eating and breathing (Chapter 6). I cover each of these in the following discussion.

7.4.1 Sameness

As noted in section 7.3 the children spoke of their condition in non-pathological terms, highlighting their status of being the same as others despite their bodily differences. I argue that particularly the children’s presentation of themselves in terms of sameness might be seen as a way of coping with the disruption that CLP-associated stigma caused in their social lives but also as a result of a parental normalisation discourse in which the children were encouraged to see their differences in positive ways. Although I did not explore their parents’ accounts, I mentioned in Chapter 4, 5 and 6 that there was an indication of a normalisation discourse in the interventions of some parents in the interviews.

Normalisation is a central aspect in the notion of biographical disruption, as it is a common resource which individuals use to cope with the negative effects of a health condition in their lives (Bury, 1982). Particularly in the case of children, this strategy entails the reframing of concepts of health and illness in which illness becomes a phenomenon more accepted and common in life (Emiliani et al., 2011; Protudjer et al., 2009).
There are different ways to operationalise this normalisation process. For example, some authors have noted how some children construct a sense of normality by comparing their ‘different’ bodies with other bodies with differences. From these comparisons they look at them as normal and fortunate children in relation to others, this being a way of adjusting to their condition (Kirk & Hinton, 2019; Monaghan & Gabe, 2016). There is also the tendency to highlight their status of sameness in order to downplay the role of their differences in social lives and to depict an image of a non-disabled child (Connors & Stalker, 2007). Connected to this last point, Scambler (2009) also signals that individuals with certain health conditions often present themselves as the same and normal as others in order to manage the stigma associated with their health issues. Similar to these authors, I suggest that my participants might have found a way to deal with stigma and social relational difficulties through the presentation of themselves in terms of sameness. This shows how children mobilised resources, in this case presenting themselves as equal to others, to cope with the CLP-related stigma. I expand on stigma, another dimension of the children’s experiences that speaks of the disruptive character of CLP in their lives, in the following subsection.

The children’s mobilisation of resources to minimise the negative effect of stigmatised responses (to their differences) in their lives is also evident in their views of treatments. My participants not only presented themselves in terms of sameness and controlled information about their bodily differences as a strategy to manage stigma (Chapter 5), but also engaged with treatments as forms of relational works to minimise the disruptive effect of CLP in their social lives. As discussed in Chapter 6, treatments offered them the opportunity to show (mainly nasal shape) and perform (a ‘correct’ speech) more typical bodies. I further discuss this point in section 7.5.

7.4.2 The effect of stigma on children’s social lives

Stigma is a common experience of those with facial and visible differences and the participants’ experiences of stigma discussed in Chapter 5 reflect research with children and young people with CLP in other contexts (Beaune et al., 2004; Murray et al., 2010; Rumsey & Stock, 2012; Strauss et al., 2007). However, the characterisation of these experiences that I offer in Chapter 5
(drawing on Link & Phelan’s notion) not only generates local data about this issue, but also helps to contextualise these social and relational issues. This is important as it contributes to the construction of a more in-depth picture of the socio-relational problems experienced by the children (in a majority world context) from their own perspectives.

As noted in section 7.2 and Chapter 5, stigma and communication difficulties had a significant negative impact on the participants’ social lives and this can be seen as having a biographical disruptive effect. According to Bury (1982) social relationships is a dimension of individuals’ lives frequently affected by the presence of a health condition. This negative effect tends to be more severe in childhood and adolescence (Grinyer, 2007) where social relationships and identities tend to be more ‘fragile’ (Grinyer, 2007, p. 275). The social lives of children and teenagers are more likely to be altered by therapeutic regimes, symptoms and impairments that come with certain health issues (Bray et al., 2014; Grinyer, 2007), unlike adults who tend to have a certain stability with regard to their relationships, careers and identities. Some authors have exemplified the disruptive character of certain health conditions predominately in young people’s social lives. For example, Kirk & Hinton (2019) analyse how young people with multiple sclerosis (MS) experienced difficulties in constructing and maintaining friendships due to school absences related to therapies and symptoms. They also report that mobility impairments and physical appearance changes, according to their participants often provoked negative social responses such as bullying, clearly affecting their social interaction. These social and significant changes in their everydayness led these young people to feel that they were not in their present lives what they used to be in their past.

In a similar way to these studies, my participants experienced relational and social struggles as a result of the stigma enacted towards their differences. In Chapter 5, I demonstrated how stigma affected the children’s social lives in broader and significant terms (Link & Phelan, 2001). Status loss, social discrimination and stigma self-awareness (all part and outcomes of the stigmatisation process) (Link & Phelan, 2001) marked important social costs in the lives of my participants. For example, clear and subtle forms of discrimination made it difficult for some participants to
construct friendships and belong to groups when playing, these both leading to social isolation (e.g. spending the breaktime on their own). Self-awareness of the stigma (Link & Phelan, 2001) also contributed to the children’s limited social interaction as the awareness that speech difficulties might be appraised negatively by peers (an anticipation) led to them refraining from interacting verbally with others. These results show how their social lives were affected by the stigma associated to their condition, an affection that in the light of recent debates of biographical disruption notion could be seen as disrupting.

As discussed in Chapters 1 and 2, to some extent social difficulties that children with CLP experience has been explored by cognitive and behavioural disciplines, mainly through quantitative or mixed method research approaches (Demir et al., 2011; Feragen & Stock, 2016; Murray et al., 2010; Rumsey & Stock, 2012; Sousa et al., 2009; Stock et al., 2016). Indeed several tools have been developed to assess and measure the psychological risk of those with CLP (Feragen & Stock, 2018; Wong Riff et al., 2018). Social inhibition, isolation, low self-esteem, anxiety, and depression are some of the mental health and social difficulties most frequently experienced during childhood (Murray et al., 2010; Rumsey & Stock, 2012; Stock et al., 2016). Although these studies are valuable in noting mental health and psychosocial difficulties that children with CLP often experience, and how, by strengthening their self-confidence and self-esteem these problems can be managed (Prior & O’Dell, 2009; Rumsey & Stock, 2012; Stock et al., 2016), these studies only provide a partial picture of the problem.

The children’s accounts of stigma experiences demonstrate how their limitations to interact and set up social relationships were interwoven with stigma. This complicates findings from psychological research in which children’s social isolation and difficulties in constructing friendships is framed as stemming mainly from their lack of self-confidence, low self-esteem (Endriga & Kapp-Simon, 1999; Murray et al., 2010; Rumsey & Stock, 2012) and mental health problems (Demir et al., 2011; Feragen & Stock, 2016; Sousa et al., 2009). These factors stem from the child, instead of the socio-relational context. Although these studies in some way recognise that children’s behaviour (e.g. social inhibition) and mental health issues are partially due to the
negative effect of teasing and bullying on their identities, these social-relational issues are associated with the psychological profile of the child, instead of the stigma process itself. The way in which stigma and social difficulties are intertwined in the accounts of my participants indicates that beyond children’s psychological issues, stigma is something that significantly shaped their socio-relational struggles.

7.4.3 Bodily discomforts and functional impairments associated with CLP: impacts on their social interaction

Communication difficulties were also important reasons for the children’s socio-relational issues and can be seen as contributing to the disruptive character of CLP in their social lives. As seen in Chapter 5, the participants’ troubles in being understood by peers during initial approaches, made their interaction with new peers difficult. This is not surprising as speech impairment has been linked with significant communication issues, hampering the interaction between adults and children with children with CLP (McCormack et al., 2010; Nyberg et al., 2020). Although improving speech is one of the things that ‘matter’ to those with CLP (Wong Riff et al., 2018 p. 442), there are important barriers of access to speech rehabilitation such as the lack of speech pathologists in rural areas and travel costs (Lincoln et al., 2014; Verdon et al., 2011; Wylie et al., 2015). As mentioned earlier, speech therapies are an important part of the CLP healthcare plan, but not as central as surgical care. The relevance of communication for improving social interaction suggests that this component of a CLP health care plan should be reinforced. Access to these treatments is particularly important to ensure among those who face structural barriers of access (Wylie et al., 2015) and children with greater impairments because of the severity of their condition (CP, CLP and syndromic forms).

With a focus on embodiment, I also argue that CLP could be seen as disrupting certain aspects of children’s everyday lives, including their social interaction. Apart from speech difficulties, and most notably hearing difficulties in the case of Lina, hampering a fundamental activity in individuals’ lives – verbal communication (important for social interaction), nasal breathing issues also affected basic everyday activities such as sleeping and playing times. Particularly my participants’ descriptions of breathing issues contrast starkly with findings from previous
research which reports that breathing and eating issues are not frequently raised nor discussed by those with CLP (Wong Riff et al., 2018). Another finding that supports the biographical but temporal disruptive effect of CLP in children’s lives, concerns the bodily discomforts associated with their treatments. In Chapter 6, some children reported and raised concerns about school absences and physical and eating limitations related to the postoperative stage. These could be seen in line with an intermittent but still disrupting effect of therapeutic regimes associated with their condition.

7.4.4 Biographical contingency

I suggest that instead of a fixed pattern of causing or not biographical disruption (Bury, 1982), the disruptive character of CLP is closely related to the type of CLP, sequels and more acutely felt within peer culture. This links to the concept of ‘biographical contingency’ defined by Monaghan & Gabe (2015) as: ‘the way in which a chronic illness may be an ‘only sometimes’ problem and takes account of the ‘now you see it, now you don’t’ nature of a condition that varies in terms of its symptoms, meanings and consequences’ (Monaghan & Gabe, 2015, p. 1256). They argued that asthma might be problematic for some children when everyday activities are altered, such as running, or when the use of an inhaler in public might undermine the masculine figure of a boy within peer groups. Drawing on this concept, it is possible to see some aspects of my participants’ experiences as contingent.

I found evidence that the disruptive character of CLP might vary with the type and severity of CLP and the contexts which children inhabit: e.g. school or home; this is similar to Monaghan and Gabe’s biographical analysis of young people’s experiences with asthma. For example, the children’s experiences of stigma and their social effects (e.g. limited access to play groups, loneliness during the breaktime), were previously discussed as markers of disruption, took place predominately in the school context, and were triggered by certain activities such as oral presentations (Chapter 5). Similarly, nasal symptoms and communication difficulties were more frequent at certain times and contexts and were particularly conditioned by CLP type. For instance, while nasal bleeding in Ricardo’s case was experienced during playing times and his
stuffy nose exacerbated by eating, breathing issues with Marcos were predominately during sleep. Also of note is that those children who experienced severe communication difficulties and bodily discomforts such as Ricardo, Marcos and Lina had CLP bilateral, potentially results of earlier surgeries (nasal deformity and palate fistula) and particularly Lina a syndromic form. It is important to highlight that Lina’s barriers of access to speech therapies might have also influenced the severity of her speech and listening difficulties. Although my study did not explore the relationships between the children’s socio-cultural contexts and their symptoms or communication difficulties, it is clear that there are negative impacts of CLP in those living in disadvantaged socio-economic and rural contexts (Chung et al., 2019; Mbuyi-musanzayi et al., 2018). There may be other aspects of biographical contingency related to the intermittent nature of symptoms associated with CLP (e.g. nasal breathing issues), however this did not emerge strongly from the findings.

