

UNIVERSITÀ DEGLI STUDI DI VERONA
DIPARTIMENTO DI SCIENZE
UMANE SCUOLA DI DOTTORATO DI SCIENZE UMANISTICHE
DOTTORATO DI RICERCA IN SCIENZE UMANE

CICLO XXXI/2015

TITOLO DELLA TESI DI DOTTORATO

The Lived Experiences of Parents and Healthcare Professionals in
Treating Children with Chronic Conditions. Distinct Roles and
Common Points of View.

S.S.D. M-PED/01

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The Lived Experiences of Parents and Healthcare Professionals in Treating Children with Chronic Conditions. Distinct Roles and Common Points of View.

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Verona, 9 Maggio 2019

Sommario

I bambini con patologia cronica complessa sono attualmente circa il 49% dei bambini ospedalizzati. Il ricovero in ospedale e le frequenti riammissioni sono eventi vissuti come drammatici sia da parte dei bambini che delle loro famiglie. Anche gli operatori sanitari in ambito pediatrico e di area intensiva pediatrica sono coinvolti nella difficile gestione dei continui ricoveri e vivono, parallelamente alle famiglie, il peggioramento ingravescente a cui questi piccoli pazienti sono sottoposti. Sono ad oggi scarse le evidenze di ricerche condotte nel contesto europeo al fine di esplorare i vissuti dei genitori dei bambini cronici e degli operatori sanitari che partecipano alla loro cura. L'obiettivo di questo studio è esplorare il vissuto dei genitori dei bambini affetti da patologia cronica complessa e degli operatori sanitari all'interno della Terapia Intensiva Pediatrica dell'Ospedale Civile Maggiore di Verona.

Questo studio aderisce ad un approccio fenomenologico-ermeneutico. I partecipanti sono stati arruolati in base al loro accesso presso il Dipartimento di Pediatria ad Indirizzo Critico dell'Ospedale Universitario di Verona. La raccolta dei dati è avvenuta attraverso interviste semi-strutturate, per l'analisi si è attuato un processo induttivo e ricorsivo, volto a identificare il senso profondo delle esperienze descritte. Sono stati intervistati ventidue genitori e dodici operatori sanitari. I risultati emersi dal lavoro di analisi sono presentati secondo le sei dimensioni dell'esperienza in cui si situa quanto narrato dai genitori e dagli operatori. I genitori hanno identificato 33 elementi comuni e sono emersi 3 elementi sporgenti, mentre per gli operatori sono stati rilevati complessivamente 20 elementi comuni. Sono inoltre emerse 8 categorie trasversali ai due gruppi: Decisioni condivise, Atteggiamenti di vicinanza, Unicità del genitore, Mancanza di fiducia, Paura dei cambiamenti, Sorriso e sofferenza, Cosa è meglio per il bambino, Necessità di dare e ricever fiducia. Le categorie sopracitate sono fortemente correlate tra loro e rappresentano un punto di vista innovativo per lo studio del fenomeno dei bambini affetti da cronicità complessa. La revisione della letteratura ha portato alla luce diversi studi condotti particolarmente nel Nord America nei quali sono stati esplorati i vissuti di genitori o operatori sanitari, tuttavia questi studi erano principalmente orientati ad esplorare un argomento predefinito (es. comunicazione, qualità della vita) o ad esplorare il vissuto di uno dei due gruppi di partecipanti. L'emergere di punti di vista comuni riguardo la cura del bambino affetto da cronicità è uno degli elementi rilevanti ed innovativi di questa ricerca. Questi risultati

dovrebbero essere considerati al fine di migliorare la qualità dell'assistenza erogata al bambino e alla famiglia. L'autore ha lavorato nell'unità in cui sono stati raccolti i dati e questo status di insider è stato un elemento favorevole per il reclutamento e la presa in carico dei partecipanti. Il progetto è stato presentato a tutti i partecipanti, i quali hanno espresso in forma scritta il loro consenso alla partecipazione. Il comitato etico istituzionale ha approvato lo studio prima di iniziare il processo di reclutamento. Approvazione n° 976CESC (Comitato Etico per le Prove Cliniche di Verona e Province di Rovigo).

Abstract

Research problem and background

Scientific development for treating life-threatening illnesses combined with an increase of home-based health support contributed in reducing children mortality but it also increases the number of children suffering from pediatric chronic critical illness (PCCI, approximately 49% of hospitalized children have chronic illnesses). Hospitalizations and recurrent readmissions are dramatic experiences for children and they also have a huge impact on their families. The lived experiences of child with PCCI parents and health care workers (HCW) have been poorly analyzed. When the disease is so severe to prompt an admission to a PICU, the impact on the emotional, clinical, ethics, psychological, and relational spheres of the different actors is very complex and often hard to manage. In this research, both parents and health care professionals were the focus of interest.

This study aims to explore the lived experience of child with PCCI parents in the Pediatric Intensive Care Unit (PICU) and the experience of health care workers.

Methodological framework

This study adheres to a phenomenological–hermeneutic approach, suitable for exploring the meaning of lived experiences. Parents and HCW involved in the research were recruited through the Pediatric Department of the University Hospital in Verona. The data has been collected by recording and transcribing semi-structured interviews. Data analysis was developed through an inductive and recursive process, aimed to identify the overall sense of the described experiences.

Results

At the end of the data collection, a total of twenty-two parents (fourteen mothers and six fathers) and twelve healthcare workers were interviewed (six nurses were woman, four clinicians were woman, two clinicians were man). The analysis reveals fifty-six emerging dimensions (33 common and 3 protruding elements for parents, 20 common elements for HCW), among which some eight cross-cutting elements between parents and healthcare professionals, as well as some elements that represent the experiences of each group individually. The author identified as crucial the following eight cross-cutting categories: complexity of decision-sharing, close-quarter attitudes, no one like

parents, lack of trust, fear of change, smiling and suffering, what's best for the child and, finally necessity to trust and be trusted. All those categories are strongly interrelated among them and provide an innovative point of view to comprehend the lived experience of child with PCCI parents and HCW. The analyzed literature (Bry et al., 2016; Huang, Kellett, & St John, 2011; Meert et al., 2008) usually report the experiences gathered from parent or HCP interviews on pre-defined topics, such as communication, quality of life, and end of life. The presence of relevant common thoughts and lived experiences that can bring parents and HCP closer with regard to life experience, is one of the innovated outcomes of this research. These findings should be considered in order to improve the quality of pediatric care and other services for children with chronic illness.

Setting and Ethical considerations

The author worked in the unit where data were collected and, this insider status has allowed her to access directly to the research setting and recruit potential participants. This information was presented to all participants firstly during the introduction of the study and secondly at the informed consent process. The institutional ethic committee approved the study's before starting the recruiting process approval code 976CESC (Comitato Etico per la Sperimentazione Clinica delle provincie di Verona e Rovigo).

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List of Abbreviations

CCC: Children with Chronic Conditions
CCI: Chronic Critical Illness
CIC: Chronically Ill Children
CMC: Children with Medical Complexity
CSHCN: Children With Special Health Care Needs
HCW: Health Care Workers
HCP: Health Care Practices
MCFC: Medically Complex and Fragile Children
PCCI: Pediatric Chronic Critical Illness

Introduction and Statement of Originality

This research explores the experiences of children with pediatric chronic critical illness parents and of Health care workers. To date, there is very little evidence in this sense, but above all, will be presented later, the evidence is often quantitative or qualitative with grounded method. The analyzed literature (Bry et al., 2016; Huang et al., 2011; Meert et al., 2008) usually report the experiences gathered from parent or HCP interviews on pre-defined topics, such as communication, quality of life, and end of life. The presence of relevant common thoughts and lived experiences that can bring parents and HCP closer with regard to life experience, is one of the innovated outcomes of this research.

The author identified as crucial the eight cross-cutting dimensions and categories: complexity of decision-sharing, proximity attitudes, necessity to trust and be trusted, waste of trust, no one like parents, fear of change, what's best for the child and, finally, smiling and suffering. All those categories are strongly interrelated among them and provide an innovative point of view to comprehend the lived experience of parents and HCW.

This is to certify that to the best of my knowledge; the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes. I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

CHAPTER 1. LITERATURE REVIEW

1.1 Protocol of the Literature Review

Introduction

Scientific development for treating life-threatening illnesses, combined with an increase of home-based health support, contributed to reducing children mortality, but it also increased the number of children suffering from chronic diseases. Hospitalizations and recurrent readmissions are dramatic experiences for children and they also have a huge impact on their families. For all the parties involved with taking care of children with chronic conditions, there are many and varied challenges.

This Chapter will present a literature review conducted in order to explore the concept of chronicity in childhood. The review in question is an attempt to create an understanding and awareness of the main concepts discussed in this thesis. The first paragraph will report on the multiple definitions and acronyms used by authors to describe children affected by chronic conditions. The second paragraph will describe the reasons and chronicity shift timing-wise in children, as well as the related patterns. The third will take into account the costs of health care assistance for children.

The review highlights various core concepts underlined by many authors, some of which are the following: the costs of children with chronic conditions, being a CCC family, the relationship between health care workers and families, the communication theme, and the health care workers' point of view.

Research methodology

In order to perform a complete narrative literature review, two distinct searches were conducted: the former from inception to May 2015, the latter from May 2015 to August 2018. The searches in question were conducted in three databases and in one search engine: Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE (PubMed), EMBASE, and Google Scholar. The search strategies were adapted from the Medline search and also, were based on the different ways to name children with chronic conditions. The Medical Subject Heading (MeSH) was consulted to find out synonyms and alternative words. The searched Keywords were: child, children, infants, chronic conditions, medical complexities, and complex conditions. Boolean operators AND, OR, and NOT were used to narrow down the search.

Moreover, multiple hand searches were conducted to avoid the limitations of electronic browsing, to involve high-impact journals, and select papers from reference lists contained in relevant articles. To explore the concept of chronicity and complex chronicity in childhood without restriction in any specific field, author decided to avoid the use of key words like treatment, care, pediatric intensive care unit, neonatal intensive care unit and hospitalization. With regard to case study selection there was no restriction about methodology, language, and year. The researches' methodologies are described or resumed on the summarizing tables.

Research strategies

((“Children with special health care needs” OR "chronic condition" OR “Medical complexity”) AND ("Child"[Mesh] OR "Child, Preschool"[Mesh] OR "Infant"[Mesh])), identified 980 records;

(“chronic conditions” AND (("Child"[Mesh]) OR "Child, Preschool"[Mesh]) OR "Infant"[Mesh], “chronic complex conditions” AND (("Child"[Mesh]) OR "Child, Preschool"[Mesh]) OR "Infant"[Mesh] OR “Children with Chronic conditions”), identified 45 records;

(("complex chronic conditions" OR "medical complexity") AND Children), identified 405 records.

Exclusion criteria

The following topics were considered as being irrelevant for the purposes of research: nutrition or diet, schooling, case reports, and clinical trials about specific illnesses. At the end of the search process, 156 papers were selected.

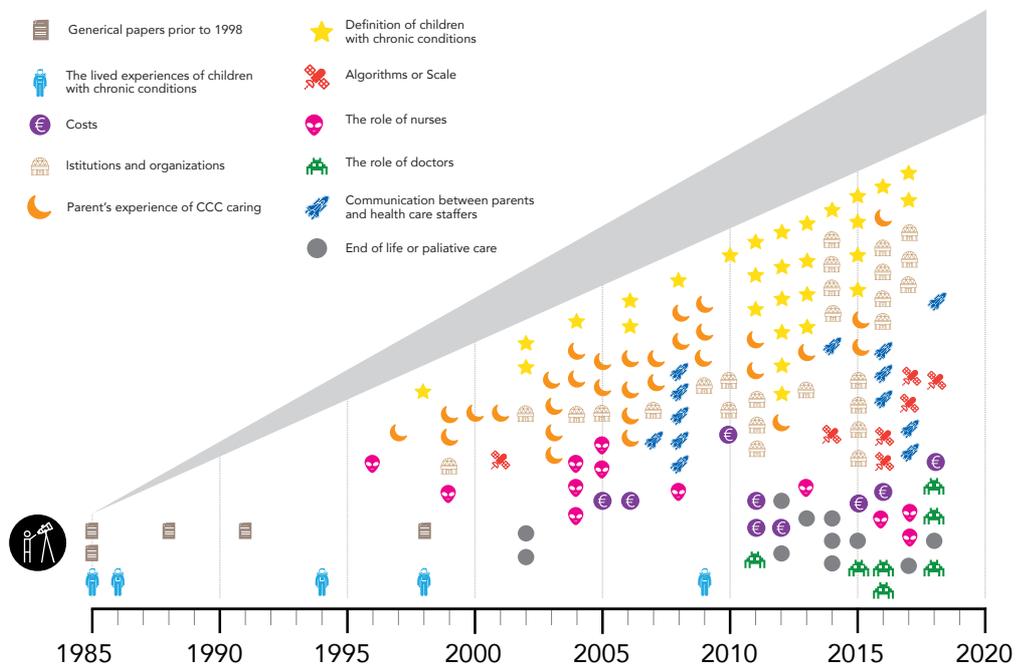
Analysis and Selection of studies

During the literature review various papers have been collected. A thematic analysis was conducted to identify the patterns in the selected studies. All of studies have been read and organized with regard to the core topics presented. At the end of the analysis, the following eleven main thematic areas emerged: 5 generic papers prior to 1998, 5 papers since 1989 about the lived experiences of children with chronic conditions; 9 papers since 2005 about costs; 27 papers since 2007 regarding institutions and

organizations¹; 31 papers since 2000 concerning the lived experiences of parents; 29 papers since 1998 defining children with chronic conditions; 7 papers since 2001 describing an algorithm; 12 papers since 2007 concerning the role of nurses; 7 papers, since 2011 concerning the role of doctors; 13 papers, since 2007 on communication; finally 11 papers, since 2002 dealing with end of life or palliative care.

The literature included in the review is represented below in order to clarify how the study of the phenomenon of CCC has evolved throughout the past three decades (Figure 1).

Figure 1_ Summary of the Literature Review on CCC's Phenomenon



Each symbol represents one of the thematic areas that emerged during the literature review, and it is possible to observe how the topics are distributed along timeline at once.

¹ Papers regarding institutions and organizations frequently involved, since 2007, a section about CCC costs.

Some CCC-related topics have been explored more in details than others, as it is apparent from observing the distribution of the literature according to both the topics that are discussed and the year in which they are discussed.

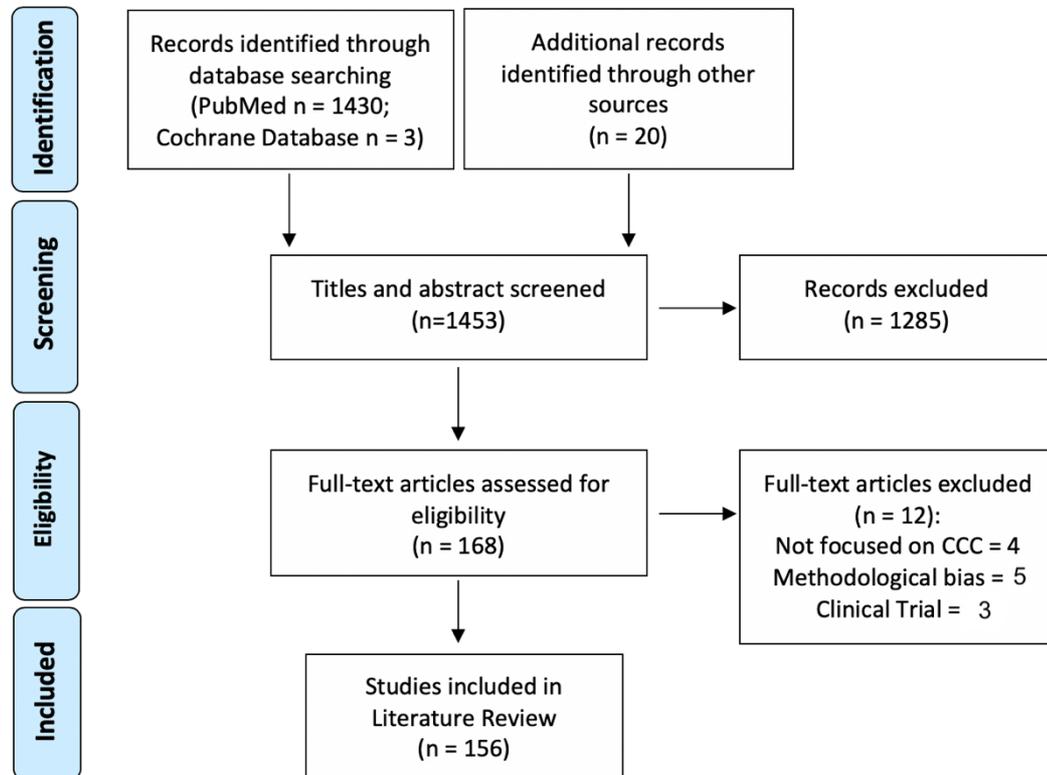
By looking at the table above, it become clear that the topic of CCC begun being explored only around 1998, from different points of view. In later years some research line were more debated than others, whereas others were abandoned.

Before 1995, the author discovered few traces in literature that focused specifically on the lived experiences of CCC. Nowadays, the latter are less studied, probably because of the growing level of complexity in CCC who are often unable to communicate. For this reason, it is perhaps more relevant than ever to explore the parents' experiences. The difficulty of finding a definition of CCC, which is impart due to the rapid changes that occur with this kind of condition, has resulted in continuous researches. Studies on this topic are still been conducted today by many different authors.

The nurses' role has been explored throughout, probably because of the high proximity that they have to patients' families, both in the hospital setting and in home care services. Unfortunately, the role of doctors is poorly researched, and frequently emerged only when talking about communication or with regard to training programs for residents. Only a few studies were cost-oriented, after which the majority of the studies have been conducted within the thematic area of institution and organizations. Such studies have been frequently conducted to test innovative models of CCC care and cost reduction, probably because it became clear how expensive those patients were becoming. The communication theme has emerged recently, probably as a consequence of a prolonged observation of the parents' experiences. Indeed, the latter, have represented the most studied thematic area throughout during the within the entire three decades under consideration, perhaps, because this represent a particularly critical issue due to the fact that CCC are often put in the exclusive care of parents.

The flow chart presented in Figure 2 summarizes the selection studies for inclusion on literature review.

Figure 2_Flow Chart of the studies selection process



To accurately describe the phenomenon of chronicity in critical pediatric patients the author will report on and discuss all the reviewed studies in the next paragraph. The discussion will focus on the following seven relevant issues: the definition of children with chronic illness population and the evolution of the CCC phenomenon (“children shift”); the costs related theme; what it means to be a CCC family, the power struggle between health care workers and families, the communication themes, and finally the health care workers’ point of view.

A reference list of all the included studies connected to the corresponding thematic areas has been outlined (Appendix A).

1.2 Results of the literature review

How to define children with chronic illness

Children with medical complexity constitute a growing population all over the world. Wise reported that in 1962 approximately 4% of hospital bed days for children were accounted for by children who had already had two or more admissions, and therefore identifiable as children with special health care needs; “by 2000 this (...) had risen to approximately 25 percent”(Wise, 2004). Starting in 1998, The Maternal and Child Health Bureau estimated that in the US almost 16 % of children under 18 years of age had special health care needs (11.2 million children, in (MCHB).

Cohen presented comparable data, which excluded special-needs children “at risk”, and thus tallied children with special needs somewhere in between 13% to 18% (E. Cohen et al., 2011). More to the point, based on a screening questionnaire, 23% of US families with children claimed to have at least one child with special health care needs (MCHB). In Canada three distinct studies analyzed the data from the Hospital Information System, and also showed a prevalence of Children with Chronic Conditions (CCC), approximately between 13% and 18% (Moura, Moreira, Menezes, Ferreira, & Gomes, 2017). Simon et al. conducted a retrospective observational study that used the 1997, 2000, 2003, and 2006 Kids Inpatient Databases examined US hospitalizations for children, and estimated that, CCC represented almost 9% of all pediatric hospital admissions in 1997 and 10% in 2006; on the other hand, that population used almost of 40% of pediatric hospital charges, and 70% to 90% of technology use (T. D. Simon et al., 2010).

Despite the growing number of this population, in the case of CCC a consensus definition never exists. This lack of a definition created a lot of difficulties with regard to studying and quantifying this phenomenon. The difficulties of defining CCC may be attributed to the high variability of this population. Children with medical complexity differ in a number of characteristics, such as: age, diagnoses, prognosis, care requirements, and complexity level. Some examples of CCC include: children with multiple cardiac surgeries, infants with congenital heart diseases, children with progressive neurological and functional decline due to a genetic syndrome, children who will need advanced respiratory support, spinal cord injury and quadriplegia

(Seltzer, Henderson, & Boss, 2016). Some attempts to define the CCC population were made by many authors, some of which will be presented below.

In 1994, Spirito & Stark, conducting an observational study on 125 children, identified as Chronically Ill Children (CIC) all the children with Congenital orthopedic conditions Cancer, Asthma, Cystic fibrosis, Diabetes, Kidney disorders, Ulcerative colitis, Sickle-cell anemia, and Hemophilia. The Maternal and Child Health Bureau (MCHB) is one of six Bureaus within the US Health Resources and Services Administration, and, since 1998, the MCHB defined Children With Special Health Care Needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”.

Later on, McPherson et al. took into account the risk of a chronic physical, developmental, behavioral, or emotional condition when attempting a definition of Children With Special Health Care Needs (CSHCN), as well as the necessity for health and health-related services (1998).

Law and Rosenbaum based their analysis of the topic at hand on Wise’s definition of Medically Complex and Fragile Children (MCFC, in Wise, 2004). The authors defined this group of children from a conceptual view point as “a severely affected subset of children and youth with special healthcare needs whose problems are multiple in terms of health/developmental needs, services, sectors of care and locations of care” (CYSHCN, in Law & Rosenbaum, 2004).

According to Burns, who analyzed the Nationwide Inpatient Sample of US, Children With Special Health Care Needs (CWSHCN) “are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”(Burns et al., 2010).

When defining the concept of children with medical fragilities, one subgroup that required the most intensive health care needs emerged. Since 2011, the children in this subgroup were described by including a combination of one or more of the following terms: children with complex, chronic, medical, conditions, and/or needs, complex medical needs, complex medical conditions, and complex health conditions, as well as medically complex children.

In 2011, Cohen explored the diversity of existing care models and identified those children in the following way: “children who have a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, or patients with cancer/cancer survivors with ongoing disability in multiple areas”. Cohen, moving from Feudtner’s identification of the 9 CCC conditions, outlined a definitional framework for describing Children with Medical Complexity (CMC). This framework consisted of the following four main domains:

Needs. CMC have relevant family-identified health care service needs (medical care, specialized therapy, and educational needs). This weigh on the family unit, especially with regard to the time needed for care, the frequent health checks, the coordination of care, and the costs. **Chronic conditions,** CMC are characterized by one or more chronic clinical conditions. Sometimes those conditions are diagnosed, but sometimes they remain unknown. All conditions in question (and related sequelae) frequently become lifelong conditions (only a small number of children may improve with optimal care). **Functional limitations,** CMC have typically severe functional limitations that require technological support (tracheostomy tube, feeding tube, gastrostomy tubes). **Health care use,** CMC present a higher utilization of health care services than CSHCN². CMC experienced recurrent and prolonged hospitalizations, multiple surgeries, and the use of multiple subspecialty services and providers. (E. Cohen et al., 2011).

Coller et al. identified two different strategies available in literature to define medical complexity in children. The former is the diagnosis-based strategy, also known as “categorical” (Feudtner, Christakis, & Connell, 2000; Feudtner, Silveira, & Christakis, 2002), whereas the latter is a consequence-based or “noncategorical” system (Gordon et al., 2007; Palfrey et al., 2004). The noncategorical systems appears as being potentially more inclusive; nevertheless, it is difficult to apply it to large administrative datasets (E. Cohen et al., 2011; Coller et al., 2016; J. M. Neff et al., 2002).

In 2017, Shapiro, reviewing the existing papers, proposed a definition of Pediatric Chronic Critical Illness (PCCI) adapted from the concept of Chronic Critical Illness (CCI) in adults. The author emphasized similarities and differences between adult and

² Children With Special Health Care Needs

pediatric patients with chronic critical illness. By way of example, Shapiro pointed out that Khan et al. estimated the prevalence of CCI in adults at 7.6% of all ICU admissions (Kahn & Angus, 2015). On the contrary, the CMC population makes up 50% of PICU patients (Chan et al., 2016; Typpo, Petersen, Petersen, & Mariscalco.M.M., 2010). Authors highlighted that tracheostomies also have different implications for adult versus pediatric patients. Tracheostomies involve many complications in children. Despite the fact that tracheostomy is currently performed within 14 days mechanical ventilation in adults, in pediatric patients, the average time to perform a tracheostomy is more variable, between 22 and 41.5 days (Holloway A.J., Spaeder M.C., & S., 2015 Association of timing of tracheostomy on clinical outcomes in PICU patients). Moreover, the Length of Stay (LOS) is crucial to define CCI in adults. On the contrary, many external factors mediate the LOS for chronic children, some of which are the following: hospital bed availability, possibility of home discharge, ability of caregiver to look after a ventilator-dependent child, the paucity of non-ICU pediatric or long-term care settings, and the variability in home care services³. For all the listed above, LOS cannot be considered as being crucial when defining PCCI⁴. In addition to this, Shapiro emphasized three other additional “pediatric considerations that may inform the definition of PCCI: underlying medical complexity; recurrent ICU hospitalizations; and the impact of age and developmental status on pediatric disease processes” (Shapiro, Henderson, Hutton, & Boss, 2017). All those considerations are shown below. Many authors tried to describe children’s medical complexity by drawing distinct algorithms. The new definition of CSHCN⁵ (McPherson et al., 1998) was more an attempt to describe an emerging population, than actual algorithm. On the contrary, Feudtner (2001) identified, on the

³ Different type of home care services are described in literature (Breneol, Belliveau, Cassidy, & Curran, 2017), some of them are the following: complex care programs that are primarily outpatient programs, based out of tertiary pediatric hospitals; comprehensive care plans that are documents to outline the major medical issues and care-related needs of CCC, created by the health care providers (HCP) in collaboration with families; and, finally, integrated delivery models that are aimed at provide support for CCC parents.

⁴ Pediatric Chronic Critical Illness

⁵ Children With Special Health Care Needs

International Classification of Diseases codes, a list of possible conditions to define the CCC algorithm. In 2014, Simon et al. based on Feudtner's work, proposed the PMCA, Pediatric Medical Complexity Algorithm (Tamara D. Simon et al., 2014). PMCA was a modification of the Chronic Disability Payment System (CDPS) developed at the University of California (2013). Simon removed several types of International Classification of Diseases codes in the following manner: "those consistent with adult illness (e.g., myocardial infarction), related to childbirth, consistent with acute illness (e.g., acute otitis media), and representing pediatric chronic conditions that are most often mild in severity (e.g., eczema, myopia, iron deficiency anemia)". In order to detail the PMCA⁶, some conditions associated with deteriorating health and an increased risk of shorter life expectancy in adulthood, as well as body system items⁷ were included. Children were categorized into the following 3 levels of medical complexity: children with complex chronic disease, children with noncomplex chronic disease, and children without chronic disease. Simon stated that "Children with complex chronic disease are most likely to benefit from care coordination and other resources, and accurate identification of this group is critical" (Tamara D. Simon et al., 2014). In 2017, the author published PMCA 2.0, an update of the previous tool (T. D. Simon, Cawthon, Popalisky, Mangione-Smith, & Center of Excellence on Quality of Care Measures for Children with Complex, 2017). Other examples of algorithms are represented by the Clinical risk groups (3M Health Information Systems, in Jay G. Berry et al., 2015), the Chronic Condition Indicators (Agency for Healthcare Research and Quality, in Berry et al., 2015), the CSHCN Screener (Bethell et al.), and the PMCA 3.0 (T. D. Simon, Haaland, Hawley, Lambka, & Mangione-Smith, 2018). Other specific tools were developed for children with complex chronic conditions or medical complexity; for example Dumas et al.

⁶ Pediatric Medical Complexity Algorithm

⁷ The author defined "shorter life expectancy in adulthood" as: "death in the fourth to fifth decade due to cystic fibrosis, complex congenital heart disease, malignancy" or "cardiac, craniofacial, dermatologic, endocrinological, gastrointestinal, genetic, genitourinary, hematologic, immunologic, mental health, metabolic, musculoskeletal, neurologic, ophthalmologic, otologic, pulmonary, respiratory, and renal" failure.

elaborated the computer adaptive test to evaluate the disabilities faced by CCC (PEDI-CAT, in (Dumas, Fragala-Pinkham, Rosen, & O'Brien, 2017).

All those tools described CCC has having a range of underlying medical conditions, including Children with Medical Complexity (CMC), who comprise 50% of the Pediatric Intensive Care Unit patients. According to Shapiro, medical complexity is not synonymous with PCCI⁸, since the CMC population also included PCCI, and the latter represented the subset of the CMC population who spent the majority of their time in a hospital setting (C. Feudtner et al., 2001; E. Cohen et al., 2011; 1998; Shapiro et al., 2017). The adult CCI definition did not include recurring ICU hospitalizations, probably due to the high death rates occurring during the same. On the contrary, PCCI “survive for months to many years”, all the while needing multiple readmissions (C. Feudtner et al., 2001) . The benefits of having a consistent definition of CCI are known. Such a definition “allows clinicians and families to recognize the transition from an acute critical illness to CCI, which can inform evolving ICU goals of care” (Shapiro et al., 2017), and becomes crucial in building research agendas and highlighting gaps in medical knowledge. And it is crucial to create opportunities for improved care delivery and outcomes for adult CCI patients and their families, in order to define and identify the patient population in question. Nowadays, on the contrary, the benefits of a uniform definition for pediatric CCI patients are not yet available. For all the reasons above, in accordance with previous papers (M.M. Pollack, J.D. Wilkinson, & Glass, 1987; Marcin, Slonim, Pollack, & Ruttimann, 2001; P. Namachivayam, A. Taylor, T. Montague, & al, 2012), Shapiro adopted the Length of Stay as a relevant issue for the PCCI definition. Moving from the CCI definition of adult patients, He proposed a definition that incorporated all of the considerations reported above, as well as “age, developmental status, and the existence of congenital or acquired underlying conditions and comorbidities”. The author highlighted the core points of PCCI and outlined the following definition: PCCI involved “pediatric patients who remain hospitalized in a Neonatal Intensive Care Unit more than 28 days post term corrected age, or in a pediatric intensive care more than 14 consecutive days, or who have a history of prolonged ICU stay and two or more acute care or ICU

⁸ Pediatric Chronic Critical Illness

admissions within 12 months. Ongoing dependence on one or more technologies to sustain vital function”, such as the following: tracheostomy, invasive or noninvasive mechanical ventilation, gastrostomy or jejunostomy tube, dialysis or persistent multiple vital organ system involvement (Shapiro et al., 2017). This definition seems to be actually the more adequate to define this population.

The “children shift”

The children-chronicity phenomenon was noticed about 50 years ago and increased up to becomes more than double in terms of the prevalence of chronic conditions (1960-1980). Since the 90s, many authors have observed a substantial decrease of children’s death rate (Boyd & Hunsberger, 1998); at the same time, they registered the increasing survival rate of children with a chronic illness or disability (Gortmaker, 1985; 1991; R. E. K. Stein & Jessop, 1982).

In 1986, Newacheck, while reporting the data from the division of Vital Statistics, National Center for Health (Maryland), asserted that “improvements in infectious disease control, sanitation, housing, and medical care services have had major beneficial effects on the health of children. For children ages 1-14, mortality rates have fallen dramatically from 870 per 100,000 children in 1900 to 38 in 1981”. According to Newacheck, while this trend of children mortality was decreasing, the problem of CCC was growing (P.W. Newacheck, Budetti, & Halfon, 1986).

Feudtner et al. (2001) conducted a retrospective cohort study using the US national death certificate data (National Center for Health Statistics), including all people aged 0 to 24 years in the United States from 1979 to 1997. The authors examined counts and rates of CCC-attributed deaths by cause and age. They showed a significant reduction on both cancer CCC mortality rate among children (1-9 years old), adolescents, and young adults (10-24 years old), as well as non-cancer CCC mortality rates among infants (<1 year old) and children (Feudtner et al., 2000). On the basis of Feudtner’s study, CCC live longer than 20 years ago. Other authors asserted that Children with Medical Complexity (CMC) is a growing part of the pediatric population. They have severe chronic multiple-system conditions, functional limitations, and incremented family needs (E. Cohen et al., 2011; Tamara D. Simon et al., 2014); (Glader, Plews-Ogan, & Agrawal, 2016). CCC were defined as children with “any medical condition that can be reasonably expected to last at least 12 months (...)

and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center” (Feudtner et al., 2000). On the basis of this definition, Feudtner drafted a list of possible conditions based on the *International Classification of Diseases, Ninth Revision* codes. (Feudtner et al., 2000). Those are the following: cardiovascular, malignancy, neuromuscular, respiratory, renal, gastrointestinal, hematology and immunodeficiency, metabolic, genetic and other congenital anomalies (C. Feudtner et al., 2001).

During the Conference on the Future of Pediatric Training (2003), Wise presented a paper about child health policies and care delivery systems within which he listed the Social Determinants of Child Health. The author asserted that “the marked improvements in the survival of premature (...) due to advances in high-risk obstetrics and neonatal intensive care”, had the effect of incrementing the risk of serious medical and developmental effects among the survived infants. The author tried to explain the increase in childhood chronic illness as “the result of changes in survey procedures, improvements in diagnosis, and a greatly expanded public awareness of behavioral and developmental disorders”. According to Wise, the reasons for the increase in the prevalence of CCC in 2000, compared to 1980, mostly unknown. However, he highlighted that “hospitalization rates and lengths of stay for children with chronic illness have fallen more slowly than among children without a chronic disease” (Wise, 2004).

In 2010, Burns, Casey et al. used the United States Nationwide Inpatient Sample (NIS) database to analyze all of the available data from 1991 to 2005. The NIS database contains data from 1000 hospitals and includes 7 to 8 million hospital discharges annually in the US. Through the NIS database, they have identified the rate of hospital admissions for medically complex children for each of the 9 categories defined by Feudtner et al. From 1991 to 2005, they found a significant increase of the hospital admission rate for medically complex children aged 8 days to 4 years. Children diagnosed in CCC categories such as cardiovascular disease, respiratory disease, renal disease, metabolic disorders, and other congenital defects/genetic disorders, also increased the hospitalization rate. On the contrary, Children diagnosed for CCC in all other categories (Neuromuscular, Gastrointestinal, and Hematologic/immunologic) remained stable or decreased the hospitalization rate. The authors also showed an

increasing hospitalization rate for all category combinations with regard to children with diagnoses in multiple CCC categories. They also stated that the cerebral palsy diagnoses alone (CP) had remained stable over the 15 years under consideration. Nevertheless, “the hospitalization rate of children with CP plus at least 1 comorbid diagnosis in a CCC category has increased” (Burns et al., 2010). Burns’ findings were supported by previous studies on the increasing hospitalization rate for renal disease, cardiovascular disease, and other congenital defects/genetic disorders].

The etiology behind the increase in the hospitalization rate for children with multiple conditions is still unknown at this time. Burns et al (2010), analyzing the United States Nationwide Inpatient Sample (NIS) database, about the “combination of increased survival rates, resulting from lowering mortality rates of preterm infants and children born with congenital defects, and shorter hospitalizations with increased use of home therapies” (Burns et al., 2010). Referring to the period between the late 1970s and the early 1980s, Hall asserted that many illnesses in children were unknown or still incurable. For example, children with hypoplastic left heart or affected by trisomy 18 did not survive. Fibrocystic pediatric patients survived with difficulties. Ill children died not only because of the primary diagnoses, but also due to all the related comorbidities, as pneumonia in children with severe neurological conditions and, in extremely low birth weight infants, necrotizing enterocolitis, hyaline membrane disease, or sepsis (David E. Hall, 2011). Nowadays, the trend in chronicity prevalence is still growing; on the other hand, a decline in mortality rates, hospitalizations for common acute conditions and injuries, and school absence days due to illness can be observed (Halfon & Newacheck, 2010). To clarify this change in the children populations health status, many authors added various argument, the most relevant are presented in table 1.