In this subsection I have drawn two key arguments: although integral to the children’s lives, CLP might be experienced as a biographical contingency in two main life dimensions: their social lives with peers (this includes communication) and certain basic and physiological activities (eating and breathing). The participants mobilised two main recourses to cope with these biographical contingencies: presenting themselves in terms of sameness and engaging with CLP treatments as forms of relational works and improving bodily impairments and discomforts (communication, eating, breathing). With a focus on the children’s views of and experiences with treatments discussed in Chapter 6, in the following section I discuss the fixing and normalising nature of the CLP healthcare plan and how this can be seen in line with a body project.

### 7.5 The Body Project –‘Fixing’ CLP

#### 7.5.1 What is the Body project?

I discussed in Chapter 2 how the malleable and unfinished character of our bodies means that we can alter, transform and shape them according to our preferences (Shilling, 2012). As we transform our bodies, the way in which we feel about ourselves and the social messages we project about our identities and roles also change. This possibility of our bodies and therefore
identities to be reconstructed has, arguably, led us to see our bodies as a project. The body project thus entails the production of a specific identity through the engagement with a constellation of body works and practices which discipline, transform or shape the appearance, function and social performance of individuals’ bodies. It is worth highlighting that the notion of the body project came out of works primarily developed in minority world contexts and therefore with mainly white adults. As such my application of this concept to children with CLP from a majority world context is a novel repurposing of this concept.

Different options and resources are available to operationalise this project, from invasive medical works such as plastic surgeries to more conservative practices such as makeup, diets and physical exercise (Featherstone, 2000; Shilling, 2012). These activities as mentioned in Chapter 2 are often known as body works and practices and have different meanings, with those which concern works performed on our own material bodies, to transform, shape, fix them (Gimlin, 2007) being the focus of this discussion. In this section as mentioned in Chapter 6, I use the term body work or practice to refer to those activities performed on the material bodies of the children, predominately by healthcare practitioners. These entail plastic and reconstructive surgeries, speech therapies and dental treatments.

Body projects tend to be temporally orientated. People often engage with works and practices that not only are promising in changing their present physical bodies and identities but also offer them further control over their future selves and who they want to be (Ferreira, 2014; Shilling, 2012). This temporal dimension was visible in the accounts of the participants of their treatments discussed in Chapter 6. Embedded in a process of improving and fixing their physical and functional bodies (those aspects of their bodies affected by the cleft such as speech and teeth), the children’s bodily transformations (e.g. closure of lip and palate gaps, speech improvement) started early in their lives and continued through adulthood. For example, their lip and palate gaps were aspects fixed early in their lives, whilst improving their speech and dental appearance and function were the focus of present therapies. Nasal structural issues would be addressed before transition to adulthood.
Having recapitulated and extended some key conceptual elements of the body project notion discussed in Chapter 2 and used to analyse the children’s views and experiences with treatments in Chapter 6, I discuss two key findings that speak of the normalising nature of treatments but also the importance of this disciplinary character in giving children the opportunity to improve their future social lives.

7.5.2 The normalising dynamic of the body project: appearance and functional outcomes

Styles and types of body work practices and transformations are diverse. Although some people may engage with certain body practices to transform their bodies in ways that challenge accepted societal and cultural ideas of normality and beauty, most commonly bodily modifications tend to be in line with socially and culturally constructed norms (Coffey et al., 2016; Shilling, 2012). This is given that embedded in a disciplinary structure, the body projects are attempts to bring individuals to normality standards (Balfe, 2009; Coffey, 2016).

As noted in Chapter 2, this normalising dynamic is more stringent with regard to different bodies, those with impairments or disabilities, as those individuals who display and perform a body more consistent with social norms have more chances to fit into the world (Garland-Thomson, 2006, 2011). However, it is also important to remember that the body project, including some regimes that aim to discipline and regulate the body, offer individuals the possibility to express themselves in ways that are consistent with their identities as well as to gain certain control over their lives and bodies (Ferreira, 2014; Shilling, 2012). For example, some may find plastic surgeries scary, but the bodily transformation of a stigmatised attribute or a discomforting body trait that came with them was an opportunity to enjoy a better life (Gimlin, 2006, 2010).

It was stated in Chapters 2 and 5 that a CLP health care plan could be considered a series of body projects designed and regulated by medicine (Hall, 2009). This is because the comprehensive nature of a standard CLP healthcare plan involves multidisciplinary works in which the restoration of bodily structures and functions affected by the cleft is performed and regulated by a specific discipline; dentistry, plastic surgery, and speech and language rehabilitation. This is not surprising
as often therapeutic outcomes and interventions to treat health conditions are structured and assessed by healthcare practitioners and medical conceptions of normality (Conrad, 2007; McLaughlin & Coleman-Fountain, 2014). But central to seeing the bodies of children with CLP as a medical body project is that CLP had the potential to improve with treatments. Abualfaraj et al., (2017) describe in their work that although CLP and long term conditions (LTCs) share some commonalities, such as both being non-communicable conditions with potential negative impacts on individuals’ social lives and identities (Hunt, 2005; Murray et al., 2010), they differ in substantial ways. CLP does not have a progressive and degenerating nature; rather it improves significantly with treatments over time (Abualfaraj et al., 2017). This sense of improvement was explicit in Chapters 4 and 6. For children such as Javier and Carolina, their first surgery represented the means through which their lip gaps were fixed and the reason why they felt ‘well’ and ‘free of pain’ in their present lives (Chapter 4). Similarly, in general the children spoke of their bodies as improving with treatments, rather than deteriorating or declining with time (Chapter 6).

The normalising and ‘fixing’ imperative implicit or explicit in biomedical discourses (e.g. diagnosis process) and interventions is seen with critical eyes by disability studies. This is because certain medical interventions and practices performed on disabled bodies tend to hold a discourse of bodily normalisation which involves fixing and finishing faulty and non-complete bodies (McLaughlin & Coleman-Fountain, 2014). This is problematic as those bodies with certain differences and impairments are judged against imaginaries of normality that are not only difficult to achieve but also demand that people make extraordinary efforts to be recognised within such ideals (McLaughlin & Coleman-Fountain, 2014; Runswick-Cole et al., 2018).

In Chapter 6 my participants’ accounts revealed how the medical dominance and regulation over their bodies was operationalised at both discursive and empirical level (Lupton, 2013; McLaughlin & Coleman-Fountain, 2014). Some children spoke of how treatments and therapeutic outcomes were assessed and regulated by healthcare professionals and biomedical norms of what is considered ‘normal’ and correct bodily function (e.g. speaking well) and physical appearance (e.g. 
teeth alignment). For example, dental success outcomes and the children’s progression with their speech were defined, regulated and determined according to their doctors’ criteria. Likewise, the children’s lips and noses that were not normal and functional were or would be transformed into normal shape through primary and secondary surgeries designed by surgeons.

Despite these medical actions of surveillance and dominance over their bodies, the children in this study showed that bodily transformations such as the improvement of their speech and nasal shape, although not designed by them nevertheless allowed them to change aspects of their physical bodies and social lives they wanted to change: reducing chances of stigma, improving communication and alleviating bodily discomforts and basic functions such as breathing and eating (Chapter 6). Clearly these desires were socio-culturally informed. As noted earlier in this chapter and Chapters 5 and 6 their difficulties with social relationships and interaction (both part and outcomes of the stigmatisation process) and communication issues greatly shaped these desires. This is reflective of how society shapes individuals’ body projects (Shilling, 2016). However, the fact that these bodily transformations implicitly fulfilled some of the participants’ needs and desires suggests that this body project was also their project and therefore that these transformations were not passively received. I return to this point in section 7.6.

Looking at the children’s past, present and future bodily improvements beyond the positive impacts on their social lives there was a real need to improve certain bodily functions. As mentioned earlier and in Chapter 6, despite clear physical appearance improvements that came and would come with treatments (e.g. teeth alignment, closure of lip gaps and nose shaping), treatments also had significant functional purposes: improving communication, nasal breathing and feeding (Berkowitz, 2013). For instance, dental care, reparative and reconstructive surgeries and speech therapies, all from the children’s views, aimed to improve their speech, vital for verbal communication. Similarly, primary and secondary corrective CLP surgeries as well as rhinoplasties were and would be instrumental for improving functions such as feeding and breathing.
As stated earlier in this section, the normalising nature of certain medical interventions have been strongly criticised by disability studies (Garland-Thomson, 2011; McLaughlin & Coleman-Fountain, 2014). Despite recognising the benefits of certain interventions such as reparative CLP surgeries to helping individuals to overcome bodily impairments (Garland-Thomson, 2011), the normalising discourse embedded in these medical interventions, instead of contributing to make the experience of illness or impairment better, have the potential to accentuate exclusionary actions towards different bodies (Conrad, 2007). This is for two main reasons: the normalising dynamic of some interventions might work as an implicit rejection to diverse forms of embodiment (Garland-Thomson, 2011; Shildrick, 2005) and secondly, interventions frequently promise a normal, stable, predictable and manageable body, a discourse in some instances ‘fictional’ (McLaughlin & Coleman-Fountain, 2014 p. 77) given that bodies are complex, diverse, often unpredictable and do not always respond to treatments and follow medical rules and premises (McLaughlin & Coleman-Fountain, 2018; Shildrick, 2005).

This fictional discourse was evident in some of the participants’ accounts with regard to their treatments. The potential to change appearance to be normal (e.g. nose) might be seen as somewhat unreal particularly when there is no clear definition of what normality entails (Rose, 2009; Runswick-Cole et al., 2018). Likewise, some interventions looked unreal such as the reconstructive surgery in which Lina’s ear would be opened and a graft placed in her tongue. Particularly a tongue graft sounded not only technically complex as her mother said, but also difficult to attain given the social and geographical barriers to healthcare services mentioned earlier in Chapter 6. Despite the potential fictional and normalising nature of some therapeutic promises, something that is particularly problematic bearing in mind that plastic surgeons often fail to recognise the implications of this discourse in how human appearance variations become socially less accepted (Marsh, 2006), the majority of participants reported positive effects of treatments in their lives (e.g. ‘speaking well’).

Although some of the children might have felt instigated to achieve, in some way, a ‘fictional’ medical standard of normality (McLaughlin & Coleman-Fountain, 2014, p. 77) with regard to their speech, nose shape and hearing (Chapter 6), my study has demonstrated that these treatments
(including their explicit or implicit normalising discourse) were fundamental to mitigate both inherent vulnerabilities associated with CLP and the social costs of having bodily differences in my participants’ lives.

7.6 Children’s agency: early life stories, stigma resistance and the body project ownership

In Chapter 2 I noted that within childhood studies, agency is a concept frequently discussed, but sometimes in a repetitive and less scrutinised way. In order to examine this ‘mantra’ (Tisdall & Punch, 2012 p.251) from a more critical, and less minority world dominant position, in this section I discuss three main findings with regard to agency: the children’s capacity to make sense of CLP, its origin and early life treatments; their strategies of stigma resistance; and their engagement with treatments.

7.6.1 Models of causation and early life treatments: agency and dependency

In Chapters 4 and 5 I demonstrated the children’s capacity to construct meaning about what is CLP, its origin and early life treatments. As mentioned in section 7.2 this is reflective of their competency in knowledge production (Hackett et al., 2015; James, 2009) but also evidence of their ‘been’ agentic roles (Hanson, 2017). Children’s capacity to construct stories in the here and now about their early life and non-remembered events illustrates how they are able to incorporate traces of their past into their present lives (Orellana & Phoenix, 2017). This is important to note because as stated in Chapter 2 the ‘been’ or past is an aspect of children’s lives that has been largely neglected and absent in childhood studies. Not recognising the ‘been’ is problematic as it means looking at children’s agentic contributions only in two dimensions: being and becoming (Hanson, 2017). A ‘triolectical’ conceptualisation, composed by the ‘been’, ‘being’ and ‘becoming’ offers us the possibility of seeing children’s agentic selves in three different dimensions: past, present and future (Hanson, 2017, p. 282).

The way in which the children produced meanings about the origin of CLP and early life treatments reflects their agentic contributions. The most visible form of agency is how the
children actively incorporated their parents’ stories of both the origin of CLP and initial treatments into their own accounts. The participants were also agentic when making decisions on whether and how much to include of their parents’ stories in their own versions and particularly when they demonstrated that they could make sense of non-remembered events.

An important point to reflect in relation to the children’s explanatory models and accounts of early life treatments is the extent to which these versions (based on the retelling of parents’ stories) were modified by the children. As noted in Chapter 4, this is something that remains uncertain from the data generated, given that my study was limited to exploring the children’s views, not their parents’ accounts. However, it is highly probable that these parents’ narratives were modified by the children as stories about our past are shaped by our present life circumstances and therefore the way in which we talk about our past tends to change as our life circumstances also evolve (Orellana & Phoenix, 2017).

As mentioned in Chapters 4 and 5, the influence of parents’ stories in the children’s religious and environmental models and their accounts of early life treatments indicate that parents have a key role in helping children to make sense of the origin of their condition and early life events. I noted in Chapter 4 that the parental influence on the children’s stories was not surprising for two main reasons. Firstly, parents have a dominant presence in most children’s early lives. It is expected that they play a key role in shaping children’s understanding of many aspects of their lives, including the origin of their health conditions and treatments. Secondly, the congenital nature of CLP and the fact that treatments started very early in their life meant that children did not have memories of these events. Clearly, the presence of others’ stories about non-remembered events assisted the children in the meaning production of those non-remembered life episodes (Hall et al., 2013).

Further examining the role of parents’ narratives in how children become aware of early life treatments and their CLP, Hall et al. (2013), argue that children’s capacities to provide detailed accounts about initial treatments are in part due to the presence of ‘the collective fabric’ (p. 23).
For these authors events such as primary CLP surgeries are part of collective memories which are transmitted across generations and become part of the family’s and therefore children’s own memories. Although my results reflect partially those of Hall et al. (2013), given the dominant role of my participants’ parents stories in the construction of their own versions, there are also some points of contrast. In Chapters 4 and 6 I showed how parents’ stories were not passively absorbed by the participants, but rather they made decisions on whether and what to incorporate of those stories into their own versions. There were two explicit examples: while in Chapter 4, Camilo drew on his own imagination rather than the stories of others to explain the potential cause of CLP, in Chapter 6, Isa explicitly challenged her mother’s story of an initial surgery in her lip, something that she did not include into her own accounts and life story work. This complicates the idea that family stories necessarily become part of the child’s own biographical story as proposed by Hall et al. (2013). Rather than a ‘collective’ or family ‘fabric’, parents’ stories might be seen as part of a pool of available stories which might or might not be used by the children.

As mentioned in Chapter 2, traditional approaches of agency tended to see children’s agentic practices on the scale of how active and autonomous their actions and choices were. Isa and Camilo’s cases illustrated this more traditional but narrow view of agency characterised by active and autonomous decisions (Alderson, 2007; James, 2009; Prout, 2000). Camilo was active and autonomous in the way he constructed his own model from scratch (without the help or presence of others’ stories), and Isa implicitly challenged and did not incorporate her mother’s story into her own stories. These two examples might also be reflective of a ‘thick’ agency in which children decide actively within a range of options (Klocker, 2007). The flexible and open nature of the interviews implied that both children could have used any resource available to them to make meaning of those events (e.g. asking family members present at home).

From this traditional notion of agency that privileges autonomy, self-determination and individual freedom (Larkins, 2019), the children’s dependency on others’ stories (the predominant tendency in my participants) might indicate their limited agentic roles in
constructing their own views and models of their condition. However, as discussed in Chapter 2, determining children’s agency on the basis of the characteristics of their actions (active vs passive/ autonomous vs dependant) is problematic (Abebe, 2019; Spyrou, 2018). Particularly ideas that see this concept in terms of autonomy tend to overlook children’s vulnerabilities and dependency, both also part of their ontological condition (Bluebond-Langner & Korbin, 2007). Furthermore, it is also important to remember that contemporary and cross-world views of agency advocate for an understanding of agency as a spectrum of actions, omissions and decisions shaped by relationships, children’s preferences and socio-cultural and political contexts rather than only as being autonomous or active (Abebe, 2019; Eßer, 2016; James, 2009; Larkins, 2019; Spyrou, 2018; Tisdall & Punch, 2012).

My participants were aware of their dependency on others’ stories to speak of pre-birth and early life events. Despite this dependency, which might also be a vulnerability given the lack of memories of these events, they were able to produce meanings around these life episodes. This indicates that their condition of dependency or vulnerability did not go against their status of social agents (Mizen & Ofosu-Kusi, 2013; Spyrou, 2018), but rather has the potential to enhance their agentic contributions. The participants were aware that the shortness of their age when these events happened implied that they cannot remember these events and therefore that they relied on others’ stories to make sense of the origin and initial treatments. This connects with works that demonstrate how children who recognise their vulnerabilities both create and move forward resources to cope with or overcome those vulnerabilities (Mizen & Ofosu-Kusi, 2013; Zakayo et al., 2020).

In the absence of their own memories of their birth (or the antenatal identification of their CLP), in the quest for an explanation of the why of their condition and purposes and details of early life treatments, the presence of parents’ stories (recounted at some point in the children’s lives) helped the children to make sense of these events. This findings shows how children’s competence is not always diminished by adults, as discussions with parents in which they shared stories and memories, were key for the children’s making meaning of their condition and
therefore key for the enactment of their agentic roles (Britton, 2015). The positive role of parents reinforces Benwell’s (2013) argument about being cautious of prevalent ideas that look at adults’ power over children as always detrimental for their agentic positions.

In this section I have drawn two key arguments: the children showed different types of agency in the construction of stories around CLP, from an active and autonomous type of agency to subtle and more dependant forms. Their dependency on parent’s stories did not obscure their capacity to produce meanings around their condition. With the same focus on agency in the following subsection, I discuss other forms in which the children exercise their agency in a relevant aspect of their lives: their experiences of stigma.

7.6.2 Resisting Stigma: ‘everyday’ and ‘ambiguous’ agency

Stories of how my participants responded to stigma offered me the opportunity to scrutinise the context in which their agentic selves were enacted. This discussion contributes to the need to better understand the contexts and relational forces that allow, or limit the unfolding of their agentic roles (Abebe, 2019; Edmonds, 2019; Spyrou, 2018).

As noted in Chapter 2, traditionally the figure of a child is often placed in a register of vulnerability, risk, and victimhood (Coffey et al., 2016). However, the way the children resisted and challenged their stigmatisers depicted an empowered image of them, troubling the picture of the vulnerable, shy, passive victim child with physical differences represented frequently in previous studies (Murray et al., 2010; Rumsey & Stock, 2012). Viewing the children’s actions of resistance through the lens of agency typologies, ‘everyday agency’ (Payne, 2012, p. 399) has some similarities with the form in which my participants resisted, counteracted and responded to their stigmatisers. According to this notion, children make everyday decisions and actions in order to deal with the adversity of their everyday lives (Payne, 2012). These everyday decisions are implicit in the way the participants used different forms of resistance (e.g. physical fights, verbal retaliation, reporting to adults, etc) strategically in order to minimise the detrimental effect of devaluing actions or comments on themselves.
Although understanding that children are not only actors but agents is important, it is necessary to go beyond the recognition that children have agency to examine the spatial, relational contexts and processes in which their agentic positions unfold (Abebe, 2019; Punch, 2016b; Spyrou, 2018). Despite the different styles and strategies which the children used to resist and challenges their peers’ actions and comments, my participants’ agentic positions were enacted within a ‘thinner’ agency context (Klocker, 2007, p. 85). As I noted in section 7.4.2, stigma implies important socio-relational limitations that can been seen as thinners or restrictors of their agency. However, the way in which the children made decisions in relation to how to act (active/contentious vs more subtle and adult-dependant) even in the presence of a constrained context (stigma and the adult-controlled context of school), reveals not only their agency practices shaped by adversity rather than dominant ideas of agency enablers (e.g. a context in which children’s rights are protected), but also demonstrates how children’s vulnerability and highly constrained contexts do not go against their agentic roles (Mizen & Ofosu-Kusi, 2013; Payne, 2012).

Acknowledging people’s capacity for resistance is a crucial political issue (Bordonaro, 2012; Bordonaro & Payne, 2012). However, this capacity for resistance tends to be overlooked when the minority world notion of agency is uncritically embraced in theory and practice. This notion of agency recognises as agentic, only those practices that follow normative precepts of good citizenship and responsible actions; an ideal that children’s agentic practices within adverse contexts may not always follow (Bordonaro, 2012; Edmonds, 2019). Recent debates on what type of agency is good, highlights the complexities of only recognising as agency those practices that go in concordance with what is morally and ethically accepted in the minority world. In particular, when in order to cope with poverty, power imbalances and global inequalities, children have to engage in actions that might be morally and ethically reprimanded, their practices are at risk of not being recognised as agentic (Edmonds, 2019).

My participants’ actions of resistance did not always take the form of this morally accepted and normative agency. Instead their actions and omissions were triggered by emotions such as anger,
and featured contentious responses such as physical fights, stigmatised comments and verbal retaliations, that connect with an ‘ambiguous agency’ (Bordonaro & Payne, 2012, p. 365). This concept refers to children’s actions and decisions that are going ‘against the grain’ (Bordonaro & Payne, 2012 p.367), the traditional, normative and minority world centric but problematised and narrow view of agency (Abebe, 2019; Bordonaro & Payne, 2012; Edmonds, 2019). Many of children’s and young people’s decisions categorized as ambiguous agency involved efforts to act in interpersonal contexts in which they have limited power (Johnson et al., 2018). While these behaviours might raise questions about the adequacy of my participants´ actions, as they can lead children to resolve problems through contentious actions rather than dialogue, they also reflect children’s active efforts to cope with adverse events as best they can (Johnson et al., 2018).

The extent to which children´s actions are or not accepted depends on the moral and therefore socio-cultural codes used to assess and evaluate their behaviours (Edmonds, 2019). In line with this, the participants´ actions were consistent with what was accepted by their families as a correct and appropriate defensive behaviour. As noted in Chapter 5, contentious actions such as Santi’s fights and Coni’s verbal retaliations (an agency morally ambiguous) were accepted and allowed by their parents. This acceptance can be seen in connection with the idea that anger and subsequent actions are morally legitimate forces when it comes to social justice (Muldoon, 2008). Clearly stigmatised attitudes are an insult to children´s selves and therefore protective actions and responses were for the children and their parents irrespectively legitimate.