Table 1_ Author’s Statements on the Topic of CCC Health Status Change

Author, year Title	Method	Statement
Moola, 2008 Physical activity and sport participation in youth with congenital	Qualitative Methodology, inductive analysis of 13 interviews.	“Advances in medicine have improved the life expectancy of children with diseases that were at one time considered to be life threatening”

heart disease: perceptions of children and parents.		
Mokkink, 2008 Defining chronic diseases and health conditions in childhood (0-18 years of age): national consensus in the Netherlands	Systematic search of the literature on definitions of chronic conditions	“Improvements in therapeutic possibilities in developed countries in the last few decades have led to increasing numbers of children and young adults who have survived congenital, perinatal or other severe medical conditions (...)” The downside of this situation is that “many survivors of serious and acute childhood diseases are not without symptoms, and mortality has often been replaced by lifelong morbidity”
Halfon, 2010 Evolving Notions of Childhood Chronic Illness	Analysis of 3 cohorts of children spanning 1988 to 2006 included in the National Longitudinal Survey of Youth (NLSY)	“Access to and improvements in the delivery of specialized care have resulted in a growing number of survivors of complex congenital disorders, prematurity, and cancer whose survival was almost unimaginable a few decades ago. Better access to care and better tools to diagnose chronic conditions, particularly emotional and behavioral conditions, may also contribute to the upward trend in prevalence”
Cohen, 2011 Children with medical complexity: an emerging population for clinical and research initiatives	Systematic review to explore the diversity of existing care models and identified those children	“Ongoing advances in neonatology, pediatric care, and medical technology are steadily increasing the prevalence of” CCC

<p>Casey, 2011</p> <p>Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children</p>	<p>Before and after intervention study to explore the care costs.</p>	<p>“Improvements in surgical, general medical, and intensive care have increased the survival of low- birth-weight children born preterm with various congenital anomalies. As a result, an increasing number of children with multiple chronic conditions now live at home. Many such children have an associated chronic neurodevelopmental disability and are in need of assistance with special medical equipment, such as tracheostomy and gastrostomy tubes”</p>
<p>Coller, 2016</p> <p>Medical Complexity among Children with Special Health Care Needs: A Two-Dimensional View</p>	<p>Latent class - secondary analysis of the 2009-2010 National Survey of Children with Special Health Care Needs</p>	<p>“Survival in more common congenital disorders (...) has increased considerably (...) the morbidity and health care needs have certainly not decreased. (..) the prevalence of chronic conditions in children and young adults is increasing. This can be the result of either the improved survival of children with a particular condition, such as end-stage renal disease or of the survival of a previously fatal condition, at the cost of long-term <i>sequelae</i>”.</p>
<p>Moura, 2017</p> <p>Complex chronic conditions in children and adolescents: hospitalizations in Brazil, 2013</p>	<p>Analysis of the International Classification of Diseases Revision</p>	<p>“The prevalence of CCC among children and teenagers is growing around the world because of the reduction in infant mortality, improvements in surgical techniques and biomedical engineering, increased immunization cover and health- care and improvements in social indicators”</p>

Due to all the reasons listed on the table above, not only is the number of children with medical complexities growing, but also the rate of technology-dependent children

(E. Cohen et al., 2012). In 2011, Casey observed 225 medically complex children receiving care at the multidisciplinary clinic at the Arkansas Children Hospital (US). Casey found that of all the 225 participants, 67% were born preterm, 37% had bronchopulmonary dysplasia, 56% received a gastrostomy tube, 7% received a tracheostomy tube, 33% had cerebral palsy related to brain injury or anomaly, 72% were developmentally delayed, and 40% had a genetic syndrome or congenital anomalies. In 2014, while studying children enrolled in complex care coordination services, Russell showed that 56% of them had a gastrostomy tube, 13% a spinal fluid shunt (CSF), and 12% were tracheostomy-tube dependent. The author also stated that 10% of all admissions of those children was dependent on a technological malfunction (Jay G. Berry et al., 2011; Russell & Simon, 2014).

Russel studied children with various disabilities and multiple technology-dependent levels. Some of the studied technology-dependent children had hydrocephalus and required the positioning of a cerebrospinal fluid shunt, children affected by a chronic respiratory failure or anatomic abnormalities benefited from a tracheostomy placement, and children who were unable to meet their nutritional needs required a percutaneous feeding tube. Some of them had vagal nerve stimulators, intratracheal baclofen pumps, cardiac pacemakers, and central venous catheters (Russell & Simon, 2014).

In conclusion, nowadays, in economically wealthy countries the changing demographic in children has prompted a renewed analysis of the role of pediatric medicine, also because chronic illness has become more prevalent than acute (Eccleston, Fisher, Law, Bartlett, & Tm, 2015; Halfon & Newacheck, 2010). The World Health Federation (2011) asserted that this phenomenon presents different clinical challenges in other parts of the world: for example, in south Africa the most prevalent chronic conditions are HIV-related disease, malaria and tuberculosis (Eccleston et al., 2015; WHO, 2011). According to Hall (2011) most of the advances in technology and medical science “do not provide a cure. Rather, they sustain a chronic disease that requires ongoing management”. Most children with chronic conditions need to be cared for by multiple specialists and have multisystem impairments. In the last few decades, this is has become an emerging problem for all health care institutions. The growing number of CCC “take up an increasing percentage of children’s hospitals beds and healthcare resources. It behooves us to improve the way we treat them” (D. E. Hall, 2011; "Health

Information Technology to Facilitate Communication Involving Health Care Providers, Caregiver," ; Tomashek, Shapiro-Mendoza, Davidoff, & Petrini, 2007). Despite the benefits of higher rates of technological support, and the high assistance quality, chronic children present an extremely high level of readmission and mortality rates. Cohen reported that nearly 25% of CMC would experience readmission within 30 days of hospital discharge (E. Cohen et al., 2012). This item is relevant due to the fact during hospitalizations children are at higher risk of an adverse event or medical error. Indeed, complex chronic condition or technology dependency are “independently associated with higher odds of experiencing an adverse event among hospitalized children”(Dewan & Cohen, 2013; Matlow, Baker, Flintoft, & al., 2012). Health care providers have to rise to the enormous challenges that CCC represent. According to Dewan (2013) organizations, when deciding about a new treatment, must take into consideration all the(E. Cohen et al., 2010) multiple conditions of CCC (Dewan & Cohen, 2013).

The costs of Children with Chronic Conditions

Recent researches have showed that CCC accounted for 55–60% of hospital discharges, whereas the prevalence recorded in 1962 was 25% (Feudtner et al., 2002; J. Neff & al., 2002; Wise, 2004). Of all the medical expenditures for children, the costs for CCC appeared to be more than 42% (P. W. Newacheck & Kim, 2005). Moreover, Cohen found that the costs for CCC health care were three times higher, and hospital expenses four times higher, than expenditures for healthier children(E. Cohen et al., 2010). The effect of CCC on organizations and healthcare costs did not receive a lot of attention in past years, although the population in question has a disproportionate effect on hospitals’ bottom lines. Multiple studies, as presented above, have reported data showing the impact of CCC care on costs, based on which, in recent time, many institutions established a clinical program mainly oriented at: reducing costs (Jay G. Berry et al., 2011), reducing the length of stay in Intensive Care Units (Berman et al., 2005), reducing the number of readmissions (Jay G. Berry et al., 2011; E. Cohen et al.,

2012), and supporting patients from hospital to home (J. G. Berry et al., 2014; Gold et al., 2016)⁹.

In the last few years, some relevant studies were conducted to analyze the costs related to the implementation of various programs, and also to track the expenditure trends related to CCC (Berman et al., 2005; Jay G. Berry et al., 2015; Casey et al., 2011; E. Cohen et al., 2012; Perkins & Agrawal, 2018). The lack of evidence before 2005 demonstrates how this problem was previously underestimated.

In 2005, Berman analyzed the payments and expenditures for children who had multisystem disorders. The author, by comparing data before and after the enrollment in Special Primary Care Clinic in Denver, observed a higher level of costs due to CCC and hospital overall loss per child per year of \$956. Moreover, during the analysis the problem of the readmission rates that were higher than all other children emerged (Berman et al., 2005).

Cohen (2010), observed a repeated decrease in the number of hospitalization days in the findings of many studies about the implementation of a complex care clinic, as well as an increase in the utilization of ambulatory hospital-based clinics. Similar data emerged from another American study specifically from a complex care co-ordination program in Milwaukee (Gordon et al. 2007). Both the studies of Gordon and Berman (2005) showed increased outpatient costs that were offset by inpatient savings (Cohen, 2010).

Casey, conducting a before and after intervention study to explore the care costs, evaluated the costs of care for medically complex children at the Arkansas Children Hospital. The aim of his paper was to compare the costs before and after the implementation of a hospital-based multidisciplinary clinic. Casey observed a significant statistical decrease of \$1766 of the mean annual cost per patient for inpatient care, and \$1179 for overall pediatric patients (Casey et al., 2011).

Cohen's retrospective cohort study was one of the most cited and extensive (2012). The study involved 15771 children aged 0 to 16 years, hospitalized in Ontario between 2005 and 2007. Cohen asserted that this a small proportion of the population,

⁹ It is worth observing that the support in question is related to the wellbeing of children and parents. This particular attention to families' need has emerged only recently.

accounted for a substantial proportion of health care costs; indeed “the 2-year expenditure on CMC accounted for 32.7% of total spending on health care for children in Ontario”(E. Cohen et al., 2012).

In 2014, Collier published a review in which he identified some practices that might help reduce CCC readmissions, give higher-quality assistance, and improve the patient experiences. In order to do that he suggested increasing the number of home visits to children, guaranteeing care coordination and chronic care-management, and also to promoting continuity across settings (Collier et al., 2016).

In 2015, Berry observed the hospital utilization and the characteristics of children with recurrent readmissions. He showed how a small cohort of children was the major contributor to inpatient utilization and expenditures with regard children’s hospitals. Berry stated that 3% of children with recurrent admissions (patients who experienced 4 or more readmissions within a 1-year period) often were CCC, and their care accounted for one fourth of all inpatient bed days and charges in the children’s hospitals taken into considerations (Jay G. Berry et al., 2015).

In 2017, Breneol et al. conducted a scoping review¹⁰ to identify and characterize the most implemented models for interventions, frameworks or programs that support CCC during the transition process from hospital to home. This review could help us to better comprehend the institutional choices in responding to the emerging CCC problems. Breneol identified three major categories of interventions represented by: Comprehensive care plans, Complex Care Programs, and Integrated delivery models (Breneol et al., 2017). The author described the comprehensive care plans as documents to outline the major medical issues and care-related needs of CCC. Those plans were created by the health care providers (HCP) in collaboration with families, and potentially involved emergency care plans or advanced directives. They were developed to promote communication between families and multiple health care providers. Many authors analyzed these documents and concluded that they “have the

¹⁰ According with the Joanna Briggs Institute (2015), a scoping reviews allow for the examination of broad areas of interest “to identify gaps in the evidence, clarify key concepts, and report on the types of evidence that address and inform practice in a topic area” (Institute, 2015).

potential to support or empower parents in communications with HCP, but are less valuable if they are duplicated, are not up to date, or are non-modifiable by the various care providers, including parents”(Breneol et al., 2017). In accordance with previous authors, Breneol highlighted the necessity for comprehensive health care plans to become dynamic and accessible, on providers’ part, through an electronic platform as the major challenge (Adams et al., 2013.; Luca et al., 2011; Quigley, Lacombe-Duncan, Adams, Hepburn, & Cohen, 2014).

Complex care programs were the second model observed by Breneol. They were primarily outpatient programs, based out of tertiary pediatric hospitals. Only a few complex care programs engaged a multidisciplinary team, and most of them were staffed at minimum with a nurse and a pediatrician (Breneol et al., 2017). As results of those programs’ implementation, the author proved there were “decreases in hospital patient costs due to statistically significant decreases in hospitalizations and inpatient days”. Breneol highlighted that “inconsistent findings were identified across studies related to parental, child health, and family impact”. Integrated delivery models were the third instance analyzed by Breneol. The programs in question were aimed at providing support for CCC parents, and parent satisfaction was the primary measured outcome. Breneol’s conclusion underlined the “importance in developing and implementing a nursing care coordinator role to assure successful transitions from hospital to home for these children”. He also highlighted the necessity to give more attention to child and family health outcomes (Breneol et al., 2017).

At the same, time over the last few decades, health policies have supported a shift in location and care for children with chronic health care needs, from institutional settings, such as hospitals, to primary care within the community. Because of this, CCC were often cared for at home (Breneol et al., 2017). Data emerged from the analysis of hospitalization rates showed that as many as 89% of patients with significant complex chronic conditions were sent home (J. G. Berry et al., 2014). Many authors asserted that providing complex care outside of the hospital setting had relevant implications for families (Breneol et al., 2017).

Adams et al. (2013bbb), through a grounded theory based qualitative study, describes that comprehensive care plans for children with medical complexity were described by as useful on the inquiry data analysis of both health care providers and parents of CCC (Adams et al., 2013). Nevertheless, Kuo et al. (2013) also explored parent health, child

health and functioning, family stress¹¹, and overall satisfaction with clinical services. In spite of the conclusion that comprehensive care oversight might improve care coordination for parents of CMC, they did not find any association with improved parent health (D. Z. Kuo et al., 2013).

Until a few years ago, the most relevant CCC-related topics were all cost-reduction oriented. Despite this, an increasing emphasis on “improving health care delivery (...) in the context of family” has developed in institutions and for researchers (Willits, 2013). Many studies have proved that the presence of a CCC can have a profound negative impact on the economic and social health of families (D.Z. Kuo, Cohen, Agrawal, Berry, & Casey, 2011; D. Z. Kuo et al., 2013), and it is fundamental to take into account that the majority of care for CCC is provided by families in the home environment (Christian, 1998). The transition of CCC care from hospital to home created many demands and needs on parents. Throughout the years, increasing researches were conducted by taking into account the families’ point of view.

Being a CCC Family

In 1975, Massie and Massie defined the diagnosis of chronic illness as a cataclysmic event (Massie & Massie, 1975), given that the diagnosis risked shattering the parents’ prior reality. Batshaw (1991) thought that a CCC diagnosis could generate an emotional crisis within the entire family (Batshaw, 1991). Many authors asserted that the well-being of parents had an impact on the health of CCC and the well-being of the overall family unit, and that supporting the family system¹² was essential to the child’s well-

¹¹ In 1949 Hill developed the “family stress theory”, through which he described how families experiencing the same stressor could respond in different ways. The author identified the following factors that seemed to influence the ability of families to react to the crisis: “family’s resources, perceptions, and stressors”. He stated that the susceptibility of the balance between these factor could determine a crisis (Hill, 1949).

¹² “Family systems theory” is a theory of human behavior developed by Bowen, who viewed the family as an emotional unit, and used systems thinking to describe the complex interactions in the unit. According to the author, a change in one family member affects all other members and the system as a whole (Bowen, 1978).

being (M. Z. Cohen & Omery, 1994; Cousino & Hazen, 2013; Hentinen & Kyngas, 1998; Johnston & Marder, 1994). Moreover, it is well known that providing care for a child with chronic illness and disability caused a relevant stress level, especially for the primary caretakers (Cousino & Hazen, 2013).

There was strong evidence to suggest that CCC had an impact on all family members, especially parents. Despite this, the theme in question has received growing interest with regard to institutions only recently. The same, have come to a dual conclusion: firstly, if parents suffer from a significant emotional distress of their own, and the family functions poorly, it can affect the child's outcomes (Logan & Scharff, 2005; Palermo, 2000); secondly, institutions also observed that parents' adaptive strategies can have a positive effect on the child's adjustment to chronic illness (Eccleston, Palermo, Fisher, & Law, 2012; Logan & Scharff, 2005).

Glader (2016) described the family system as a "unique entity that needs to be concretely addressed": this entity should be integral to the child's care, through a holistic vision (Glader et al., 2016). According to the author, the following key points should be taken into account to provide a holistic care: the necessity of assessing the mental health status of the entire family system as a whole; the importance of supporting anticipated transitions from pediatric to adult care or independence, and improving health care workers' specific skills and knowledge to promote communication with families (Glader et al., 2016).

As described by Christian (1998), throughout a translational research, parents who provided daily care for CCC at home experienced multiple stressors related, firstly, to their child's condition, secondly, to the necessity of coordinating specialty health care, and, thirdly, to the complexity of interfacing with a variety of systems, such as schools and hospitals. Parents of CCC seemed to be poorer in emotional and physical health than "parents of healthy children due to the demands of caregiving" (Christian, 1998, 2010). The first review conducted to identify CCC parents' needs was written in 2001 by Fisher. This review was based on the analysis of eight studies conducted between 1987 and 1997 and identified the following three "subheadings": the need for normality and certainty; the need for information; and the need for partnership. Fisher

concluded underlining the necessity to explore more attentively both parents' and families' needs.

A Cochrane review, published by Eccleston (2012) and summarized by Trivedi in 2013, also confirmed that psychological interventions focused on parents could improve "child symptoms for painful conditions post-treatment". According to the authors, a cognitive behavioral therapy could improve child symptoms post-treatment, whereas a problem-solving therapy might show positive effects on parent behavior. On the contrary, no significant effects or improved functioning outcomes were reported, for many common chronic illnesses in children (Eccleston et al., 2015; Eccleston et al., 2012; Trivedi, 2013).

For all the reasons above, in the last few years the treatment focus of CCC has been changing. The criteria used to evaluate patients' outcomes prompted a consideration in terms of growing number of patient-centered outcomes, such as well-being and quality of life in symptom control, in addition to the usual medical endpoints (Bullinger, Schmidt, Petersen, & Ravens-Sieberer, 2006; Kazak, Simms, & Rourke, 2002; Rolland, 2003). Compared to the initial examination of CCC, the focus has shifted toward including the patient's caregivers (Butler, Copnell, & Willetts, 2014). The acknowledgment that "a chronic condition affects not only the patient but also the family as a system" has widened the focus from the child to the overall family system. Many authors observed that a "positive and supportive family environment can reduce patients' stress"; moreover, it emerged that the involvement of family members in the management of CCC could contribute to ensuring a better adaptation to the appropriate medical therapies (Denham, 2003; Fiese, 2006; Rolland, 2003).

Multiple studies suggested that CCC parents experience highly fragmented care, with a significant negative impact on the family's well-being (J. G. Berry et al., 2014; Collier et al., 2016; D.Z. Kuo et al., 2011).

In 2016, Leeman et al. conducted a meta-analysis on family functioning and well-being of CCC. The study samples included 53 studies in which a "relationship between family functioning and child well-being was analyzed using one of four family measures: Family Adaptability and Cohesion Evaluation Scales, Family Environment Scale, Family Relationship Index, or Family Assessment Device" (Leeman et al., 2016). From the meta-analysis the following nine dimensions of family functioning emerged: cohesion, adaptability, conflict, expressiveness, organization, overall family

relationship, role clarity, affective responsiveness, and general functioning. Leeman organized the findings according to the relationship between family functioning and “six children outcomes: children's psychological health, problem behaviors, social competence, quality of life, adherence to regimen, and physical health”. The author illustrated a relevant association between family functioning and many children dimensions of well-being (Leeman et al., 2016).

In 2016, Kuo analyzed 441 surveys out of the 968 that had been mailed to CCC families in the US. After the analysis the author asserted that, despite a large number of conducted studies and projects conducted to support CCC and their families, a substantial percentage of them reported a “high number of unmet health care needs” (D. Z. Kuo et al., 2016).

When analyzing the topic of CCC addressed to medical foster care, Seltzer (2016) stated that medical homes¹³ and written care plans could promote collaboration and improve communication between health care workers and families for the purpose of taking critical decisions on medical interventions for CCC (Seltzer et al., 2016). Ruth Nightingale also (2017) focused on the parents’ learning needs and preferences when carrying out home-based clinical care for CCC (Nightingale, Wirz, Cook, & Swallow, 2017).

Knakl et al. also highlighted the importance of engaging families in caring for CCC. He conducted an analysis of 70 interventions for families of CCC and described three key dimensions of family engagement, such as: focus of engagement, structure of engagement, and level of engagement. According to the author, the dimensions in question should be taken into account as key aspects of family engagement that “should be addressed in reports of family-focused interventions” (Knafl et al., 2017).

In 2015, Oxley interviewed seven parents of CCC (six mothers and one father) using the methodology of interpretative phenomenology developed by Heidegger. The data

¹³ The concept of medical home was introduced fifty years ago by the American Academy of Pediatrics (AAP). Initially, it was organized as a central location for CCC medical records. In 1970, Dr. Calvin Sia Hawaii had a relevant role on the development of medical homes. He thought that “Every child deserve(d) a medical home”, and his efforts culminated in the birth of the modern concept of Pediatric Medical Home. In its basic conception, the medical home involved comprehensive, coordinated, continuous, and accessible primary care.

analysis uncovered the following emerging themes: “post-traumatic stress symptoms”, that is to say parents’ symptoms of heightened anxiety, nightmares and flashbacks; “communication”, due to the lack of communication that in turn increased parents’ anxiety levels; “not my boy” expressed the inability to recognize their child due to intubation and the sedation; “cannot leave” expressed the worry of some parents, who asserted that they could not leave their child alone in pediatric intensive care unit because they “felt more reassured if there was always a relative at the bedside just in case [their child] woke”, and other parents thought there was no one to watch them while they were away; “too much pressure”, referring to the responsibility perceived by parents to look after their child at the pediatric ward; and, finally “nightmare”, given that some parents described the pediatric intensive care unit experience as one of the most frightening things they had ever had to face (Oxley, 2015).

In 2014 Gardner described processes and strategies associated with becoming the mothers of CCC. The author found an overlapping of mothering and caregiving. In the study, mothers identified the latter as a part of their being mothers; on the contrary, in Kirk’s research this theme also emerged in terms of a “dual roles as parent and nurse” (Kirk, Glendinning, & Callery, 2005). Responsibility was another emerging theme and was also described by previous authors. Becoming the mother of a CCC was presented as a progressive path towards achieving a sense of routine within 6 months of the discharge date. Mothers’ views of “medical technology evolved in concert with views of their infants’ health and confidence in their skills and decision-making competence; they felt free to innovate and experiment”(Gardner, 2014).

In 2012, Cousino conducted a systematic review and meta-analysis to “critically review, analyze, and synthesize the literature on parenting stress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, and/or sickle cell disease” (Cousino & Hazen, 2013). The author showed that parenting stress related to a CCC disease was not illness-duration dependent or illness-severity dependent (Mitchell et al., 2009; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Wu, Graves, Roberts, & Mitchell, 2010). However, some studies have highlighted that the level of parenting stress was directly related to the intensity or frequency of child pain episodes (Anthony, Bromberg, Gil, & Schanberg, 2011; Barakat et al., 2007). Cousino et al. observed a “paucity of research on coping mechanisms and both general and disease-related parenting stress”; moreover, they

discovered that a higher stress level perceived by parents might contribute to reducing the positive outcomes of children (Barakat et al., 2007).

In 2016, Edelstein published a scoping review to explore previous interventions that had been made to support caregiver stress. Within the 49 studies included on the review, the following 6 domains of intervention were identified: care coordination models; respite care; telemedicine; peer and emotional support; insurance and employment benefits; and health and related support. Generally, care coordination models were associated with broad decreases in stress level. An essential component in reducing overarching strain and depression, and increasing satisfaction of the caregivers, was the implementation of care coordinators. Respite care was defined as a model able to “offers families opportunities for short breaks from their caregiving duties, via in-home care where nursing teams provide coverage (...) or out-of-home care where a child resides for a day or brief stay in a hospice setting”(Edelstein, Schippke, Sheffe, & Kingsnorth, 2017). Regarding telemedicine, all the studies included in the review showed “benefits for accessing care from home on enhancing information sharing, reducing stress, anxiety, isolation and consequently, increasing quality of life”. Programs identified as peer and emotional support were divided in those focused exclusively on peer support, such as peer support group sessions, support for coping and facilitative processes for parents by using a one-to-one peer matching approach. Contrary to these in-person approaches, the increased use of social media and internet as a support mechanism was also analyzed. Others studied interventions were represented by clinician-led emotional support.

Edelstein noticed that all the approaches “noted promising and positive impacts on targeted skills, enhanced social-emotional support and increased knowledge and awareness of disability related issues”(Edelstein et al., 2017). All the studies within the insurance and employment benefits domain “reported direct and positive impacts on families’ precarious financial positions”. Finally, the author described some studies on health and related supports, such as the introduction of a mechanical lift or assistance with care. Edelstein concluded by stating that there were multiple approaches to support family caregivers, more specifically “to reduce caregiver stress and alleviate burden, a single approach may not be best suited to achieve these goals”. According to the author, it is crucial to ensure a type of care that is attentive to the unique needs of families (Edelstein et al., 2017).

Many authors observed that CCC parents experienced “a significant disruption of their ‘normal’ lives”. This happened not only during hospitalization, but also in the years that followed (F. Carnevale, 1999; Hagstrom, 2016). In 2017, Hagstrom interviewed 9 parents of CCC to uncover sources of stress in families of LOS children in the PICU, and to extend knowledge about family stress in a PICU setting. Although this was a mixed-method study, it was conducted analyzing mainly by analyzing qualitative data, such as interviews. At the end of the analysis, quantitative data was only used to quantify and define stressful life events experienced by families during the previous 12 months. Eight themes emerged as being predominantly related to “sources of stress: separation, not knowing, child's illness and distress, care and caring, emotional stress, physical stress, job and financial stress, and what we've been through before”. The other following subthemes were deemed as relevant for parents: as for the separation theme, being apart, a constant pull, family role changes, leaving the hospital, and siblings at the hospital; as for child's illness and distress theme, the child's distress, critical illness, future illness and health care needs; as for the not knowing theme, unknowns, we thought we were prepared, and the roller coaster (Hagstrom, 2016). Trowbridge suggested using specific models to analyze family functioning. According to the author, exploring the family functioning could help to develop family self-management behaviors, such as social, family awareness, skills, and values (Trowbridge & Mische-Lawson, 2014). In 2013, Crespo analyzed 39 empirical papers on CCC family routines and rituals. The author found that chronic condition of a child affected the CCC family as a whole, and that the chronic condition “impacted the frequency and nature of family's routines and rituals”; on the other hand, he showed that family interactions were strategic resources in the management of the chronic conditions, as well as opportunities for an exchange of emotional support. Finally, routines and rituals were associated with positive “health and adaptation outcomes for both patients and family members”. According to Crespo, the studies included in the review confirmed that “routines and rituals are natural resources available to families to achieve such a task”(Rolland, 2003). The author concluded by proposing that the resources in question ought to be conceptualized not as intrinsically healthy or unhealthy, but rather by having specific regard for the routines and rituals that will work for a given family and its unique condition (Crespo, Santos, Canavarro, & Kielpekowski, 2013).

In a qualitative study, Kimura and Yamazaki used the interpretative phenomenological analysis (IPA) to uncover the lived experiences of mothers of more than one CCC. The authors identified the following three main themes and seven subthemes: “abandoned hope for having an ordinary family”, related to losing a child’s health and being surprised third parties behaviors; “accumulating physical and mental fatigue”, connected to facing difficulties in parenting multiple children with disabilities, and lack of an adequate support system; and finally, “searching for positive experiences in parenting multiple children with disabilities”, drawing on difficult experiences, acknowledging those who share the burden, and feeling grateful for children with disabilities, given that they possess unique characteristics (Kimura & Yamazaki, 2013). Using a thematic analysis, Smith et al. (2013) analyzed thirty-four studies to critically evaluate the existing research on parents’ experiences of living with a child with long-term condition. Parents stated that they had to follow the child’s diagnosis and respond to the challenges of integrating the child’s needs into family life. They also perceived that they were not being supported enough with regard to receiving information and forming effective relationships with health care professionals. The author observed that parents rapidly developed the expertise to manage their children, and they wanted to work in partnership with health professionals. Nevertheless, parents perceived that their expertise was not taken into account, and they also felt that they were seldom included in decisions about their children (Smith et al., 2013).

In Table 2 are synthesized the characteristics and relevant findings of the studies involved that described the parent’s experiences of caring of children with Chronic conditions.

Table 2. Summary of the studies on CCC parent's experience

First author	Title	Purpose	Methodology	Findings	CCC's condition
Gibson, 1999	Facilitating critical reflection in mothers of chronically ill children	Exploration of empowerment of mothers living with their child with a chronic illness	Qualitative study based on feminist inquiry. Data collection included participant observation and in-depth interviews	Initial frustration and disbelief are replaced with accepting the situation Critical reflection enabled mothers to develop an awareness of their own strengths and resources and own values and goals, Mothers developed confidence in their own abilities to care for the child.	Neurological problems
Monsen, 1999	Mothers experiences of living worried when parenting children with spina bifida	Explore mothers' experiences of living with a child with spina bifida	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Mothers had on-going worries about the child and family's health and worried about not coping Mothers were anxious the child would not fit in with peers and gain independence Mothers' struggled with the daily complexities of care	Spina bifida
Johnson, 2000	Mother's perceptions of parenting children with disabilities	Explore parents' experiences of parenting children with physical disabilities	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Mothers lived in the present to meet the child's needs but relived the past as grieving continued, Mothers treated the child as normal while securing services because the child is not normal, Mothers dealt simultaneously with the child's and their own issues and feelings.	Cerebral palsy, Hydrocephalus, Spina bifida
Balling, 2001	Hospitalized children with chronic illness: parental care giving needs and valuing parental experience	Explore parents participation in care when a child with a chronic illness is hospitalized	Mixed method survey. Descriptive statistics and Content analysis	Higher quality of care provide at home Nurses workloads limited care delivery Child not always incorporated in care Parents want greater involvement in care Professionals' struggle to incorporate parents expertise into ward practices	Home enteral or parenteral nutritional needs
Ray, 2002	Parenting and childhood chronicity: making the invisible work visible	To validate a model designed to describe the work relating to parenting a child with chronic illness	Qualitative study based on phenomenology. Interviews analysed using thematic analysis	Parents' perceived their role of caring for the child was influenced by professional attitudes, information provision, and available services Other influences on families caring for a child with a long-term condition included the feminization of care and societal perceptions of disabilities	Least one care intervention

First author	Title	Purpose	Methodology	Findings	CCC's condition
Salfors 2003	A Parental Perspective on Living with a Chronically Ill Child: A Qualitative Study	To explore parents' experience of living with a child with chronic pain related to Juvenile Chronic Arthritis	Constant comparative method for grounded theory, Interviews	The emergent core category was labeled "parental vigilance." This core category was related to two other emergent conceptual categories, labeled "emotional challenges" and "continual adjustment." "Parental vigilance," "emotional challenges," and "continual adjustment".	Juvenile Chronic Arthritis
Sullivan-Bolay 2003	Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes	To provide a detailed description of day-to-day management experiences of mothers raising young children under 4 years of age with type 1 diabetes.	Naturalistic Inquiry	The central theme that emerged was "constant vigilance." Mothers described having to use hyper-vigilant caregiving behavior to accomplish the day-to-day management. This theme incorporated a cluster of management behaviors that included (a) ongoing monitoring of illness-related care, (b) identifying appropriate and safe resources that could meet the child's needs, and (c) "juggling" illness-related care with the developmental needs of the child.	Type 1 Diabetes
Maitby, Kristjanson, & Coleman, 2003	The parenting competency framework: learning to be a parent of a child with asthma	Describe and explore the daily life of mothers of children with asthma	Qualitative study based on phenomenology. Interviews analysed using Colaizzi's stages of phenomenology	Mothers' parenting competency and identity was challenged as a result of the child's condition Uncertainties about their own abilities and managing the condition existed	Asthma
Ray, 2003	The social and political conditions that shape Canada special-needs parenting	To describe the social and institutional factors that affect families living with a child with a chronic illness	Secondary analysis of interview data. ⁵² Interviews were analysed using thematic analysis	Parents' perceived their role of caring for the child was influenced by professional attitudes, information provision, and available services Other influences on families caring for a child with a long-term condition included the feminization of care and societal perceptions of disabilities	Least one care intervention

First author	Title	Purpose	Methodology	Findings	CCC's condition
Trollvik, 2004	Parents' experiences of asthma: Process from chaos to coping	To describe nine parents' everyday experiences of living with a child suffering from asthma. Secondly to illuminate the parents' experiences of encounters with healthcare professionals.	Qualitative research interview method	Four main themes emerged: feelings of uncertainty, helplessness and guilt; the need for support and help from healthcare professionals; adaptation to everyday life; and the development of coping strategies	Asthma
Goble, 2004	The impact of a child's chronic illness on fathers	Explore fathers' experiences of caring for a child with a chronic illness	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Financial impacts strained family life Fathers missed previous social activities, Relationships with partners were supportive and strong but parents had no time alone, Fathers filled the gap in becoming the main care giver to siblings, Fathers worried about the child's future.	On-going care
Fawcett, Baggaley, Wu, Whyte, & Martinson, 2005	Parents responses to health services for children with chronic conditions and their families: a comparison between Hong Kong and Scotland	Explore parents' experiences of health-care support in children with a chronic illness across two cultures	Mixed methods descriptive study Self-developed questionnaire analysed using descriptive statistic	Both cultures wanted more information than provided and to participate in care decisions	On-going care
Heaton, Noyes, & Sloper, 2005	Families' experiences of caring for technology dependent children at home	Explore families' experiences of caring for a technology dependent child	Qualitative study. Interview data analysed using the framework approach	Family routines were influenced by the type of equipment and duration of treatments	Technology dependent child

First author	Title	Purpose	Methodology	Findings	CCC's condition
Kirk, Glendinning, & Callery, 2005	Parent or nurse? The experience of being a parent of a technology dependent child	Explore parents' experiences of caring for their technology dependent child	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Home is dominated by medical equipment and the frequent presence of health-care workers Parents caring role dominated their parenting role Parents differentiated themselves from health workers because care giving was interwoven into their lives with no respite and emotionally draining	Technology dependent Children
Dickinson, Smythe, & Spence, 2006	Within the web: family-practitioner relationship in the context of chronic illness	Explore parent-relationships in families living with a child with chronic illness	Qualitative phenomenological study. Group interviews analysed using Caelli's approach to phenomenology	Families enter a complex web of care with few choices in services and practitioners Tensions occur because of differences between professionals' working practices, Moving between practitioners and services is disruptive	Child requiring home care interventions
George, Vickers, Wilkes, & Barton, 2006	Chronic grief: experiences of working parents and children with chronic illness	Explore parents' experiences of chronic grief in children with chronic illness	Qualitative phenomenological study. Interviews analysed using Van Manen's approach to phenomenology	Range of emotions on receiving the diagnosis and recur at times of uncertainty, Chronic grief resulted in sadness which increased as the condition progressed, Satisfaction in dealing with professions was variable.	Neurological problems
Mulvaney, Schlundt, & Mudasiru, 2006	Parents' perceptions of caring for a adolescents with type 2 diabetes	Explore parents' experiences of living with adolescents with type 2 diabetes	Qualitative study. Focus group data were analysed using the framework approach	Role modelling had positive and negative impacts on adolescents self-management of their diabetes Parenting skills impacted on adolescents self-care Maintaining treatment was challenging Environment (clinic, home, school) influenced health behaviors, and the development stages of adolescence amplified consequences of diabetes	Type 2 Diabetes
Nuutila & Salanter, 2006	Children with a long-term illness; parents' experiences of care	Explore parent-relationships with families with a child with chronic illness	Qualitative study. Interview data was analysed using qualitative content analysis	Assuming responsibility for child's care is scary; Observation of their child's condition and possible symptoms is difficult; advice is followed in detail Need to integrate care into other aspects of a family's everyday life Learning to deal with one's own feelings and recognizing need for taking care of oneself are important learning tasks	Physical long term illness