The way in which the children´s actions of resistance were against a normative agency but accepted by their parents, highlights the importance of seeing children’s agency in context (Edmonds, 2019). When we treat agency as a socio-culturally grounded concept, reflective of situated socio-cultural expectations, there are more opportunities to understand agency as a diverse and variable phenomenon, which otherwise is obscured by privileging certain cultural premises and expectations in relation to agency such as those of the minority world (Abebe, 2019; Edmonds, 2019).
7.6.3 Emotions and agency

I stated in Chapter 2 that a key action for moving forward the debates and theoretical issues with regard to agency, is drawing further attention to the embodied practices of agency (Eßer, 2016). At the epicentre of these practices are emotions (Burkitt, 2014; Harden, 2012). As discussed in Chapter 2, emotions are closely connected to the body reflected in its hybrid nature: emotions are materially experienced but also emerge from, and shape our relationships. The role of emotions in patterning our relationships means that they have an agential component, and this is very well theorised by Hochschild (2012) in the notion of emotion management. This is the type of work which people engage with to regulate their emotions and to show through their bodies emotional responses more consistent with cultural and social requirements. Two key actions entail this work: deep and surface acting. While the former entails a process through which people modify their emotions to match an expected role, in surface acting we hide our true emotions and show bodily signs discordant to our deep emotions.

I argued in Chapter 5 that the children’s actions and avoidance towards their stigmatisers were greatly shaped by their emotions (predominately anger), the embodiment of them and emotion works. Clear examples of emotion work in the children’s responses towards their stigmatisers were Mariana and Natalia’s cases. Although being mimicked for her speech made Mariana feel angry, she would not ‘dare to fight’, given that this might cause problems with her teachers. Similarly Natalia, who despite feeling anger when peers made comments about her nose, preferred to report the incident to her parents rather than arguing. Despite the apparent subtle, adult-dependant character of these girls’ actions, their decisions were accompanied by clear forms of emotion work. Certainly, Mariana and Natalia controlled the expression of their anger and refrained from fighting in order to avoid trouble with teachers. This reflects how certain emotions are not seen as positive or appropriate to display in an educational context such as school (Harden, 2012). Although the management of their emotions was in line with surface acting, given that they felt, but not embodied anger, at the epicentre of their emotional works is that anger was directed towards a more useful action – reporting their peers’ insults to powerful figures- teacher and parents. This not only would bring them more advantages in term of the
severity of the reprimand that their peers would receive but also would offer them the option of not getting into trouble. This reflects how despite the regulation of the embodiment of emotions, these actions still have the power to shape our relationships (Hochschild, 2012).

On the other side of these emotion-driven responses, some children decided to express and embody their anger by means of verbal and physical retaliations. These types of responses were driven by strong feelings of anger as Carlos described his peer mockery as ‘making his blood boil’. Particularly anger is understood as a prelude to action (Ahmed, 2014) and a force that allows people to recover and protect their social selves (Katz, 1999). The children’s contentious actions reflect a more open and less regulated emotional self, contrary to what may be expected of a ‘civilised’ being (Elias, 1994; Lupton, 1998). Nevertheless, we need to be careful in making assumptions about how such emotional responses may be viewed. The children’s embodiment of anger was consistent with their socio-cultural contexts, a Latino context in which the public expression of emotions is socially allowed (Ariza, 2021; Scribano, 2019).

It is also significant to highlight that these emotion works and responses were gender-dependant. While emotion works and verbal retaliations were more frequent among girls, physical fights were more common for boys. This reflects how emotion work and the embodiment of emotions tend to follow expectations and rules in relation to particular social roles (Lupton, 1998): the emotional picture of women as good at mastering anger (Hochschild, 2012) and the masculine image of a man expressing anger and physically retaliating against others (Lupton, 1998).

The role of emotions in allowing the children to assert their agency demonstrates that intense and deep emotions such as anger are as key for human interaction (Shilling, 1999), as it is for asserting our agentic roles (Burkitt, 2014). In a similar way to theories of agency, this invites researchers and practitioners to look at ‘negative’ emotions and its regulation as locally situated phenomenon and not only from the vantage point of predominant socio-cultural systems.
7.6.4 Children’s agency and the body project

Although research investigating children as health actors has increased recently, works published in this area tend to be disparately located (Brady et al., 2015). Research production on children’s agentic contributions with regard to health, wellbeing and care has been focused on exploring their participation in decision-making processes, involvement in care, and their abilities to perform certain health behaviours and promote healthy choices and practices (Montreuil & Carnevale, 2016). This is because although highly problematised, the gold standard of children’s agentic roles in healthcare contexts continues to rely on their positions as autonomous decision makers and actively involved in their care routines (Sorbring & Kuczynski, 2018). However, the recognition that agency is a ‘mantra’ (Tisdall & Punch, 2012, p. 251) with significant theoretical concerns (e.g. a concept dominated by minority world premises), and particularly debates on the pernicious view of agency as only in connection with autonomy, independency and individual actions (Abebe, 2019; Eßer, 2016; Larkins, 2019; Spyrou, 2018), has uncovered the need to further scrutinise and contextualise children’s roles as health actors (Brady et al., 2015).

In response to this, recent studies have revealed that children might manifest their agency even when they do not explicitly make decisions on treatments or are not allowed or invited to have an influence in their care (Olli et al., 2012). Children are agentic when they can make meaning of their health conditions, speak about treatments and care in their own terms and language, and be part of therapeutic decisions even if not in explicit ways (Franklin & Sloper, 2009; Olli et al., 2012). This is because recent developments in theorising agency within childhood studies have moved away from a dualist approach to agency, to embrace one in which agentic contributions involve both individual and collective healthcare practices, dependant and autonomous actions regardless of the presence of agency enablers or constrainers (Eßer, 2016; Larkins, 2019).

Acknowledging the diversity of children’s agentic positions with regard to health and care, the participants showed their status as health actors in subtle but discernible forms. This is visible in two main findings: the implicit ownership of the body project discussed in section 7.5, and their subtle but active engagement with certain treatments and the ways in which they started to
explore the implications of making decisions about future treatments (Chapter 6). To discuss the former, it is important to return briefly to the idea of the body project discussed previously.

Central to this notion is that bodily transformations that come with medical treatments or other body works practices should be in line with the owner’s design (Shilling, 2012). This means that although individuals may not always be directly engaged with the performing of certain body works such as plastic surgeries for instance, bodily transformations resulting from these works should be consistent with the owner’s explicit choices (Shilling, 2012). This clearly involves a process of making implicit or explicit decisions on the how and where those bodily changes should occur. I noted in section 7.5 that although CLP treatments were not designed by them, transformations were in line with their needs and desires. This indicates that these medical works, often seen as part of a medical body project, were also part of their own body projects and therefore the children made implicit decisions to accept these bodily transformations in the light of benefits for their social lives and physical bodies. The fact that these medical body projects were also their projects demonstrates that the participants were not passive recipients of these works but rather health agentic beings.

The children were also agentic when they engaged with certain treatments as everyday routines. For example, despite the painful and discomforting nature of dental treatments and the eating limitation that these implied for some children, they wore their removable dental appliances everyday (Chapter 5). Although the focus of my research was not to explore the children’s participation in decision making processes of treatments and care, some children showed how they started to navigate the potential difficulties of making decisions about their future treatments and bodies when weighing up therapeutic drawbacks and benefits of particularly future surgeries (Chapter 6).

A clearer and more explicit display of their position as health agents was evident in the way Lina was seeking alternatives to practice her speech without the support and supervision of an adult. This example apart from demonstrating children’s engagement with care routines in autonomous and independent ways (Khair et al., 2015), and their commitment to the body
project, further supports the idea discussed in sections 7.6.1. and 7.6.2. that expressions of agency can arise through experiences of vulnerability, so that both agency and vulnerability can exist simultaneously (Mizen & Ofosu-Kusi, 2013; Zakayo et al., 2020). Lina’s agentic practices were triggered by the recognition of her vulnerabilities – the poor support from her parents to develop home speech practice and the already mentioned barriers to access speech therapies.

The participants’ subtle but discernible contributions to their treatments, and the fact that these medical works were not passively adopted by them, but rather were in line with their body projects, shed light on another dimension of their roles as health actors, a dimension that does not necessarily imply making explicit decisions on care and preferences or holding an active position within the dynamics of a patient- doctor relationship (Rindstedt, 2014), but rather took the form of delicate but active practices of agency.

Having discussed the main findings of my research, I move on to present the contribution of the biographical focus of my methodology to research methodologies with children.

### 7.7 Methodological contributions: a biographical approach to researching with children

Apart from discussing the research findings, I also found it pertinent to outline the contribution of my methodology to an area largely underattended, namely biographical research with children. Although my research did not have a biographical nature, as the exploration of biographies often involve in depth accounts of individuals’ wholes lives or certain aspects of their lives (Riessman, 2012; Ritchie et al., 2013), in this section I highlight some of the contributions of the methods used in my study to biographical research with children.

As noted at several points throughout this thesis, biographical research with children is an underdeveloped area in childhood studies (Bray et al., 2014). This in part due to assumptions that children have not got the cognitive competence to speak of their lives in a coherent way but also
because of the shortness of their lives (Baker, 2013). However, troubling this assumption, my study showed how my participants were capable of talking about their lives by making explicit references to their past, present and future, thus reflecting their agentic positions as ‘been’ (Hanson, 2017) ‘being’ and ‘becoming’ (Uprichard, 2008). The children’s past (been) was visible in their accounts and stories of the origin of CLP (Chapter 4) and past treatments (Chapter 6). Their present (being) and future (becoming) were evident in their stories of current and future treatments and how these were promising in changing their future social lives and material bodies (Chapter 6). With a more cross over nature, stigma experiences (Chapter 5) were part of their past, present and future. For some children, stigma-related events had started in their initial years at school and continued to happen in their present lives; children also imagined a future life free of stigma. Key for capturing and working with these different temporalities of the children’s lives was the use of interviews, creative tools and particularly walking interviews for exploring their past.

In relation to interviews, the structure and questions of the interviews facilitated the exploration of certain themes and aspects of the children’s lives. For example, my invitations to talk about their school lives led the children to speak of past and present friendships and experiences of stigma but also expectations about their future social relationships. Equally important is to mention that the place in which the interviews took place also contributed to privacy and confidentiality, aspects that made the participants feel safe and confident about talking. Bedrooms (home base interviews) and outdoor settings (walking tours) were particularly places which the children found private this being key for the enactment of narratives of certain life episodes. My position as an insider (Gair, 2012), which means that I was not only culturally and socially familiar with the context of my participants (e.g. I was familiar with some of the activities Colombian children from middle and lower class often do in their everyday lives at home and school), but also aware of the medical issues and some potential social difficulties that children with CLP experienced (this from my work as a clinician), also facilitated the construction of questions and prompts to explore their past, everydayness and expectations and plans for the future.
Life story works (a creative tool) were relevant for looking at what and how the children incorporated events of their lives narrated in the interviews into more visual and public representations. The children’s life story works allowed the construction of a more in depth picture of the significance and position of certain events related to CLP in their lives. These tools alongside photo-elicitation, also served as an opportunity for the children to expand on certain past events of their lives. For example more detailed stories of early life treatments were prompted by these works and supported by the presence of photos that evoked memories of these events. This is not the first time life story works have been used in research with children and young people with CLP. Through timelines, a type of life story work, the work of Hall et al. (2013) found that CLP and treatments were only a part of young people’s lives among other important events unrelated to their condition. This is something I could also observe from the biographical representations of the participants in my study: CLP was one among many other significant events in children’s lives (e.g. parents’ divorce, siblings’ birth were key events in the lives of some children).

The walking tours also contributed significantly to this biographical exploration, and were perhaps the most novel aspect of the methods used (as discussed in Chapter 3). These tours favoured emotional connection with spaces, something that facilitates the elicitation of past memories and more recent experiences (Anderson, 2004; Evans & Jones, 2011) both prompting the children to speak of their past and present lives. For example, seeing other children playing in playgrounds, made Fabian and Jeronimo speak of their difficulties in taking part in playing groups in both their past and present school lives.

This section has shown that although without a biographical nature, the methods implemented in my study facilitated the exploration of certain aspects of children’s lives, following a temporal dimension.
7.8 Strengths and Study limitations

One of the strengths of this research study is that it explores the experience of living with CLP through the children’s perspectives, an area that has been dominated by studies with parents rather than children, and largely unattended in the Latin America context.

This study could also be considered as unique as it sits at the intersection of both theoretical and empirical research that have not been fully developed within childhood studies: children’s bodies, emotions, biographical research and the sociology of health. It could also be considered as interdisciplinary and cross-world given my medical background, the sociological focus of my Ph.D. but also the theoretical and empirical examples of the majority and minority worlds I use to analyse and discuss the data.

When considering the limitations there are some important points for reflection. I recognise that despite my efforts to reflect on my position as a researcher and my preconceptions throughout the study (particularly my efforts to remember and reinforce that my position in the interviews was not that of a doctor), the participants’ stories and accounts might have been influenced by the interviews being conducted and interpreted by a doctor and adult researcher. It is possible that some of the children viewed me as a part of Operation Smile and then favoured giving positive accounts of treatments and interventions.

In some cases, the presence of parents in the interviews also may have influenced how the participants presented their accounts and experiences. This is because power differences and the children’s fears of being disapproved of by their parents might have influenced the way in which their accounts and stories were portrayed as well as their content.

In relation to the sample, these findings are based on a purposive sample and emerged from and within a specific socio-cultural context. This implies that these findings might not reflect the situation of other contexts. Also of note with regard to the sample is that recruiting through a NGO limited the incorporation of participants from upper class and more privileged socio-
economic status, as these often attend other type of healthcare services. Equally important is to reflect that minority ethnic groups are not part of the prevalent population of Operation Smile-Colombia and therefore my sample did not include these groups of people. Not having particularly indigenous population in my sample is a noteworthy limitation in terms of the generalizability of the findings. Their socio-cultural contexts differ significantly from the dominant ethnic Colombian groups and this implies that their experiences of living with CLP and views towards this condition might also differ.
Chapter 8  Conclusions

8.1  Introduction

This thesis aimed to examine children’s understandings of CLP and their experiences of living with this condition with a focus on their social lives and treatments. In particular a focus on children’s own perspectives rather than accessing their opinions by proxy has provided a nuanced picture of what they thought of their condition and what is implied by having a different body (physical and functional) within their everyday lives. CLP is a theme scarcely examined by qualitative research approaches and even less attended by researchers in the majority world. This study therefore means a significant move forward in the production of qualitative research with children about this condition within a majority world context. This concluding chapter offers a reflection on the implications of my research for practice, suggests avenues for future research into CLP and provides some conclusion remarks.

8.2  Implications for practice

This study has demonstrated how the children’s views and understanding of their conditions (including its origin) might differ from biomedical definitions and etiological models of CLP. This invites healthcare professionals to be sensitive to these particular views of CLP and models of causation when providing and discussing information about treatments and genetics counselling, for example, by using a language that connects with their particular beliefs and understandings. Although these participants were active attendees of the clinical site, thus denoting that their views do not limit their search for healthcare, it is possible that with other groups such as indigenous and minority groups from remote and rural areas their understanding and conception of CLP did limit their seeking care. As commented in Chapter 2, stigma and fatalistic views of the origin of CLP are frequent among certain communities and this might limit children’s access to treatments.

Government measures to protect the rights and welfare of people with disabilities and impairments in Colombia includes several statutes and public policies (Ley Estatutaria 1618,
In summary, this legislation states that both public and private sectors should design and implement strategies to afford inclusive spaces and practices for those with disabilities and impairments, this in order to allow their free and unrestricted participation in society. In particular with regard to children and young people, it is mandatory for both public and private educational institutions to ensure inclusive environments and spaces inside and outside the classroom but also attend to the educational needs of those with certain health conditions (Decreto 1421, 2017). Despite this strong legislation in theory, the participants’ stories of stigma experiences, particularly those who described limited support from teachers such as in Jeronimo’s and Valeria’s cases (Chapter 5), speak of potential failures in practice.

The stigmatised acts against the participants’ differences illustrated in Chapter 5 are indicative of a poor culture of respect towards others’ differences within the school setting but also denote the absence of actions to educate peers about CLP. There were also no clear examples of how these acts were penalised at the institutional level. This is an important area to be investigated in future research to better understand the extent to which policies of inclusion are being implemented adequately in the school context.

Also of note is that despite the psychological support that a CLP healthcare plan offers, the children seemed not to recognise this as a central component of their treatments, neither did they mention practical benefits of this support to face their experiences of stigma. To some extent this finding is expected given that as mentioned in Chapter 6, surgical care forms the axis of a CLP healthcare plan with psychological support during childhood tending to hold a secondary role (Stock et al., 2016). However, the significant social difficulties experienced in the school context invite both CLP healthcare plans designers and practitioners to reinforce the emotional and psychological support provided to these children.

Communication and speech difficulties were not only salient concerns for the children because of the risk of stigmatisation for their speech differences, but also for the oral communication issues that were caused by their speech difficulties. This suggests that equally important to lip
and palate surgeries and dental treatments, is speech rehabilitation. Speech is a key aspect of the children’s bodies that should start to be rehabilitated from very early in their lives. Often speech therapies do start in pre-school lives, but it is necessary to implement strategies to initiate this rehabilitation sooner given the negative impact of these difficulties on children’s communication.

Also related to children’s speech difficulties, it is important to put in place strategies to address access barriers to therapies. Although in particular Operation Smile has a satellite branch closer to certain rural areas in Boyacá, cases such as Lina’s show that an extra branch is not sufficient to overcome these difficulties of access. Apart from the important changes that are needed on a structural level in order to ensure children’s equal and timely access to treatments, the third sector can also contribute to minimise these barriers, for instance, through the development of social enterprise ideas for the implementation of telemedicine. Having therapies at home supported by a speech pathologist remotely could address the economic and geographical difficulties that children such as Lina experienced in accessing therapies.

8.3 Future avenues for research

Findings of and the methodology implemented in this study suggest some areas that could be investigated in future research. It is important to investigate the construction of explanatory models among children from other socio-cultural contexts, for example the minority world and minority ethnic groups such as indigenous communities. The focus on indigenous groups is particularly important given the high prevalence of CLP among these communities and the negative beliefs associated with its origin described in African studies. It is especially relevant to scrutinise whether certain cultural perspectives towards the origin of CLP might work as a barrier for access to CLP treatments.

Although this study highlighted that certain bodily discomforts associated with CLP might compromise certain aspects of the children’s everyday lives such as sleeping (Marcos) and playing times (Ricardo), there is a need for further investigation on the intermittence and nature
of these symptoms. Further research would improve understandings of the impact of functional issues on children’s lives and then the generation of better targeted treatments and care.

Research on children with CLP who also had other ‘major’ medical conditions (e.g. congenital cardiopathies, developmental delay, learning difficulties) is mainly quantitative. Further qualitative research which examines the experiences and views of these children is needed given that the presence of additional congenital conditions might imply important differences in how CLP is understood and experienced. For example the expectations, needs and experiences with treatments might differ from those children with isolated CLP given that the presence of additional medical issues means different healthcare needs, other type of treatments and symptoms.

Walking interviews is an approach that could be further implemented with children, particularly when exploring potentially sensitive topics. As commented in Chapter 3, some children found the walking interview an opportunity to ensure privacy, especially when having a private talk in their homes was not attainable. This method could be implemented by subdisciplines of childhood studies such as children’s geographies interested in investigating children’s relationships with and understandings of public space, or their experiences of migration.

Stigma experiences of particularly young people with CLP are important to scrutinise in majority world contexts. This is because adolescence brings about important changes in children’s and young people’s physical appearance, identities and social relationships. Although there are some studies examining stigma associated with visible differences among young people, these are developed in the minority world. As mentioned at several points throughout this thesis, there are important socio-cultural differences between these regions of the world and therefore research should be sensitive to this differences when investigating certain phenomena.

This thesis has also highlighted the role of emotions in the configuration of children’s agentic practices. As mentioned in Chapter 2, children’s emotions have been explored in implicit rather
than explicit ways within childhood studies. Further examination of how embodiment of emotions and emotion management are used by children to assert their agentic positions may contribute to the development of more child-centred theories on emotions.

8.4 Conclusion remarks

This research has explored children’s understandings of CLP and their experiences of living with this condition with regard to two main dimensions: their social lives and treatments in a majority word context (three regions in Colombia). Its key contribution was to show that children’s understandings of CLP definition and origin did not follow a biomedical discourse and that CLP, despite being a congenital condition was experienced as a biographical contingent event. The participants’ accounts shed light on the social cost of having a different body, the functional impairments and bodily discomforts that come along CLP, but also how treatments were promising in offering them the opportunity to display a more common, socially safer and more comfortable body.

Importantly, this thesis has served to problematise the registering of children with CLP as vulnerable. Children with CLP are often deemed as vulnerable given the socio-relational difficulties they experience as a result of their visible differences but also because of medical risks and complications resulting from their condition (e.g. eating issues, ear infections, etc). However, the participants in my study revealed an agentic self, capable of dealing with the social costs and bodily discomforts, and of engaging with the process of fixing their bodies which suggests as complicating of this register of vulnerability. The diversity of their agentic practices: subtle, active, ambiguous, emotion informed and mediated, enacted within a context of agency constrainers, emphasised the importance of seeing agency practices in context.
References


https://doi.org/10.1597/12-255


https://doi.org/10.1016/j.ajodo.2013.08.016


https://doi.org/10.1016/j.socscimed.2007.08.005


https://doi.org/10.1177/1476718X10387896


https://doi.org/10.4135/9781446268377


https://doi.org/10.1007/s00266-006-0241-2


https://doi.org/10.1146/annurev-soc-021021-054653


https://doi.org/10.1177/0038038512450804


https://doi.org/10.1007/s10730-013-9226-0


https://doi.org/10.1111/spc3.12389


https://doi.org/10.1080/14733280701445796


https://doi.org/10.1080/13674676.2013.795138


https://doi.org/10.1057/9780230583511


http://es.presidencia.gov.co/normativa/normativa/LEY%201885%20DEL%202018.pdf


https://www.icbf.gov.co/cargues/avance/docs/ley_1878_2018.htm#:~:text=Derecho%20del%20Bienestar%20Familiar%20%5BLEY_1878_2018%5D&text=Por%20medio%20de%20la%20cual,y%20se%20dictan%20otras%20disposiciones.&text=DECRETA%3A,ART%C3%8DCULO%2010.


http://es.presidencia.gov.co/normativa/normativa/LEY%201885%20DEL%202018.pdf

https://doi.org/10.1080/09687590601056162


https://doi.org/10.1177/0907568211422748


https://doi.org/10.1027/1192-5604/a000054


https://doi.org/10.1177/0961463X15590744


https://doi.org/10.1111/j.1547-5069.1999.tb00482.x

https://doi.org/10.3390/laws5030035

https://doi.org/10.1016/j.genhosppsych.2011.06.006


https://doi.org/10.1177/2043610619860994

https://doi.org/10.1080/0300443900570101


https://doi.org/10.1177/1049732311417456


Folayan, M. O., Oginni, O., Arowolo, O., & El Tantawi, M. (2020). Association between adverse childhood experiences, bullying, self-esteem, resilience, social support, caries and oral


https://doi.org/10.4324/9780203715109


https://doi.org/10.1111/j.1099-0860.2007.00131.x


https://doi.org/10.1177/1077801214543384


Halasz, J. (2018). About the right to be ill. *Medicine, Health Care and Philosophy, 21*(1), 113–123. https://doi.org/10.1007/s11019-017-9790-1