First author	Title	Purpose	Methodology	Findings	CCC's condition
Green, 2007	e're tired not sad': benefits and burdens of mothering a child with a disability	Explore the social experiences of mothering children with disabilities	Mixed methods survey. Quantitative measure related to stigma and care giving burdens, range of statistical tests applied Analysis not described for qualitative interview data	Mothers' lives are emotionally complex, they developed confidence but care giving was time consuming, expensive and physically exhausting. Socio-cultural constraints and stigma associated with disability added to the burden of caring.	Neurological problems
MacDonald & H. Gallery, 2007	Parenting children requiring complex care: a journey through time	To describe the care trajectory of children with complex needs	Qualitative study based on ethnography. Interviews, participant observations, eco-maps and documentary review were coded, categorized and interrogated to find connections across data	Caring processes began at birth and continued throughout infancy and into adulthood Parents needs changed in relation to the child's stage of development, condition changes, family circumstances and parents age. Respite care was important and the need for respite changed over time	Complex feeding and medication regimes, bowel care, catheterization, oxygen therapy
Lauver, 2008	Parenting Foster Children With Chronic illness and Complex Medical Needs	To view the experience through the lens of the foster parent	Phenomenological inquiry, van Manen's methodology, Recorded interviews	Five essential themes emerged: committing to parenting a foster child with complex needs, coming to know the needs of a medically complex foster child, intervening, sensing the loss of a foster child, and becoming.	Hydrocephalus, Cerebral palsy, Physical developmental or cognitive delay, Respiratory insufficiency, Spina bifida, Stroke, Gastroesophageal reflux. Epilepsy
Mu, 2008	Transition experience of parents caring of children with epilepsy: A phenomenological study	To investigate the essence of the family health-illness transition experience from the parental perspective when a child is afflicted with epilepsy.	Phenomenology, Colaizzi's method with both deconstructed and restructured analysis, Interviews	The parents' perceptions of the family health-illness transition process fall into three major domains: parental psychological reactions, parental coping patterns, family resources.	Epilepsy
Wongvatunyu 2008	Helping Young Adult Children With Traumatic Brain Injury: The Life-World of Mothers	To report features of the life-world of mothers that were toward their young adult TBI survivors.	Interviews descriptive phenomenological method, Porter's phenomenological method for describing life-world.	Five features of life-world: having a child who survived a TBI as a young adult, perceiving that life has really changed, having sufficient support/feeling bereft of any help, believing that my child is still able, and believing that I can help my child.	Traumatic Brain injury

First author	Title	Purpose	Methodology	Findings	CCC's condition
Cashin, Small, & Solberg, 2008	The lived experience of fathers who have children with asthma: a phenomenological study	Explore fathers' experiences of caring for a child with asthma	Qualitative phenomenological study. Interviews Van Manen's approach to phenomenology	Relief in knowing the diagnosis Need to gain knowledge about the condition and treatment options, Living with concerns is constant, Being vigilant to illness symptoms is part of everyday life Expertise gained through knowledge	Asthma
Waite-Jones & Madill, 2008	Concealed concern: fathers' experiences of UK having a child with type juvenile idiopathic arthritis	Explore fathers' experiences of caring for their child with juvenile idiopathic arthritis	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Fathers described a range of losses in relation to their ability to maintain a normal family environment which was exacerbated by comparisons with fathers of healthy children The amount of care their ill child required resulted in fathers feeling that they did not spend quality time with their ill child	Juvenile Chronic Arthritis
Wennick, 2009	Everyday Experience of Families Three Years after Diagnosis of Type 1 Diabetes in Children: A research paper	To illuminate family member's everyday experiences 3 years after a child had been diagnosed as having Type 1 diabetes	Third part of a longitudinal study including qualitative interviews with family members.	Eight categories to describe the families' everyday experience: (a) knowledge and tried experience give skills, (b) capricious blood sugar level, (c) ambivalent parenthood, (d) stressful daily planning, (e) physical activity as pleasure and annoyance, (f) fear of losing control, (g) a private and public concern, and (h) needed and not needed medical service	Type 1 Diabetes
Bowes, Lowes, Warner, & Gregory, 2009	Chronic sorrow in parents of children with type 1 diabetes	Explore parents' experiences of living with a child with type 1 diabetes	Qualitative study. Interviews analysed by developing codes and categories	Parents' grief following diagnosis is on-going Acute illness episodes, hospitalization, change in treatments, development changes evoked a resurgence in grief	Asthma
Miller et al., 2009	Continuity of care for children with complex chronic health condition: parents perspectives	Explore parents' experiences of care across services for children with complex needs	Qualitative study. Interview data analysed by the framework approach	Effective communication was integral to achieving continuity of care Compartmentalization of services inhibited continuity of care, parents assumed the role of coordinator Consistent care providers were valued by parents because of their knowledge of the child	On-going care

First author	Title	Purpose	Methodology	Findings	CCC's condition
Graham 2009	Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities	To describe the experience of pediatric intensive care hospitalization from the perspective of a parents of children with severe, antecedent disabilities	Descriptive qualitative approach with semi structured interviews	<ol style="list-style-type: none"> 1. Know my child's baseline 2. Integrate and bridge multiple services 3. Disconnect between role of parent at home vs. parent in the PICU 4. PICU care does not equate with respite 5. High stakes learning environment 6. Heterogeneity within group 7. Lack of fit within the acute care model 	Epilepsy, Spinal atrophy, Spastic quadriplegia
Huang, Kellett, & St John, 2011	Being concerned: caregiving for Taiwanese mothers of a child with cerebral palsy	To describe a range of challenging caregiving experiences for mothers providing care for children with cerebral palsy (CP).	Hermeneutic phenomenological research, Interviews, hermeneutic analysis (Heidegger, Gadamer)	Four main themes on being concerned of: Experiencing burden as a sole primary caregiver Managing the challenges of balancing demands Being marginalized by others Encountering limited or no professional support	Cerebral palsy
Swallow, Allen, & Williams, 2012	Mothers' evolving relationship with doctors UK and nurses during the chronic illness trajectory	Explore the relationship between parents and health professions when a child's has a chronic illness	Qualitative study based on grounded theory. Interview data analysed using framework approach	Mothers needed to develop effective relationships with health-care professionals which was a continual source of stress Building effective relationships was reliant on mutual respect and good communication particularly early in their child's illness	Juvenile Chronic Arthritis
Kimura & Yamazaki, 2013	The Lived Experience of Mothers of Multiple Children With Intellectual Disabilities	To explore the lived experience of mothers of multiple children with ID in Japan	We used interpretative phenomenological analysis	The superordinate themes were: abandoned hope for having an ordinary family, Losing a healthy child again, Being surprised by others; accumulating physical and mental fatigue, facing difficulty in parenting multiple children with disabilities, lack of adequate support system; and searching for positive experiences in parenting multiple children with disabilities, Drawing on difficult experiences, Recognizing those who share the burden, Feeling grateful for children with disabilities possessing unique characteristics.	Autism/PDD, Down syndrome, and other chromosome anomaly
Hayles, 2015	Parents' Experiences of Health Care for Their Children With Cerebral Palsy	To explore parents' experiences of health care for their children with cerebral palsy	Grounded theory with open and focused coding, Comparative analysis, Focus group and interviews.	Parents experienced health care as a constantly evolving process and felt that they held primary responsibility for meeting the needs of their child. They identified six categories important aspects of their child's health care: evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance.	Cerebral palsy

First author	Title	Purpose	Methodology	Findings	CCC's condition
Oxley, 2015	Parents' experiences of their child's admission to pediatric intensive care unit	To explore the lived experience of parents whose children have been admitted to a PICU and to illuminate potential changes that could help parents in the future	Interpretative phenomenology, descriptive comments, linguistic comments and concepts	Post-traumatic stress symptoms, Communication Not my boy, Cannot leave, Too much pressure, Nightmare	PICU admission
Hinton 2016	Living with uncertainty and hope: A qualitative study exploring parents' experiences of living with childhood multiple sclerosis. Chronic Illness	To explore the experiences of parents of children with multiple sclerosis.	Grounded theory, semi-structured interviews, constant comparative method	One core category 'living with uncertainty' to explain parents' experiences of living with childhood MS was identified. Parents experienced: Diagnostic uncertainty, Daily uncertainty, Interaction uncertainty, Future uncertainty	Multiple sclerosis
Hagstrom, 2016	Family Stress in Pediatric Critical Care	To describe sources of stress in families of children who had been hospitalized in the PICU for more than one week.	A variant of a convergent parallel design was used. In this type of de- sign, qualitative and quantitative data are collected concurrently, analyzed separately, and then merged to create a more complete understanding of the phenomenon (Creswell & Plano Clark, 2011)	Eight themes related to sources of stress resulted: Separation: Being apart, A constant pull, Family role changes, Leaving the hospital, Siblings at the hospital; Not knowing: Unknowns, We thought we were prepared, The roller coaster; Child's illness and distress: Child's distress, Critical illness, Future illness and health care needs; Care and caring, Emotional stress, Physical stress, Job and financial stress and What we've been through before.	Cardiac surgery, Acute respiratory failure, septic shock, Ventriculoperitoneal shunt infection, Transplant, cancer, neurologic event, metabolic disease;

The relationship between health care workers and families: the power struggle

Another crucial CCC-related topic was the relationship between families and health care workers, mainly during PICU hospitalizations. In 2005, O'Haire and Blackford also discussed the high risk of role entwining between parents and staff during PICU hospitalizations. They underlined the necessity of a negotiation process between parents and nurses to guarantee the best care for children (O'Haire, Blackford, & 2005).

Ames et al. (2011) used a qualitative interpretive design to investigate the experiences of CCC parents experience, as well as the prevailing perception of the parental role in a PICU. The data analysis revealed that parents felt various emotions, such as “fear, guilt and helplessness to relief, hope and cautious optimism”. Moreover, parents underlined the following three dimensions of the parenting role: being present and participating in the child’s care; forming a partnership with the PICU health care team; and being informed of the child’s progress and treatment plan as the people who “knows” the child best. Despite the difficulties of being a CCC parents in a PICU, parents felt that their role and presence were of fundamental importance. According to Ames, “this consisted of being present and actively participating in their child’s care, forming a trusting partnership with the PICU team, and keeping abreast of their child’s progress and treatment plan as the one who “knows” the child best” (Ames et al., 2011).

Consistently with other authors, Macdonald et al. (2012) described the “inequality” of the respective roles of the nurse and the parent in a PICU (Ames et al., 2011; M. E. Macdonald, Liben, Carnevale, & Cohen, 2012; O'Haire et al., 2005; Rennick & Childerhose, 2015). She observed that although the staff actively encouraged families “to decorate the child’s bed area” and to stay close to them, parents were invited not to touch the child (or the equipment). Parents were regularly reminded to reduce noise levels, and were “required to stay close to their own child for confidentiality”. In spite of the fact that the behaviors described above, were requested of parents, the same noted that nurses frequently spoke about other patients, significantly adding to the noise level in the PICU (Butler et al., 2014; MacDonald & H. Callery, 2007).

Within a review conducted by Butler et al. (2014), the following four main topics concerning family-centered care implementation in PICU, were presented. According to the author, the main features of the “nurse and family” topic were connected to the

power struggle, which was due to the existing differences in the “parents’ knowledge and the nurses’ highly technical knowledge”; moreover, many studies noted a discrepancy between the role expectations of nurses and parents. Even though nurses expected all parents would want to be involved in the basic care of the child, mothers would often like to be involved more than nurses were willing to allow, and that was also through for highly technical activities, for example burns dressings, endovenous medications, and hygiene care of complex ventilated children. With regard to the possibility of involving in parents on highly technical activities, Martens reported a negative attitude on the staff’s part (Martens, DeLoof, & Idrissi, 2008). The second topic that emerged was “family presence”, described as a key element of family centered-care, crucial to support and incorporate family “as an equal partner in the child’s care”. From the study’s analysis, it emerged that “information sharing”, that is to say the third topic, was not adequate in the PICU. “Needs of parents” was the final topic. Butler, referencing many studies, highlighted the families’ necessity of being able to trust the attending nurse or doctor (Latour et al., 2010; Sturdivant & Warren, 2009). Families, albeit considering the presence of parents essential, would “rather trust that their child is safe with medical professionals than maintain a constant bedside vigil”(Butler et al., 2014). Other relevant emerging data regarded the mothers’ desire to share their emotions: despite the fact that a large number of mothers expressed this need, some studies showed a lack of awareness on the nurses part (Roets, Rowe-Rowe, & Nel, 2012). Butler concluded by supposing that there was a “difference in the perceived needs of the families by the nurses and the parents themselves, even though both groups ranked information and proximity to the child as more important than support or comfort” (Butler et al., 2014).

In 2015, Rennick et al published a statement in which they interpreted the current situations of CCC and their families. Rennick defined a large part of CCC parents as “full-time caretakers, adept at recognizing signs that their child is not well”. Nevertheless, the author underlined the parents’ expertise to manage all the medical technologies that sustained their children’s life outside the PICU. The migration of care-taking responsibility from a hospital setting to a home setting was defined as a “significant shift in practice”, and a challenge for clinicians who were used to replacing the expert care provider role of parents.

Rennick was unconvinced about the ability of clinicians to accommodate parents “as technologically sophisticated caregivers inside the PICU”, and also highlighted the risk of an emerging conflict between the treatment goals of PICU staff and CCC parents. The concept of a successful PICU treatment outcome could be very different when comparing the point of view PICU staff and the parents respectively.

The author distinguishes the different positions regarding the successful treatment concept. Whereas for some it amounts to returning the child to a state of previous health, for others the best care possible could be oriented to avoid further deterioration. Different points of view on CCC outcomes could result in communication problems and tensions between families and the PICU staff, which could interfere with treatment and recovery (Rennick & Childerhose, 2015).

Many authors observed that, initially, PICU families were at high risk of experiencing boundary ambiguity¹⁴. Families were often “uncertain...about who is in or out of the family and who is performing what roles and tasks within the family system”, and the degree of ambiguity determined the level of family stress (P. Boss & Greenberg, 1984). The defined “boundary expansion” was described as “necessary when the family felt threatened by the situation of their child's critical illness”(Mu & Tomlinson, 1997; Tomlinson, Swiggum, & Harbaugh, 1999). During a critical illness, health care workers, or other people were empowered to take part in family roles, tasks, and functions, therefore assisting the family in maintain its integrity, and sustained the family system as a whole (Mu & Tomlinson, 1997). In the same way, nurses also played an integral role in supporting parents' roles and reinforcing family boundaries. The nurses' collaboration was focused on “supporting parents' roles with their hospitalized child

¹⁴ "Boundary ambiguity is defined as the family not knowing who is in and who is out of the system"(P. Boss & Greenberg, 1984). The first theoretical and research papers on boundary ambiguity were presented by Boss, who illustrated the degree of boundary ambiguity as a major stress variable for the family. According to the author, boundary ambiguity could result from multiple or single stressor events coming from inside or outside the family system. Many authors considered it more useful for clinicians and researchers to better explore the family's degree of boundary ambiguity rather than focus on specific stressor events or coping strategies; indeed, they noticed that the ambiguity, more than the event itself, determined the family's level of stress (Buckley, 1967; Goffman, 1974; Hill, 1949).

and other children, and their partnership with each other; acknowledging and supporting families to fulfill roles and responsibilities outside of the hospital; and promoting social support from other sources” (Hagstrom, 2016).

Graham (2009) used a descriptive qualitative approach to explore the experiences and needs of parents of children with severe antecedent disabilities in the critical care setting. The author observed that CCC and their parents “are inextricably linked with critical care services”. In accordance later studies (Crespo et al., 2013), the author observed that, although communication was essential, the structure and processes of critical care ought to be tested and tailored to better meet parental needs and expectations (Graham et al., 2009).

The communication themes

In 2008, Meert et al. published a secondary analysis of a qualitative interview study focused on exploring “parents’ perceptions of their conversations with physicians regarding their child’s terminal illness and death in the PICU”. It was a multicentric study conducted in six PICUs where 56 parents were involved in participating through semi-structured telephone interviews. The following communication topics were identified by interviewed parents: “Physician availability and attentiveness”, was the most mentioned communication issue; indeed, parents stated that they “wanted physicians to be accessible”. Many parents would have like to have received a complete, candid, and straightforward illustration of the relevant information (“Honesty and comprehensiveness of information”), and appreciated physicians who “explained everything”, and that were “straight up forward” and “honest”. The attitude with which information was provided was important for parents; as a matter of fact, they thought that information ought to be expressed “with a caring emotional tone”. Parents described the latter as “compassionate, kind, consoling, and supportive”(Meert et al., 2008). Many times, parents felt that physicians withheld information (“Withholding of information”); in other words, they felt that they deserved to know, and conveyed that the withholding of their child’s prognosis kept them “in the blind”. Moreover, being provided with false hope led some parents to be angry and to forgo trust.

Parents stated that sometimes communications were given in “doctor talk”, even though they preferred “layman’s terms” or, at the very least, “English terms”

(“Complexity of vocabulary and peace”). Parents perceived “contradictory information, stress and frustration”, since they received conflicting information from different PICU physicians. Finally, parents noted the physicians’ nonverbal behaviors (“physicians’ body language”) when conveying bad news. Sometimes, the physicians’ body language even led some parents to suspect the physicians themselves as though they were guilty (Meert et al., 2008). Carnevale (F.A. Carnevale, 2008), examined this paper and asserted that “it is important to consider the multidimensional nature of communication”, not only with regard to the information’s transmission; moreover, he thought that communication could affect the “quality of the relationship between health care professionals and parents and the corresponding level of trust” (F.A. Carnevale, 2008).

On the same trail, Huang (2011) conducted a hermeneutical phenomenological analysis of qualitative interviews described that mothers felt confused and angry when receiving inconsistent medical information, and they also felt disempowered and disinvolved in the decision-making process. According to the author, mothers, on the one hand, perceived a reduction in the possibility of ensuring the best available treatment to their disabled children; on the other hand they perceived a threat to their roles (Huang et al., 2011).

In 2016, Bry et al. tested the efficacy of a course to improve the nurses’ ability to respond to the empathic needs of parents in a Neonatal Intensive Care Unit (NICU). The nurse-parent encounters were recorded before and after the communication course (before and after study). Four authors independently explored the number of empathic opportunities (EO), and the correspondent nurses’ responses. An EO was defined as an expression of emotions, stressors or concerns. The authors observed that, after the course, 42.9% of the participants’ increased empathic responses more than tripled. The empathic responses were assigned based on the following categories: Empathic response, when “the nurse recognized the parent’s feeling, understood the reason for the feeling and responded by acknowledging the feeling”; exploring response, pursuant to which “in situations where the feeling of the parent and/or its cause were unclear, the nurse asked follow-up questions to find out what the parent was feeling and what caused him or her to feel that way”; generalizing response, when the nurse generalized the parent’s feeling; ignoring response, when the nurse ignored the parent’s expression of emotion and changed the subject or ended the conversation;

and, finally, giving inadequate advice, when the nurse gave advice to the parent without addressing the parents' feeling or its cause (Bry et al., 2016). The author observed that nurses were using a rising number of expressions used to involve parents in the child's care, as well as increase the amount of positive feedback. Bry observed an increasing number of spontaneous expressions of interest and a higher level of caring for the parents. After the course, the conversations were less nurse-centered than before; moreover, nurses talked more about psychological and social issues. Nurses put in more time to talk about the infants' illness and care or hospital rules and schedules (Bry et al., 2016).

Other studies conducted on cancer patients have shown that nurses and physicians rarely respond to patients' emotions with empathy, thus showing results consistent with Bry's study (Alexander et al., 2011; Epstein et al., 2007; Levinson, Gorawara-Bhat, & Lamb, 2000 ; Pollak et al.).

Carnevale explored the communication's theme in the PICU context many times, even if not focusing specifically regarding to CCC patients (F. Carnevale, 1999; F.A. Carnevale, 2008 ; F.A. Carnevale, 2012; F.A. Carnevale, Farrell, Cremer, Leclerc, & Lacroix, 2016). In 2016, he performed a secondary analysis on three qualitative studies that had been previously conducted. All the studies examined data regarding communication between parents and health care professionals. All the data was examined by the author to identify communication-related themes. The study data was collected through semi-structured interviews and focus groups, and subsequently analyzed using the Grounded Theory methodology. The analysis identified the following three interrelated communication dimensions:

Ensuring access to information and providing clear and understandable information were the components identified among parents as topics of the "informational communication" (F.A. Carnevale et al., 2016) representing the first dimension. Carnevale highlighted the will of parents to understand what was happening to their child in a comprehensible language, thus avoiding medical talk. Parents also felt respected when clinicians "demonstrated consideration toward their concerns and wishes" (F.A. Carnevale et al., 2016).

Health care workers described as highly distressing the management of uncertain or ambiguous information that sometimes conflicted "with parents' wishes for clear information". When the professionals expressed uncertainty about the child's

condition or prognosis, parents found the same difficult to understand. The uncertainty led parents to wonder if clinicians were “withholding information”, “not fully committed to their child’s care”, or “not competent to manage their child’s condition”.

The expression of uncertainty by HCP compromised communication by challenging the relational dimension of the exchange between parents and professionals.

The second dimension was described as “Relational communication”. Parents and professionals formed either favorable or unfavorable relationships with each other. The respectfulness and trustworthiness of health care workers was crucial for parents’ communication accounts. According to the author, “parents’ perception of truthful disclosure by HCP fostered parental trust toward them”. Health care professionals repeatedly discussed communication and the parents’ involvement in treatment decision-making. Both groups of participants highlighted the importance of attending to children’s wishes. The perception of an inadequate respectfulness and/or trustworthiness generated less satisfaction with the quality of the information received by parents’, whereas their dissatisfaction with the received information led to a perceived relational dissatisfaction (F.A. Carnevale et al., 2016). Parents also stated that communications concerning budgetary constraints that might run the risk of limiting some treatments, compromised their sense of respect and trust. On the other hand, Carnevale highlighted the dual role of professionals who had to provide “optimal care to individual patients while they are also expected to responsibly manage limited publically funded resources to ensure timely access to critical care for the entire population that they serve”(F.A. Carnevale et al., 2016). The author underlined that “parents appreciated HCP’ attempts to (...) adapt tailored the timing, content, and methods they used to convey information.” Despite this, parents reported that sometimes they were unable to hear, understand, and retain information, because of their state of shock. Sometimes the group meetings with parents were problematic because some parents felt overwhelmed when they had to meet a large number of health care professionals at once (F.A. Carnevale et al., 2016).

Finally, the third dimension was “Communication and parental coping”. The author asserted that parents desired information about their child that would help them to prepare for the future, and they were sometimes devastated by the way the information was presentation, which made them feel that “all possible hope was being crushed”.

On the other hand, the professionals revealed that they were worried about the future life of the child and family with regard to the consequences of the critical illness, and the of their actions.

Parents describe the “disagreements within the treating team” as their major source of distress, and they reported that they had been exposed to disagreements “during formal encounters (...) or informal one-on-one discussions with HCP”. All those happenings made parents feel confused and led them to wonder “who they should trust, who knew best, or who was most committed to helping their child” (F.A. Carnevale et al., 2016). Conversely, professionals reported the necessity of increasing the team consensus and cohesion in decision-making and communication.

A review published in *The Lancet* (Fallowfield & Jenkins, 2004) summarized the studies about giving sad, bad, and difficult communication, and, also assessed whether interventions could be useful in those situations. The author also focused on difficulties of involving parents in the pediatric setting. Fallowfield summarized the following guidelines and recommendations to help clinicians prepare themselves before encounters regarding the communication of bad news:

setting up an interview, assessing the patient’s perception, obtaining the patient’s invitation, giving knowledge and information, addressing the patient’s emotions, providing a strategy and summary; ensuring privacy and adequate time, assessing the level of understanding, providing information in a simple way and encourage patients to express feelings, giving a broad time frame, arranging review, discussing treatment options, offering assistance to in telling others, providing information about support services, documenting information handed out; preparation, i.e., determining who should be present, tuning into parents, providing effective communication; advance preparation, that is to say building therapeutic relationship, communicating well, dealing with patients’ and families’ reactions, encouraging and validating emotions” (Fallowfield & Jenkins, 2004). The author concluded by suggesting the implementation of specific communication training sessions that ought to be based on educational principles, evidence based, and constantly monitored (Fallowfield & Jenkins, 2004). Many health care workers reported that in the absence of adequate communication training there was an increasing risk of using inappropriate ways to deliver bad news (Bry et al., 2016; F.A. Carnevale et al., 2016; Fallowfield & Jenkins, 2004; Huang et al., 2011).

The health care workers' point of view

CCC require competent care that should be provided by the child's care team. This involved many medical specialties such as primary care, hospital medicine, rehabilitation, developmental medicine, neurodevelopmental disabilities, palliative care, orthopedics, otolaryngology, pulmonology, gastroenterology, and neurology. Based on the child's problems, an appropriate specialist might be required. Nursing could be the key profession with regard to CCC care, and could be carried out when children are hospitalized, in the home environment, and in a variety of outpatient settings. According to Glader (2016), nurses might function as case managers and discharge planners for CCC (Glader et al., 2016). Moreover, parents recognized that, during the hospitalization, nurses are the closest professionals to them and the child. Despite the consideration in question, few experiences in which the nurse acts as a communicator have actually been implemented.

In 2017 Denis-Larocque conducted an interpretative descriptive study to explore the nurses' perception of caring for CCC parents in the PICU. The author, when analyzing the semi-structured interviews via an inductive content analysis, identified three major themes: "Thrown to the wolves", that is to say adjusting to a new caregiving role; "Getting to know each other", i.e., merging caregiving roles; finally, "Keeping connected" by working to preserve the partnership (Denis-Larocque, Williams, St-Sauveur, Ruddy, & Rennick, 2017). According to the author, nurses knew the importance of highlighting parents' expertise, and recognized the necessity of leading parents to a change in their caregiving role. Nurses viewed negotiation as a crucial process in the relationship with parents, and also considered essential the partnership with parents, managed through open and transparent communication. Larocque asserted that nurses felt unprepared when initially interacting with CCC parents, and that they suggested the importance of recognizing parental knowledge and expertise with regard to CCC care. Nurses thought that establishing mutually agreed upon caregiving roles was essential, and also that "demonstrating flexibility and respect in seeking to understand parents' preferred level of involvement in their child's caretaking routine can empower parents of CMC and foster open communication, crucial in establishing trusting relationships". Nurses underlined the necessity of an open dialogue "when the child transitions to a more acute state and when facing ethically-difficult situations" several times; on the contrary they stated that open and transparent

communication might enhance the partnership and improve the care provided to CCC parents. According to the author, educational sessions regarding CCC parents should be implemented to facilitate the nurses' competence development (Denis-Larocque et al., 2017).

As reported by Maytum (2004), nurses that worked with CCC frequently experienced compassion fatigue and burnout (Maytum, Heiman, & Garwick, 2004). According to the author, nurses reported work overload and lack of support as triggers for burnout, all the while reporting exposition to traumatized individuals as a trigger for compassion fatigue. Moreover, the participants identified "dealing with the emotional burdens of families" as particular triggers for compassion fatigue and burnout. The provision of educational and psychological support courses was endorsed by all the participants (Maytum et al., 2004).

Many authors observed that pediatric generalists and clinicians encountered CCC, and recognized that caring for them was challenging. It required expertise in terms of specific medical knowledge and management, as well as in the navigation and coordination of health systems. Pediatricians recognized that the care of CCC was increasingly interdisciplinary, since they acknowledge that it required many new competences, particularly with regard to "depth of knowledge regarding common clinical issues, skills in care coordination, delivering difficult news, working in teams comprised of professionals with a broad array of backgrounds, and setting goals of care with patients" (Jay G. Berry et al., 2011; Glader et al., 2016).

Despite all the considerations above, Glader (2016) observed that the available information to guide the training of health care workers in taking care of CCC and their families was scarce. The author highlighted that the approach to professional training was specialty-specific, and he also stated that the lack of a precise focus on the CCC world during professional training ought to be corrected with education, competency and program development (Glader et al., 2016). Cohen identified thirteen different physicians representing six subspecialties involved in every CCC care team (E. Cohen et al., 2012), for this reason, one of the major challenges regarding CCC is to ensure clear communication among members of the care group.

CHAPTER 2. THE RESEARCH

PARENTS OF CHILDREN WITH CHRONIC CONDITIONS AND HEALTH CARE WORKERS - A RESEARCH ON LIVED EXPERIENCES

To guarantee the replicability and the reliability of a research, researchers need to clarify and accurately describe the frame they operate in accordance with. That is to say, it is crucial for researchers to identify, firstly, the paradigm pursuant to which they are progressing; secondly, the chosen research philosophy; thirdly, the method they intend to follow; and, finally, their strategies and research techniques. In this chapter the author will present the research design by exploring all the elements that constitute the research. The structure of the text have been organized in accordance with the order proposed by Mortari (2007) that theorized the methodology that have been chosen. The referring texts that have been mostly taken into account to describe the methodology are the following: *Cultura della Ricerca e Pedagogia*, Mortari, L. (2007); *Gestures and thoughts of caring*, Mortari, L., & Saiani, L. (2014); *Decidere in Terapia Intensiva. Una ricerca fenomenologica - Volume 1 and Volume 2*, Mortari, L., & Silva, R. (2014); *La ricerca qualitativa in ambito sanitario*. Mortari, L., & Zannini, L. (2017). In accordance with how asserted by Shapiro (2017) the author chooses the definition of child with PCCI to describe the children with complex chronic conditions that are involved in the conducted research.

2.1 Methodological choices

Research question

Children with chronic conditions are the center of their parents' world. The children with PCCI family system ought to be flexible in sustaining a sudden crisis due to an acute deterioration, and also ought to be able to adapt the system as a whole as a consequence of decline in the child's health status. All those potential risks and prolonged situations are strenuous and stressful for parents. On the other hand, child with PCCI are subjected to frequent readmissions in PICUs due to an acute illness or a deterioration of their basal situation, which is why the family system is strictly connected to the appropriate PICU.

Many problems and questions regarding the topic of children with PCCI have emerged in the last few years due to the increasing CCC rate of admission and length of stay

(Ananth, Melvin, Feudtner, Wolfe, & Berry, 2015; Gold et al., 2016; P.W. Newacheck et al., 1986).

From a nursing point of view, a second emerging issue has been noticed: it is commonly said that children, who survived thanks to technology and improvements in the pertinent research fields, cannot remain in hospitals (Wells et al., 2017; White et al., 2017; Willits et al., 2013). Furthermore, the costs of management in public facilities are too high for society to support, and the rare centers that welcome them are full of patients who have life prospects up to even 30/40 years (Ralston, Harrison, Wasserman, & Goodman, 2015; Srivastava, Downie, Hall, & Reynolds, 2016). Given that PICU workers are frequently involved in stressful situations concerning chronic children or their parents, they are also part of those children's care. This study is aimed at exploring the lived experience of children with PCCI parents, as well as the lived experiences of health care professionals employed in the PICU. Through an accurate examination of the descriptive data resulting from interviews it could be possible to better comprehend and describe the perception of parents and professionals regarding to the phenomenon of chronicity in childhood. Furthermore, the author will seek to explore the complex theme of communication between health care workers and child with PCCI parents. Communication appears to be one of the most critical issues for parents in PICU, and for professionals too (F. Carnevale, 1999; F.A. Carnevale, 2008; F.A. Carnevale, 2012; F.A. Carnevale et al., 2016; Quigley et al., 2014; Wocial et al., 2017).

The question that this research aims to answer is: What are the lived experiences of children with PCCI parents, as well as what are the lived experiences of health care professionals employed in the PICU?

The answer to this kind of question requires a qualitative-inquiry methodology, since with this methodology it is possible to examine technical-experience environment. This is the reason why it is necessary to conduct a qualitative research.

Morse affirms that one of the aims of qualitative health research is to interpret people's health-related experiences (J. M. Morse, 2016). Moreover, "when seeking to understand the human condition (...) qualitative research is held to be in some ways superior to rigidly quantitative research"(Caelli, 2001).

Qualitative research rests on the epistemic principle that, in order to understand experience, we ought to study the sum of understandings characterizing a person's

attitude, given that human beings live in an “interpreted world” (Luigina Mortari & Saiani, 2014). Indeed, the phenomenological method turns out to be the most suitable for the exploration of lived experiences, because it provides instructions on how to perform a rigorous analysis of the phenomenon, thus acting as a solid foundation for further investigation (Mortari, 2007; Mortari & Saiani, 2014).

In the next paragraphs the author will describe the reasons for the described methodological choices:

- With regard to the epistemology of research, the naturalistic – emergent one;
- With regard to the philosophy of research, the phenomenological one;
- With regard to the method of research, the Phenomenological Empirical - Grounded Method one.

Epistemological framework

This inquiry is aimed at describing the lived experiences of children with PCCI parents and HCP. To explore this topic, it is necessary to uncover the meanings that experiences have for participants. Due to the fact that qualitative research is based on the epistemic principle that “a qualitative approach allows access to the world of meanings that the subjects themselves attribute to their experience” (Mortari & Silva, 2015 p. 14), the qualitative approach represents the most appropriate methodology in exploring lived experience.

The author will describe below all the considerations that support this methodological choice, particularly on the field of human sciences and nursing.

Narrated experiences are highly variable; due to this, qualitative research ought to analyze each case in-depth. Therefore, the chosen inquiry methodology shall depend on the lynchpin quality that will guide the research process. Qualitative research has recently been used in many fields, particularly in nursing and human sciences but, however, there are still many criticisms against this approach, principally because of the alleged absence of rigor.

Modern research has been guided for a long time by the positivist paradigm (PP), and there has been a heavy emphasis on quantification in sciences (Luigina Mortari, 2007). Nowadays, an ancient concept of mathematics as “science of sciences” (Arendt, 1958) is still considered valid by many researchers. This mechanical-atomistic vision of reality is based on positivism’s fundamental ontological premise: things really can be

discovered through a scientific method (Y. Lincoln & Guba, 1989). Indeed, physics, chemistry and other sciences that lend themselves especially well to quantification are generally known as “hard” (Y. Lincoln & Guba, 1989). To be accepted within the scientific community, some authors in the field of human sciences and nursing have also implemented the positivist paradigm to achieve more reliability. However, in recent years, strong objections to the quantitative method have emerged and, Mortari (2007) has shown the reasons why the positivist paradigm, on which the quantitative methodology is based, is inadequate to support research in the field of human sciences; the author also extensively discussed the reliability of the qualitative methodology. According to Mortari, many critiques of the qualitative methodology are based on the idea that the positivistic paradigm (PP) is the only one that is able of producing a valid research. Some of the critiques that support the use of qualitative methodology and that confirm its rigor as methodology are discussed below.

A relevant issue regards the inapplicability of general data to individual cases (called nomothetic/idiographic disjunction). This point has been highlighted because, an individual data element could fall within the margin of error of statistical analysis, whereby generalizations have no applicability in the individual case.

In response to the positivistic-originated request of providing generalizable data, it is crucial to consider the fundamental role, in terms of specific value, that a theory developed at the local level can play. Mortari has underlined the importance of theory specificity when exploring real-life contexts. Quantitative research is conceived as being able to define generalizable theories; on the contrary, the qualitative approach focuses on local-specificity and brings to light a locally situated theory that, fundamentally, could not be completely replicable in other contexts. Indeed, a locally situated theory, obtained through an inductive data analysis, is characterized by a strong adherence to reality, and provides reliable information about the explored field. According to Guba and Lincoln, the positivistic method of using highly selected data certainly increases the theoretical rigor of a study; conversely, it reduces the external validity and relevance of the results, given that the outcomes would only be applicable in a similar context. Moreover, Mortari in the book ‘Cultura della ricerca e pedagogia’ (Luigina Mortari, 2007) highlights the importance of qualitative research in producing an *emic view* that emphasize the participants’ point of view, instead of the researcher’s perspective:

The etic/emic¹⁵ dilemma: quantitative methods show the perspective of the researcher (etic views) but not the views of the participants (emic views). Qualitative data is useful for uncovering emic views. In order to be valid, theories should be qualitatively grounded, as stated by Glaser and Strauss (1967). (Luigina Mortari, 2007)

In conclusion, it could be argued that the essence of reliability for qualitative research is related more to its consistency than its replicability and is directly connected to another relevant matter of concern about qualitative research, which is the choice of design for the research.

A positivistic-quantitative approach is usually based on a previously established method: in order to learn about the object, the same is manipulated and governed within a predefined research project. Mortari assumes that any preordained research design is not suitable for the complex reality of the human experience (Mortari, 2011, p. 34), and therefore, she suggests developing a research method in accordance with the naturalistic paradigm (Lincoln & Guba 1985; Erlandson, 1993).