Hall, M., Gibson, B., James, A., & Rodd, H. D. (2012). Children’s experiences of participation in the cleft lip and palate care pathway: *Participation in the cleft lip and palate care*
https://doi.org/10.1111/j.1365-263X.2011.01214.x


https://doi.org/10.1080/14733285.2011.638178


McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2010). My Speech Problem, Your Listening Problem, and My Frustration: The Experience of Living with Childhood Speech...
https://doi.org/10.1044/0161-1461(2009/08-0129)

https://doi.org/10.1111/j.1748-3743.2010.00219.x

https://doi.org/10.1111/j.1467-9566.2011.01388.x

https://doi.org/10.1016/j.socscimed.2014.09.012


https://doi.org/10.1597/07-085.1

https://doi.org/10.1111/0735-2751.00083


http://colombia.operationsmile.org/quienes-somos/historia/


https://doi.org/10.1177/0907568216671178

https://doi.org/10.16925/od.v12i24.1658


270


función y el sentido del fenómeno violento dentro la familia. Interdisciplinaria, 36(2), 97–110. https://doi.org/10.16888/interd.2019.36.2.7


*Emotions and Society, 1*(2), 147–161.

https://doi.org/10.1332/263168919X15664311976691


https://doi.org/10.1038/sj.embor.7400195


https://doi.org/10.1080/000713199358527


Shilling, C. (2016). *Natural bodies or social bodies?* Oxford University Press.

https://doi.org/10.1093/actrade/9780198739036.003.0002


https://doi.org/10.1177/0907568214529600


https://pdfs.semanticscholar.org/14cf/5cc0ea7cdccc12e230c77c87773614bb196a4.pdf


https://doi.org/10.1037/hea0000262


https://doi.org/10.1016/j.jpainsymman.2010.02.021

https://doi.org/10.1177/0018726711409263

https://doi.org/10.1016/j.ypmed.2004.02.036


https://doi.org/10.3109/17549507.2011.573865

https://doi.org/10.1111/eos.12605

Vindrola-Padros, C., & Brage, E. (2017). What is not, but might be: The disnarrated in parents’ stories of their child’s cancer treatment. Social Science & Medicine, 193, 16.


Wei, H., Roscigno, C., Swanson, K., Black, B., Hudson-Barr, D., & Hanson, C. (2016). Parents’ experiences of having a child undergoing congenital heart surgery: An emotional
rollercoaster from shocking to blessing. *Heart & Lung, 45*(2), 154–160.

https://doi.org/10.1016/j.hrtlng.2015.12.007


https://doi.org/10.1017/BrImp.2012.16

Clinical and Experimental Research, 28(4), 578–587.
https://doi.org/10.1097/01.ALC.00000121651.75952.39


https://doi.org/10.1177/1609406916677594


https://doi.org/10.1159/000365752


Appendices

Appendix 1 Example of mind map

[Handwritten mind map with medical psychology and biological sciences branching out to various topics like physical, emotional, and psychological aspects, along with notes on medical conditions and the rise of practices.]
Appendix 2 Guidance for recruitment- healthcare professionals

Children’s Experiences of Living with Cleft Lip and Palate (CLP)- Recruitment selection process-
CGT staff

Guidance- recruitment selection process

Dear Doctor,

Thank you very much for your collaboration. It is a pleasure to have you both on board!

As you know, my name is Liliana Arias-Urueña. I am a second year PhD student in population health sciences at the University of Edinburgh- Scotland. I am investigating the experiences of children living with cleft lip and palate (CLP). To do this, I will be interviewing children with CLP aged 6-12 years across 3 separate visits to their hometowns.

Please find below further details of my study and some important information you need to know. Feel free to make questions/comments. Find my contact details at the bottom of this leaflet. We could also chat further during our meeting.

Why am I doing this study?

Children with CLP experience a wide range of health issues, some of them relating to stigmatized attitudes and limitations in their social involvement and interaction. However, studies on children’s experiences in Colombia tend to be conducted by proxy, by asking parents about what their children think of a particular topic. This approach shows limitations as children’s own views and experiences are not explored.

For that reason, this study aims to investigate for the first time what children say about CLP and its significance in their daily lives.

What does taking part involve?

Children with CLP will be interviewed 3 times in their homes with permission of their parents/caregivers. Please find below criteria of eligibility.

Inclusion criteria:

1. Children living in Colombia aged between 6 and 12 with at least one of following features:
   a. Cleft lip and/or palate (unilateral or bilateral)
   b. Alveolar cleft
2. Residence location within Cundinamarca and Boyacá region
3. Fluency in Spanish

Previous research has reported children with CLP are likely to experience a number of social difficulties during their early years at school (1). Therefore, it is pertinent to the aims of this study.
Children’s Experiences of Living with Cleft Lip and Palate (CLP)- Recruitment selection process-
CGT staff

Where?
Children’s homes- Geographical region: urban or rural areas in Cundinamarca and Boyacá.

Who will know what participants have talked about?
Confidentiality and anonymity will be preserved throughout the study. Interviews will be conducted exclusively by me, the chief researcher.
Digital recording of interviews will be listened to and translated into English by me. Analysis of data will be undertaken following data anonymization.

What happens after interviews?
I will be go back to Edinburgh, where analysis of the data will be completed. Findings will be core topics for my PhD thesis, although some briefings and scientific articles will also be written. Children will receive two individual newsletters updating on the research in progress (Dec 2018 and Jan 2020).

What to do if children want to take part in this study?
Eligible participants interested in knowing further about the study will fill out a contact form. Then, I will make contact to discuss further details of the study/questions.
One week after initial contact, I will contact potential participants (parents) by phone to check agreement with possible participation. A date for the first interview will be also arranged.

What if potential participants change their mind?
Any opt in participant who changes his/ her mind about her/his participation will be able to withdraw at any point of the study. They could contact me at any time. My contact details are provided in information sheets. They will not be asked to give explanation for their decision.

What is expected from you?
If you find individual(s) with the above mentioned eligibility criteria, explore if there is interest/willingness to know further about the study.
Below find some helpful instructions on how to introduce the study to potential participants at the end of your clinical consultation:
-Explore if there is interest-willingness to hear about the study.
Children’s Experiences of Living with Cleft Lip and Palate (CLP)- Recruitment selection process-

CGT staff

-Briefly describe what the study is about and who is the researcher (name, nationality, background, PhD student at the University of Edinburgh in Scotland).

-Explore if there is interest/willingness to obtain further information (recruitment package).

-Emphasize on the importance of reading without pressure for time.

-Explain purposes of asking for contact details and instructions on how to get back completed forms.

-Emphasize that Operation Smile is not involved in the study and participation/no participation will not affect access to health care services for children.

Key points

☐ The eligibility criteria should be retained in the foreground in order to ensure quality of the study and the best research practice.

☐ This study aims to explore the experiences of children from distinct socio-demographic backgrounds. For that reason, include individuals from both rural and urban areas (Cundinamarca and Boyacá) and distinct socio-economic status (you can use basic socio-demographic information from pediatrics’ antecedents). Please do not pass this information onto me; it will be only for your use.

☐ This Initial introduction to the study is not intended to affect the relationship between you and your patient(s), neither the quality of health care provided. Please talk about the study only if you consider there is room/time for a brief talk.

How to get in touch with Liliana?

If you have any question or wish to talk further with the researcher, find below her contact details.

Liliana Arias-Urueña

Email: s1686799@sms.ed.ac.uk

What if you want to discuss this study with anyone further?

If you would like to speak to someone else about the study please contact:

Dr. Jeni harden

Dr. Amy Chandl

Thanks,

Liliana Arias-Urueña
Children’s Experiences of Living with Cleft Lip and Palate (CLP)- Recruitment selection process - CGT staff

References.


Exemplar brief script for broaching the research to child/carer.
Dr. Briceño (CGT-leader) could say to potential participants at the end of the consultation:
I would like to tell you about a study that might be of your interest. Would you like to hear about it?........(if so)... Liliana Arias is a researcher who has been working with children with cleft lip and palate since 2012 in Colombia. At the moment though she is a student and researcher with the University of Edinburgh in Scotland.
She is interested in knowing what children think about cleft lip and palate, what it is like to live with this feature. She wants to hear the views from children themselves.

She is inviting children from 6-12 years from Boyacá and Cundinamarca to participate in her study.
I wonder if you would like to have some further information about her study? .......(if so).......I will give you some information for you and your child (Dr. hands recruitment package over to potential participants). You might want to read it........please take your time to read it, here or at home, at a convenient place and time for you. If you like to know further about the study or chat with/make questions to the researcher, please feel free to do it. She is here in the clinic at all times, in fact, you can find her in the waiting room..... she is wearing a blue name tag.
If you wish the researcher to contact you and talk about the study further or arrange a meeting at good times for you, this is a contact form (Dr. points out the contact form). Please complete it with your contact details and get/post it back to Liliana. She will get back to you shortly.
Operation Smile is not involved in this research, also, your decision of participation will not affect in any form your child access to healthcare services provided by Operation Smile (clinical appointments, surgical care, therapies, etc).
Thank you for your time, have a nice day.....
Who am I?
Hello! My name is Liliana; I am from Bogotá and a researcher at the University of Edinburgh in Scotland- Europe.

What do I do?
As a researcher, I like finding out about things. I used to be a doctor with Operation Smile and children told me stories about their lives. I want to hear from more children about what it is like living with cleft lip and palate. I want to know what you think, not what an adult says about you.

Why do I want to do this?
I think it is important to listen to what children think. I hope that after I have all the children's stories, I will be able to talk to the doctors about them to make sure they give children the best care.

What would you have to do?
I would like to come to your house and chat with you. Of course I will ask permission from your parents/ caregiver first, no worries.

Have a look at the plan:

1. **IN YOUR HOME**
   We will talk about friends, school, family, things that you like, and do some activities together like reading cartoons and seeing photos. We can chat with your parents or just you and me.

2. **TAKE YOU FOR A WALK**
   This time we will chat as we walk through your town. You can show me your school or things you do everyday.

3. **YOU CHOOSE WHAT WE DO**
   Finally, I will come for another chat. we can have another walk together if you wish. I would like to listen to more stories from you and know others places you might want to show me!!.

   - I will use an audio recorder (a tiny machine into my pocket) to record our chats if that does not bother you. I still want to chat with you even if we don’t use that recorder!....I will take some notes too.
   - There are no right or wrong answers; I just want to listen to your thoughts and stories.

Who will be know if you are in the research or what you have talked about?

I will not tell anybody you are in my research. Although your parents and your siblings will probably know. I will not tell your parents or your doctors what we have talked about (though if you choose for your parents to be in the interviews, they will hear what you say of course!).

The only time when I could not keep what we have talked about secret will be if I think you or someone else could get hurt. In that case, I will have to ask someone for help.

What will happen to our recording?
I will listen to our audio recording in my home in Bogota. No one else will hear the recording.

I will use some parts of our chats to write a big report about what children have told me during my research. But, I will not use your real name. I will pick a nickname for you, so no one who wants to read my report will know your real name, nor any particular you said. After finishing my report I will destroy all of the information I kept about you, the recordings and my notes.