Whereas positivism and post-positivism are considered vulnerable regarding voice, training, accommodation, and hegemony, these areas are considered especially important by alternative paradigms.

About the paradigm's topic Gage (1989) writes about "paradigm wars". Guba and Lincoln think that only the emergence of a new paradigm that is more comprehensive and sophisticated than any existing one, could potentially be a solution to the differences among them.

In the next paragraph, the intent of the author is to describe the challenges of the ecologic paradigm and the reasons for the using on this study.

This was first theorized by Mortari (2007), based on Bateson's thought, and has been tested several times by conducting qualitative researches in the fields of human

¹⁵ Linguist Kenneth Pike coined the terms in question in 1954. Emic and etic are derived from the linguistic Greek terms phonemic and phonetic respectively. Researchers use etic to refer to objective or outsider accounts (from the perspective of the observer) and emic to refer to subjective or insider accounts (from the perspective of the participant).

sciences and nursing (Mortari, 2011; Mortari & Saiani, 2014; Mortari & Silva, 2014; Mortari & Silva, 2015).

From the researcher's journal: I have a preferential position as insider and a qualitative approach may be interpreted as less strict than a quantitative approach.

Interviewing participants allows them to narrate what they decide to narrate without creating preconceived answers. The pilot study previously conducted confirmed that parents needed to narrate their experiences and interviewing them have been revealed as a perfect strategy, I suppose that it could be the same thing for HCW.

The ecologic paradigm

The ecologic paradigm (EP), was the paradigm chosen for the conduction of the research on the lived experiences of child with PCCI's parents and HCW. This paradigm has been conceptualized by Mortari (2007), and are following described by analyzing its ontological, gnoseological, epistemological, ethical, and political assumptions.

Whereas the positivistic paradigm (PP) has been developed on the basis of a mechanistic, atomistic and disjunctive vision, the EP goes beyond the notion of a single reality that can be fragmented into subparts. Bateson showed his students the following simple example: "One claw is bigger than the other, but both claws are made of the same parts" (Bateson, 1979), thus showing that the most important characteristic of the claws was to embody similar relations among parts. Nowadays, a modern perspective on research is to consider as crucial Bateson's theory on the relationship among subparts. This "ontology of interdependence", as defined by Mortari (2007, p. 33), requires first and foremost that researchers explore the connections weaved into the phenomenon pattern. The most recent biological theories based on an evolutionary approach describe the idea of the unexpected as the fundamental characteristic of reality, moreover, an evolutionary perspective requires that the research method also be conceived as an evolutionary process. According to a positivist gnoseological view, the researcher discovers reality and comes to know the world as it is (von Glasersfeld, 1984). Conversely, the constructivist hypothesis states that reality always results from a construction process carried out by the human mind. Nevertheless, the constructivist position doesn't deny reality, but rather, it simply

posits the impossibility of obtaining an isomorphic knowledge of reality. The PP¹⁶ considers scientific language as the only one capable of grasping reality, because it is also the language of nature. Furthermore, the PP idealize the experimental research approach as the only one capable of unlocking knowledge. The principal idea behind the positivistic views is to observe phenomena separately from the context because of the necessity of controlling variables. On the other hand, the ecologic view allows for the possibility of multiple epistemological options in order to unlock knowledge. Positivism considers the results of scientific research as being objective and corresponding to reality. According to this vision, the researcher does not have agency over the outcomes. The EP¹⁷ is attentive towards the researcher's position, and considers knowledge as a version of the world, not an absolute reality. Finally, scientific research in the PP is tested on the basis of its capability to predict and control events. On the contrary, the EP challenges the predictive ability of research by highlighting the ability to explore relevant issues with regard to improving human life. The EP is characterized by all the assumptions explained above. Due to all those considerations it could be considered the optimal theoretical frame for research in the fields of human sciences and nursing.

The naturalistic approach considers the qualitative method as being suitable to explore the essence of human beings. Given this, in order to explore a “multi-meaning world” in which we are all involved (Mortari, 2007, p. 63), from a naturalistic perspective the researcher should not codify the epistemic structure beforehand, but rather work based on the emerging data in order to build the epistemic structure of the research gradually (Mortari, 2007, p. 62). According to Mortari, a method consistent with the naturalistic paradigm requires the researcher to adopt an “emergent design” (Mortari, 2007; Mortari 2011; Mortari & Saiani, 2014; Mortari & Zannini, 2017).

For all the reasons explained above, the author decided to conduct a qualitative research which assumes as its object of investigation the development processes of meanings of the lived experiences within the naturalistic epistemological framework,

¹⁶ Positivistic Paradigm

¹⁷ Ecologic Paradigm

that is in turn consistent with the EP¹⁸, and characterized by: a natural setting, a purposeful sampling, an evolutionary emergence design, and an inductive processing of theories.

The author has previously shown the importance of stating and clarifying the following components of the research: the frame within which to operate with, the paradigm, the design of the research, the methodology, and, finally, the employed strategies and research techniques, all of which are introduced and discussed below.

A phenomenological Philosophy of research

Many authors consider the phenomenological approach appropriate to explore the complex phenomenon of relations within the fields of human sciences and nursing. Moreover, “phenomenology has become a dominant philosophy that guides knowledge generation in nursing” (Norlyk & Harder, 2010, p. 420). Adopting phenomenology as a framework for conducting nursing research is challenging (ibid., p.420). As argued by Mortari, the philosophy of research that is the most capable of exploring the field of lived experiences is the phenomenological one, within the EP. However, phenomenology is aimed at grasping the essence of a phenomena, and, according to the Husserlian theory, knowledge is not gained through empirical intuition, but rather, it is the knowledge of essences, and phenomenology can consequently be defined as the “theory of the essences of pure phenomena” (Husserl, 1990 p. 139). Many arguments support the use of phenomenology with regard to the study of human experiences: firstly, lived experiences are the subjects of phenomenological research, and to explore the human experience, the same must constitute the object of investigation; secondly, phenomenology tends to structure itself as a rigorous science, the primary goal it has in common with all research on human experiences; thirdly, the fundamental characteristic of phenomenology is that it is a rigorous method, which is what any research on human experience requires (Mortari 2017, p. 57). Theoretically, it is possible to distinguish two different approaches to phenomenology: the eidetic (transcendental or descriptive) approach, on the one hand, and the hermeneutic (interpretative) approach, on the other. The

¹⁸ Ecologic Paradigm

transcendental approach is also called descriptive, because Husserl does not seek to explain the genesis of phenomena, but rather focuses on seeing “what stands before our eyes” (ibid., 1990 p.134). Indeed, the “eidetic description” is the founding principle of the transcendental approach, as it reflects the description of a meaning that is eidetic, that is to say fundamental and essential to the experience, no matter which specific individual has that experience (Cohen M.Z. & Omery A., 1994).

In the transcendental approach, the researcher can arrive at the essence of a phenomenon by maintaining an objective perspective and an open mind: “(*Epochè*)... bars me from using any judgment that concerns spatio-temporal existence” (Husserl, 1913, p.111). In other words, the researcher must not attempt to interpret phenomena, but should rather be open to phenomena as they reveal themselves. This openness on the researcher’s part ought to be maintained throughout the research process. In order to use a transcendental phenomenological approach, the researcher must discover the essence of something without preconceptions or prejudice (Ray 1994).

The hermeneutic approach, based on Heidegger’s and Gadamer’s (Gadamer, 1983) theorizations, takes the focus off of the description of phenomena, choosing to focus on the meaning that experience assumes for participants instead. According to Van Manen, in human science research it is possible to make a distinction between phenomenology, that is to say a pure description of lived experience, and hermeneutics, that is to say the interpretation of experience, either in written form or in a “symbolic form” (Van Manen, 1990 p. 25). A hermeneutic researcher is focused on uncovering the meaning that experience assumes for participants. Language is the instrument through which humans may acquire consciousness with regard to their own experiences, and thus make it investigable. Therefore, language becomes the focus of hermeneutic research (Luigina Mortari, 2007, p. 79). Descriptive eidetic phenomenology, as described by Husserl, requires that the researcher bracket every preconceived notion and focus on uncovering the essence of pure phenomena; a phenomenological reduction is therefore essential.

The phenomenological approach is strongly supported by scientific literature, but it is important to shed light on what the specificity of empirical phenomenological research consists of (Luigina Mortari, 2007, p. 81). Indeed, the empirical research cannot obtain the universal conceived within Husserl’s theory; but rather, it is aimed at grasping the

description and characteristics of a specific phenomenon as it is perceived by the participants. Many authors have explained the core concepts this process is based on. Mortari (2007) described the essence of the phenomenological method through two core concepts (Table 3) and eight epistemic cognitive actions that are following summarized (Table 4)

Table 3_ Core Concept of Phenomenological Method

<p>Faithfulness to the phenomenon</p>	<p>To arrive at “the things themselves” (Husserl, 1980, p. 29) is the essence of phenomenology.</p> <p>Husserl suggests that phenomena cannot be separated from how they are experienced, and the access to the phenomenon is through the participant’s own words, at the same time avoiding any preconceptions (Paley, 1997). “Any ‘subject of possible true predications’... has, prior to all predicative thinking, precisely its modes of becoming the object of an objectivating, an intuiting regard which perhaps reaches it in its ‘personal selfhood’, which ‘seizes upon’ it” (E. Husserl, 1980, p. 10).</p> <p>To be faithful to the phenomenon, researchers must apply the principle of transcendence and the principle of evidence (explicitness) (E. Husserl, 1964, p.39; Mortari, 2007, p. 86). Whereas the principle of evidence requires us to be faithful to the way things manifest themselves, the transcendental profile asks us to explore the hidden profile of things, albeit in the manner suggested by the evidence principle (Luigina Mortari, 2007, p. 87).</p>
<p>Anticipated experience and <i>Epochè</i> – The fundamental epistemic “move”</p>	<p>H. Arendt states that “scientists formulate their hypotheses to arrange their experiments and then use these experiments to verify their hypotheses” (Arendt, 1958, p. 278). Phenomenology highlights that both a mathematics research approach and an experiment-based approach cause a loss in terms of the possibility of accessing reality in its original givenness (Luigina Mortari, 2007, p. 88).</p>

	<p>The phenomenological <i>epochè</i> “shuts off... from any judgment, from taking any position predicatively” (E. Husserl, 1980, p. 61).</p> <p>Sanders states that <i>epochè</i> is a “temporary suspension of all existing personal biases, beliefs, preconceptions, or assumptions, in order to get straight to the pure and unencumbered vision of what a thing essentially is” (ibid. p. 355). However, it is “difficult to carry out in a radical way, since it is constantly threatened by misunderstandings” (E. Husserl, 1970, p. 180).</p> <p>It is clear that <i>epochè</i>, despite its importance, is difficult to apply and, more to the point, Husserl does not give detailed instructions on how to accomplish this “reduction”.</p> <p>According to Heidegger, " When an assertion is made, some fore-conception is always implied; but it remains for the most part inconspicuous because the language already hides in itself a developed way of conceiving" (Heidegger, 1962, p. 199).</p>
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Tab 3_ Translated from the original text “Cultura della ricerca e pedagogia” (Mortari, 2007)

Table 4_ Epistemic Cognitive Actions of Phenomenological Method

<p>Open disposition</p>	<p>An open disposition is the representative cognitive action of the phenomenological approach; it is, in other words, the ability to faithfully grasp the way in which phenomena manifest themselves (Luigina Mortari, 2007, p. 91). If we consider that “the amount of creative genius in any period is strictly in proportion to the amount of extreme attention” (Weil, 1956, p. 441), each act of attention translates into an increase of knowledge.</p> <p>To make this effort of passive attention “consists of suspending our thought, leaving it detached, empty, and ready to be</p>
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	penetrated by the object” (Weil, 1959, p. 111) in order to faithfully receive the other ¹⁹ (Luigina Mortari, 2007).
The non-deliberateness of the search	<p>Simone Weil states that to keeping one’s attention tied to something that is already known is the wrong way to proceed. She defines the phenomenological action as a “non-acting action” (Weil, 1956). Indeed, in order to find something, you don’t need to search for it, but it is necessary that you focus your attention on little things for a long time to grasp as much as possible. That is another reason why the phenomenological researcher must bracket expectations and prejudices. To better understand this epistemic attitude, we can refer to the text <i>Claros del Bosque</i> (Clearings in the Forest) by Maria Zambrano, where she develops the concept of passive epiphany. It is as though the researcher is inside the forest searching for any dim light but, to find it, he does not have to seek it out: “It is not necessary to seek. It is the immediate lesson of clearings in the forest: it is not necessary to seek them out or to seek anything from them either. Nothing determined, imagined or familiar” (M. Zambrano, 1991 p.111). The researcher comes out of the branches’ shadows and arrives at a bright clearing where things may reveal themselves (Luigina Mortari, 2007, p. 94).</p> <p>Both Zambrano and Weil approach research in a way that ensures that the researcher avoids being led by questions that could restrict their gaze.</p> <p>Heidegger also asserts that “releasement... that is waiting... And waiting means: to release oneself into the openness” (Heidegger, 1969, p. 72). A non-active wait renders the mind clear of preconceptions (Luigina Mortari, 2007, p. 96): “Waiting we leave</p>

¹⁹ The terms *the Other* identify the other human being, in their differences from the Self.

	<p>open what we are waiting for... waiting releases itself into openness” (Heidegger, 1969, p. 68).</p> <p>Given all of the above, the passive attitude of researchers is considered fundamental in the phenomenological approach. However, Heidegger underlined that it was not to be confused with the avoidance of the questioning approach (Luigina Mortari, 2007, p. 96).</p>
Freeing of the mind	To Clarify the mind allows to dodge the usual epistemic mind frames: conceptual networks, theoretical frameworks, procedural morphology.
The disorientation of the self	<p>The disorientation of the self is the epistemic imperative that asks the researcher to free their mind of everything that was previously thought (Luigina Mortari, 2007, p. 101).</p> <p>The researcher should “be rooted in the absence of a definite place” (Weil, 1956, p. 300), that is to say, to stay within the confines of the research, avoiding any reference to pre-codified models (Luigina Mortari, 2007, p. 101). This ability to be “rooted in the absence of” occurs when researchers experience the gap between the usual tools and the possibility of attaining a true knowledge of the other (Luigina Mortari, 2007).</p>
“Hospitable” epistemology	The positivist approach (positivist epistemology), aims to obtain a substantive knowledge of the object of investigation by defining all the research-method steps. On the other hand, the phenomenological epistemology is based on the logic of acceptance, or rather on an open attitude towards the other’s way of being. Phenomenological knowledge doesn’t “snatch” things the way the positivist one does, since it tracks the manner in which things reveal themselves instead (Luigina Mortari, 2007).
Speaking in phenomenological terms	Speaking in phenomenological terms means that “words and language are not just shells into which things are packed for spoken and written intercourse” (Heidegger, 2000, p. 15). Mortari states that “it is in words that the essence of things acquires substance” (Luigina Mortari, 2007, p. 106), or, as Heidegger

	<p>argues, “in the word, in language, things first come to be and are”(Heidegger, 2000, p. 15).</p> <p>The phenomenological epistemology asks the researcher to search for words capable of preserving “empty spaces” (Luigina Mortari, 2007, p. 106).</p> <p><i>Epochè</i> should also be employed not only with regard to thought, but also with regard to language. Only searching for “empty words” can language give voice to the other's experience (Luigina Mortari, 2007, p. 107).</p>
Sentient thinking	<p>From a phenomenological view point, emotions become an integral part of the exploratory act.</p> <p>According to Stein, empathy is a non-primordial experience that reveals the meaning of a primordial experience perceived by others (Luigina Mortari, 2007, p. 109): “In my non-primordial experience I feel, as it were, led by a primordial one not experienced by me but still there, manifesting itself in my non-primordial experience”.</p> <p>Thus empathy is a kind of “act of perceiving sui generis” (Stein, 1964, p. 11). Empathy is the ability to feel the experience of the other inside oneself (Mortari, 2007, p.109).</p>
Thinking within thought	<p>Firstly, the work of the phenomenological researcher is characterized by the acceptance of reflective responsibility, that is to say the monitoring of cognitive processes to bring out and make explicit the hidden preconceptions that guide our thought.</p> <p>Secondly, the fact that the phenomenological researcher ought to enact the self-reflection practice is also crucial in phenomenology.</p> <p>The “constant movement of self-elucidation” (Husserl, 1970, p. 338) should stay with the researcher throughout the inquiry process. Self-elucidation is thus a <i>conditio sine qua non</i> for the provision of fully transparent data (Luigina Mortari, 2007).</p>

Table 4_ Translated from the original text “Cultura della ricerca e pedagogia” (Mortari, 2007)

Empirical science specifically in the case of the described research, is often oriented towards a better comprehension and description of the phenomenon of chronicity,

which in turn allows for the drafting of the elements that characterize the experiences of the phenomenon from the participants' point of view. According to Mortari, in order to apply a phenomenological approach to empirical research, it is necessary to transform Husserl's "philosophical epistemological language into an empirical language" (Dahlberg, 2006, p. 18).

A method for the analysis: The empirical phenomenological grounded method (PhEG)

Mortari, with regard to the quality of empirical research in human sciences, states that "a science based on experience takes interest in contingent and secondary manifestations, that is to say those that manifest themselves in the here and now. Precisely because it is in secondary and contingent manifestations that an entity finds its identity, the same as a whole can be regarded as structuring what I define as empirical or contingent essence "(Mortari, 2010a, p.146).

The method that goes in search of these factual qualities can be defined as the Phenomenological Empirical Grounded Method (PhEG) was developed by Mortari (2007, 2011, 2014), and will be summarized below.

As explained by Mortari, an empirical phenomenological research consists of both a well-thought-out investigation, that defines what the researcher focuses on, and an investigation into concrete phenomena. Once the first part of the research is complete, the essence of the phenomenological ambit is developed (Mortari, 2011). The principles that characterize the Empirical Phenomenological Method are described below.

The faithfulness to the phenomenon, i.e. to arrive at "the things themselves" (Husserl, 1980, p. 29) is the essence of phenomenology and, even though the principle of evidence requires us to be faithful to the way things manifest themselves, the transcendental profile asks us to explore the hidden profile of things, albeit in the manner suggested by the evidence principle (Mortari, 2007, p. 87).

Anticipated experience or *Epochè*, in accordance with Husserl, is the fundamental epistemic move of phenomenology, and it requires applying the principle of faithfulness to the phenomenon.

An open disposition is the representative cognitive action of the phenomenological approach; it is, in other words, the ability to faithfully grasp the way in which phenomena manifest themselves (Luigina Mortari, 2007, p. 91).

The non-deliberateness of the search compels the researcher to come out of the *branches' shadows* and arrive at a bright clearing where things may reveal themselves (Mortari, 2007, p. 94)

Freeing the mind, allows the researcher to dodge the usual epistemic mind frames: conceptual networks, theoretical frameworks, procedural morphology.

The disorientation of the self is the epistemic imperative that asks the researchers to free their mind of everything that was previously thought (Mortari, 2007, p. 101).

Hospitable epistemology implies that phenomenological knowledge doesn't *snatch* things the way the positivist one does, since it tracks the manner in which things reveal themselves instead (Mortari, 2007).

Speaking in phenomenological terms (Heidegger, 2000, p. 15), Mortari states that "it is in words that the essence of things acquires substance" (Luigina Mortari, 2007, p. 106), or, as Heidegger argues, "in the word, in language, things first come to be and are" (Heidegger, 2000, p. 15).

Sentient thinking signifies that from a phenomenological view point, emotions become an integral part of the exploratory act. Empathy is thus a kind of "act of perceiving sui generis" (Stein, 1964, p. 11), as well as the ability to feel the experience of the other inside oneself (Mortari, 2007, p.109).

Self-elucidation is thus a *conditio sine qua non* for the provision of fully transparent data (Luigina Mortari, 2007).

Nevertheless, this phenomenological approach requires empirical application, and it is therefore necessary to transform Husserl's "philosophical epistemological language into an empirical language" (Dahlberg, 2006, p. 18). For this reason, the PhEG method is directly connected to the empirical phenomenological method, and not to phenomenology itself. The PhEG *operationalises* phenomenological concepts to develop methods that are able to support researchers in bracketing preconceptions, as well as in determining the data starting point towards examining a phenomenon. As explained above, according to a phenomenological view, it is essential to start with data to incorporate what really happens in a real-life where the phenomenon occurs (Moustakas, 1994). To solve the *impasse* related to the difficulties that arise upon

applying *epochè*, Van Kaam asserts that a qualitative empirical research should make “an attempt to return to the immediate meaning and structure of behavior” (1966, pp. 28–29). According to Van Kaam, an EP²⁰ researcher should identify how to analyze the data, starting from the characteristics of the specific research problem, in order to reveal the original *givenness* in the way a phenomenon takes form. Whereas phenomenology shows us the way to remain faithful to the qualities of the phenomenon by applying *epochè* and bracketing preconceptions, the GT shows us a systematic process made up of distinct steps of analysis. By blending together, the aforementioned points of view, we can determine the PhEG as a method that promotes the acquisition of a direct contact with the original givenness by bracketing preconceptions, and by building a systematic process of analysis through distinct steps that allow the framing of a coding system able to faithfully describe the observed phenomenon.

The PhEG method is aim at grasping the essence of the concrete, therefore, in the case of the present study, wants to grasp the essential qualities of the children’s chronicity phenomenon as it is experienced parents and HCP. Looking for the essence of the concrete is achieved by taking into consideration and analyzing a sufficient number of manifestations of the phenomenon, and then interrogating the experience of the subjects experiencing it in the first person in the widest possible way. Becoming aware of these factual qualities it is possible through an in-depth analysis of the collected material, which allows a gradual and inductive processing of the theory.

From the researcher’s journal: I agree and understand the phenomenological approach to the data. The phenomenological method seems to constitutes the best choice to uncover the meaning that participants bring to their experiences. Nevertheless, I want to the necessity to ‘give back’ something that could be used to change the quality of care that we give to patients. The Mortari’s choice to combine different methodology seems to be the more suitable to answer to the initial research question.

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Evolutionary emergent design

At the beginning of a research process, it is crucial to define the inquiry methodology. That ought to be coherent with the previous methodological choices. The PP²¹ considers an emergent-design conception as unscientific and lacking in a rigorous methodological approach. The naturalistic inquiry considers methodological flexibility of the method as an aspect of strong epistemic value, because it allows the researchers “to continuously adapt the design to the profile of the structures of the phenomena, as they are outlined in the course of the action” (Mortari & Saiani, 2013). As explained above any preordinate research design is not suitable for the complex reality of the human experience (Mortari, 2011, p. 34), for this reason it is necessary to use a research method in accordance with the naturalistic paradigm (Lincoln & Guba 1985; Erlandson, 1993).

The naturalistic epistemology is characterized by a non-predefined design that structures itself in an evolutionary manner throughout the research; moreover, the researchers are induced to articulate the design in question in the course of the research process pursuant to the data’s unpredictability (Mortari, 2007).

Taking into account this vision of unpredictability, Lincoln and Guba stated that naturalistic epistemology was “more indeterminate than pre-determinate” (Lincoln & Guba, 1985, p. 195), and asserted that the same as allowed “the research design to emerge (flow, cascade, unfold) rather than to construct it pre-ordinately (a priori) because it is inconceivable that enough could be known ahead of time about the many multiple realities to devise the design adequately” (ibid., p. 195). Due to the data unpredictability, a continuous data analysis throughout the research becomes necessary; for this reason, Mortari suggests planning a routine data analysis to discuss the data and to draft the subsequent research steps (Mortari, 2007, p. 70). To explore the human experience, the *epistemic attitude* of researchers must be aware of the impossibility of anticipating what reality will make manifest, and the former also ought to develop the ability to change and revise the design on the basis of the encounter with reality. Moreover, researchers should continually practice self-reflection to be open to reality without preconceptions (see chapter 2, p 55). This approach should not

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be confused with the absence of a method, on the contrary it implies rethinking the research plan on the basis of an uninterrupted critical analysis of the ongoing process. An emergent design has the first epistemic imperative of keeping a constant eye on the phenomenon at hand; it cannot be conceived beforehand, and requires the researcher to exert constant and rigorous reflexive activity with regard to the methodology, in order to adapt the original research design to an increasingly complex reality. To support this process, and to align it with the evolutionary perspective, Mortari underlines the necessity of a continuous data analysis throughout the whole research period (Mortari, 2007, p. 70).

Natural setting

The positivistic approach is aimed at observing a phenomenon outside its context, analyzing what occurs in controlled situations, that is to say when all the independent variables are manipulated except for the object of inquiry, i.e. the dependent variable. On the contrary, a naturalistic research ought to be developed in settings where the explored phenomenon usually occurs and evolves (Lincoln & Guba, 1985). This epistemological choice is meant to uncover the complexity of reality, and therefore the role of all the possible unpredictable factors. Consistently with the naturalistic approach, this research has been conducted in the natural setting of the Pediatric Intensive Care Unit of the University Hospital of Verona. All the interviews were carried out in a setting chosen by participants. The author worked in the unit where data were collected, and this insider status allowed her to directly access the research setting and to recruit potential participants. All the relevant information was presented to all participants, firstly during the introduction of the study, and secondly at the informed consent process. The institutional ethic committee approved the study before the start of the recruiting process (VICOM_2016, app. 976CESC).

Purposeful sampling

To conduct a quantitative analysis, it is frequently necessary to carefully select the participants based on their characteristics. Conversely, a naturalistic research is focused on the meaning that experience assumes for participants, explores personal experience, and requires a description or interpretation of the meanings of the phenomena experienced by participants. There ought to be a preference towards participants who are

especially experienced with the phenomenon of interest; in other words, the criteria for the identification of the participants who are representative of the population is the fact that they have or have had direct experience with the phenomenon (Merriam, 2002). Since this method is one of the many qualitative research approaches, the number of participants is limited (can range from 5 to 20 subjects). If the object of the survey is the experience of parents and the health care staff in a Pediatric Intensive Care Unit, it is essential to identify the subjects who have had highly representative experiences, both in terms of time and complexity. In this research all the CCC parents will be involved, and the characteristics of children should be identified according to one the following definition of a child with a chronic pathology:

Children with complex chronic conditions (CCC), Children with medical complexity (CMC) or Chronic ill child.

"CCC represent (..) pediatric respiratory, renal, gastrointestinal, metabolic, hematologic, congenital or genetic defect, malignancy, cardiovascular and neuromuscular diagnoses that are expected to last longer than 12 months and involve either several organ systems or 1 organ systems severely enough to require pediatric care and hospitalization "(Berry JG et al., 2011).

"Children with CCC require significant care on a daily basis, often use medical, and are at risk for complications" (Rehm RS, 2013).

the health care personnel employed in the Pediatric Intensive Care Unit of the Pediatric department at Major Civil Hospital of Verona will also be involved.

Research tools

Narrations. In a qualitative research a phenomenon can be investigated either through observation (direct or indirect) or by asking the involved subjects to give voice to their experience, and the latter is preferable within the phenomenological approach because it allows the researcher to be involved into the participant's world of meanings. On the contrary, observation presents a greater risk of keeping the research trapped within the researcher's gaze. The core concept of narration is not that of understanding the opinions of the interviewees, but rather their own direct experience.

The most adequate technique to collect data in the qualitative phenomenological approach is the in-depth interview, because it needs a prolonged amount of listening

on the researcher's part, and also requires participants to provide analytical descriptions of the meanings attributed to their lived experiences.

Interviews. Based on phenomenological principles, open questioning was used to encourage participants to reflect on their experiences. The interview questions and techniques were designed to capture the scope of the phenomena under consideration. The phenomenological approach is oriented towards understanding the human experiences lived by *another*, by describing the latter relationship with reality and their interpretation of the world (Mortari, 2007). In other words, the in-depth interview is a useful tool to help discover the participants' points of view via firsthand narrations of experienced episodes. According to Sità (2012, p.52), qualitative interviews are not governed by standardized procedures, but they should be prepared by following some specific steps: thematic focalization, subjects' involvement, collection of valid descriptions, and identification of the meanings and essences of the phenomenon (ibid., p.52). Avoiding restrictions does not mean avoiding to accurately prepare a plan for conducting interviews (Kvale, 1983, 1997; Hummelvoll & Barbosa da Silva, 1998). The steps defined by Sità, could be utilized to develop a guide through which it becomes possible to investigate a phenomenon and the participant's lived experiences without predefined views.

In this specific research, the interviews were meant to comprehend the lived experiences about child with PCCI parents and healthcare professionals who are closely involved in child with PCCI care. The purpose of using the interview was not that of arriving at a description of events, but rather to understand how an event has been experienced and perceived by the participant. The listening time was conceived to underline the central role of the experience that individuals acquired, and that's why it became crucial to involve participants who were especially experienced with the phenomenon of interest. This methodological choice is typically phenomenological and directed at promoting self-reflection on practical experiences. The attitude of self-reflection has been presented before (tab. 4) as a fundamental action in the phenomenological approach, since it has the potential role of helping experts to re-think on their own experiences to and develop knowledge themselves as a result. This promotion of self-reflective action has to be employed in supporting both health care workers and parents, who are the main holder of knowledge in the field of child chronicity. This research is woolly framed within a phenomenological framework, and

all the methodological choices have been made consistently with the related EP²², in order to arrive at a deeper level of knowledge with regard to the phenomenon of chronicity in childhood, through an emergent design, taking into account how this phenomenon is perceived by the principal stakeholders, i.e. parents and HCP. Moreover, the communication approach has been analyzed as an emerging theme emerged in the relevant literature. According to the described theoretical framework the interview structure was conceptualized as a way of understanding the phenomena as perceived by participants, by planning a sequence through which to explore the core concepts.

All the parents' interviews began with an open question: "Can you describe your experience in hospital with your child?". Subsequently, the following questioning techniques were use (and misuse): reformulation, paraphrase, follow-up questions, encouragement speech, specifying questions, and interpreting questions. Other questions were: what does it mean for you to have to deal with a new hospital stay?, could you, please describe a moment that was particularly difficult for you?, Could you also describe a positive moment?, Could you please describe how communication regarding the health of your child are dispatch?, When doctors or nurses talk to you about your child situation, do you feel comfortable, or would you rather something were different? Conversely, the interviews with HCP consisted of the following questions: Could you please describe your personal experience with regard to a presence of a child with PCCI can? Could you please recount an episode that was especially difficult for you? Could you please describe a positive moment? Could you please describe how communication between HCP and parents take place? When you have to give out information to parents, do you feel comfortable, or would you rather something different if you could? They were also asked to give examples of episodes and how they handled these situations. Facilitative techniques were used to obtain descriptions that were as complete as possible. The interviewer had to improve their skills with regard to the following: structuring, the interviews purpose; being clear, gentle, and balanced, and not talking too much; being sensitive, listening and being empathetic with the interviewee, remembering what has previously been said;

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interpreting, that is to say, clarifying and extending the meanings of interviewee statements without imposing a particular meaning on them; and, finally, being ethically sensitive, that means being sensitive to the ethical dimension by ensuring the interviewee that their answers will be treated confidentially. To analyze the communication events between HCP and parents, the encounters were recorded and transcribed.

2.2 Research conduction

In this chapter the author will present all the steps taken throughout the research on lived experiences of child's with PCCI parents and HCW.

Setting: The Pediatric Intensive Care Unit

The intensive care and intensive neonatal care units, pediatrics for critical conditions, and the birthing unit and pediatric emergency room constitute the first complex department (in the pediatric emergency ward of the Major Civil Hospital of Verona. From an infrastructural viewpoint, the ward is on floor 0 of the "Woman and child" (Donna Bambino) hospital, built in 2017.

The OU of the pediatric intensive care unit is part of the complex pediatric department for Critical Conditions the departmental director and nursing coordinator, the latter also being the spokesperson for nurses in the pediatric ward, report to. The Pediatric Intensive Care Unit medical supervisor, the doctors and the administrative personnel report back to the OU director, whereas the coordinator is the main liaison for nurses. nine medical directors, nine supporting professionals, and twenty-eight nurses, two of whom with a 50% and 70% part-time contract, respectively, operate in the OU of the Pediatric Intensive Care Unit. The Pediatric Intensive Care Unit's mission statement is to ensure appropriate care for severely ill child with PCCI and children and infants transferred from other wards because their conditions have worsened, to train parents whose child requires a recovery period at home, to transport pediatric patients in critical condition to diagnostic, therapeutic, or other settings to receive care, and finally, to provide transport for infants during emergencies.

The Relocation

It ought to be noted that the research began in 2016, before the relocation that occurred in March 2017. Initially, 18 beds were provided, and subsequently divided according to the required care efforts as follows: children and infants with severely compromised vital functions needing invasive ventilation support; premature infants placed in an incubator, infants requiring non-invasive ventilation support, and infants under observation while awaiting surgery; finally, infants older than a month and children with chronic conditions waiting to be discharged after an operation or a tracheotomy, and, finally, patients with contagious diseases. After the relocation, the logistics changed significantly, and the beds have increased to 24, of which 8 are reserved for intensive care with regard to patients with compromised vital functions, and the remaining 16 for semi-intensive care patients, although 6 beds are awaiting regional authorization because of personnel shortage.

However, in order to paint a comprehensive picture, it is necessary to also take into account that the relocation produced a change in terms of patient characteristics. Patient complexity in the Pediatric Intensive Care Unit is due to many factors: the first variable has to do with age, given that patients admitted to the PIC range between ages 0 and 17. That in turn has even more complex implications, not only with regard to the management of the clinical setting and instruments, but also the required synchronization of care models for patients with distinct needs, be it in terms of timing, methods, priorities, or emergencies. The health care staff thus needs to be competent with regard to different kinds of patients: very low birth premature, infant, child, teenager. A second variable is represented by the fact that the pathologies often require a high level of specialization and occur simultaneously. Given that this is the case, the staff must also be ready to face and deal with critical occurrences that can happen as a consequence of issues not necessarily defined within the clinical framework of a specific illness. In 2017, premature newborns and formerly premature newborns were transferred to the Neonatal Intensive Care, a ward that used to be located in a completely different area of Verona. At the same time, more severely ill and chronic patients with elevated levels of complexity were admitted, as well as newborns in critical condition from other wards of the Woman and Child hospital, other provincial hospitals, and even out-of-province hospitals.

A structural and “geopolitical” relocation also took place. The entire Pediatric Intensive Care Unit was moved into a new building, and thus became the epicenter of numerous relational and organizational dynamics. The Pediatric Intensive Care Unit was previously located on the same floor as pediatrics for critical conditions and the pediatric emergency room, and it shared a nursing manager and director with the same. That particular organizational and structural model had favored a high level of interdependence among the various actors. Patients were treated according to common protocols within a larger “task force”, clinical practices were uniform, and patients were subject to consistent dynamics in the various settings. The new Pediatric Intensive Care Unit is located next to Neonatal Intensive Care, thus shifting the focus from intensive care to specialized wards, in other words a “complex care” system that encourages interactions among wards dealing with extreme levels of complexity. On the one hand, this approach increases efficiency; on the other hand, it runs the risk of causing disservices between intensive care and ward from a managerial point of view. As for patient management, this complexity-centric system can guarantee a more efficient management of costs and inpatient flow, but it is also fragile, in that it reduces the potential “preferential channels” that occur naturally within organizations. In the instance of the Pediatric Intensive Care Unit and pediatrics for critical conditions, a core advantage was the transversal care reserved for chronic patients. With particular regard to the topic of this study, management seems to be more fragmented and less coordinated, given that distinct wards that do not communicate among themselves care for patients. Parents and children with PCCI need to go through a hospitalization process that can amount to different rules and practices based on the setting they are transferred to, despite the fact that the wards are structurally and organizationally connected. This has also resulted in a significant deal of complications with regard to managing the relationships of staff personnel in close proximity.

The internal structure of the ward before and after the relocation represented a further source of disorientation for the staff, who had to reorganize the care process for children and the terms of parents’ presence.

At the previous site the spaces were cramped, and it was therefore difficult for parents to be there, despite being taken good care of. At the moment, there is a lot more room for parents, and the available space has been organized to guarantee their comfort, for example: a dedicated kitchen, a relax area, a bathroom in the hospital room with

showers in the semi-intensive area, the chance to use a bed or a pull-out sofa, the possibility of having a meal brought inside the room, in-house professional psychological assistance, assistance, both internal and external (an example is represented by volunteers, such as the association for child within the hospital, with managing the timing of the hospitalization process). Nevertheless, there isn't as much attentiveness towards taking on and accompanying children.

Methodology of the research

At an early stage, the author illustrated the project to the OU and Pediatric Intensive Care Unit medical and nursing supervisors, respectively. Once the project received their endorsement, the documents to be submitted for approval before the Ethics Committee for clinical trials at the AOUI of Verona were prepared. The approval process was long and laborious, given that it required putting the following documents forward:

- A summary in Italian of the study that included the relevant information related to the research process
- The study protocol with all its annexes
- A declaration as to the non-profit nature of the study
- The study flow chart
- The CRF
- A patient information forms
- An informed consent forms
- A form relating to the processing of personal data
- A form containing information to be disclosed to the GP
- The insurance forms
- The principal investigator's CV
- A declaration concerning the existence of a conflict of interest

The documents listed above were retrieved between November 2015 and June 2016. On 20 July 2016 the documentation pertaining to the study was submitted to the Ethics Committee for Clinical Trials of the Provinces of Verona and Rovigo, and examined on the same day. On 25 July 2016 the study received the official approval of the

Committee (Appendix B) and the relevant information was passed on to health care professionals and parents in the Pediatric Intensive Care Unit.

Meeting the Staff

Having explained the project to the coordinator and director of the Pediatric Intensive Care Unit for critical conditions, respectively, the researcher proceeded to meet with each member of the medical team in order to describe the project and attend to their questions. Subsequently, certain medical professionals were identified as being experts in treating child with PCCI, and thus asked to take part in the project. Initially, the researcher had to proceed with caution with regard to both the choice of participants to be involved in the study and the ways to conduct the study. As a matter of fact, whereas some doctors and nurses received the idea of taking part in a research touching on experiences with chronic illness enthusiastically, they were less enthused by the notion of having to disclose their experiences with communication. In the latter phase, a cautious attitude towards participant selection was especially crucial in order to attempt a consistent divulgence of information; conversely, the researcher's task was to promote the project as an opportunity to take advantage of university-level competencies and resources for the benefit of ill children, their parents, and the medical team entrusted with the child's treatment on a daily basis.

From the researcher's journal: I am meeting with nurses and doctors individually to illustrate the project, share its basic ideas, and determine whether they wish to participate. A nurse told me: "I would like to participate, but I do not want to be recorded". A doctor declined the request to be involved in the project for fear of being recorded. I am not sure about the strategy I ought to implement to face this situation, i.e., the entire staff being afraid of recordings. Nevertheless, I believe in using recordings as a research instrument, because it allows for an analysis of that very moment when information is exchanged, one of the most critical issues according to the pilot study and consistently with a literature review, but I confess that I am not sure as to whether it is a viable method.

Choices about how to proceed had to be reassessed with the supervisor, the coordinator, and the director. The previous research had involved parents, and the

Pediatric Intensive Care Unit health care staff had found it interesting for its focus on staff members' professional choices. At that re-defining point in the research process, the outcomes of the research in question were re-submitted and discussed anew, not in an official manner, but rather in an attempt to create a focus for health care professionals as parent engagement began. Both elements were useful in creating an "inside movement" within the group, and in the course of the following weeks, several health care professionals took the initiative of requesting to be included in the study. An *ad hoc* space within the intensive-care unit was assigned for interviews, but participating parents had the choice of remaining close their child during the interview, and also to be interviewed in a more private setting, that is to say a recovery room, meeting room, or "relax area". Health care professionals had the same set of choices. Identifying an environment that would make interviewees feel comfortable was deemed necessary to inspire reflection. Collecting significant data within interviews was not an even process: health care professionals were initially wary, and later had to deal with a logistical move; parents were interviewed on the basis of their children's hospitalization, which could be recurrent or not.

Potential Bias

The author during the research played the double role of researcher and insider. The condition of insider could have compromised the validity and the reliability of the research. To guarantee the methodological rigor of the research, the author followed the methodological phases described above (table 3, table 4) and accurately reported to the critical situation on the researcher's journal. Despite this potential bias, the privileged position of insider helped the researcher to better understand the lived experience of parents and HCW; moreover, as participants asserted, the physical and emotional closeness to the researcher allowed them to narrate critical situation and emotionally strong events that are probably not narrated to an outsider.

2.3 Results

The interviews lasted as long as the interviewees needed. A total of 29 hours of recording were performed, interviews lasted between 45 and 70 minutes, communication encounters lasted between 10 and 35 minutes. A total of 145200 words of single-spaced transcripts were generated. 648 excerpts have been individuated.

For each one participant were collected the demographic data that are described in participants paragraph. Data collection continued for 20 months until we had achieved theoretical saturation and had fully developed the categories. The qualitative interview was semi-structured, and conducted by an interview guide that focused on specific themes. The participants (parents and HCP) were asked to describe their experiences of the child with PCCI. They were also asked to give examples of episodes that, have been perceived as positive and negative by them, and also to describe the communication in the Pediatric Intensive Care Unit context. The author conducted all of the audio-taped interviews, transcribed the texts and set aside personal bias and assumptions in order to obtain pure descriptions of the phenomena presented by the informants (Moustakas, 1994; Mortari, 2007).

All audiotapes were kept confidential (no identifying names were used in the written transcripts). The material on audiotape was reviewed again and then checked against the transcription to ensure the accuracy of the data.

All the transcriptions were analyzed according to the methodology described above.

2.4 Data Analysis Methodology

Initially a first coding system was elaborated using Microsoft word as program for writing the texts analysis and paper posters for collecting the structure of the research. As showed in Figure 3 the author tried to use a paper poster to record the participants' coding with regard to: presence of one or both parents and number and type of data collected. Figure 4 and 5, represents a first attempt to organize the labels on categories, this labeling work resulted difficult to carry forward and have been replaced by a computerized system.

From the researcher's journal: I collected an enormous the amount of data. To manage them using basic writing programs like Word, became impossible. I tried to report the excerpts in other files to order and categorized but there is an increased risk to lose data. To perform the analysis I decided to rewrite the labels and related excerpts on a flip chart, also because of my photographic memory. It was a bust. After many attempts I chose to consider the use a program to organize the data.

Figure 3_Initial Organization of all the Materials



Figure 4_Example of the Initial Analysis of Text on Posters

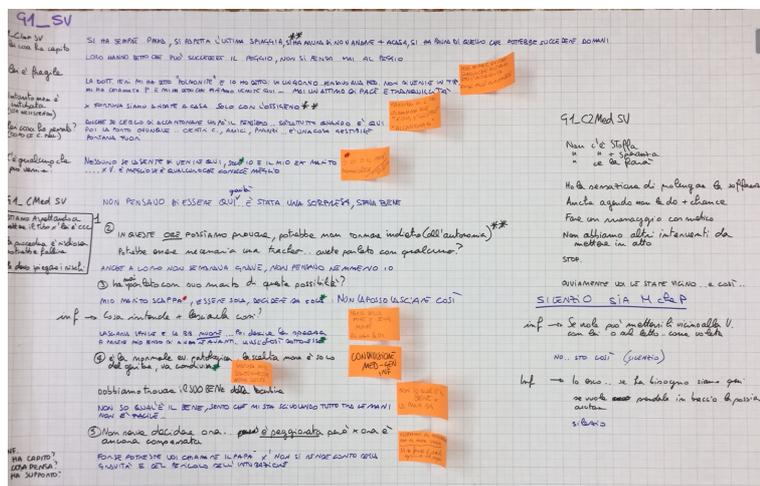
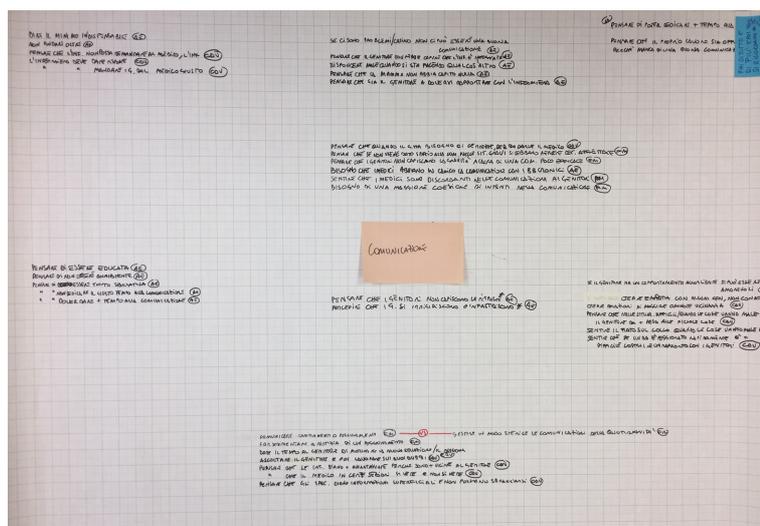


Figure 5_Example of Initial Coding



Due to the enormous quantity of the collected material, it became necessary to use a program to organize all the data. MAXQDA was chosen according to the methodological tutor because it allows to collect and organize, permitting a hand work on all the text. According to the declared PhEG no one quantitative or qualitative computerized analysis were conducted on the data.

The author developed initial codes through line-by-line coding and the re-reading of transcripts, as well as by paying close attention to the behaviors reported by participants. In accordance with the theoretical framework and methodology explained above (Mortari, 2007), the author started with the examination of each meaningful part of the text individually, and then gave each a descriptive label to identify its specific feature. Furthermore, the author, provided a draft list of the types of labels that had been identified. Finally, the author regrouped the descriptive labels into categories in order to favor a gradual construction of the theory. Similar labels were grouped into as many categories.

Once the first level of categorization was completed, the resulting categories were examined in order to attempt to group them into homogeneous sets, each of which was included into a superior category. All the processes in question have been detailed on the table 5. All the texts were analyzed independently by a clinical expert who was specifically prepared on the methodological strategy employed in the research, aside from the researcher herself. Once the process ended all categories and labels that had emerged were discussed in order to achieve an adequate level of concordance. Where it was impossible for a concordance between the researchers to be reach, the relevant labels and categories were both keep. In some cases, the excerpts were also discussed during research group meetings that involved a panel of expert methodologists.

The process of analysis made on the data will be detailed below in order to show the steps that led to the results. This process derived from the Phenomenological Empirical-Grounded (PhEG) Method Phases (Mortari, 2007)

- **To prepare the data (preliminary action), actions on material [am 1]**

This heuristic action consisted of transcribing and organizing the text into a table consisting of three columns with the text in the first, and the noting of the results of the analysis process on the other two (fig. 6).

Figure 6_Example of the Action on Material [am 1]

G20	Labels	Categories	Notes
R. How would you describe your hospital experience? I. Bad as I was in hospital .. For what happened obviously in the sense that I would rather be somewhere else .. how environment instead depends on the hospital, in the sense that there are hospitals in which I found myself very well, where I gave birth to her very badly.			
R. What do you think makes the difference? I. The level of competence, in the sense that there are places where you see that people are really prepared, it takes commitment because they are prepared and others in which they are organized so in short			
R. Can you give me an example? I. Where she was born there have been very good nurses instead I went to the hospital where they have never seen a PEG and it is not that there are many, but with adults even if you do the internship somewhere I think .. and they were wrong .. they put the medicine in the balloon and the balloon burst with all the medicines twice in a row in two days away So I think it's a serious thing.			

- To familiarize with the material (holistic reading), actions on material [am 2]

The second heuristic action have been acted by the author reading the text several times to get familiarized with the text. Reading were not theory-oriented²³, but rather open, guided only by the principle of familiarization with the texts, and achieving an “overall vision of the material” (Giorgi, 1997). The product was invisible and derived from a tentative summary and acquaintance with the text.

- To identify and label the specific quality of each meaningful part of the text, action on material [am3]

Through the third heuristic action, the author examined individually each meaningful part of the text and gave it a descriptive label to identify its specific quality (Fig. 6, Fig. 7).

Figure 7_ Example of Action on Material

G20	Labels	Categories	Notes
R. How would you describe your hospital experience? I. Bad as I was in hospital .. For what happened obviously in the sense that I would rather be somewhere else .. how environment instead depends on the hospital, in the sense that there are hospitals in which I found myself very well, where I gave birth to her very badly.			
R. What do you think makes the difference? I. The level of competence, in the sense that there are places where you see that people are really prepared, it takes commitment because they are prepared and others in which they are organized so in short			
R. Can you give me an example? I. Where she was born there have been very good nurses instead I went to the hospital where they have never seen a PEG and it is not that there are many, but with adults even if you do the internship somewhere I think .. and they were wrong .. they put the medicine in the balloon and the balloon burst with all the medicines twice in a row in two days away So I think it's a serious thing.			

Label	Excerpt	Notes
communication \	do not know I was did not we did not even know what, what did the baby then you had an emotional part even know what, what did the baby then you had an emotional part did the baby then you had an emotional part	do not know what your child has
communication \	if you see a shift people who are quiet, who work well together, not that others differences in were not good, but if I saw L, R, A .. enough, I was happy, that is and I tell you communication \ if you that the L was, the first time he was there, he had half bickered with my partner are a shift people who but for stupid things, which he called every second because the monitor are quiet, who work well sounded and that monitor always sounded, but here she was and she is not too sweet in telling you things, in the sense I is quite direct in things, but it is pleasant, incredible, in the sense it already had to be in there, to hear someone talking to you that smiles that makes a joke, helps you pass the day, after all a neonatal is not that will give you so much satisfaction. So to the nurse who laughs and makes you joke, your day passes by. So, surely it is positive when you come in and see "How nice I have her in turn and the day starts you well". And then positive when you meet the doctor and he does not tell you anything in reality, or, yes, hi, good morning, then he passes and says nothing so it means that it's okay	relationship is that which is built with nurses. The doctor gives on giving the information, but the nurses are always there. The doctor who passes by and says nothing is already a gain.
communication \	when the doctor arrives to update you, you have anxiety, if he tells you that he communicative has done well, he did the analysis all right but does not tell you anything precise experiences \ when the ... it was not positive for me because I did not know anything I did not know doctor arrives to update what the problem was real, and so he talks but I did not understand and felt you, you have anxiety, if I only anxiety tell you	When I talk to the doctor I'm anxious

²³ When a researcher is developing their research method, they must make use of to bibliographical references, but, while analyzing data, they must implement *epochè* (Mortari, 2017).

- **To practice self-reflective inquiry, reflective action 1 [ra 1]**

In this phase represented by the first reflective action, the researchers acted the self-reflective inquiry that included keeping a journal of the state of mind (Appendix D) and experience that accompanies the action of labelling. The journal of the state of mind is a description of cognitive experiences that accompany the labelling.

Ex. "Until we managed to find a balance for him, for the breath, we also lived, not bad but we were not calm". The label could concern the search for tranquility or be brought back to the continuous absence of equilibrium, it may concern N. or the parents

- **To repeat actions [am.3] and [ra.1] for each text and enact the principle of *epoché***

All the collected data were made up of a plurality of texts and the analytical work to identify the labels and the self-reflective inquiry were performed on each text, trying each time to approach the material with a fresh mind and without preconceived ideas resulting from all the data. At this point there were many lists of labels.

- **To order the first level of data, action on material [am 5]**

Once labelling was completed on all the texts, a first provisional list of the types of labels that have been identified was drawn up. At this point the researcher has produced a list that includes all of the resulting labels. Ex. Learning to communicate, Trust, Parents are more competent than medical professionals

- **To enact the principle of suitability (comparison phase), action on material [am 6]**

Once the first level of codification was completed, researchers compared the obtained data (labels) with the meaningful textual units to verify the descriptive suitability of the labels.

This phase was carried out in order to remain as faithful as possible to the meaning expressed by the respondent in the given textual unit with the greatest accuracy. Once this analysis was complete, a set of labels, phenomenologically capable of faithfully representing the content of the meaningful units of text,

was produced. Finally, the researcher had a list of labels capable of expressing the quality of discursive acts as faithfully as possible.

- **To implement the principle of faithfulness, action on material [am 7]**
Once the codification system was more faithful to the data, the analysis of the texts was resumed to test the tool that has been developed. At this point, the author compared the data enables researchers to verify: (a) whether there are parts of the text that, although meaningful, have not yet been suitably labeled; (b) whether labels are clearly distinct from each other, with no overlapping. This phase guarantees the further accuracy of the labelling system.

- **To regroup labels into categories, action on material [am 8]**
To reach the next level in the ordering of the material that should lead to the gradual construction of the theory, the researcher regrouped the descriptive labels into categories. The labels were compared, and was established which among them identify similar types of textual units. Each group of similar labels was amounted to a distinct category. This heuristic action represented the first level of abstraction in the inductive process of the theory and produced the drafting of a list of categories. (Appendix C)

- **To regroup categories into macro-categories, action on material [am 9]**
Once the first level of categorization was completed, the resulting categories were examined in order to attempt to group them into homogeneous sets, each of which was embodying a category of a higher order. Heuristic actions “am.8” and “am.9” were defined as “cluster” actions, since they group together the conceptual material produced via an analysis “in cluster”. The analysis cluster was structured according to as many levels as needed to order the data.

- **To identify the concrete essence of the concept, action on material [am.10]**
At this point, quantitative analysis commenced to calculate how many times each label comes up in the texts. The calculation in question enabled researchers to highlight the following: common qualities, extended qualities,

singular qualities. To calculate the extensiveness of a concept, it was crucial to understand how important the way in which the concept was identified by the participants. The orderly presentation of the results that have been obtained represented the descriptive phenomenological theory of the observed phenomenon. The results were an orderly map of the qualities characterizing the phenomenon as it is experienced by participants.

Participants

Study participants were selected out of a pool of twenty-eight nurses whose Pediatric Intensive Care Unit work experience ranged from 2 to 20 years, and eight clinicians whose Pediatric Intensive Care Unit work experience ranged from 3 to 25 years.

The parents of children with PCCI, admitted during the study period were involved.

Twelve HCP and twenty-nine parents of children with critical chronic conditions were interviewed during their child's hospitalization over a 20-month period between 2016 and 2018. All participants agreed by signing a consensus form.

The proportions of nurses according to years of Pediatric Intensive Care Unit experience were as follows: 33% had 3-10 years, 33% had 10-15 years, 33% had 15-20 years (data provided by the Pediatric Intensive Care Unit Nurse Manager).

The proportional distributions of doctors according to years of PICU experience was as follows: 33 % had 4-5 years, 33% had 7-9 years, 33% had 10-12 years (data provided by the Pediatric Intensive Care Unit Chief). Two male and ten female HCP participated in this study. Participants ranged in age from 25 to 45 years (mean = 32 years), and their experience working in the Pediatric Intensive Care Unit ranged from 3 to 20 years (mean = 11.5 years).

Nine male and twenty female parents participated in this study. Five couples and seventeen singles were interviewed, whereas twenty encounters for the purpose of communication between nurses and parents were recorded, as well as eight encounters between doctors and parents.

Regarding Children's illnesses: eight children, of which six have had multiple cardiac surgeries, had congenital heart diseases, four had hypoxic ischemic encephalitis, two had metabolic disorders, three had oncologic or hematologic diseases and three had a

genetic syndrome or congenital defect (tot= 20, age from 1year to 14years, mean 5,4 years). Eleven out of twenty children had an illness-associated neurological and functional disorder, two needed respiratory support, and nine had a gastrostomy tube. All of the children had been in a pediatric critical care setting at list twice or more often; eighteen out of twenty children had prior Pediatric Intensive Care Unit admissions.

CHAPTER 3. DATA ANALYSIS

This chapter presents the main data emerging from the personnel involved in the study. The quantitative dimension of labels and categories was taken into account when dealing with the qualitative dimensions of the significance of the content present throughout all interviews. The collocation of each single label was not exclusively derived from its quantitative dimension, but also from the qualitative relevance of its meaning. Sometimes, for example, a label that is scarce in term of frequency conveys crucial themes expressed in a transversal way in the narratives, albeit with different degrees of specificity.

3.1 THE PARENTS

The overall analysis and codification of collected narratives are summarized in Table 5, where the set of categories and their descriptions in the respective conceptual labels is schematically shown.

The codification of the materials concerning the parents is shown in Table 12, where the outcomes of the categorization process and their corresponding labels are evidenced. The results of the analysis are ordered according to three dimensions extrapolated from the contents of the experiences narrated by parents: lived experiences, relationships, and communication. The narratives collected within the first category recount the positive and negative experiences that the parents regarded as being significant. The relationships category includes the parents' takes on their role, including their relationships with medical professionals, critical issues, and their views on their children's illnesses. The final category contains all of the accounts regarding instances of communication between parents and health professionals.

When fleshing out the descriptions included in this chapter, both quantitative and qualitative criteria were utilized, one to determine the scope of the labels and categories, and the other to determine their significance. Therefore, in order to determine the relevance of each label, the author did not limit themselves to numbers and quantitative indicators, but rather placed special focus on how the significance of each label fared within the broader context of the data collection process. Other PICU experiences were taken into account in the categorization process, given that they constitute elements that tackle the same issues and can be placed within the same context as this research, even if the scope of the study is different. In order to

guarantee anonymity, an ‘m’ and a ‘f’ are associated with the narrations of mothers and fathers, respectively, when the occasion calls for it. Sensitive data and other information that would have made it easier to recognize the interviewees were omitted from the study, all the while ensuring that this need for privacy would have no influence whatsoever on the study itself. Some of the elements encountered in the course of the study were regarded as being cross-cutting or common, given their recurrence in various accounts from different participants, whereas others were described as prominent, albeit recounted by single interviewees, given that they were useful in conveying the sense of the phenomenon as a whole.

The various conceptual categories and labels identified throughout the analysis were situated within the dimensions listed above, and are briefly shown in the table below.

Table 5_ Analyzed data about Parents

Dim.	Categories	Labels
Lived Experiences	Difficult Lived Experiences	Abandonment and Loneliness
		Hospitalization as a Constraint
		Time Unlived
		The Physical and Emotional Toll of Intensive Care
		A sense of Helplessness
		Life’s Uncertainty
	Axiomatic Lived Experiences	Capturing the essence of the moment
		Feeling Welcome – Receiving Attention
		Taking Care of the Child
		Enjoying the Child
Relationship	The parent’s role	Caretakers
		Being Forced to Demand Attention for One’s Child
		Bearing the Burden of Care - Managing the Family System
		Loneliness and the Difficulties of Forming Connections with Others
	The Relationship with Medical Professionals	The Role of the Individual
		Trust
		<u>Alliance</u>
		Fear of Change
	Critical Elements	Necessary Humanity
		The Alleged Superiority of Doctors
		Losing Sight of the Child
		Medical Errors

	The Relationship with the Illness	The Responsibility of Choice – Making Choices for Life
		A Child Who Is Not There
		Being Aware of the Illness
		The Comparison with Healthy Children
		Accepting the Illness
		Accepting the Worsening of the Illness
The communication	The need for communication	A Non-remedied Need for Information
		Unclear Communications
		A Difficult Communication Process
		Being Afraid of Communication
		Waiting for News
		The Need for a Person to Refer To
		Where the Communication Takes Place

Common elements, Protruding elements

3.1.1 Lived Experiences

This dimension distinguishes between experiences that the parents described as positive and those they described as difficult or negative.

Difficult Lived Experiences

Abandonment and Loneliness

Some of the experiences narrated by parents communicate a profound sense of abandonment, and some examples of the same can be also found in other sections of this chapter. The process of returning home after a hospitalization period is particularly indicative of this sense of abandonment, since parents are not yet prepared to tackle such a difficult situation with the right instruments. The main issue in this situation is represented by the fact that parents are still not aware of their children's needs, nor of how they communicate said needs, and, as a consequence, they do not know how to appropriately respond to moments of crisis, suffering, and crying.

By the time we returned home, we had not received any indication as to how to help him, feed him, wash him. He couldn't suckle (...). We returned home, and I did not know what to do, and he couldn't even suckle... G9_274

Another kind of instance where the sense of abandonment is apparent is the failure on medical professionals' part to take on the child's illness by authorizing hospitalization, pursuant to the belief that there are no clinical prerequisites to do so. The failure in question causes parents to feel uneasy, and to be forced to deal with the situation entirely on their own, and without the appropriate instruments to do so, a condition that the professionals who omit to afford proper care do not take into consideration.

My worst memories have to do with the time that they told us they couldn't take charge of her because she had nothing. From a medical standpoint, our little girl was not unwell, so they discharged us. Once we were home, she kept wailing all day for a month, so we stayed at a tavern... because we couldn't stay home, with two more children... we stayed at a tavern and made sure to hold her in our arms... (...) we really felt like we had been abandoned then. G7_287

CCCs may feel pain, cry, have a tonic-colonic crisis, throw up or discharge, be inconstant need of aspirations, and a parent may have to confront these situations alone at home. If parents attempt to build a network of support via the help of experienced professionals, the costs become exorbitant, which is why asking for help within the family can become a necessity, also due to the fact that institutional resources are limited and not at all comprehensive.

We had a turnover mechanism with our relatives (...) She was really, really tough to take care of... you can go an entire night without being able to sleep, and she keeps crying, crying, crying. G20p_232

The aftermath, especially in hospital, was hard, but even when we returned home she would cry every day, all day, probably because she felt pain (...) We had no idea. G4_308

We did not sleep at night for months (...) We had to ask for something to make him sleep, I didn't want to ask, but it was necessary to go on. Because after six months, it becomes a lot to deal with. G2_12

*They discharged us with a mentally disabled daughter who kept feeling ill at home (...)
We had no one to take care of her, all the doctors work in private practice (...) and it
has been two years since we started managing the situation ourselves. G7_289*

The emerging picture is that of an increasing difficulty on parents' part in dealing with a situation that, albeit possibly stable for a certain amount of time, is geared towards a slow and gradual worsening, thus increasing the difficulties associate with managing such a process.

*Things get worse and worse, and so they get harder and harder (...) When she was little
she cried so much, we were desperate, she would never sleep, by the time she turned three
and a half she never slept. G4_310*

Hospitalization as a Constraint

Some of the lived experiences are emotionally intense, and provide a detailed account of the feeling's parents went through in the hospital environment. In some cases, parents spontaneously described episodes or moments pertaining to hospitalization when referring to themselves or their children, as if to imply that their lives were equally divided between the hospital and the outside world.

We talk about the hospital because it's the kind of place we often go to. G9_258

*We prefer spending more time at home than in hospital (...) but the hospital is also a
second home. G4_302*

In the following excerpt the parent uses the term "sabbatical" to describe the intermittent periods between hospitalizations. In the case of CCCs, the overall hospitalization and management of the child's condition can become an exhausting feat for parents.

*I call it sabbatical, because it was the only year during which we didn't have to come to
hospital. G2_18*

A prolonged hospitalization also represents the upset of family rhythms and lives. From a structural and organizational standpoint, parents sometimes get the feeling that they are in a prison, burdened by obligations to which no corresponding rights or spaces are associated.

With regard to 4x4 rooms, we have a 4x4 room, but the bathroom is at the end of a corridor (...). There are two beds along the wall, and an open cot that needs to be moved in case someone needs the bathroom at night. G7_280

That whole structure is worse than a concentration camp... it's where the trauma resides for me... G7_279

12 years ago,... I was let in to feed my son, and then required to leave the ward and wait in a locked room with bars (...). I would cry desperately, and they left me there until the following meal, I was not allowed to regularly see my son as you do here. I was locked into a room all alone... there were no other mothers (...)... at one point I couldn't withstand it any longer... it felt like prison, and in the evenings, I went home. G9_276

The 42 days following intensive care were very hard, we were at the hospital, we were there all the time, it wasn't easy. G4_306

I think that, if you want to be able to see the bright side, you have to leave the hospital. G1_135

Nevertheless, in the following excerpt a parent observes how they re-evaluated the hospital as their child's illness progressed, moving away from its association with suffering and deprivation, and rather focusing on the "ally" that a hospital can be by providing support and relief, in spite of the initial rejection and fear (as confirmed by the following parent).

Going to hospital means sailing into a safe port, and you know that it's to make your daughter feel better. When she was feeling very well (...) it was tough. Then, as things

got worse... I need to go to the hospital from time to time... every time we go, we learn something new. G7_281

The hospital stay was not terrifying, I was afraid, I hated hospitals. (...) I was terrified of hospitals. G3_52

Even though positive moments may occur after an initial acclimatization phase, hospitalization is reported as being the most critical moment in literature, since parents and families as a whole, not to mention the ill children themselves, come under a massive amount of stress.

Hospitalization is a trauma for us (...) it is necessary to rally, and there are arguments a fight because decisions need to be made: to go or not to go, I say we should go, she says we shouldn't, we should wait a moment, and you always need to make decisions quickly, because it's not always clear what the best course of action is. G4_304

Traumatic... because it was a psychological trauma. G8_189

Coming to hospital is a big trauma for all three of us... first of all, he is unwell, and when the acute episode is over, we have trouble dealing with him in this environment, because he looks scared when in hospital (...) whereas at home he looks much calmer. G9_260

The occurrence is so destabilizing for families that one parent uses the term 'anguish' to describe it.

I feel a sense of anguish at the idea of a new hospitalization... not because I need to stay at the hospital, but because I need to make arrangements, and I have another son (...) the fact that he is healthy does not mean that he has less need of me. G20p_249

Time Unlived

The time spent at the hospital is a relevant factor for parents. This kind of time cannot be governed, it slips away, it is difficult to manage and withstand, disrupting everyday

family life. The hands of the clock do not exist, or rather they exist in an exasperated form, melding the dualistic distinction the Greeks made between *Kairos* and *Kronos*. Being at the hospital equates losing points of reference, the ability of managing time, and living a normal life, all the while imposing a new time schedule.

Days end... and then you wake up the following morning, and it feels like it has been a year, each day lasts a year (...) a month has gone by, but it feels like six at least, and then you realize that a month is a really long time, it's a nightmare, a nightmare.
G3_62

As soon as you step into intensive care... time stops. G8_26

We have been here for three weeks, after a few weeks it all becomes distressing. In the morning we work, then we come here, and spend the rest of the day here, at least in intensive care parents can go home for the night. G1_113

In the end, you're always here... and, naturally, every little thing becomes the end of the world... I can't even explain what it feels like to receive big news all of a sudden.
G8_194

You can't move, you're just there, time comes to a halt in intensive care, it's (...) the air you breathe, what you feel in your gut, really. G2_26

You can't know until you know how things work in intensive care. G10_158

The Physical and Emotional Toll of Intensive Care

The first impact with intensive care represents an intense, sometimes traumatic experience for parents, and some lived experiences expressed in sensory terms are therefore relevant, for example those pertaining to seeing one's child in critical condition, surrounded by foreign elements, or those remembering sounds that were ever-present and distressing.

The sound of intensive care gets so deep into your head that it's impossible to forget for a long time. G2_27

I was shaken by the sight of her in intensive care. Yes, they're naked there, she had plasters over her eyes, a cushion under her head, she was full of wires and tubes, (...) I had never seen her like that. (...) It was hard, and then she was taken here. Intensive care gets to you. G1_131

A Sense of Helplessness

Albeit not often found in the narrations, the sense of helplessness parents can feel is relevant, in that it strips them of their role as the main providers for their children.

It gets to you because you can't do anything. You can't, you can't do anything. (...) You can only hope that the machines and doctors will do their jobs. Intensive care also got to me because at the time we didn't know what would happen. (...) You can't bear to stay there, and you can't even bear to go home. G1_130

When you're confronted with certain things you feel helpless, in the sense that all our hopes were invested into giving our daughter the best possible life, and then... G5_324

Parents are thrown into an environment where emotions run high, and can impact the fragile condition parents are in with traumatic consequences.

Chance willed that two kids died that day, and all the while she was throwing up, and in the meantime the priest arrived to give last rites, and I had to go wash my hands, I tried not to look, but in the corner of my eye I saw a gray shadow next to me, a creature, a child. When you tell such stories they sound made up, and sensitive people start crying. G8_198

On the day he was put back into the cot, I had to store away the baby clothes I had bought for him, and the cot, it didn't even have drawers, and so I didn't know where to put the woolen socks, the only item he was allowed to wear. I (...) entered, and the nurse said, 'Madam, I must ask you to pull away the socks. In that moment, I wanted to

bite her on the neck, I insulted her, at least I think I did, but I didn't mean to... (...) you can't know what had gone down that morning... that is a lived experience, everything is amplified here, even the smallest things are amplified here. G3_67

From the researcher's journal: I see that parents will likely not forget what they've seen here, they are at risk of being exposed to tragedies occurring at the hospital on a daily basis, and the kids at the centre of those tragedies are just like their own. Despite the fact that they sustain the psychological burden placed upon them, I believe that this "promiscuous" environment is of no help, and I am reflecting on the possibility of making rooms more private, so that parents may keep interacting, but only when they feel it is necessary, thus avoiding the risk of juxtaposition.

Life's Uncertainty

The uncertainty of day-to-day life can be accompanied by the perception of uncertainty in the here and now. The impossibility of governing one's life, which Mortari defines as a dual lack of being and governance (2015, p. 17), characterizes the days and weeks of parents who are obliged to deal with a particular situation for an indefinite amount of time. Parents lose their sense of time, events, and hope with regard to their children's possibilities. This is in turn related to what is expressed below, given that said uncertainty is often connected to axiomatic lived experiences, in the sense that parents feel compelled to adopt a vision of the here and now that allows them to carry on in their precarious predicament.

Now he's here and feels fine, but that could change in an instant, and maybe one night (...) and maybe I can't even get here in time. G3_98

No one knows if this little girl will survive today (...) these kids either die in the womb within three months or, if they are born, they die immediately, (...) maybe she'll live a day, or not even a day, maybe tomorrow is a possibility, you never know, but we carry on, no one believed it, she wasn't supposed to live more than a day, we carried on. G6_194

When he was born, we didn't even know what we would have to tackle and what not, when we'd see an improvement, or even if we'd see one. G4_307

Maybe I go home, and they call me to tell me to come back because my kid's condition has worsened a great deal. G3_96

Just yesterday things were looking up, but instead there has been a major respiratory crisis. G1_118

Axiomatic Lived Experiences

Capturing the essence of the moment

Most of the children of the parents who were interviewed for the purposes of this research have serious psychomotor retardations that heavily compromise their communication abilities, many cannot walk or even stay erect, many are hooked to a feeding tube, and some even have respiratory difficulties (see the summary of the pathologies affecting CCCs). In spite of all this, parents see themselves as being fortunate, an element the author did not come across in the relevant literature.

Each morning (...) I see five, maybe six kids with no hair, and I tell myself... we're not the only ones, it's not just us... there are many... I don't know how many, but there are so many that you can't even imagine, and there are people who see no light at the end of the tunnel, and there are people who are worse off than us. G10_171

Just twenty-five days ago we thought he wouldn't come out of the operating room (...); we thought he would never breathe on his own (...) Seeing him now, sitting, laughing, joking about... yesterday he tried calling out for mum, it's just a question of time, there are worse cases, and it's not worth it... there are worse things in life. G10_169

Parents learn to savor the here and now, to which they cling in order to live day-by-day. Being in the present, caring for the child's today, the here and now is expressed as care

I had the good fortune of seeing him live, if I look back I tell myself: some people get to go home on the second day, but some didn't even get to see their kids, being in the moment is key, when he won't be here anymore than a week of thinking, getting angry, crying will probably occur, but until he's here, it's worth being beside him. G3_93

Each time he overcomes a difficult situation, it's a truly great moment. G2_36

When he saw us, he would cry... and it was him, he couldn't answer, but you could see it was him, he moves his fingers, his toes... so I thought, he may have a deficit, but not so big of a deficit. G10_160

Until today we have been fortunate (...) Compared to her there are both worse and better cases. You realize it could be worse... but she is active, lovely to watch, not perfect, but there are children who are worse off, they do not move, they are as still as vegetables. G1_91

Being here is an opportunity for us to reflect on some things, we are in the best place possible to give our daughter her best chance, and we feel fortunate to be here. G5_325

In the following excerpt, the necessity of giving one's child a similar perspective is explored, i.e., living for the day, all the while understanding the risks and opportunities it brings, a strategy to live in this world while fighting illness.