**What if you want to drop out or stop talking?**

If you say yes, but later you change your mind, no problem at all, just let me know.

I hope we spend a great time chatting and walking, but at times children do not want to talk about some things and they do not know how to say it. So, we will have a small foam ball next to us as we chat. You will hold it if you want to change the topic of conversation or just stop talking.

**Do you have to take part?**

**Not at all.** you will only take part if you want to. Just let your parent/guardian know your choice.

**How will we keep in touch?**

I will send you two letters to tell you how everything is going with my study. I will send you the first letter when I am back in Scotland writing my report (December 2018), and the second one when I finished it (Jan 2020). If you have an email I will email you!

If your parents and you would like to have further information on my research and chat with me, just let me know! (or tell your parents to let me know)

**Thanks,**

Liliana Arias

Mobile number:

Email: s1686799@sms.ed.ac.uk
Children’s Experiences of Living with Cleft Lip and Palate (CLP)

Dear parent(s)/caregiver(s),

My name is Liliana Arias, I am a Colombian researcher and a medical volunteer with Operation Smile. Currently, I am carrying out a research study at the University of Edinburgh, Scotland, UK. This study seeks to explore what children understand by cleft lip and palate and what it is like to live with this feature from children’s own perspectives.

Why is it important to investigate and understand children’s views and experiences of living with cleft lip and palate?
Research on cleft lip and palate has been mainly focused on exploring its genetics causes and how to offer children better surgical care. But there is still little research looking at what children with cleft lip and palate say about their own lives. Questions such as: what do they think causes cleft lip and palate? Cleft lip and palate makes them different from others? What do they think about different bodies? Have their lives been shaped by the fact of having this feature? If so, how? have not been yet explored.
Knowledge about what it is like to live with cleft lip and palate will enable us (parents, caregivers, teachers, health professionals, civil society, state and government) to better understand what it is important to children, therefore, put in place strategies to enhance their wellbeing and health.

Could your child take part in the study?
This research is designed for Colombian children aged 6-12 with any type of cleft lip and palate attending Operation Smile- Bogotá.

What does taking part involve?
I would like to chat with your child across three visits I will make to your hometown. Date and times will be arranged, suit your both.
Our first chat will take place at home. There I would like to hear from your child what she/he thinks is cleft lip and palate and how is their everyday life at home. Also, I will like to chat about some life events they might want to talk through. For example, holidays, school days, birthdays, Christmas, etc. Some family pictures might help your child with remembering, so I will ask you to pick some family pictures that I might use. Your child may want you to stay at home during the interview. I will
also need to get some general information about the household before starting. For that reason, it would be ideal if you can be around.

In the second visit (3-4 weeks from date of first interview), we will have a walk and chat together. Your child will set out a route for our walk based on their preferences (they might want to visit some places important to him/her. For example, school, the park, etc). You will check the route and assess if changes are necessary (you might think some places are not safe or others worthy of visiting). You could come along if your child wants to.

In my last visit (6-8 weeks from the date of the first interview), your child will be chosen where we chat. She/he might want to stay at home and chat or rather have another walk and talk through.

Interviews with your child will be audio recorded with his/her permission (If your child prefers not to be recorded, no problem at all she/he can still take part in the research). To do this, I will place a high fidelity- tiny voice recorder into my pocket, therefore it will not be visible. Then, I will make a written record of our conversation (transcript).What your child says in interviews, recordings (when your child allow for them) and transcripts will be treated as confidential information by me.

If your child asks for you to stay in any of the interviews, then you will hear what we talk about. However, for any chats for which you are not present, I will not be able to repeat to you what your child has said. It is important in research that we do not pass on what people have said to us. You will be able to read about the overall research findings in the newsletter I will be sending later.

I will send the first newsletter once I have got some results from analysing all participants’ data (Dec 2018); the second one will be sent when I have completed my scientific report (Jan 2020). Interview data will be read repeatedly in order to reflect on all what has been said. This reflection will enable me to make some conclusions.

**Who will be know if your child is in the research or what she/he has talked about?**

I will not tell anybody that your child has taken part in the research. I will keep everything your child has said confidential. However, there are limits to this confidentiality. If your child tells me about something that has caused them harm, or could cause them harm, I may need to let someone else know.

When I am finished my study I will write a final report where I will include quotes from some children but I will change their names so no one reading it will know who said it. Anonymity of your child will be preserved by not using your child’s real name or any other information that could identify him/her in any report of my research.
What if your child wants to drop out or stop talking?
Your child’s participation is voluntary, therefore, if he/she changes her/his mind, just let me know.
You can email me or call me, find my contact details at the end of this leaflet.
Your child will only talk about topics she/he wants to. Their decisions will be respected at all times,
and they can skip or ignore any or all questions.

What happens after the study is finished?
I will send your child two newsletters updating on the research in progress.
I will also write a thesis based on this research. Some scientific and non-scientific articles will be
written and events will be organised to share the study findings. All data will be anonymised before
analysing and reporting.

Are there possible benefits to my child from taking part?
There are no direct benefits to your child or you from your participation. But, the results of this study
might contribute to better understand what it is like to live with cleft lip and palate and then improving
healthcare services for children with cleft lip and palate in the future. I also hope that your child will
enjoy taking part and having the chance to talk about their life.
You will be able to read about what I have found and concluded from the research in the newsletters.

What should you do if you and your child are interested in taking part?
If you want to know further about the study just fill in the attached contact form and I will make
contact to arrange a suitable time to chat. If you want to talk to me right now, we can have a brief
chat today here in Operation Smile or somewhere else; either after your medical appointments or at
a convenient time for you, just let me know.
Operation Smile is not involved in the development of this study, so if you have any question please
contact me.

How can you get in touch with me?
Call me, email me or chat with me in Operation Smile.
Mobile number: 3107899235.
Email: s1686799@sms.ed.ac.uk

Many thanks,

Liliana Arias Urueña

If you want to make a comment about this study please contact Jeni Harden- jeni.harden@ed.ac.uk
If you have a complaint on this research please contact Prof Sarah Cunningham-Burley
sarah.c.burley@ed.ac.uk
Contact Form

If you are interested in chatting with Liliana- the researcher- and knowing further about this study, please complete this form. This is not consent or pre-agreement to take part in this research. You are merely providing contact details to let her contact you, then discuss further what this research is about. If after chatting you are interested in participation, Liliana will store this form in secure premises and your contact details on password protected files. Otherwise, she will destroy this form and delete your personal information from her records.

Please hand this form back to Liliana (wearing a blue name tag) available at all times in the clinic (she is usually in the waiting room). You can also post it back to her (Liliana Arias Urueña- Fundación Operación Sonrisa Colombia Calle 90 No. 19c – 41, Bogotá D.C., Colombia). Please do not forget to put the form in the envelope attached to this form before handing in.

Date the form is completed __________

Child Name___________________________

Parent (s)/ caregiver (s) Name (s) ______________________________________________________

Mobile number________________________ Town of Residence________________________

Home phone number_____________________

Child Email ______________________________

Parent Email ______________________________

When are good days/times to call? ______________________________

How would you like Liliana to make contact?

Call phone ☐

Email ☐

Liliana might speak to you during your visit to the clinic, would you like this?

Yes ☐ No ☐

If so, could you note your appointment (s) times today and next please?

________________________________________________________________________________

Liliana will try to meet up with you during your visit to Operation Smile. However, in case either you or she do not manage, she might contact you and set up a good time for a meeting.
Appendix 5 Pictorial Cards
Appendix 6 Emotion body maps
Appendix 7 Consent form for children

Research finding out from children what they think about living with cleft lip and palate

Consent Form—Section 1
Hi, I would like to check if information we have discussed and my explanations have been clear to you. To do that, let’s complete this table together.
Just ask if you have any questions.
Let’s start!
1. We are going to read each phrase on below table, (I can read out for you If you like).
2. Then, I will ask you if you agree with what each phrase says.
3. How can you answer?
   - If you agree with what is said, please say “yes” or tick the yes option.
   - If you are not or would like me to explain it a bit more, you can say “I’m not sure” or cross the unsure/question mark option.
   - If you do not agree what a phrase says, just say “no” or cross the No/cross option.

Let’s have a look at this example:

<table>
<thead>
<tr>
<th>I (Liliana) understand football rules</th>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
<tbody>
<tr>
<td>I crossed No, because it’s not true, I don’t understand football rules at</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I (Liliana) love cookies</th>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
<tbody>
<tr>
<td>I ticked yes, because it’s true, I love</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. I understand that Liliana’s research is about the experiences of children with cleft lip and palate

<table>
<thead>
<tr>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
</table>

2. I understand that I can stop taking part or say no to any question at any time

<table>
<thead>
<tr>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
</table>

3. I understand that it is up to me whether I take part in Liliana’s research.

<table>
<thead>
<tr>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
</table>

4. I understand that Liliana wishes to record our chat and how this would be done

<table>
<thead>
<tr>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
</table>

5. I understand that if Liliana thinks there is something that might hurt me or someone else, she will have to ask for help. If that happens she might have to tell someone else what I have said

<table>
<thead>
<tr>
<th>Yes ✓</th>
<th>Unsure ?</th>
<th>No ×</th>
</tr>
</thead>
</table>
Consent Form-Section 11

Now, I would like to check if you agree to take part in this research. Let’s have a look at phrases below. If you are happy with each phrase, please tick yes, if you are not please cross no.

1. I agree to take part in Liliana’s research
   - Yes ✓
   - No ✗

2. I am okay with our conversation will be audio recorded
   - Yes ✓
   - No ✗

Could you write down your name and sign on below lines for me please?

Name: ____________________________
Signature: _________________________
Date: _____________________________

Researcher’s Name: ____________________________
Researcher’s Signature: _______________________
Researcher’s Date: _____________________________

ID (unique identifier)____________________
Appendix 8 Consent form for parents

Children’s experiences of Living with Cleft Lip and Palate (CLP)- Consent form for Parents

Consent Form
Please read this form carefully. For each statement, if it is true for you, please initial the box alongside.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Initial</th>
</tr>
</thead>
<tbody>
<tr>
<td>I confirm I have read and understood information and details of this research and my questions/doubts have been discussed with and answered by the researcher</td>
<td>☐</td>
</tr>
<tr>
<td>I have understood that my child’s participation in this research does not imply that medical appointments with Operation Smile and/or surgical/medical care for my child will be arranged and/or provided earlier</td>
<td>☐</td>
</tr>
<tr>
<td>I consent to the researcher to come to my home and chat with me and my child</td>
<td>☐</td>
</tr>
<tr>
<td>I consent to the researcher to ask me some information about my household and my level of education</td>
<td>☐</td>
</tr>
<tr>
<td>I consent to the researcher and my child taking a walk through a set route in my hometown. This walk will include visits to places such as my child’s school.</td>
<td>☐</td>
</tr>
<tr>
<td>I understand that my child’s participation is voluntary and I might withdraw at any time.</td>
<td>☐</td>
</tr>
<tr>
<td>I understand that Operation Smile is not involved in this research.</td>
<td>☐</td>
</tr>
<tr>
<td>I understand that interviews with my child will be audio recorded; provided my child agrees to this, or otherwise notes will be taken. Conversations, notes and transcripts will be treated as confidential information by the researcher, therefore, parents will not have access to children’s accounts.</td>
<td>☐</td>
</tr>
</tbody>
</table>

I, ___________________________ consent to my child’s participation provided my child also agrees to participate.