We try to get our daughter used to the idea of being positive, winning, never giving up (...) when she looks at herself in the mirror and says she's ugly, I ask her what she's missing, and note that she has two eyes, two hands, whereas other kids do not have an arm, and so she begins to understand... maybe she starts looking at her scar because she starts to comprehend, and says I'm right... and she remarks on not having long hair, and I tell her that not all princesses have long hair. G8_204

Feeling Welcome – Receiving Attention

For parents, feeling welcome does not exclusively mean receiving attention for themselves, but especially feeling that their children are taken good care of. As one

mother says, “they carried these children as if they were their own”. Such an observation accounts for an assumption of charge that is not solely relate to practical assistance, but rather implies an involvement in the child’s medical journey on medical professionals’ part, and involvement that is simultaneous to the loss of parents’ ability to take care of their children themselves.

I was able to go to a hospital where, (...) I shall always be thankful because there is a warm welcome (...) I saw that they carried the children as if they were their own.
G6_172

When we sat for a consultation and they told us our son would die, the nurse was on the verge of crying... I could have gone to a different place where they worked just as well, but here I did not find hospital professionals, I found people. Therefore, I cannot repeat enough that when this experience will be over (...) with all the trauma it will bring (...) this will nevertheless feel like an experience that gave me something. G3_90

There is another dimension connected to the welcome describe above, similar to a sharing of experiences, a form of empathy that can be found in healthcare professionals as a spillover from their profession. Despite the fact that there is no communal experience, such empathy can be described as a non-original perception of another’s original perception, as Stein describes it (E. Stein, 2009). With years of experience comes a great deal of exercise in listening to others, it is not about acting directly for someone, but rather about perceiving their emotion, and exercising towards increasing that perceptiveness. The capacity for empathy and quality of such depend on both the quality and quantity of time spent listening to others, as well as the will of the individual in terms of wanting to listen to others.

Anyhow, it’s difficult to find doctors and nurses who support you, who help you, but they helped me more than my relatives, because actually living through this kind of situation is different. And you do live through it, you feel it in your bones, even if you don’t show it. G2_8

Taking Care of the Child

In some of the parents' accounts, the importance of individual action in the care process emerges. The individual who actively takes charge in helping parents overcome the uncertainty of the moment is essential, especially in a context where the absence of effective, responsible, and continuous care is often felt. Individual action deals with a critical situation in which parents feel fragile and in need of support.

My daughter was unwell and (...) she was in terrible pain, and a female doctor on call in the emergency room left what she was doing, and stayed in the bed with her for three hours, she lay down and tried to cuddle and rock her, to soothe her dystonia as if she had nothing else to do that night, and I will carry this with me forever. G7_287

I remember the first day in which he began breathing without oxygen and I remember the first time I walked into intensive care. I was afraid, afraid to get attached, afraid to lose him, and I remember that a nurse was in the room (...) she basically changed my world view. She was the first person I saw, the first I trusted. G2_30

At the time he had to take essential medication to keep epileptic crises under control, and so we returned home needing to give this medication (...) we were discharged at 5:00 PM, and we began looking for the medication as soon as we left the hospital, but it's impossible to buy it with no prescription. We went home and called our pediatricians who said she couldn't write it because her shift had ended, and at that point it was already 5:30-6, and then we went to all the pharmacies we knew of, they said no, until finally we went to one we had never been to before, they gave us the medication and asked us to bring the prescription the following day, and they were so kind, they didn't even know who we were... and we had the medication for the night, otherwise we would have had to go without. G9_278

I didn't know anything, but I found open doors, I am grateful, grateful to God, to you, to whoever manage to make sure that this little girl will have a better life in spite of what she has, I am truly glad of how we were treated. G6_181

Enjoying the Child

Parents experience the small victories of their children as miracles. Despite the fact that the illness is the predominant factor in shaping family dynamics and relations, parents are able to look at their children's lives with awe and wonder, which is in turn connected to the ability of being in the here and now, capturing every nuance. The ability to communicate with their children is another essential factor for parents, especially the child's first smile, which only occurs after the cure process has begun, and the parent is aware of the condition.

At first it looked like a grimace, because you know, when you wait for a smile that just won't happen, the first time was when she was four, and it was incredible, when she smiles like that she is telling you she is well and happy, and that means a lot. G4_312

It was wonderful to hold her... and then when we realize she recognized us... and gave us these little smiles... and it is crucial that she recognizes her brother, it creates a bond. G20m_255

Her eyes are so expressive, not just towards us parents, but after a little while the babysitter and her friend understand what she wants, or what cartoon she likes. G7_283

Every time he smiles... every single day he smiles I feel good... for sure... and this is happiness. G20p_243

Seeing him laugh and joke about, despite being here... his wanting to play... it's wonderful. All good news equates good moments, but my son's smile is indescribable. G18_229

The first time they gave her to us to hold, that direct contact with our daughter was the best moment, I cannot imagine a better one. G5_329

3.1.2 Relationship

The Parents' Roles

Caretakers

The following series of excerpts shows how parents experience a shift in their role as time passes and the pathology changes by becoming increasingly complex. This is strictly connected to the notion of 'power struggle' that can be found in literature (Martens et al., 2008), and it mirrors the perceived change in role on healthcare professionals' part.

As the child's condition worsens, parents become more and more acquainted with its technical and practical aspects, acquiring more knowledge about the illness itself, and thus becoming *de facto* nurses and doctors for their children.

Nevertheless, medical professionals do not always accept the parents' views as being equally important or worthy of note as their own.

If I identify as a mother, there are things I can't do (...). But then you become a nurse, and every mother becomes a sort of nurse, and at that point you gain the ability to do everything. Any mother becomes a sort of nurse. G2_49

If he feels that someone who is not his mother is touching him, he feels as though he were being violated, the fact that even his mother has to execute certain maneuvers makes them easier to accept when coming from an actual nurse. G2_34

Sometimes parents see what doctors and nurses don't, since they know the child better, but this is not properly acknowledged by the medical staff.

The doctor kept saying that, from a cognitive standpoint, my daughter was absent... I insisted that she was cognitively active, but poor man, he was right, because she didn't do anything whenever he was there... and we kept saying that our daughter was alert to no avail. G7_285

It's just that sometimes they're in a rush... I tried explaining that our daughter is not used to eating all the time, (...) that could be the reason she is wailing, her stomach needs

a break, it's putting pressure on her lungs (...) and then we can't sit her down, I can't hold her in my arms because there is too much going on. G4_320

If he feels that someone who is not his mother is touching him, he feels as though he were being violated, the fact that even his mother has to execute certain maneuvers makes them easier to accept when coming from an actual nurse. G2_48

As Solodiuk et al. put it, “[CCC] parents-identified descriptors showed a wide variety, including 22 variations of eye descriptors” (Solodiuk et al., 2010), and this goes for looks the same way it goes for the interpretation of vital parameters, thus turning parents into medical professionals.

I am split in half, sometimes I speak as a mother, sometimes I speak as a nurse. On some things it is absolutely necessary, I have to tear myself away from my emotions to be able to do something with him. G7_39

Being Forced to Demand Attention for One's Child

Despite the role juxtaposition within chronic illnesses, parents maintain a quantum of willpower that has nothing to do with clinical considerations, but is rather focused on the child's wellbeing as a whole.

At one point I asked one of the doctors to come in, and I told her that if they would not accept a transfer, I would force a discharge and take the ambulance on my own. Because they were talking about a transplant, but I could see that he was withering away. G2_39

When it came time for First Communion, the priest was not willing, but I put my foot down. She had to be at her First Communion. She went through it like everyone else, despite her problems with swallowing, she did it. G1_123

In the following excerpt, a mother recounts the difficulties she encountered when she felt like she was being watched and silently scolded by medical personnel, not having any experience with her child. All new parents go through this, but this circumstance

is particularly poignant for CCC parents, because the children have specific needs that parents may be wary of confronting.

During the first hospitalization I felt monitored, under examination, it's hard, and the personnel expects you to already know what to do, and some things are underestimate. G18_222

Parents know their children, they are always taking care of them, they need to be updated. Just like doctors and nurses have handovers, parents also feel they need to be brought up to speed on their child's condition.

Because of my personality, I was able to speak to the doctors here, because if I don't see them at least once a day, I call them, they get frustrated, and then they come over... on the one day I was not here no one came (...) to communicate... when I am here... I always ask... how is it possible that I have to speak to a resident, who looks at me with wide eyes if I ask something...? I need to speak to the doctor... at least once a day... G7_298

This next mother describes a similar experience to the previous one, stating the need to be informed and updated, and noting that sometimes forcing the attention of medical professionals is the only way.

If I have to stay there for two days without being able to leave... one gynecologist, for crying out loud... can I speak to a gynecologist? It is mandatory to stomp your feet and shout... because in hospital you either get mad and make threats, or you achieve nothing, however you put it: I understand that there is little money... but we're talking about lives... the same gynecologist for everyone, by the way... one young woman died six months after she'd given birth. G20m_247

Bearing the Burden of Care

In the accounts of the mothers of CCCs, it is apparent that mothers often bear the brunt of their children's care (Logan & Scharff, 2005; Monsen, 1999). Taking on the responsibility of care implies a certain set of choices in terms of rhythms and expectations, which is why work often shifts to the sidelines.

One side is stronger than the other, it's a characteristic that the female sex often carries with it. Some people can rely on that extra energy. G1_113

Dedicating one's entire life to an ill child means putting the child first all the time.

At the moment, I don't want more children... I left my job, I did so gladly... you don't think about a first child, you think about a second child... I decided to go (...) he received so many stimulations at home, and if I had kept on working, I could not have taken care of him this way. G18_223

In some instances, mothers take on all of the specific care needs of their children, and then realize they cannot do it alone.

My one mistake with my family situation was putting everything on myself. (...) I have always winged it. But maybe now I've realized that I made a mistake and isolated myself too much. G1_126

Managing the Family System

In line with what was expressed above, family time equates taking care of the chronic child (White et al., 2017), or rather is organized so as to answer the child's needs. Families approach the chronic illness like an organic system responding to the malfunctioning of an apparatus by employing its own set of compensation mechanisms (Quigley et al., 2014). This seems to be inevitable, as observed in the excerpts below, given that there is no time left in the day for anything else.

I am completely devoted to her care, luckily, I don't have anyone else, except the dog... and of course, he suffered too, with another person at home. G8_201

For the family system to work, it is necessary to involve other relatives outside the immediate nucleus, as often observed in literature (Rafferty & Sullivan, 2017; White et al., 2017), but it is not simple to determine how this involvement should occur.

I established a good dynamic with my mother to take care of my other daughter (...) It's pointless to give her fifty figures to refer to... one is enough, and I told her I want her to stay with my mother... starting today until she'll be with me again... because she has her own life and rhythms. G10_165

It's difficult to balance work, outside life, finding someone who will help you, my mother in law helps a bit more now, and my sister too, but I need to schedule everything and work at least three to four hours a day. G1_136

Maintaining the system means prioritizing in such a way that parents can forget to take care of themselves.

This life is also physically draining... because hours go by without me eating anything. G8_200

Loneliness and the Difficulties of Forming Connections with Others

Feeling alone, thinking that no one can understand, because those who are outside such a context cannot possibly comprehend the dynamics that occur in a place that does not exist in the minds of those who do not frequent it so regularly.

You are alone in the world... it's like raging against the current... you don't know whom you're fighting against. G8_196

In our village, our friends betrayed and abandoned us, and when we took our son outside, they looked at him as though he were a monster (...) When he was born, we were abandoned (...) not even the priest came to visit. G9_268

The day my daughter started breathing, I could not be happy, because two children next to her died, I had to go wash my hands, and I tried not to look, but in the corner of my eye I could see grey shadows... creatures. And when you tell this story, it sounds made up, and sensitive people start crying. One time a priest who had made a home visit cried over it. G8_198

From one day to the next, you are catapulted into a world you know nothing about, and no one, not even relatives, can understand what you're going through, and you find no help anywhere, from no one. G5_332

It's hard to interact with others when your child is ill. G2_2

Outside the hospital, it is hard to find support. The risks that these children are exposed to are high, and no one can if and in what way the illness will become more complex.

Some people have suggested to me that with a few operations my child will get better, but it's not true, (...) You need to be aware of what can happen, you need to be aware of the actual risks. G2_47

Not only is the parent of a CCC forced to accept their child's illness, but they also have to accept how their child is perceived in the outside world. In some cases, like the one below, the potent mix of loneliness and judgmental stares can make parents feel distraught.

Seeing my daughter in the wheelchair, seeing how they look at her, people on the outside ruin your life. The average citizen ruins you because they cast you aside, they judge you, you are pushed to the sidelines. G1_122

Of course, people always give you looks. G4_317

The scrutiny of others is felt so intensely that it is sometimes difficult to venture into the outside world and interact with others. Going out is an emotional and physical feat, a conquest that requires overcoming fear, judgement, and embarrassment.

One Saturday everyone was dressed up, but she was with us, and the pulse ox sounded off, and she was crying out, and everyone was looking at us... but her little brother was happy holding his ice cream (...) and everybody else was taken aback, staring at us, but

still (...) going out felt like a conquest, you run the risk of closing yourself off, to protect her, and because of prejudices, basically. G4_315

The Relationship with Medical Professionals

The Role of the Individual

One mother describes the relationship with healthcare professionals as being *in fiery*, with an initial phase of wariness and getting to know each other, followed by the establishment of an actual bond that is sometimes described by parents as a friendship, and by medical professionals as being part of the family, with the *caveat* that each bond is singular and different from the others based on the individual dynamic.

Maybe at first a nurse doesn't know how to deal with a parent, (...) but then the parent opens up or confides in them or something happens in the mechanism, and I'm not saying it becomes a friendship, but it's good to have such nurses. G1_104

Sometimes it's not easy to understand what you tell each other. But it suffices to ask, to get informed, this morning I asked (...) I sometimes ask whether I should ask a certain question, or if it's a stupid question for a doctor. Yesterday I wanted to ask (...) but I lacked the courage, and maybe I was wrong. (...) Sometimes I prefer to ask the nurses. G1_126

The following parent distinguishes between two kinds of relationship. The nurse tends to be closer to the child and the family, not just because of the practical role they play, but also because of the eminently assistive approach that is required of them.

Interacting with nurses is different from interacting with doctors. There's the nurse you laugh and joke with, the one who looks reserved, so maybe you react by being reserved because of her manner. G2_6

With individual acts and a capacity for empathy, a single individual can bring a lot in terms of support and ability to face the rapid changes in the child's situation.

The on-call nurses' shifts rotate, I was a bit scared of a particular one (...) because she was not maternal. (...) She loves her job, she loves doing it well and she wastes no time (...) as a mother you think that if your child is unwell, everything will be alright (...) but as a nervous mother you hope your child will be good during the night, or someone like her will roll him like salami. G3_75

The one who changes the medication comes in, and maybe she does everything quickly, but at least you understand that she is keeping an eye on my daughter, and then there are some who come in (...) and you instinctively feel if they are checking on the children, one glance is enough... it's not about time... G7_301

A parent is able to spot those who manifest closeness, those who take care of the child.

Nurses go by... they stop... they play with cardboard... they don't simply come by because it's their job... you can tell they care. G10_163

And we are there too, I was feeling low at one time, but seeing how they treat those children, as if they were family, you know? They do that thing, they represent, represent the father who is not there, the mother who is not there. G6_175

Having a connection with those who take care of the child is important.

There was a doctor I couldn't stand because he seemed so hardhearted, but then came to see my son, and I saw how moved he was, even though he had always seemed a grouch, and I understood that it was his way of approaching the job, a mask, but now I see him as a person. G2_19

Parents need nurses who make them feel valued, and are able to lighten the load of sadness that comes with tackling a disability.

Attitude is everything. How a nurse approaches you or your child matters. Some are beautiful and have sunny dispositions, others not so much, but you need someone to cheer you up. G1_108

There is a baseline sensation throughout that is best expressed by the following mother:

We are always dealing with disability, so, even though I am not suggesting that we are always (...) sad (...) disability is always on our minds. G1_108

This plays into the necessity of finding openness, closeness, support within a hospital to tackle a complex, and at the time of hospitalization critical, situation.

It's wonderful to have nurses like this, who are so beautiful, sunny, and open with you (...) First the nurse will check to see if parents are ok with something, and then they proceed, it great in a place like this to have these manners, because there are some terrible moments. G1_108

Nurses are also required to have an eye towards what, according to the parents, is important to the child, never underestimating their habits and possible reactions to various treatments.

We have a hard time with some nurses, because they treat our son like a puppet (...) we tell them to be careful with his little legs because they hurt (...) many nurses don't listen to parents... it's like talking to a wall: we know our son better than you do, so listen to us... I understand you have other children to care for, but come on, give him a bit of attention... don't pull his leg like that... it hurts... and it has almost always gone like this...G9_272

The power-struggle dynamic that emerges in literature (Butler et al., 2014; Martens et al., 2008), and in this research too, can essentially be described as a conflict in the respective roles played by nurses and parents in caring for the child. As narrated by the following mother, nurses are the ones with whom the bond is formed , but they are also the ones who replace the mother's role.

The ones who spend time with your kid are nurses, not doctors, therefore, (...) the nurse does your job, by the way, she is the mother to your child, not you, and perhaps that's when you get frustrated, because you realized you're not the mother, she is. G3_87

Trust

Being able to trust a professional with the care of the child is essential, because transferring care that is solely placed on the family, ordinarily at least, to the former requires a quantum of mediation, an understanding that comes with building trust, and judging the professional worthy of the child's care.

Some doctors and nurses seem so trustworthy that you'd let them do anything. G8_212

One mother underscores the importance of dialogue:

The way you answer me, the way you treat me is important to me (...) I have to understand if I can trust you or not. G6_174

The emphasis on trusting the person who takes care of the child, whereby everything else is secondary, cannot be underestimated.

Some tend to be more direct with the information they share, others are gentler, but in the end, you can't run around in circles, you need to say what needs to be said. Overall, in terms of communication, (...) why even bother discussing how information is doled out? I can only expect for the doctor to be competent, but not necessarily affable too (...) The important thing is that they are good with my son, and then if they want to talk they talk, if they don't, maybe they don't have a great personality, they are not pleasant, but the important thing is that they check on your kid. G3_86

This father recounts his experience with his son's hospitalization and operation. They came from a different hospital where they had waited a while before deciding what to do, also perceiving the incompetence of the doctors in dealing with the situation, and witnessing the ongoing worsening of the child's condition, to find a new surgeon who finally made them feel safe.

The surgeon thought he had taken out a relatively small portion of the tumor, about 40 to 50 per cent, we were not disappointed, but we were upset, because we had hope for more. He later told us that he had in fact remove 80%, and that what looked like a huge tumor based on the MRI was in fact a lot of edema, he also removes two vertebrae... to clean up the bone marrow, and then he repositioned the second... I can't even imagine what would have happened elsewhere, he took one vertebra out and repositioned another, there is a whole life flowing inside... he took it out to see if more cerebrospinal fluid goes through... G10_161

After initial fears of leaving the child in the care of someone else, in the PICU parents realize that they are not alone in dealing with the illness, and are finally able to relinquish control over every moment of their children's day.

On the first day in a new ward I was afraid I would not even know if my child was feeling unwell, but in intensive care you know that someone will be there to help. G2_28

Alliance

Trust allows for a pact between parents and medical professionals, through which the personnel becomes part of the family and gets to weigh in on what is the best course of action for both the child and the family.

We would like to take our son home as soon as possible, but we place a great deal of importance on what the doctors tell us, and if treatment requires spending more time here, we will. G2_20

Even though the hospitalization process scared me at first, now the hospital feels like home, because I know everyone has the same intent, to give the best care possible to my son, and to make his remaining years as good as the realm of possibility allows. G2_20

Fear of Change

Fear is the greatest obstacle towards the establishment of an alliance as described above. A lack of trust can come from either side, instilling fear, which is often related

to incipient changes, such as a change in the management of the illness, the worsening of the condition, and the introduction of new technologies.

I remember this nurse who kept touching my daughter, and that annoyed me, but then she was right on some things (...) we fear changes a bit, but we have learnt to have some trust, and see what happens. G4_303

Parents find it hard to deal with change, and, generally, for a chronic patient a change usually implies a worsening of the condition that will eventually become stable with time, but it is nevertheless necessary to adapt the treatments to the person, it is not feasible to adopt a conservative approach towards a patient whose condition changes over time, albeit slowly and gradually.

Even a PEG is not easy to accept, as well as dealing with movements, at first, it's fine because they're small and you can take them around in pushchairs, but then you have to look for a special chair, and deal with specialized technological instruments. The wheelchair was an impactful choice to make for me. G1_119

Critical Elements

Necessary Humanity

The fact that the medical/nursing approach implies a quantum of emotional detachment is an issue for parents.

I saw this doctor outside the hospital, and that was when I realized he cared about S., whereas I had always seen him unaffected here... so I thought (...) and understood that trying to detach yourselves is part of your job. G2_19

It is true that you operate on two different scales, being humane (...) cannot interfere with your job and your ability to do it. G8_193

That mother believes that a sense of humanity should not affect one's discernment when working with the child, but it is also important to maintain a close relationship

and a sense of involvement with the child and their family, albeit on a professional level.

Sometimes the humane aspect is lacking... I understand that it should not interfere with the work... but it cannot be completely missing. G8_180

Each environment has its own features, but there (...) they did not only treat the illness, they treated me too, my soul. G6

The Alleged Superiority of Doctors

The interviews also showed that parents perceive a superiority complex on doctors' part.

You always see doctors as superior entities, to go speak to them you have to ask, raise your hand. As if they were teachers. G2_44

This approach generates rage and frustration. In some cases, the parent demands to be treated equally, as if a classist attitude placing doctors above all were at the basis of the profession.

Doctors come from a cultural background in which they were the only learned people in their village, so a dynamic of subjection. Now it's no longer the case, some parents have studied more than they have, maybe one is a nuclear engineer (...) and so this social deference towards doctors makes no sense (...) a bit of humility instead of a know-it-all attitude. G7_298

For some doctors, talking to parents equates talking to simpletons... G18_192

This alleged superiority is apparent in instances where decisions are made without taking into account what is best for the child or the family. Parents thus underline the importance of voicing their opinions to come to a solution that is consistent with their own views.

The doctor told me they had done this with parents who didn't want to do it, but I wanted to tell that sweetheart that he had never gone to someone's home to see how those kids were doing... maybe they no longer come to hospital, but being home does not automatically mean being well... the doctor can only know so much. G20m_252

If I have to stay there for two days without being able to leave... one gynecologist, for crying out loud... can I speak to a gynecologist? It is mandatory to stomp your feet and shout... because in hospital you either get mad and make threats, or you achieve nothing, however you put it: I understand that there is little money... but we're talking about lives... the same gynecologist for everyone, by the way... one young woman died six months after she'd given birth. G20m_247

Losing Sight of the Child

A mother gave an account of her experience at a centre specialized in cardiac surgery where the medical team wanted to give her child a new heart. She had already discussed the possibility of choosing whether to go ahead with the surgery or turn to palliative care with the doctors in the PICU. In remembering said moment, the mother observed how she had perceived a firm intent on the doctors' part to go ahead with the surgery, describing their position as "mandatory", and also noted that she had doubts about their intentions being focused solely on the child's wellbeing, rather perceiving that the notion of the surgery constituted an exciting challenge for the team. The surgery itself, and not the child undergoing it, felt like the primary objective.

We came from a different hospital, there it was obligatory to talk about a transplant, but I could see that my son was wasting away. Their objective was the transplant, as it would have been the first transplant of the kind in Italy. G2_39

In this instance too, the parent describes the surgeon's attitude as that of someone who believed he could do the surgery, despite never having performed it before, this in itself constitute a higher risk, aside from the fact that it would have been a waste of time and a reduction in terms of chances of survival, or would have meant survival with dire consequences. A similar episode is described by medical professionals to call attention to the importance of communication.

We lost useful weeks, two weeks, during which he could have been operated on without feeling much, whereas unfortunately he was in pain for weeks, (...) they took their sweet time and the cardiac surgery unit evaluated whether they could do this kind of surgery they had never performed before (...) luckily, they then transferred us here. G10_145

Medical Errors

It is always worth noting how a child's condition may be the result of problems that manifested themselves during a hospitalization period or of medical errors committed throughout the child's life. Despite the fact that the personnel taking charge of the child's condition may differ from the one that committed the error, and the hospital itself may be a different one, the trauma associated with the error remains, in some cases also because of the legal evolution of the issue in the parents' eyes.

We reached a settlement, and we didn't go to trial, because they accepted our demands... you do not accept to pay me if you think you did nothing wrong. G20m_246

In the following excerpt a great deal of frustration due to the difficulty of proving the error is on display:

They had falsified the schedule (...) they shifted everything so that all would be consistent in terms of timing... the problem is that whoever modified the file forgot to change what the anesthesiologist had stated, and this data discrepancy (...) constituted our only anchor. G9_266

They had falsified the medical file, but (...) this falsification was the lesser evil compared to the damage they caused on the whole. G9_265

And the doctor told the father they he had followed protocol, and if that (pointing at our little girl) was the result, the protocol needed to be changed. G20_245

It's not so much the error itself that the excerpts above denounce, but rather the management of the same in terms of lack of honesty and transparency. Making

mistakes is human, but parents cannot tolerate the attempt to hide those mistakes by pretending it never happened or sweeping it under the rug.

In the following excerpts, a parent laments not being listened to when they realized that a hospital ward in a suburban area had not taken responsibility for what had happened.

It was probably a student, and she was giving my son the wrong IV, I asked her to tell me what it was (...) but she left without saying anything (...) Then I never saw her again, when I spoke to the head of the ward she said that nothing had happened...but the dosage was all wrong. G9_273

Aside from that, there is a risk of oversimplifying what is going on by attributing it to a lack of care on the parent's part, and, in a difficult moment, a parent may start believing that what is happening is their fault.

I had a perfect pregnancy, and I carried to term (...) then an obstetrician wanted me to give birth naturally... but he had two passes of umbilical cord around his neck and he couldn't get out, the more she told me to push, the more he choked; when she finally desisted (...) it was too late... but until the very end she insisted that, given it was my first child, I was incapable of pushing properly. G9_261

The most critical and risky moment for a child's future survival and health is birth, as described in literature (Solodiuk et al., 2010), medical errors committed at birth often turn into permanent damage.

If the gynecologist made a mistake, it's human, but to a certain extent, because (...) the hospital... it has become a business where only money matters, and therefore caesareans are not performed, because they make you lose money and, all things considered, a little girl with a permanent disability is less expensive (...) I said I was in pain, and they asked me if I had talked to my daughter during the pregnancy, given that the pains had to be calls for attention, all the while my uterus was coming apart, and it wasn't just one person who erred... because I couldn't speak to a gynecologist. One must stomp their feet and shout... because at the hospital you either get mad or make threats... otherwise

you achieve nothing, it was the same gynecologist by the way... a young woman died six months after giving birth. G20m_247

The Relationship with the Illness

The Responsibility of Choice – Making Choices for Life

When dealing with the illness, parents are called upon to make important choices for their child's future. In the prenatal phase, a choice as to whether the pregnancy ought to be terminated can come up.

I can say I made a choice, because I chose to carry on with the pregnancy despite being offered termination... I thought about what I could do for him, and not to terminate a pregnancy... but one day he could end up asking himself why I let him be born. G18_227

When they gave us the news, because we were not ready for it... it was during the pregnancy, when we had to decide what to do... that evening at the latest, actually. G8_209

A parent must then make choices later on, when the child grows up with a different set of problems, and may need complex and uncertain surgeries. In some cases, parents must decide whether to continue with treatment or not.

Transplants can go one of two ways, it is well known, but at least you give them another chance, and it was so hard not to give that chance... however, for his own good, we decided not to go ahead with the transplant, and to do the best with what we had. We are well aware of the fact that there will be no improvements because (...) we would need three transplants: heart, intestines, and liver, in the hope that with time no other organs would be compromised. Thinking about all we decided to avoid, to leave his life as is, all the while knowing things will get worse... G2_42

In many cases parents observe that there is a “hard line” they will not step over when treating their children's illnesses. Despite the clear demarcation in theory, in practical terms there is a shift from an initial phase of prolonging treatment until it's feasible to

a sense of guilt for the child's suffering, since it was the parents' choice to give birth to them.

We are in favor of intervening until it is feasible, in the sense that as parents we don't quite know to what extent we shall push ourselves with treatments and operations, but at the moment we are in favor of giving our daughter her best chance, and then they told us that, in any case, we have to take it day by day, that things can change from one day to the next. G5_331

It is common to find a sense of guilt in these parents for what their children are going through, often as the result of overthinking and doubting their decisions.

Why did I bring you into this world? I would want to go through what you're going through. I put you here to suffer. Sometimes you just ask God to put an end to it all... it' doesn't feel good to say this because it's hard to endure the loss of a child. G1_132

In some cases, the guilt is associated with the inability of bearing a healthy child.

I bore something with an expiration date, essentially, I bore something that is wrong, because it has a malformation that has no expectancy of survival... why did I do it then... G3_82

I can love... I tried to make her healthy... it's not my fault. G8_214

You ask yourself what terrible things you've done. G20_241

Or, as we can tell from the following excerpt, which is connected to the initial ones, guilt associated with the choice of carrying to term in spite of the known risks can emerge when the ill child has difficulties that parents feel responsible for.

To understand and to make him understand why he is ill... it's probably my fault, because I chose to bear a child I knew to be ill (...) the world wants perfect individuals

and if you have any kind of problem... in a society like ours you have to be brilliant and perfect now. G18_225

Another element that hits parents hard when making choices is the fear that others may not understand or share their views and thus judge their choices, increasing the perception of abandonment and isolation.

I have a son with cardiac issues, I made difficult choices, I chose not to go ahead with the transplant and to keep it to myself, to allow him to live his life as best he can, I don't know if this is selfishness, but I think that many people act like this because they are afraid, I am so afraid, afraid of others' judgement, afraid of others' judgement. G2_50

The cooperation of medical personnel is an element of support for parents' difficult choices. The following excerpts show how important it is for parents to share their decisions and feel supported instead of judged.

The decision to return home, for example, we were not convinced, but then talking amongst ourselves and with the nurses, we made the decision. Even the most important decision we made, that of not going ahead with the transplant, was pondered. What I appreciated the most was that they never commented until we made the decision. G2_38

That mother feels understood and supported, more so in the hospital than in the outside world, she feels safe. She does not feel alone and isolated the way she would feel outside the hospital, and life at the hospital runs along lines that are parallel to those of CCC families' daily lives, it comes with reassurance, understanding, and support.

In six years, S. has been more here than at home, I understand how attached to him you have all become, and I realize you gave us confidence in sending us home to deal with him until today (...) The fact that doctors and nurses are on our side and have helped us gave us a great deal of energy. When I come to the hospital I don't experience

it as a burden, because I know I can talk and let it all out here, I am calm because I know they understand me here. G2_10

It is on the basis of trust and the inclusive, non-judgmental hospital environment that parents sometimes feel capable of making important decisions, such as asking to nurse and accompany towards death.

We specifically opted for DNR, so I can imagine (...) the only thing to do will be to alleviate the pain until his heart stops beating. He has two beautiful eyes, and that is enough. We have already asked too much of him, and I live with the knowledge that everything that could be done was done... in the knowledge that we asked for two things: for this kid to have a full stomach, so they increased feeding. We asked to accompany him, and we were told he will be accompanied. What more could you ask for? G3_99

Parents feel they can choose not to go ahead with a surgery that would be unlikely to save their children's lives, and would rather be likely to reduce survival time outside the hospital, increasing the little ones' suffering.

Neither myself nor my partner believe in going ahead with a surgery because even if it went well (...) The average life expectancy for this kind of clinical picture is three months maximum. When you hear that, what do you do? You operate on a two-kilo baby, let him be cut, intubated for what, one month's worth of life? G3_84

A Child Who Is Not There

A lot of mothers who give birth to chronically ill children have the perception that they never gave birth at all, as if the child had yet to be born. The void, the absence of the child is felt more than their illness. This can be the consequence of a betrayal of expectations or a comparison with other mothers who went through the normal process. They feel as though their status as mothers has been stolen away.

Not having him with me, not feeling him inside me, I felt empty. G3_59

In other words, the inability to establish a bond, to inhabit the role of mother because the child is ill, to hold the child and lead it through its first days.

The baby was two months old and I caressed her, but I had never taken her into my arms to feel her, never bought any baby clothes like it is usual (...) we live without knowing. Until you're not in this situation, it's frivolous, but it hurts. G8_216

Mothers feel as though they have lost a child, not being able to touch them feels like indescribable violence. In the case of an illness, the sense of loss at birth is especially strong.

You feel as though you've lost your child, I hadn't been able to establish a normal relationship, and being unable to be close to him for a whole week, it's a horrible form of psychological violence (...) and it is violence (...) I cannot even describe it (...) there are no words to describe the void you feel, he was inside me, mine, I carried him for nine months, he made me feel good, he made me feel bad, and now I can't even hold him in my arms. G3_59

Illness is therefore loss, the loss of the child at birth or upon the discovery of the condition.

It was devastating to wake up without my daughter beside me (...) I woke up and my pregnant belly was gone, but so was my little girl, and I remained in hospital for four days only ever seeing her in a photograph... it's unnatural. G20m_253

Emotionally, you do not feel like you have given birth, it's as though you had evicted something from your body but do not possess it (...) You were happy at the end of the line, but you didn't get what you'd signed up for. G3_58

Being Aware of the Illness

Initially, the sense of loss and mourning of not having a child to care for is acute, but as the days go by and the clinical picture evolves, there is a slow acknowledgement of what is happening and of the child's condition.

You see some of the things that the child does, and you realize that something is wrong, it's in front of your very eyes (...) you look for excuses but, in the end, you see it (...) you hope until the end that they are just fears, but it's not the case. That the child had something that was not right, right away, (...) I saw it in the face and I understood.
G3_53

Even before I knew of the heart (...), the face was not that of a normal child, and each new day was further confirmation that something was wrong. G3_56

The discovery can occur in a context of apparent normalcy that is suddenly turned upside down.

He was an ordinary child, the only issue he had was neck pains (...) He had these crises that solved themselves and at times he lost his balance (...) but something wasn't right... on Saturday we went for a visit, and the following Friday the MRI showed a brain tumor as big as a potato (...) and suddenly his life was at risk. From there we never returned home. G10_143

We didn't know she was sick when we went in for a visit (...) she was acting strange, had no energy, did not grow, a doctor (...) told us she had nothing... that I had to feed her more, but I knew she wasn't healthy... G7_293

Before then we had no problems, financial, personal, as parents: everything was going incredibly well, and we decided to add to the family (...) then the cardiologist told us in no uncertain terms: a transplant or a miracle. G8_190

The betrayal of expectations is destabilizing for the individual because they feel helpless before what is happening.

They told me my daughter was brain-damaged, and the day before she was like any other little girl you see in the street (...) I wished I could exchange her with one of the

boys, I am not ashamed to say it... I said that should have happened to one of the boys because I wanted a girl. G7_290

The Comparison with Healthy Children

Accepting the illness is a crucial part of managing the same, and the following excerpts show, on the one hand, the initial critical moments relating to an often unexpected condition, and, on the other hand, the acceptance process that follows.

In the first case, the mother compares her situation to that of mothers with healthy children, eventually stating that she feels as though she never gave birth.

The first night was awful (...) the other mothers had their babies with them, it was devastating, I asked for sleeping aids (...) the other babies cried because they wanted to be fed (...) but mine was not there and I didn't even know what was wrong with him (...) it was awful. G3_57

At first, I didn't feel as though (...) anything could go wrong. I was not worried. But when I got to the room there was another mother with her babies (...) Look at that, she has hers, and I don't have mine. When I saw her, I thought she was too beautiful for anything to be wrong with her, but then I went back to the room and I saw that same woman there with her son (...) I felt unbearable pain, and I wanted to cry, cry, cry. G6_183

Accepting the Illness

Accepting the illness is a complex and singular phase for each involved parent. Each parent has their own way of finding a strategy to live on by making the condition a part of their daily life.

You have to accept the illness, wherever it may take you, and however it may take you, it can be a short journey or not (...) Today you're ok, but not tomorrow, today you're at home, in an hour you'll be at the hospital (...) You cannot plan anything, there is nothing, it suffices to accept, and you become aware that you live day-by-day. G2_12

In all of this, maintaining a relatively normal lifestyle, giving meaning to one's life is necessary to avoid losing the meaning of life in the constant pursuit of an impossible status of normalcy.