Signature ______________________
Name ______________________
Date ______________________

Researcher’s signature ______________________
Researcher’s name ______________________
Date ______________________

ID (unique identifier) ___________

Researcher contact details:
Liliana Arias Urueña- Mobile number: 3107899235. Email: s1686799@sms.ed.ac.uk
Appendix 9 Interview Topic Guides

Children’s Experiences of Living with Cleft Lip and Palate- Topic guides for home-based and walking-based interviews

Interview Topic Guides

The topic guide below was carefully designed considering aims and related research questions of this study. However, this is indicative and will be adapted and reflected upon following discussion with participants and initial piloting of the schedule. This tool will allow for follow up of topics to be covered over the course of interviewing process. However, the structure and development of each interview session will be flexible and sensitive to social and cultural contexts of participants. The topic guides provide a scheme for how research questions will be covered, outlining the sort of questions and probes that will be asked and the tools that may be used. The range of topics to be addressed across the interviewing process (Interviews 1-3) are included in the tables below.

<table>
<thead>
<tr>
<th>Interview 1- children with CLP’s understanding of the definition and aetiology of CLP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
</tr>
<tr>
<td>- The researcher will introduce herself and acknowledge children and parents for their participation.</td>
</tr>
<tr>
<td>- Indicative outline of the interview will be presented.</td>
</tr>
<tr>
<td>- Children will be reminded that there are no right or wrong answers.</td>
</tr>
<tr>
<td>- Children will be reassured that their participation is voluntary and they can stop the interview or decline to answer specific individual questions at any time.</td>
</tr>
<tr>
<td>- Children will be encouraged to use “the non-talkative object” across interviews if they do not want to answer any question or stop the interview at any point (the child will be reminded of instructions for how to use it.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Prior to starting first interview the researcher will check understanding, then signing consent will be sought from both parents and children.</td>
</tr>
<tr>
<td>- Agreement to audio-recording will also be checked.</td>
</tr>
<tr>
<td>- Bearing in mind the dynamic nature of consent, children will be encouraged to use “the non-talkative object” to skip questions or let the researcher know that interview should be stopped.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Basic socio-demographic information</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Parents will be asked to fill out a basic socio-demographic information (BSD) form.</td>
</tr>
<tr>
<td>- Instructions and assistance when required will be provided.</td>
</tr>
<tr>
<td>- Hard copies will be stored securely in the researcher’s travel password protected suitcase.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Child will be asked whether their parent/caregiver presence during interview is wished. If so, parent/caregiver will be invited to sit in and stay.</td>
</tr>
<tr>
<td>- When the child prefers to be interviewed alone, parents will be told in a polite way that they are not expected to contribute to the interview at all.</td>
</tr>
<tr>
<td>- Room where the interview will take place will be agreed with the child, maintaining in the foreground the child’s comfort and privacy.</td>
</tr>
<tr>
<td>Ice-breaking chat</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>This section will allow for building rapport and decreasing the potential imbalances of child-adult relationship.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Interview Prompts</th>
<th>Participatory tools</th>
</tr>
</thead>
</table>
| What do children think causes CLP and what is the basis for these ideas? | - Why are people born with CLP?  
- Introduce how story cards will be used: let’s have a look at this story... | Story cards will be used to prompt children to talk about their views. (See story cards sample 1 doc). |
| How do children describe “different”/“healthy”/“unhealthy”/“normal”/“abnormal” bodies? | - What kind of bodies we can find in people?  
- What makes someone different from another one?  
- Introduce pictorial prompt cards: let’s have a look at these drawings... | Children might like to use drawing/images to help think about this (see pictorial prompts sample 2 doc). |
| -What aspects of children’s everyday lives have been affected by the experience of having CLP? | **Home: relationships with family, roles and responsibilities at home.**  
Tell me a little bit about your family.  
**Probe for:**  
- Who are they?  
- Who do you live with?  
- Who looks after you?  
Introduce photo elicitation method: let’s have a look at some photos of... | Family photos might help children talk about their roles and interaction with family members. |
| -What resources and strategies do children draw on to negotiate their participation and interaction in social encounters/contexts? | | |

**End: Introduce walking interview for session 2.**

1. How the route will be set out. Explain instruction to plan an outdoor walking route (to be done with the researcher).

   e.g. “On my second visit to your home, we will chat as we walk through your town if you wish. I would like we set out a route for our walk together. You might want to show me your school, places you love or do with me things you do every day, let’s draw it on a paper”.

2. Seek parents’ agreement to outdoor walking route.

   e.g.” Once we have the route, we will show it to your parents. They will check it and tell us if we should make some changes. Your parents could come along if you wish.”
Sometimes parents think some places are not safe for their children. If your parents think we should change our walking route, we will listen to them carefully and take on board their suggestions. If they think that having a walk is not a good idea, it is good to obey our parents, so we’ll stay at home and chat there.

As we walk, it is possible some neighbours or friends of yours ask us what we are doing, why I am with you, who I am or where I come from. I would like to know from you what you would like me to answer to them.

**Closing point**
What would you be doing when you are 12, 16, 20?
What would you like to be when you grow up? Children will be asked to think about the above questions between sessions.

**Checking in on well-being questions:**
How was the interview for you?
Are you feeling OK about what we talked about just now?

---

**Interview 2- Meanings children give to having CLP within the context of their everyday lives**

| Introduction |  |
|--------------|  |
| - The researcher will (re)introduce herself and acknowledge children and parents for their participation.  |
| - Indicative outline of the walking interview will be presented.  |
| - Children will be reminded that there are no right or wrong answers.  |

| Consent |  |
|---------|  |
| - Prior to starting second interview the researcher will check consent with the child and parents.  |
| - Check that children agree for the walking interview to be audio recorded.  |
| - Children will be reassured that their participation is voluntary and they can stop the interview or decline to answer specific individual questions at any time.  |
| - Bearing in mind the dynamic nature of consent, children will be encouraged to use “the non-talkative object” to skip questions or let the researcher know that interview should be stopped.  |

| Setting |  |
|---------|  |
| - Child will be asked whether their parent/caregiver presence during interview is wished. If so, parent/caregiver will be invited to join them on the walking interview.  |
| - The route of the walking tour will be checked.  |
| - The child’s preferences for what to do if they meet someone when on the walking tour will be checked.  |

<table>
<thead>
<tr>
<th>Ice-breaking chat</th>
<th>Interview Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second session will be started by a small “catching up talk”. The child and the researcher will talk to each other about what they have been doing between interviews</td>
<td>How is school going?</td>
</tr>
<tr>
<td></td>
<td>How are things going with_______ (best friend’s name)?</td>
</tr>
<tr>
<td></td>
<td>What did you do over the weekend?</td>
</tr>
</tbody>
</table>
### Research Questions

- What relationship do children have with features of CLP?
- What factors facilitate or are barriers to children’s involvement in social interaction?
- What resources and strategies do children draw on to negotiate their participation and interaction in social encounters/contexts?
- What is it the significance of CLP in their biographical narratives?

### Interview Prompts

Prompts will depend on specific places- child’s everyday routine, below some examples:

**School (the child & the researcher at school)**
Let’s talk about your school,
Probe for:
- Relationships with friends-classmates.
- Relationships with teachers.
- Subjects, sports, school activities.
- Speech activities

**Parks/town squares/theatre/shopping centre, etc.**
Probe for exploring:
- Participation on community-based activities.
- Leisure activities.
- Relationship with others within public spaces.

**Eating (the child & the researcher at child’s favourite restaurant)**
Let’s talk about food.
If you could have a perfect meal... what food would you have and who would you be with?
Probe for:
- Eating practices.
The place of food/eating in their everyday lives

### Participatory tools

### End:

Ask the child preferences for session 3 (home based interview vs outdoor walking)

When outdoor walking is chosen:

- Remind/explain how the route will be set out. Explain instruction to plan an outdoor walking route (to be done with the researcher).
- Seek for parents’ agreement to outdoor walking route.

**Closing point:** what would you be doing when you are 12, 16, 20?
What would you like to be when you grow up? Children will be asked to think about the above questions between interviews 1-2 and 2-3

**Checking in on well-being questions:**
How was the interview for you?
<table>
<thead>
<tr>
<th><strong>Interview 3- Meanings children give to having CLP within the context of their everyday lives</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
</tr>
<tr>
<td>- The researcher will (re)introduce herself and acknowledge children and parents for their participation.</td>
</tr>
<tr>
<td>- Check of child’s preferences for the format of the final interview.</td>
</tr>
<tr>
<td>- Children will be reminded that there are no right or wrong answers.</td>
</tr>
<tr>
<td><strong>Consent</strong></td>
</tr>
<tr>
<td>- Prior to starting third interview the researcher will check consent with the child and parents.</td>
</tr>
<tr>
<td>- Agreement to audio-recording will be checked.</td>
</tr>
<tr>
<td>- Bearing in mind the dynamic nature of consent, children will be encouraged to use “the non-talkative object” to skip questions or let the researcher know that interview should be stopped.</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
</tr>
<tr>
<td>- Child will be asked whether their parent/caregiver presence during interview is wished. If so, parent/caregiver will be invited to sit in and stay. When the child prefers to be interviewed alone, parents will be told in a polite way that they are not expected to contribute to the interview at all.</td>
</tr>
<tr>
<td>- If the child has chosen a home based interview, the room in where the interview will take place will be agreed with the child, maintaining in the foreground the child’s comfort and privacy.</td>
</tr>
<tr>
<td>- If the child has chosen a walking interview, the route of the walking tour and the child’s preferences for what to do if they meet someone when on the walking tour will be checked.</td>
</tr>
<tr>
<td><strong>Ice-breaking chat</strong></td>
</tr>
<tr>
<td>Third session will be started by a small “catching up talk”. The child and the researcher will talk to each other about what they have been doing between interviews</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Research Questions</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>- What resources and strategies do children draw on to negotiate their participation and interaction in social encounters/contexts?</td>
</tr>
<tr>
<td>- What is it the significance of CLP in their biographical narratives?</td>
</tr>
<tr>
<td><strong>Participatory tools</strong></td>
</tr>
</tbody>
</table>
Children’s Experiences of Living with Cleft Lip and Palate: Topic guides for home-based and walking-based interviews

| -Activities-Roles within family settings.  
- Significance of places-spaces in biographical narratives.  

**Best friend’s home:**  
What do you like most about visiting ______(friend’s name) home?  
-Relationships with others.  
-Activities-Roles within non-family settings.  

**Home-based interview:**  
-Timeline of child’s day: Let’s draw a timeline of your day.  
-Introduce story cards: let’s have a look at these cards.....  
- A timeline of their life trajectory (using photos-drawings) will be built between participant-researcher.  
- Introduce photo-elicitation method, let’s have a look at these photos.....  
- Drawings and images will be used to explore sensitively self-perception and body image. Using cartoons representing another person with CLP, the child will be prompted to think about how that person would feel.... what do you think about him, what do you think how he/she feels? This will be used as probe for capturing how children talk about/represent/feel themselves.  
- Introduce emotional-body map method.  

| emotion-body map sample 3 doc)  

- Family pictures will be used to prompt children to remember past events.  

- Emotional-body maps might be used to help children talk about their bodies (see Story cards emotion-body map sample 3 doc).  

| Closing point- what would you be doing when you are 12, 16, 20?  
Checking in on well-being questions:  
How was the interview for you?  
Are you feeling OK about what we talked about just now?  

|
Appendix 10 Map of Colombia - Instituto Geográfico Agustín Codazzi (IGAC)

Bogotá, Cundinamarca and Boyacá regions are marked in red colour