It is necessary to give meaning to one's life. G2_12

When someone close to you is sick, it can bring your whole world down, it is necessary to go on and give a renewed meaning to your daily routine leaving the illness aside (...) Daily routines are necessary to give meaning to life. If you can't manage that, (...) you have no purpose and you become a robot. G2_14

The decision to keep him home makes it feel like we are able to carry on with a normal life, made up of work, his sister going to school (...) you need to provide a sort of normal life, (...) even if only to do to kindergarten or to school. Now we are trying to take him to school. G2_13

In order to do this, that is, accepting an illness while maintaining a life that is not exclusively devoted to the former, it is necessary to work on oneself, to work together as a couple, a constant and exacting activity.

*To sustain your child's illness (...) you must work on yourself, within the couple too.
G2_4*

Accepting the Worsening of the Illness

A CCC parent is always afraid that the condition will worsen, since each instance means lesser chances of survival for the child. The awareness is so high that a parent may think that being well is the exception, and that things are inevitably bound to get worse, thus requiring more support.

The wheelchair was a difficult development for me to accept (...) She had a PEG done because she was wasting away (...) Then I think about what will happen, in my head I know things could get worse. I went home for ten days because things seemed good, but

then there was a crisis. Will there be need for more contraptions to make her breathe in the future? G1_120

The setback was awful (...) the day before you're happy to go get some clothes, and the following day you have to put them away (...) I felt as though I had been deprived of oxygen. G3_121

It is necessary to accept one's child destiny beyond anything else, beyond one's own expectations. G2_24

He began to feel ill because the tumor was pushing against his brain, until the day before he was fine and in a second (...) it was no longer him. G10_144

We'll never be prepared, anyone may tell you are, but you'll never be, but it's what I expect each evening when I return home... G3_97

He was wasting away. He is wasting away now too, but we are dealing with it in a different way. G2_31

Accepting the illness allows to live with the situation without losing oneself in bitterness and suffering. The following parent saw two other parents be angry about their child's condition, and states that they were angry at God, a sensation she herself never felt because she was able to accept the illness and live better as a result.

It is necessary to accept the illness, I remember a little girl who got a fever after she had gotten a vaccine shot (...) the father was mostly angry at God, but anger directed at God and at life does not allow you to survive, you are unable to accept the illness, so life is difficult. If you experience the illness through a lack of acceptance, you do not live, accepting it means being able to deal with the changes. G2_17

3.1.3 Communication

The need for communication

The absence of care also manifests itself via inadequate communication on healthcare professionals' part.

A Non-remedied Need for Information

Parents need to be aware of what is happening and what may happen, being out of the loop causes a sense of anguish. This anguish is mostly due to the fact that parents feel that they do know what the actual problem is, they only have non-essential information about their children's daily lives.

When the doctor gives you an update, you feel anxious, especially is they tell you nothing specific... it was not good for me because I didn't know anything, I didn't know what the real problem was, he was talking but I couldn't understand, all I felt was anxiety.
G3_71

Whenever I saw the doctor, who only told me about blood tests, all I wanted was a set of answers about the syndrome (...) and I felt anguish because I was not interested in what they were saying, I just wanted to understand, how the encephalogram looked.
G3_72

This mother also describes the difficulty of waiting, waiting without knowing what will happen. When the time came to determine what happened to her child, she realized that the information she had received had not prepared her for what she had to deal with.

He underwent the first surgery after twenty days, and the night before I held him throughout the night (...) it was a very difficult moment because I did not know if I would see him again the following day. Then, the day after the surgery, his chest was open, we were the ones who asked to see him (...) but I will never forget him... the image of him, immobilized, asleep with this beating little heart... I could see my baby's heart beating. G18_228

This father realized only after the surgery had taken place that he had neither received adequate information about the surgery, not explanations about the future, and possible outcomes.

They did not explain anything (...) about what would happen, about the aftermath of the surgery, and what we would be facing, and in the end, there was a small deficit, in the sense that one or two years of therapy are required to turn him back into the boy he was, and then they told us that we couldn't take him away, they had to study him first. G10_148

Many things are not disclosed upfront (...) sometimes straightforward information about what happens and what the consequences are is not provided, for example those pertaining to the risks associated with a surgery, and then you are caught off guard when such things happen to you. G18_230

The information provided can sometimes be devastating and unclear, parents feel the need to know, to talk to someone who has expertise, who can provide answers. This father would like for the doctor to be more competent, whereas the doctor keeps referring him to external help (psychologist, priest) without taking into account the needs made plain by the father himself.

They told me my daughter would never be normal and that I would spend my life at the hospital, save for a miracle... in those thirty seconds I saw black... you can't fathom... you can't (...) they asked us if we wanted to speak to a priest or a psychologist but (...) I want to talk to someone who can tell me something about my little girl (...) I cared about nothing other than knowing we could go on. G8_218

Unclear Communication

In some cases, doctors provide vague or superficial information, but parents actually want to know the specifics of what is going on

I saw her for the first time in neonatal intensive care and I asked if she would ever speak again, but the doctor shrugged it off, saying he could see no reason why not. I'll

remember it for the rest of my life: he didn't say yes, he didn't say no. Either option would have been enough for me. G4_306

I think they knew since the start that they were incompetent, because this neurosurgeon kept telling me I should take my son where I was sure of what they were doing G10_150

Clarity and appropriateness in communication means that parents need doctors to treat them as equals, with respect, taking into consideration their competences rather than dismissing them

For some doctors, talking to parents equates talking to simpletons... like when we talked about the aneurysm (...) when in the presence of a parent, it is necessary to use words that are not too hard to understand. G8_118

When they told us about the transfer (...) my wife kept asking questions and they told her that answering her would hinder the mailing of the documents, but they didn't even send them (...) had it been their child they would not have waited a single second. G10_149

Doctors should take advantage of the opportunity that parents represent, since their knowledge is a resource.

It felt as though they were afraid of talking to us freely, but they ought to do so, because we are fully aware of our daughter's condition and of what is happening with her, and, being in such close quarters with her, we can give suggestions as to how to manage things for her in the best possible way. G7_297

It is fundamentally important for a parent to understand what is being done to their child.

One tells me that she needs to change some parameters to see if my daughter can breathe on her own, with a bit of oxygen and without the machine, and she'll see how it goes,

she tells me what she has to do and why, and she also tells me how she goes about doing it, she has told me everything, so I don't need to ask anything, but sometimes someone will come, (...) they'll say nothing and leave (...) then, they'll come again, do exactly the same, and leave. I need to know what you're doing, why, and what you're trying to achieve. G6_188

It's our turn, we go in and greet the doctor, she replies but she does not look at our little boy (...) we go back in and without even seeing him, the doctor tells us he could have a deadly infection, and they are looking into it, she keeps compiling documents and asking questions, then she repeats that they are conducting tests, (...) then she finishes by apologizing for the fact that she is unable of talking about serious occurrences with a smile. G9_259

Parents are looking for answers, they're asking to know how their children are.

In that moment you look for the answers you cannot give yourself... in that moment I wanted for someone to tell me what would happen, how it would go, what needed to be done. G18_231

We couldn't understand what was wrong with our daughter, because unfortunately her condition required the assistance of several experts, each with their own opinions. G8_195

In intensive care the focus is often on the work, this mother asks, she is afraid, but she never receives information, it's an endless delay, even though the parent is in need of answers.

When my daughter got here, she couldn't breathe well. They take her, they intubate her, they want to save her. Professional, concentrated on the work, but I would always come her with my heart in my throat, how is my little girl today? How are things with my little girl today? But the answer was always the same. She is stable... she is stable, she is stable. G8_178

A Difficult Communication Process

They employed tact, but the MRI outcome was not comforting, there was widespread damage, and it was no longer a question of days, but rather of hours, and they told us to think of the possible outcomes... the first few days we didn't even know if she would survive (...) those are the times when you ask yourself why you, but it's your son, it's a pain you cannot describe with words... it is bigger than you. G20m_250

The communication approach does not always mirror what a parent perceives, in other words, the impact the communication will have.

Before the surgery I was talking to my son, and I told him that in two days we would get rid of all those bad things, I was trying to encourage him, and the nurse, completely unwarranted, tells me that it's not a given, in two days something worse could come along. How can you say that to a mother two days before the operation? (...) The nurse did not do it out of spite, she was just trying to tell me not to delude myself, but it was devastating, not the content, the manner. G3_73

Some are more direct in giving you information, others are gentler, but in the end, they tell you what they need to tell you, they can't go around in circles that much. Overall, we always received information, whether it was relevant to us or not. G3_86

Being Afraid of Communication

Oftentimes parents are a bit fearful, we ask few questions because we always have the feeling that we are getting answers we don't want to hear about. G5_330

I thought the consultation would be much worse (...) but instead we went into a room and they told us that nothing would be decided, so I was relieved... they illustrated everything they were doing. G20p_238

At first, I was always afraid to ask or do, but then I understood how forthcoming you all are. G1_103

Waiting for News

Waiting for someone to tell you something. Waiting for someone else to tell you about your child's pain, waiting for those words. Silence is associated with death, words are associated with life. If silence is deliberate, it's not death, but it is when it is forced. Words are life, Jesus said: "I am the word, and you shall be reborn if you heed it".

Since 8:30 AM... the surgeon told us it was pointless to stay because the operation would not end before 7 PM (...) we waited but we were only able to see him at 3:00 AM (...) they don't explain the timing, and they tell you they'll let you in a bit... but two hours go by, and you wonder what went wrong (...) minutes last forever and... you don't know how it's going, what can happen... how you'll find him. G10_157

The way you talk to me here is not the way you talk to someone in a different room, our circumstances are different, to talk to someone you need to see who that person is, what they must be feeling, what this person needs to get off their chest. G6_173

The Need for a Person to Refer To

Finding someone who will answer your questions, someone who knows the children.

Fee

I always ask... but I cannot talk to the resident, I need to talk with the doctor... at least once a day. G7_298

Every time I come here, the resident on call requires me to give a 20-minute back story (...) but if there were an expert doctor with whom to share my doubts, it would be better because the resident gets spooked, calls a staff member, and it all starts from scratch. G4_319

Where the Communication Takes Place

Feeling thrown out, not having a dedicated space. The world falls apart for parents, but it goes on for the rest of the world, work goes on.

I would have liked to have had a place that was not a study where doctors work, so that I could stay after the consultation to have (...) the time to elaborate... instead you are

the one who has to leave, and if feels like being thrown out, once you're out it's over, whereas you would like to cry, shout. G3_94

3.2 THE HEALTH CARE WORKERS

The codification of the materials pertaining to medical professionals is summarized in Table 7, where the emerging categories and relative theoretical labels are described.

The outcomes of the analysis are introduced as three dimensions of experience, along which the contents of the parents' accounts are situated: lived experiences, critical issues, and the parent as the other.

Sensitive data, as well as information that would have made it easier to identify the interview subjects, was omitted from the study for privacy purposes, but the anonymity of the data did not significantly influence the outcomes of the research.

The accounts coming from doctors and nurses were examined contextually, since the choice to treat both groups as one larger category of third parties who encounter the child's condition. However, in order to maintaining each group's specificity, the acronyms 'D' and 'N' to identify doctors and nurses, respectively. The distinct categories and theoretical labels are situated within said dimensions and are summarized in the following table:

Table 6_ Analyzed data about HCW

Dim.	Categories	Labels
The Parents Role	The communication	Parents Have a Right to Understand
		The Responsibility of Communication
		Choosing the Right Words
		Learning to Communicate
		Trust
		Parents Are More Competent than Medical Professionals
	Suffering	The Burden of Suffering
	Defence Mechanism	
	The Parents Role	The Parents a Savior
Lived Experiences	The Relationship	The Relationship with the Child
		Establishing a Relationship Through Trust
		The Relationship with the Family
	Difficult Moments	The Parents' Word
		Asking Questions about the Child's Care

	Decisions	Making Difficult Decisions
		Accompanying a Child
Critical Aspects	Critical aspects	A Lack of Trust
		<u>Fear of Change</u>
		Organizational Issue
		<u>Absence</u>

3.2.1 The Parent as The Other

Communication

Quite a few accounts from healthcare workers focus on the issue of communication. Sincerity in communication is a keenly felt topic by the participants of the study, and, as confirmed by the relevant literature (F. A. Carnevale, 2008), it is one of the most complex aspects relating to the management of CCCs and their parents.

I don't feel at ease with myself unless I've told the whole truth... we cannot leave things hanging, but we also cannot say everything right away. MP6_519

Parents Have a Right to Understand

Medical professionals believe that parents deserve to receive clear, honest, direct communications. This view is supported by Carnevale et al., who came up with guidelines in which these issues were underlined.

The following excerpts place a particular emphasis on the importance of disclosing critical situations to parents so that they may spend time with their children in their last moments

The moment I tell you that I fear your child will die, or that I give you irrefutable words, and a parent has the right to know if their child is dying, because there are things you can do when the child is there that you cannot do anymore later. Your child's last acts cannot be repeated, you therefore need to guarantee, if possible, to talk to them for the last time, I mean, if I am intubating a child who may never wake up, or I'm not sure if they will wake up, I have to give their parents the chance to talk to them, say goodbye, tell them they love them, you have to guarantee closure. MT2_645

It is useless to soften the blow, communication needs to be sincere, poised, and respectful, leaving room for whatever they want or do not want to say. Even an eloquent silence ought not to be overshadowed by what you would like to say or would say in their stead to be consoling (...) you shouldn't feel embarrassed if you're sad together with them, and you don't necessarily have to leave the room to leave them alone, but you also need to understand when to leave them alone because you're a stranger. MP5_563

This nurse believes it is necessary to prepare parents for the worsening and possible death of the child before an acute episode occurs. This not only entails providing adequate information, but also preparing the parent for what could potentially happen from a scientific standpoint.

Sometimes professionals observe that parents are either not ready or seem to lack the willpower to fully comprehend what they are being told, then they speak of the necessity of working in a group. If communications are disclosed in an unclear manner, parents cannot understand what they are about to face in terms of worsening of the condition or death of their child.

Some parents do not wish to understand... they don't want to hear certain things but (...) many times I've heard people telling me they didn't expect it would be that serious... it happens a lot with chronic kids, or heart patients with an ominous diagnosis (...) I think that we could have dealt with the communication side of things better. IT2_394

The Responsibility of Communication

Based on the complexity of the situation, and on the nature of the communication, the same is provided by a resident, a nurse, a doctor, or the head of a unit. But, as this nurse states, sometimes parents require a kind of certainty that cannot come from a nurse or a resident.

In that moment parents need certainty, confirmation, and that cannot come from a resident (...) so I go to a member of staff and tell them that that mother, that father need their time. IT6_426

They are nevertheless residents, so they do not take stances when speaking to parents.

IT6_421

Choosing the Right Words

The responsibility of communicating in especially dire circumstances falls on the director, who coordinates all of the communication phases in order to avoid misunderstandings.

However, PICU doctors and nurses who do not directly manage the communication process are still required to provide assistance on a daily basis, and issues can arise when information is supposed to be given at certain moments and in certain ways.

It's very difficult, because these parents (...) they expect information to always come from the same doctor, who is usually the chief or their deputy, and you're in an even more difficult situation, because you're not supposed to say anything, but if you're on call there can be a misunderstanding, it's very complex. MT1_605

Difficulties also emerge from not being able to express one's opinion about the situation at hand.

It felt terrible not to tell the parents what I was thinking, because I did not want to influence them in any way, so I limited myself to perfunctory updates on the clinical picture, which is not me at all, so I felt deprived of my personhood. MT2_639

This nurse feels the weight of having to withhold some of the information she is aware of, despite knowing that this conduct is in the best interest of the child and the family.

You have a child in critical condition, and parents ask you how they are doing, and you know... the situation is critical (...) but you have to say the child is stable... I feel uneasy because I have information, I know the picture is critical, but I can't tell the parents that (...) because there is a time and a place for that information to be disclosed. IT5_464

Complex moments occur when a mother... asks questions, but there is no definitive plan, you know the answer, or you have an opinion, but you have to stay quiet, and this is frustrating for me, I cannot say what I want to say, it feels like lying. It is nevertheless necessary because there is a whole process that comes before the answer itself. There is no solution, answers cannot be given to a parent who is unprepared or when the situation does not call for it. IT3_451

For example, when you are already aware of the child's diagnosis, but consultations with the director, the psychologist, and the mediator have been scheduled, parents deserve to be informed in the best circumstances possible, but it's difficult for me to know without being able to say anything. Not being able to openly talk to the parents. IT3_452

Sometimes I know something I must not disclose to the parent for fear of making things worse, or perhaps it's destabilizing information, but I feel that sometimes they just ought to know, whereas we wait, creating a secure and protected environment, and all that hiding felt like we knew something the parents had to catch onto. IT5_461

In the following excerpt a doctor narrates of a time when the group of professionals put some relational strategies into place to get the father of a little girl to trust them. Unequivocal communication is regarded as being fundamental both by the participants in this study and recent literature (F. Carnevale, 1999; F.A. Carnevale, 2008; F.A. Carnevale, 2012; F.A. Carnevale et al., 2016; Latour et al., 2010).

We never went outside the rules. We stuck to them, but with clear, unequivocal messages, we tried to get as few people as possible to deal with communication, sharing the information itself, and this helped us reduce communicational difficulties, on the one hand, and to get the father to trust us, on the other. MT3_619

Sometimes a single worker disagrees with the majority stance, which is inevitable, but still creates difficulties and internal conflicts for the individual.

Not being able to tell the family what I thought was hard because what the group and family wanted contrasted with my conscience in regard to the topic. MT2_636

The mother said she didn't want to do it, and I agreed with her, but I didn't (...) say it because it's not my job, it's not fair for me to do something like that. IT1_343

It would be useful to make one's opinion public, even if it does not follow that of the group, despite the asserted need for unequivocal communications, but what emerges here is frustration at the idea of not feeling part of the process.

We were dealing with an extremely compromised child from a clinical standpoint, (...) the family did not wish for him to be therapeutically persecuted, they wanted to turn to palliative care, a choice I did not agree with (...) communication was managed by few people whose opinions I disagreed with, I felt shut out from the possibility of giving my opinion to the family, maybe it would not have changed their minds, but I thought I had the right to do so. MT2_634

From the researcher's journal: Being in a group means accepting compromise, and supporting the common stance, small deviations are inevitable, but they cannot undermine the integrity of the system. The group can organically sustain and absorb disagreements in its midst, but this dissonance must remain within the group dynamic to ensure the functioning of the entire system.

What can happen when a group is not cohesive in terms of communication is described in the following excerpt. In this particular case a nurse shares their discomfort caused by a change in stance from some group members. Once the decision is made, however ethically or morally complex it may be, a lack of consistency in its implementation can be even more distressing.

Sometimes there is a lack of planning... everyone gives their own opinion, and there is dialogue, but then there is no consistency: if we just decided to accompany the child, why is it that someone can decide to deviate from the agreed upon course? IT2_392

In the following excerpt the doctor describes the extent of complexity a situation can come to when consultants are involved, and the doctor perceives that the necessary

information is not passed on, but cannot intervene and support the family, if not marginally.

Communication requiring the involvement of third parties, especially consultants, is not a good thing, in my opinion, because it occurs with the use of medical terms, with parents who do not understand what is going on. The parents were not able to make an informed choice pursuant to the comprehension of the problem and of the possible solutions and statistics. (...) They were not even told that their daughter could be transferred to a hospital where they were more experienced, and the operation could thus occur with less risks attached. The sense of imminence conveyed by those who were speaking put the parents in a subordinate position, so much so that they didn't ask any questions... there was almost total asymmetry. MT3_623

Learning to Communicate

Some doctors acknowledge their scarce preparation in terms of facing interactions with families. Communication and clinical competence run on parallel lines: whereas the latter can be researched on books, or through specialists, the former requires building competence and knowledge from unclear sources.

*I feel as though I lack education, because you can study the rest, or ask consultants.
MP6_519*

I would like to possess more instruments to communicate effectively, sometimes I feel sorry that I come across as being unempathetic, or unable to say things a different way, a more empathetic way. MT1_607

Trust

Given that the focus is on children with chronic conditions, the personnel believes that it is crucial to cooperate with parents, given that the same are the main care providers for the children in question. If the aim is to work for these children's health, it is necessary to secure their parents' trust. Without trust, good communication is impossible, and without communication good care is impossible.

The basis for everything else is parents' trust, and this is the kind of thing that can really create problems for you, because if you don't have this kind of baseline, getting them to understand you, as with everything else, becomes burdensome. MP5_545

You have to get to know these people to communicate with them... you need to create empathy... and then you have to adapt your communication style to the person in front of you... there needs to be mutual trust, communication is based on trust. MP6_520

When a bond is established, and parents' trust is secured, the healthcare workers begin to feel part of the family circle, it is a singular occurrence which does not commonly happen within the doctor-patient dynamic, but this research demonstrates that it represents an outcome of treating chronic conditions. Trust occurs when the family feels that the doctor is part of the family, and this is a fundamental aspect towards creating a sound alliance.

Communication can happen smoothly when it is based on trust within an extended family. MP5_556

In this extended family communication becomes easier, because you know you have built a journey together (...) you have been welcomed into this family and you are involved in their dilemmas, you share in their defeats, sadness, and anguish. MP5_557

Seeing that a parent willingly gives away the care of their child means getting a sense of trust.

You can tell from the attitude and manner in which someone gives you their child to care for that they trust you, and you can work well as a result, you have the right balance to work in the best possible way. IT2_357

He would not let anyone get close to him because of everything that had happened before... he had trouble breathing, he was agitated, there were eight people in the room with him (...) I explained to the parents that unfortunately we had to pierce his skin (...) he reacted well because the parents trusted us, despite the hospitalization and everything

they had gone through, they were serene, and they said so, they were confident that we were not keeping anything from them about how we worked and what we were doing.
IT5_460

This nurse describes the importance of cooperation and understanding among healthcare workers and parents. As a matter of fact, taking charge does not mean providing care first, it means cooperating with the family for the good of the child.

We had exemplary parents who did everything... they did not however exclude us, we worked together, and you could tell they understood our difficulties, this particular mother taught us a lot, and we all carry her as an example for everyone else. IT2_388

When cooperation is effective, what this doctor describes occurs:

You become part of a relationship. MP5_554

Even the most critical situations can be ferried across to an optimal result if seen through the lens of cooperation, which in turn does not mean that the respective boundaries connected to the role each person plays are not respected, but rather that there is a unison and commonality of intent.

There is a good relationship between the mother and myself now, we still address each other formally because she is still the mother of a patient, but there is a bond of trust now. MP6_495

This doctor recounts a shift in his relationship with a mother who was initially wary of him in a prominent way, and he states that he understood the intense bond between her and her son, and how devastating his death would have been for her, in a wholly new way once she let him in.

I remember the tears in the mother's eyes, and the trust she demonstrated towards me, one of the most difficult mothers, who entirely rejects to be helped: she is always wary.

She lives for her son, and it will be hard for her when he will not be here anymore.

MP6_640

Parents Are More Competent than Medical Professionals

In order to build trust and cooperation with the aim of creating an alliance with parents, medical professionals believe that they need to acknowledge the fact that parents have more competences than they do when it comes to caring for the child, since they know more about the pathological evolution of their child's condition over the years.

With a child such as this one, his mother has to keep a journal. IT6_415

Parents know their children very well, and I listen to what they tell me, I don't want to tell them what they ought to do. MT2_498

Nobody knows the child better than they do (...) otherwise it would take us months to comprehend the meaning of a movement or a sound. IT4_473

I place a lot of confidence on interactions with parents, and I try not to interfere too much with the basic care they offer their child, nor with these children's habits (...) I let myself be guided in managing the treatment and in recognizing distress signals. MT3_609

On the contrary, this nurse underlines the fact that the presence of a parent, albeit useful in supporting the child's care, can be the source of extra work for the professional.

If the mother were here the child would probably feel better, I find the absence of a parent personally disturbing, but then again you can have a parent who pesters you, and distracts you from the child's care. IT2_376

In the following excerpts, some healthcare workers attempt to interpret what parents are going through, and try to provide an explanation as to why in some instances parents are perceived as a hurdle rather than a facilitating element.

Some parents are defensive rather than forthcoming:

These parents know the child better than you do, they've had enough of certain types of hospitalization, and they realize that they know more about certain things than you do.
MT1_598

On the other hand, there is an attempt to understand what lies behind the lived experience of a CCC parent. In such cases, doctors and nurses look to the process to explain why parents act the way they do, as if it were a continuous change, a transformation, under all of which the fragility and the difficulty that comes with such a feat remain.

Sometimes these parents are oppressive, but we know where they are coming from, and oftentimes the child becomes the parents' whole life. MP6_632

A lot was asked of this parent, he chose to become a father, not a doctor, nurse, medic.
IT4_483

Sometimes they just want to say they're tired, they can't take it anymore, and they want to cry. IT5_463

Suffering

The Burden of Suffering

Sometimes parents need to let it all out, to channel their fears and need, to let the suffering out. Some parents did not know about their children's conditions before they were born, whereas others chose to carry on with the pregnancy. Some are confrontational, others are absent, and very pressing towards the medical personnel.

It's different for one couple of parents who chose to become parents to a child with a chronic condition, they tend to be more careful, but at the same time they are more critical

of what we do... they are a bit more absent, but once they are here, they, especially the mother, can eat you up if you are not careful. IT3_438

From the researcher's journal: I get the feeling that in some cases interviews are important to parents, because they are allowed to blow off some steam, think through their ideas, and state what they believe, not only with regard to their child's clinical picture, but also to the organization of the hospital, where most of the criticism denounced by healthcare workers can be found.

The burden of suffering is not the only reason it is difficult to accept the suffering itself, but this is mostly due to the absence of adequate instruments to tackle it so that it doesn't transfer over to the medical professional. The capacity for empathy cannot become an overwhelming experience for the healthcare worker, but it must be such as to provide support for the suffering parent.

On the day she vented (...) she actually realized that she was going home, and she realize what she would have to do, she expressed her fears to me. She realized that she had been an obstacle to a return home, but she put all of her difficulties on me, because it looked as though I had spoken for a few seconds, but it was a long conversation, during which she repeated many times that I had ruined the best day of her life. MP6_516

Accepting suffering is hard, it's hard, and it's easy to say that one should stick to the clinical side. MP6_648

The burden of suffering on families is a hefty one, and because of it you act on a defence mechanism, survival mechanism or (...) in the sense that your level of emotional stress is higher than with other children, obviously. MP5_521

The following doctor believes that it is difficult to be close to families, because such a closeness can become painful for the professionals themselves, who may not be able to manage the emotions resulting from it.

You have been welcomed into this family and you are involved in their dilemmas, you share in their defeats, sadness, and anguish. MP5_557

It is also worth reporting the observation below, according to which a parent suffers more if the chronic condition develops after a period during which the child was healthy.

Even if the child was fine until the day before, now you have to deal with a different child: their affection and emotions were directed at a different child, a child who changed... and you are forced to live in this inferiority complex towards the life you had before. IT5_455

Defence Mechanisms

Healthcare professionals who, as evidenced above, do not have any support in dealing with the suffering they are exposed to, run the risk of creating defence mechanisms preventing them from feeling involved. Forging a bond with a parent and their child is risky, going beyond the demarcation line that exists between doctor and patient is risky. Professionals feel like they could not bear such communality and closeness on a consistent basis, given the situations.

At first, I built a relationship that compelled me to go beyond the boundaries that exist between doctors and patients, and I felt the emotional burden of it, so I took a step back, because I was in too deep. It can be wonderful, as I remember, (...) but if it happened with every patient I could not take it. MT4_564

My approach towards my patients is the standard one, there is a limit I am not willing to go beyond from an emotional standpoint. MT4_564

The doctor-patient demarcation line remains intact... so that I can maintain my integrity. MT4_566

In some instances, healthcare workers perceive that parents are being defensive, although it is the view of this research that it is not so much parents who have a defensive attitude, but rather workers who perceive a high level of attention. .

They can know more than you do (...) you approach them with difficulty because you need to be careful about what you say, each word counts (...) and they are tired of repeated hospitalizations, of doctors to, they are defensive. MT1_599

In some cases, the healthcare professional is also defensive, and has a hard time accepting the competences that parents have developed, as described in the relevant literature (Rafferty & Sullivan, 2017). In this situation, the doctor tends to view themselves as a newbie, or senses that they are seen as a newbie.

You don't always have the right competence, you don't know that kid the way they do, so you have to listen to them for example when a parent tells you that their child is not feeling well because they are eating, and you tell them that's not the case because of this problem and that problem, and then you feel desperate because nothing you've done worked, and then you stop feeding the child, and they feel better. MT2_633

Parents look at you as though to say, "We have known his kid for a long time, we have dealt with these problems for a long time", so you do feel like a new bolt in an already well-oiled machinery. MT2_630

The Parent's Role

The Parent as a Savior

Parents forge new roles for themselves to become more useful to their ill children, but they sometimes lose sight of their role as parents, as described in the second excerpt below. Rafferty looked at this issue in depth (Rafferty, 2017), focusing on the attempt on the parent's part to regain control over their child's fate, the control that was lost the moment the condition was first diagnosed.

I think I was disturbed by the sight of a parent who was frantically turning into a savior... a doctor, a nurse... a lot is being asked of this parent... because not all parents

can do this stuff, so I wonder whether this person has any time left to be a parent, or are they just a technician at this point? IT4_480

When the child has an acute episode, parents tend to become spectators, but CCC parents don't have that option, because a parent who loses their role and ability as such when the condition is diagnosed becomes an expert in the same, and in everything concerning their child, over time. A child's successful care management relies on parental caregivers overseeing care coordination, as they are often the only participant playing a consistent integrating role across a child's healthcare continuum. Parents therefore become the experts with whom healthcare workers need to form constructive relationships (ibid., 2017).

The parent of a child experiencing an acute episode is a sort of spectator... but with CCCs it's not the same, you have to find a way in, and do it with respect, but at the same time you have to be aware that you need to get to know the child, understand the problems they have, to what extent the parents can help, and the nature of the help they can provide, suggestions that would otherwise require months to be interpreted. IT4_473

The following nurse notes that there are different kinds of parents, parents who take care of each single aspect of their children's lives, and parents who are confrontational and angry because they have not fully accepted the condition.

A parent is transformed into a doctor, a nurse, a physiotherapist... psychologist, social worker... or they cannot do a single thing amongst all of those, and they try to compensate for it... parents are often affable and appropriate, but sometimes you find parents who are confrontational, angry, tired, so approaching the chronic child is a delicate issue. IT4_467

3.2.2 Lived Experiences

The Relationship

The Relationship with the Child

Some healthcare workers have a distinct consideration for the children based on their ability to reply and interact. This does not mean that the child must be normal, but rather that the quality of life the professionals perceive is based on their capacity to interact. According to some, the decisions about the child's care should also depend on an evaluation of their cognitive and relational abilities.

The MRI, the encephalogram, the ways a child interacts are indicators of their state of mind. Interaction with others is the baseline (...) I don't know what this child could understand, but whenever he saw his parents he would smile, when you spoke to him he answered somehow. MT1_590

According to this doctor, it is important for a child to be discharged with some measure of communicative ability, in line with what has been evidenced above, it is comforting to see a child smile and interact despite their limitations, and to see their parents happy to bring them home.

When we discharged him, he was playing a bit, smiling, interacting, and his parents were happy, despite his problems. MT1_596

On the contrary, the following excerpt describes the difference between witnessing a CCC with some communicative abilities, capable of interacting, and seeing that same child after she had lost these abilities.

She was a little girl who communicated with her eyes, her smiles, four-months-old, she was hospitalized, had no stimuli, but we were good, because a little girl who had been in hospital for so long, with her issues, in all seriousness the mother did a lot, but we also did a lot... and now we've lost everything, but there was a time when she gave us so many emotions. IT6_418

In the following excerpt the doctor describes how treatment makes sense only inasmuch as the child maintains a quantum of ability to understand and communicate.

I can tell that you understand me and can communicate. Maybe he could not speak, but he could communicate with his expressions. We are both capable of exchanging expressions. MT1_593

These abilities are so important for both the medical professionals and the parents, but they are very difficult to identify (Solodiuk et al., 2010), albeit so crucial in terms of allowing the former to acknowledge and build a relationship with the child.

He would look at you with such wide eyes, he loved being massaged, and you wonder about the difference between a little one you have to bathe and one who tells you everything with their eyes. IT6

Establishing a Relationship through Trust

As time passes, the child comes to recognize and trust the doctor or the nurse. In spite of the neuropsychomotor disability, children are able to identify and remember their traumas (Taddio, Katz, Ilersich, Koren, 1997). After the initial hospitalization phase, after the first period when procedures constitute the root of suffering for these children, there is a chance to build relationships based on trust and cooperation, which in turn allow the little ones to feel less scared, as this doctor describes:

He was so scared, he would become agitated and extremely sweaty... many people needed to be there to hold him down, then he would begin desaturating and feel ill (...) now he plays with my toys while I change his tube (...) I can tell that the patient recognizes me and trusts me... he does not resist, and he recognizes me. MP6_506

There is a difference between seeing chronic children every now and then as opposed to seeing them over a given period of time, and being aware of the continuity of the condition facilitates a better understanding of the suffering and burden placed on families.

I was afraid of these children because I couldn't understand them well, (...) then of course when you work with them and witness the years go by, you get a better sense of these children's predicament, because you see them over a given period of time, you understand the suffering more, and its permanence too. You get a better sense of the suffering and burden weighing down on families MT1_583

The Relationship with the Family

A description of family as a system that healthcare professionals need to penetrate in order to treat the child.

You can't separate the child from the relationship their parents have with them, an alliance needs to be made with them, and it's all about finding a non-obvious brand of empathy. Parents need to trust you, and you need to be able to inspire that trust with your competence, but also with your humanity, to the point where they find a place for you in their "dyad", it is important to feel accepted as a human being, and not just as a doctor. MP5_533

With regard to what is noted above, a nurse observes that nurses in general tend to have an advantage over doctors, because they see parents more often throughout the day, and therefore get more chances to interact with them.

We nurse have an advantage, because we get to experience parents often throughout the day (...) whereas I think a doctor is disadvantaged in the sense that you may or may not see them. IT6_420

Giving parents attention is important, because they feel acknowledged, and doctors feel the same for being listened to.

I asked a mother how she was, and when she had to be discharged she told me that the memory of when her daughter was hospitalized, and I had asked about her had stayed with her, because no one ever worried about her. MT3_620

Cooperation requires an understanding of the role each person plays. Letting parents have their say can mean a loss of control over the patient for a nurse, and the effort to let go is exactly what is required of them.

There was a parent who took over the management of emergencies, I couldn't get close, and it made me feel anguish, rage (...) I thought we were all insane but I let it go (...) and I thought it through, I realized that it was a little girl who was care for at home, that the father was even better than myself at dealing with her (...) you are used to feeling responsible, but in that moment you are not responsible for anything, you feel confused, we are used to having the situation under control, but in some cases you just can't.
IT4_478

The following nurse expresses the will to take charge not only of the child, but also of the family.

We take care of everything, including the family, so the parent is not solely the child's father. IT6_423

You have to be aware of how much the parent is capable of doing, to what extent they are capable of receiving help, how much they want to be helped, how much we can let them do as opposed to putting ourselves in their stead, you have to have a sense of timing, you cannot tell someone who has covered their child's care one hundred per cent that you're taking over there and then. IT6_470

It is necessary to adapt one's strategies and approaches to each kind of parent. It is not always possible to standardize, every case is different, and the competence and experience of the professional can be inferred from this ability too.

There are the usual things one needs to be aware of during a hospitalization, for example I would not want to interfere with the care routine a child is used to at home; I don't modify behaviors, approaches. IT6_397

Finding an ally in the child's family is useful to ensure the best care for the child, or at the very least to lighten the process.

A family that supports you and is your ally makes all the difference, you work well, or at the very least it's easier to work... IT4_468

It is important to feel understood on the job, and getting thanked represents a confirmation of the fact that the doctor's job was understood and appreciated. Feeling accepted by the family is essential.

She looked for me for the longest time, and in the end she managed to get a hold of my e-mail address, and she thanked me for how I had treated her son... who is now ten-years-old...and I was happy about that (...) it is rare to receive such endorsements by parents in this line of work, you give a lot, and you sacrifice a lot in your life, your family, your wellbeing, and you often don't (...) feel like they fully comprehended the extent of your work. MT4_575

Being accepted by a mother and her child is satisfying. Managing to get a child to smile at you, managing to understand their needs, their gestures is also satisfying.

Being able to establish a contact, being accepted gives you satisfaction, all the good memories I have refer to the child's acceptance, a smile, a situation you are able to fully take in. IT6_417

In some cases, it is important for parents to let the doctor in, to access their family dyad.

These kids have been ill for years, a bond is formed with the parents, and you have to make an effort to access this dynamic, but C.'s mother would let us in as long as she was here, other parents do not allow that. IT3_441

When my son was born, a parent wrote me a beautiful note, saying they were happy that I was happy, and they gave me a little gift, even though they were fully aware of

their misfortunes (...) the fact that they wished me well, when I could have been a scapegoat for them in other situations, made me feel good, because it means they understood what I was trying to give them (...) you become part of a relationship.
MP5_551

Communication flows well when the starting point is trust (...) because if you've built the stepping stones together, and from there you can work on acceptance, the negative aspect is that (...) you are involved in their personal tragedy, because you experience the defeats, the sadness, and the anguish alongside them. MP5_557

Becoming part of the relationship also means becoming a point of reference for the family, sometimes helping them feel more secure, for example in the following excerpt a doctor illustrates how the fact that they are in control makes the parents feel serene in going to a game.

They look for me because they trust me, there's a good energy, they come to me with her before the match so that she can go there, and this is also an aspect of the relationship you become a part of. MP5_150

Difficult Moment

The Parents' Words

This doctor describes how the parents' words can create difficulties when facing suffering, which in turn translates into communication-related issues.

"You are doing nothing for my daughter. If my daughter dies, I will kill you all" (...) it was hard to talk to someone you know hated you without knowing why they hated you. That's the difficulty. MT3_616

I remember talking with the mother, whom I already knew (...) she was not in pediatrics, but she understood everything very well. And I understood that, in the mother's view, the daughter could not die, and she kept insisting, at one point I felt exasperated, and I blurted out: "Yes, but what do you expect, what do you want?" (...) she expected me

to give her answers I couldn't provide, and I knew she knew I couldn't give her those answer. MT1_600

Despite knowing that a parent needs to express their suffering, and from time to time that happens by venting at healthcare workers, the reception is difficult and burdensome. Clinicians need to be supported in managing this kind of trauma.

I remember that, in order to deal with the suffering caused by that mother's words, I went to talk about it with two people I admire and with the psychologist, because it was taxing, I know she didn't really mean it... but she did say it... a part of me may be rational, but I am sensitive too, and I dealt with it over time, and I made my peace with it when I noticed she trusted me. MP6_518

Asking Questions about the Child's Care

This nurse gives an account of the difficulties she had in appreciating that the child would be different after hospitalization, and she is aware of the fact that the parents will eventually take the child home. The principal difficulty is envisaging what a parent is likely to go through, and that the reality of the situation could be much worse than the original hypothesis or consultation with the parents themselves.

It was hard because until he remained seated he looked normal. But then you could really see all of the damage cause by the head trauma, he was stiff, he couldn't even lie on one side, and then there was all the rest, the fixed eyes, the incoherent sounds, the grimaces of pain (...) The reality of the situation has nothing to do with our evaluations, the reality is the outcome, the state in which they will bring it back home. IT_342

This doctor wonders if everything that could have been done was actually done, and wonders if errors were committed. The most distressing aspect is acknowledging the pain and agony. Such an intense lived experience creates an indelible memory.

The worst part was that she didn't make it, seeing how she wasn't able to recover despite doing everything we could, probably within an appropriate time frame too (...) seeing the agony... I still remember it was in her eyes... this little girl's eyes were so expressive, it's

as though I could see her now, and then it ended in tragedy (...) we watched many kids die here... but she was the one who got to me the most. MT4_574

An extremely difficult situation occurs when a professional has to stand by a parent who has to say farewell to their child, they will never see their child again, or at least not as they knew their child. The doctor knows what is about to happen, they inform the parent, but there is a lack of confidence.

It was time for the mother to say farewell to her daughter, because we were about to put her to sleep, and she would never see her like that again, these are obviously difficult moments, in which you have to lead a parent to say goodbye to their child, it's a moment of farewell, from that moment on they won't be able to look their child in the eyes. MP5_542

This nurse describes a mistake she made that she never forgot about, and allows her to have a different approach with patients. She illustrates how, for a certain amount of time, she compromised her chances of communicating with a child who arrived in a coma, and woke up in what she believed were normal conditions, but actually prevented him from employing the PC, his only means of communication.

I still remember that little boy who was brought into the emergency room with a chronic condition, who arrived with long nails, long hair, I got anxious, I bathed him, I clipped his nails and hair, but when the mother arrived five hours later, she asked me who had clipped his nails. It turned out that the long nails were the only means of typing on the PC (...) this episode taught me to assist patients without spontaneously trying anything.. IT2_366

Listening to parents means listening to their needs, even if it means feeling exposed.

I remember a little girl, the daughter of two colleagues, with terminal brain cancer, and I remember they had been everywhere, to America even, they had tried everything, they would not accept she had a tumor. She died when she was sixteen-years-old. I remember

talking to the mother (...) she wanted me to give her answers I could not give, and I knew she knew I couldn't answer her questions, I couldn't see a way out. MT1_601

When a child suffers, and treatment is perceived as useless persecution with no positive outcome, a sense of failure kicks in.

Seeing this child feels like a complete professional failure to me, it's torture to imagine that we have given him and his family a different kind of torture (...) Whenever I see him, I realize it's a life of pain. It is hard enough to go into the room to visit him, (...) his condition is unacceptable. MT1_594

Decisions

Making Difficult Decisions

In the following excerpts the accounts mirror what has been illustrated above in terms of distinguishing between children who can interact and those who don't. This doctor observes that there is a lot of uncertainty with regard to the validity of the interventions that are conducted, and they wonder whether there is any consideration as to the proportionality of the same compared to the life expectancy of the child.

If you are persecuting a child with tests and consultations (...) with the excuse that you are prolonging their life by a few months or a few years of dignity and serenity, (...) then it is an effort I make more willingly. But if I simply prolong the hospitalization period, I don't know, the pain is too great. MT1_589

A child should not feel pain, and if they do, there ought to be an end to it, positive or not. MT1_587

Later on, the main issue for parents is realizing when their children have reached their limit. It's not so much about identifying terminal patients, but rather about pinpointing the moment when the sum of the treatments the child receives is no longer enough to compensate for the overall health decline. In some interviews, the need to absorb the moment when the child no longer responds to treatment is made apparent in terms of acceptance of the fact that all resources have been exhausted, and no more options are available.

It is necessary to help them live better in a different dimension. Things change when they no longer respond to treatment, you need to stop when they are exhausted, when they can't take it any longer. IT1_337

When you get to one of the final phases of the illness, you find yourself in a situation where it's difficult to discern to what extent your assistance goes, or when it is time to let them go, because they are children with complex conditions, and you realize how much you've achieved today, and wonder why you should stop. MP5_528

In other words, identifying the “limit of care” is an intricate question. As the doctor below points out, when a lot of resources have already been employed, it becomes complicated to determine when the treatments should cease.

Sometimes you question yourself, what you can provide them with, at what point you ought to stop, in terms of suffering, when you get to the final phase of the illness, you find yourself at a loss when facing a situation in which the boundaries of your intervention are fuzzy, or when you ought to let the children go, because their condition is complex, and you wonder why you should stop now that you've come so far. In other words, life expectancy is so imprescriptible, given the complexity of the pathological outlook, that putting a stop to all treatments is not an obvious choice. MP5_530

Doubts concerning the nature and necessity of the treatments put into place inevitably evolve into questions about the meaning that treatment has for the child.

If what we do for chronic children makes sense, whomever for... if a chronic child who does not speak... but just moves a finger or communicates with their eyes, you do anything to keep them alive, and you manage to do that...but whom did you do it for? For the parents who are too attached to the child? For you, so that you can pat yourself on the back for keeping a critical situation under control? For the child? How do you measure quality of life? IT5_465

Some of the healthcare workers' observations have to do with their own personal experiences, which included situations in which there seemed to be a sort therapeutic persecution towards the children. The nurse in the following excerpt clearly states that there ought to be a limit for CCC care.

When you have a kid, who is eighteen-years-old and weighs twenty kilos, and we have to keep putting and removing the mask, inserting and removing the tubes every time he comes, I think you should leave that kid alone. Or seventeen kilos at eighteen years of age, how is that even possible? (...) I understand that parents love their children, but there ought to be a limit. IT1_338

Sometimes we went a bit overboard. I especially can't stand going overboard with chronic children... sometimes I would like to put an end to it all, and I can't even fathom how difficult it is for them to go on living. I'm not saying that we should kill the children, just that, in my opinion, there should be a limit. IT1_335

There is a risk of expecting too much or hoping to do too much, but the important thing is to keep in mind the objective, which is not that of being a doctor, but doing what is good and dignified for the children and their families.

In some cases, we sometimes expect too much and hope to do too much. (...) We should rethink our objective, in order to understand if what we are doing is actually good and dignified for the child and their family. MT1_585

What gives rise to doubts about one's choices and the nature of the goal in sight is the feeling the children and families are "persecuted" by constant action and incessant treatments.

I don't know if we are doing what is good for these kids and these families, as time goes by you see how haunted they are by these situations. MT1_586

Accompanying a Child

In the previous paragraphs the notion of accompanying the child was introduced. In the following excerpt, a nurse talks about a child who was very ill and was medicated until the end, but she believes that the situation could have been handled differently.

Why not give him to his mother to hold in her arms, and leave him alone? Because you could see it was a situation from which there was no escape, she could have had the time to call home and have the other relatives come... whereas they came when everything had already happened. IT6_404

If a child is in a coma, it makes no sense to prolong their suffering until the last breath.

It was obvious that he was in a comatose state, why did we make this boy suffer until his last breath?! IT6_403

Some participants narrate the pain they felt not only upon seeing the suffering that was a direct consequence of the illness, but also upon ascertaining the absence of any improvement in spite of the various treatments that had been employed. As described by Decourcey (2018), at least twenty per cent of CCCs dies during the mechanic ventilation process and/or resuscitation maneuvers, and the approach to end-of-life decisions is still a highly debated topic (F. Carnevale, 1999; F.A. Carnevale, 2008; F.A. Carnevale, 2012; F.A. Carnevale et al., 2016).

I see too much pain, all the tests we run, the blood tests, the surgeries... I tell myself that a child should not have to endure so much suffering, and if they do, there has to be, I'm not saying a happy ending, but something. If it's just to carry on, for a few months, a few years, a life of suffering... MT1_587

3.2.3 Critical Aspects

Critical issues

A Lack of Trust

Perceiving a lack of trust on parents' part is difficult to accept, because it is strictly connected to the possibility of creating an alliance and feeling part of the family system. The healthcare workers who perceive a lack of trust narrate that they feel under surveillance.

It was hard to work while the parents' eyes were fixed on us, and every move was questioned, it was really difficult (...) I remember we did not have their trust... IT2_380

The parent plays a crucial role, given that their capacity for trust influences how the professionals approach the child, and how serenely at that. In some instances, the parents make all the difference.

The children are essentially all the same, but parents make all the difference, because even putting a needle in with the father staring at you makes you pray to God that you find the vein right away for your own good and that of the child, luckily I did, but I cannot imagine what would have happened if we had needed to puncture three or four times (...) with two eyes following your every move, it's hard to work. IT3_444

She drained me, because I had to bathe him with the mother present, and nothing was right for her... with some parents, I anticipate what they can do themselves, even if they are not there then, and I do it. IT3_439

There are obsessive parents who substitute their child's will, they do not trust anyone outside the family circle, they require absolute control. IT2_369

It becomes also necessary to negotiate the level of assistance when the CCC parent is in the room.

When you deal with children who do not communicate, it is doubly difficult to approach them if the parents are not cooperative, because they stop you all the time, ask you a thousand questions, (...) it's harder for me. IT3_443

In an attempt to understand why a CCC parents lacks trust towards medical personnel, the interviewees look to various aspects, such as the hardships associated with hospitalization, and the asymmetries in terms of treatment and attention that parents notice throughout the hospitalization process. Parents, who are the principal caregivers for their children, feel the loss of control over their child's hospital care as a trauma, which, can weigh heavily on an atmosphere of trust and cooperation.

It was so hard for them to have their son hospitalized, each time was a tragedy, so they were not happy to see the mask on him too much, the amount of meals was always wrong, too little or too much, questions about why he had or did not have diarrhea, complete distrust. IT2_384

I could feel that the mother, who did not know me well, was wary of me. MP5_545

The parents' needs, which sometimes create stressful situations for healthcare workers, create a further need on the latter's part to be listened to and understood.

You realize they have expectations, hopes, as parents should, but on the other hand you sometimes wonder what it is they want from you. MT1_600

From the researcher's journal: How can a parent understand what the medical professional's needs are in a frantic environment of urgent care such as intensive care? It is necessary for the latter to develop competences directed at managing their needs so that the same do not have to be supplemented by parents who are in a fragile state at that time.

Another aspect of healthcare workers' perceived needs emerges from recollections of fatigue, the sense that one's life, family, wellbeing, and time are being sacrificed.

You give a lot, you sacrifice a lot of your life, family, wellbeing. MT4_575

This lack of trust brings about a reflection on the need to create an alliance as a necessary element that results from a process built on mutual trust.

I could tell from the mother's attitude towards me a strong distrust towards everything I said, she did not know me well, you have to convey your intent to help her, of having her child's best interest at heart, but this is often perceived as an obstacle, you cannot establish that alliance that allows you to give proper care (...) the basis for everything else is trust, it's the kind of issue that puts you in difficult positions that eventually become stressful. MP_545

An alliance built through trust allows parents to care for the child and face difficult situations with less stress attached.

If a parent is problematic, the relationship is also problematic (...) a parent on the defensive, who does not trust the medical protocol for the child, who does not delegate... there is no doctor-patient alliance, it is almost impossible to, I won't say to cure, but to at least manage the acute phase a child goes through, it can be excruciating, or it can take much longer than it normally would to get to that stable situation. MT4_571

Fear of Change

For a child with a chronic condition, every new change is usually harmful, and will eventually become stable over time, but it is difficult for parents to accept it, since it brings with it a change in the kind of treatment that needs to be administered. Sometimes parents state their will to keep their child stable, but this is not always possible, since CCCs are subject to a slow yet constant decline in their basic functioning and abilities.

The mother called for a PEG, but I thought it was a terrible idea (...) she wanted for it to be done at all costs, and kept insisting (...) even though this would have worsened the child's quality of life by a great deal, without there being a real need for it (...) I eventually got her to come around to this choice, and now she's fine... MP6_499

I could see in her eyes that she was grateful for what I'd done, and she was happy about how we had managed to change the ventilator, and how we had gone about it... she didn't want to at first, but I managed to change her mind. Sometimes they're afraid of

change... but you have to according to the patient, to the institution's guidelines, to changing conditions. MP6_505

He still hasn't accepted the illness, he is still angry, defensive... tired... difficult. IT4_469

A slow, gradual, inevitable decline in a child's chronic condition brings the question of making sure the treatment always matches the process to the forefront, it is not possible to limit oneself to providing conservative treatments.

I saw in her eyes that she was glad for what I had done, and she was glad that we managed to do the switch (...) it's not always easy for them. MP6_505

Organizational Issues

Keeping up to date with all the details concerning CCCs is quite the task, and there is no one figurehead for that. Parents are usually the most appropriate people to manage relations among the various professionals involved, but there is no "treatment coordinator".

I keep the reins... if new issues arise, I try to schedule the consultations myself. At other hospitals you have the pneumonologist, the anesthesiologist, but not here. MP6

According to this doctor, the pediatrician does not feel competent enough to autonomously manage such patients.

The pediatrician does not feel competent. MP6

Parents often put into practice what is commonly referred to as "medical shopping", that is to say getting the opinion of several specialists, so as to solve the distinct problems autonomously, rather than in conjunction with a systematic form of treatment.

Medical shopping... in the sense that they ask for opinions left and right, they ask me for suggestions informally, and I tell them where to go. MP6

Treating a child who has already been treated by others, thus having to take the reins of the whole process, means becoming responsible for something the parent has autonomously managed up to that point.

I found myself having to reassess and treat a child my way after he had been treated a different way for ten years. MP6

Absence

Some parents ought to be more present throughout the hospitalization process.

I believe that these children ought to be cared for, not necessarily autonomously, but their parents ought to be in the picture, whereas there are parents who disappear once their chronic children are hospitalized, they are “at large”, so to speak... and you receive little support from the family as a result. IT2

On the contrary, overbearing parents prevent adequate care, or at the very least, there is no cooperation.

The little girl's father especially... he performed the aspirations, he operated the cough machine, the oxygen, this and that... it was impossible to approach the little girl, because the parent absorbed every single task. IT4

CHAPTER 4. DATA ANALYSIS: Common elements for parents and HCP

The analysis is profoundly revealing with regard to the individual experiences within each group. The same have been grouped together “emerging dimensions” (Mortari, 2007) described above and, furthermore, the analysis in question shows that there are some cross-cutting elements involving both parents and healthcare professionals on a deep level.

The analyzed literature (Bry et al., 2016; Huang et al., 2011; Meert et al., 2008) usually report the experiences gathered from parent or HCP interviews on pre-defined topics, such as communication, quality of life, and end of life. The presence of relevant common thoughts and lived experiences that can bring parents and HCPs closer with regard to life experience, is one of the innovated outcomes of this research.

The data analysis of the present research is significant, given that the relevant literature usually either described the overall opinion of each group individually (HCPs or parents) or compares the results from distinct studies (F.A. Carnevale, 2008 ; F.A. Carnevale, 2012; F.A. Carnevale et al., 2016; T. D. Simon et al., 2010). This research gives a details account of the experiences of parents and HCPs that works together for the same child and, the most relevant cross-cutting elements are described as follows:

The complexity of decision-sharing

HCPs reported difficulties due to incomplete communication with parents. In some cases, HCPs are unsure with regard to the possibility to clearly talking with parents. Usually, many professionals are required to communicate with CCC parents, such as: the phycologist, the clinical expert, the nurse, the intensive care doctor, the surgeon or other specialist on the child’s illness; moreover, the presence of someone who coordinate all the processes (for example the PICU director) is necessary. When the optimal conditions for effective communication are lacking, the doctor and the nurse who are taking care of the child must nevertheless update parents by finding a balance between known information and information that can be disclosed.

These parents (...) they ask that the consultation be conducted by the same doctor through and through, usually the chief or their deputy, and it becomes even more difficult, because

you remind yourself you're not supposed to say anything, but you're the one on call (...) it's very complicated. I don't experience this kind of exchange well. MT1_605

I couldn't tell the parents what I really thought, or it would have looked as though I wanted to influence them, so I spoke in a detached manner, it's not how I am, I felt deprived of my personhood. MT2_639

I have information I can't disclose (...) it's the kind of information I can't give out, because there is a time and a place for that. IT5_464

Professionals ought to manage critical situations and find ways to communicate with parents. Talking about daily routines makes professionals feel useless and unconsidered when they cannot express their opinions to parents.

There are complicated moments when (...) there is no definitive plan, and you need to stay vague... you know the answer, or you have an opinion, but you cannot disclose it, and this is frustrating to me, I can't say what I want to say, so it feels as though I were telling a lie. IT3_451

Sometimes you know something you can't tell the parent (...) sometimes they have the right to know, but we wait, so that we can create a secure and protected environment. IT5_461

Professionals are aware of the crucial importance of a planned communication encounter when talking about a life-threatening situation.

This is necessary because there is an entire process behind the answer itself. There is no alternative solution, you cannot give answers when the parent is not ready, or the situation does not call for it. IT3_451

A parent has the right to receive information in the best way possible, but it is difficult for me to already know and not be able to say anything. IT3_452

At the same time, parents feel that they are left partially uninformed, and thus cannot fully comprehend the extent of the child's health problem.

When the doctor comes in to give you an update (...) and tells you everything went well (...) but they say nothing specific... it wasn't good for me, because I knew nothing about the actual problem (...) My problem was that the doctor only disclosed the clinical picture emerging from the blood tests, but I was not interested, I wanted answers about the syndrome (...) I didn't care what they were saying, I just wanted to understand how the electroencephalogram looked. G3_71

They explained nothing, the we got here and they told us everything, what would happen, the aftermath of the surgery, what we should expect, and in the end there was only a small deficit, in the sense that it would only take one or two years for our son to return to who he used to be, and then, looking at the MRI, they said there was a mass that was seven centimeters wide, the only way it could be removed was surgically(...) you had to study the case...not tell me afterward's... first you tell me my son has a tumor, you tell me it can be removed, and he can be cured, and then you serve me another bad blow by telling me you cannot remove it right away, they did not seem to be particularly prepared on this. G10_148

They asked us if we wanted to speak to a priest or a psychologist... and I said no... I want to speak to someone who can tell me something about my daughter (...) G8_218

There are many things you don't discover immediately, several days go by, sometimes you do not receive a clear explanation as to what is happening or the possible outcomes. G18_230

An example of something that has not been communicated directly is exemplified by the following excerpts:

I saw her for the first time in the neonatal intensive care unit... and I had questions, like, "Will she ever speak?", but the doctor told me, "I don't see why not". I will always remember this sentence, for as long as I live, they said neither yes nor no. "I don't see

why not". All I needed, to put it plainly, was a yes or no, and instead I got, "I don't see why not". She was intubated, so she made no sound. G4_306

I think they knew from the start that they couldn't do it, because there was a neurosurgeon who kept telling me to go elsewhere with my son, where I felt sure they knew what they were doing... he told me three times (...) but I am just a parent, not a doctor, so how could I know? G10_150

Many authors reported the necessity for clarity and appropriateness during encounters (Meert et al., 2008; Wocial et al., 2017). However, this research shows that parents also consider a peer attitude relevant. They want to be respected and considered as intellectually capable by doctors. They would also like to be considered as a resource in the process of their child's care

It felt as though they were afraid of talking to us freely, but they ought to do so, because we are fully aware of our daughter's condition and of what is happening with her, and, being in such close quarters with her, we can give suggestions as to how to manage things for her in the best possible way. G7_297

In that moment you look for answers you cannot find yourself... in that moment I wanted for someone to tell me that would happen, how it would go, what I had to do. G18_231

We could not understand what problem our daughter had, because unfortunately her condition required the assistance of multiple specialists, and each one of them told you something different, we felt stuck between the hammer and the anvil, it was that whole situation. G8_195

Close-quarter attitudes

Working with CCCs and their parents runs risks of becoming difficult to sustain for HCPs. As described below, in some cases professionals develop some defence strategies, or establish standard attitudes to manage all the situations previously described as being critical.

When I first arrived here I established a close bond with couple of parents, maybe because they were very welcoming, and they inspired you to break the doctor-patient divide. (...) From an emotional standpoint, it was hard to bear, which is probably why since then I have taken a step back, because this little girl got to me (...) if I had that kind of relationship with every patient I had to treat, I couldn't bear it. MT4_572

At this point I have built my own armor. MP6_501

The doctor-patient demarcation line remains intact... so that I can maintain my integrity (...) my approach to patients is the standard one, there is a boundary I won't cross from an emotional standpoint. MT4_566

Some parents recognize that HCP formality is a natural part of the medical professional but, in spite of this they ask for a quantum of humanity.

It is part of your job to detach yourselves from the situation. G2_8

I understand that you see a lot here... and that you need to build walls, but a quantum of humanity, at the very least... G8_217

The relationship between parents and HCPs is made up of a significant number of life experiences. As described in literature, CCCs' parents experience many stressful situations, during which they are exposed to life-threatening events for their child and difficult events relating to communication. Frequently, HCPs are not prepared to manage such complex situations.

What do you want from me? (...) What do you expect of me? I am not prepared for this. MT1_602

Moreover, as described above, HCP experiences are also characterized by critical events that have changed their level of empathy towards family. Therefore, both

groups experience trauma related to proximity. Nevertheless, only HCPs can choose to avoid proximity, and thus to maintain a professional relationship.

The necessity to trust and be trusted

Parents need to trust professionals, because this allow them to feel safe. Children with complex chronic conditions are entrusted to their families their all life, and parents thus are who provide everything for their children - for example, parents end up planning their children care without institutional support. For all those reasons delegating the management of care to a third part can sometimes be strenuous for parents. Despite this, trusting HCPs' competences makes parents feel safe and gives them the possibility of confiding and putting themselves "into the hands" of someone who deserve that trust.

Some nurses and doctors inspire confidence, and you feel like trusting them completely.

G8_212

In order to trust someone, it is necessary to know and communicate with them.

The way you reply to me, the way you treat me, that's important. I need to understand if I can trust you or not. G6_174

For some parents, placing trust in HCPs is more important than effectively communicating with them

The important thing is that they are good with my son, other than that, if they want to talk they talk, if they don't want to it means that they have a different personality, perhaps less affable, but the important thing is that they take care of the child. G3_86

The following excerpts explain the dynamic unlined above very well, that is to say towards extent parents can feel safe and in good hand in entrusting their children to professional care.

He also removed two vertebrae... to clean up the bone marrow, and then he repositioned the second... I can't even imagine what would have happened elsewhere, he took one vertebra out and repositioned another, there is a whole life flowing inside... he took it out to see if more cerebrospinal fluid goes through... G10_161

Giving a little girl to be cared for by someone who tells you they will do everything that is humanly possible to save her, and who does everything in their power to achieve a positive result, if feels different, and in that moment, you feel good about your choices, because you did everything you could. G8_220

The first day in another ward I was afraid I wouldn't realize if my child was unwell, but in intensive care you have the guarantee that they will take care of your child. G2_28

We are confident that we are in the right place, essentially, (...) in this moment this ward, these personnel give us good vibes, we can see that they are doing everything they can. G5_325

HCPs also perceive the importance of parents' confidence as an indispensable element to establish an effective relationship with them.

I could tell from the mother's attitude towards me a strong distrust towards everything I said, she did not know me well, you have to convey your intent to help her, of having her child's best interest at heart, but this is often perceived as an obstacle, you cannot establish that alliance that allows you to give proper care (...) because if you don't go through the mediated intervention of the parents... the basis for everything else is trust, it's the kind of issue that puts you in difficult positions that eventually become stressful. MP5_545

When a relationship is based on trust, it is possible to create an alliance with parents that helps with the child's care.

If a parent is problematic, the relationship is also problematic (...) a parent on the defensive, who does not trust the medical protocol for the child, who does not delegate... there is no doctor-patient alliance, it is almost impossible to, I won't say to cure, but to at least manage the acute phase a child goes through, it can be excruciating, or it can take much longer than it normally would to get to that stable situation. MT4_571

You can't separate the child from the relationship their parents have with them, an alliance needs to be made with them, and it's all about finding a non-obvious brand of empathy. Parents need to trust you, and you need to be able to inspire that trust with your competence, but also with your humanity, to the point where they find a place for you in their "dyad", it is important to feel accepted as a human being, and not just as a doctor. MP5_533

Coming into contact with the child and being accepted is what gives you satisfaction, the good things I remember all have to do with acceptance on the child's part, a smile, a situation you are able to understand. IT6_417

For parents, an alliance equals a strong and trustworthy relationship. As the matter of fact the boundary ambiguity was previously employed to describe the way in which HCPs are involved in the family system during critical events (Mu & Tomlinson, 1997). However, this research shows that it is possible to identify a way of involving HCPs in the family system, represented by the alliance mentioned above, established on the basis of confidence, and constituting a significant all-encompassing involvement.

Even though the hospitalization process scared me at first, now the hospital feels like home, because I know everyone has the same intent, to give the best possible care to my son, and to make his remaining years as good as the realm of possibility allows. G2_16

I could sense a strong wariness on the mother's part, she didn't know me that well. MP5_545

Lack of trust

Both parents and HCPs reported bad episodes that had a relevant impact on them. Through the following excerpts we can understand the strong impact that parents' words and attitudes have on HCPs. What the latter report is that not only have those episodes been felt as being traumatic, but also that, the same caused a change in terms of being able to maintain a good relationship with parents.

It was hard to work while the parents' eyes were fixed on us, and every move was questioned, it was really difficult (...) The parents of a different child were also difficult to deal with, but again it was because (...) we did not have their trust... IT2_380

The children are essentially all the same, but parents make all the difference, because even putting a needle in C. with the father staring at you makes you pray to God that you find the vein right away for your own good and that of the child, luckily I did, but I cannot imagine what would have happened if we had needed to puncture three or four times (...) with the child crying and the parent's eyes following your every move, it's hard to work. IT3_444

There are parents(...) who do not trust people outside the family circle, and require absolute control. IT2_439

One parent said: "You are doing nothing for my daughter. If my daughter dies, I will kill you all" (...) it was hard to talk to someone you know hated you without knowing why they hated you. That's the difficulty. MT3_616

I understood that for the mother it was imperative that her daughter did not die, and she kept insisting to that effect, but at one point I blurted out a sentence, which I feel is chilling (...) but I felt exasperated, I asked her: "What do you expect of me? What do you want?" MT1_601

The mother tells me (...) she doesn't feel like going home, and I tell her that, if she wants, I can discharge her the next day, and she tells me that's fine. After half an hour (...) I go back into the room, and she attacks me, telling me I ruined the best day of her

life, she was preparing to go back home, and she felt deluded, I had ruined everything (...) I took it... and I told her she was right, but she would return home more serene the following day. I felt like she was venting her difficulty with this, but I felt the weight of her words (...) and I really felt... depleted... MP6_495

Many authors explored the lived experiences of parents, and subsequently detected the asymmetric relationship that they suffer: this research, in line with Meert's (2008), shows that parents perceive doctors as being insufficiently accessible, and that communication ought to be more transparent and comprehensive.

By the time we returned home, we had not received any indication as to how to help him, feed him, wash him. He couldn't suckle (...). We returned home, and I did not know what to do, and he couldn't even suckle... G9_274

My worst memories have to do with the time that they told us they couldn't take charge of her because she had nothing. From a medical standpoint, our little girl was not unwell, so they discharged us. Once we were home, she kept wailing all day for a month, so we stayed at a tavern... because we couldn't stay home, with two more children... we stayed at a tavern and made sure to hold her in our arms... (...) we really felt like we had been abandoned then. G7_287

What this study brings to light is the correlation that exists between the episodes of suffering experienced by both groups (parents and HCPs) and the changes in attitude and the reduction in terms of building a confident and safe relationship. As the following nurse states:

It was so hard for them to have their son hospitalized, each time was a tragedy, so they were not happy to see the mask on him too much, the amount of meals was always wrong, too little or too much, questions about why he had or did not have diarrhea, complete distrust. They discharged themselves multiple times, and therefore we try to do our best, but we don't always get positive feedback for the work we do. IT2_384

When CCC parents feel alone in their role of child caretakers, they use all their possibilities to provide the best possible care. In some cases, they ask for multiple specialists, they talk with many doctors, and they thus receive various opinions with regard to the same problem. The following doctor refer to this behavior as “medical shopping”

We couldn't understand what problem our daughter had, because unfortunately, because of her condition, several specialists were required, and each one of them told you something different. G8_195

This mother is into “medical shopping”... in the sense that she goes to Genoa, Padua, then says she doesn't want to receive care here... but since she has been here, she has not needed to do anything (...) she asks for opinions left and right, but then she asks me for advice, and she trusts me. MP6_496

CCC parents are subjected to many stressful situations, especially during a hospitalization in a critical care setting, where they need to trust in HCPs. However, on several occasion their experiences were riddled with bad happening that could HCPs perceive the same difficulties and the same risks in connection with previous experiences where trust was lacking.

No one like parents

At home CCC parents are the sole experts with regard to the child's illness and in dealing with an intensive care context.

HCP need to look to parents to establish an alliance that may allow them to build trust. Firstly, HCPs need to accept parents' competence in taking care of their children: for example, some studies show how child's with PCCI mothers are able to recognize the state of child's health in every move or look (Solodiuk et al., 2010).

As reported in the following excerpts, parents have a lot of expertise on the child's pathology, and especially with regard on their specific complications.

With a child such as this one, his mother must keep a journal. IT6_415

I think it's crucial for CCC parents to share in the decisions that are made and to take responsibility for them. They are the ones who know them best, so I rely on what they tell me a lot, so that the child can be provided with the best care, and I don't want to tell them how they should proceed. MT2_498

Because in the end no one knows him better than they do, they can certainly give you pointers that would otherwise take months to figure out, or it could take months to understand the meaning of a particular sound. IT4_473

I place a lot of confidence on interactions with parents, and I try not to interfere too much with the basic care they offer their child, nor with these children's habits (...) I let myself be guided in managing the treatment and in recognizing distress signals. MT3_609

A further emerging element is the presence of parents in the PICU, which have become a commitment and source of extra work for the medical professionals.

If their mothers were here, perhaps even those children with psychomotor crises would calm down, in any case you see a child in distress, and this disturbs me personally, but on the other hand you can have an overbearing parent who deeply frustrates you, because how I position their child is never good enough, they want me to turn him over every two hours, this is the kind of thing that detracts from providing care. IT2_377

These parents know the child better than you do, they rightly build up barriers because they are tired of many instances of hospitalization, and they know more than you do about many things. MT1:598

I can't do some things as a mother (...) But then the nurse in me kicks in, every mother becomes a sort of nurse, and then you can do everything that needs to be done. Any mother becomes a sort of nurse. G2_49

We know our son, so listen to us... I understand that you have to care for other children too, but, for crying out loud, be somewhat attentive... don't pull his leg like that... it hurts him... and this happens all the time... G9_272

It felt as though they were afraid of talking to us freely, but they ought to do so, because we are fully aware of our daughter's condition and of what is happening with her, and, being in such close quarters with her, we can give suggestions as to how to manage things for her in the best possible way. G7_297

Sometimes these parents can be overbearing, but think of what they've been through, so often the child takes over their parents' lives. MP6_632

The strong role played of parents is directly related to the possibility of giving the child the best care they required in the specific evolution of their pathological situation. That is to say, the necessity of helping parents understand the decline of child's health situation. To better understand this point, we can analyze a particular category.

Fear of changes

CCCs' parents describe their difficulties with accepting changes due to the high probability of a change for the worse.

I remember this nurse who kept touching my daughter, and that annoyed me, but then she was right on some things (...) we fear changes a bit, but we have learnt to have some trust, and see what happens. G4_303

Even a PEG is not easy to accept, as well as dealing with movements, at first, it's fine because they're small and you can take them around in pushchairs, but then you have to look for a special chair, and deal with specialized technological instruments. The wheelchair was an impactful choice to make for me. G1_119

At the same time, they are aware of the high complexity of their child illness, as well as the high probability of deterioration and, later on, chronicization of the child's health conditions.

They know that is necessary to give the child adequate care; in spite of this, they are desperate and sometimes they strive to fight a lost battle.

I remember when B.'s mother thanked me... I could see in her eyes that she was thankful for what I had done, and she was happy that we had manage to change the ventilator... she wanted to keep the old one, but I managed to change her mind... because they are often afraid of change. MP6_505

The mother called for a PEG, but I thought it was a terrible idea (...) she wanted for it to be done at all costs, and kept insisting (...) even though this would have worsened the child's quality of life by a great deal, without there being a real need for it (...) I eventually managed to convince her to do the opposite of what the endoscopist wanted to do, and now he is fine, with an adequate medical device. MP6_499

As previously expressed, the worry for the deterioration of child's health conditions is constantly on the parent's mind. Moreover, another challenge for parents has to do with accepting the necessity of more invasive life-support technologies that become essential for the child's survival.

The wheelchair was a tough development to accept. G1_120

In my head I know that she could get much worse (...) I thought about the fact that we escaped death two or three times (...) so in the end I had it done. She was unwell, after all, I couldn't let her waste away like that. But I do wonder what else I'll need to do to make sure she is breathing. G1_129

I could see he was withering away. He is now too, but the approach in dealing with it is different. G2_31

What's best for the child

Both parents and HCW search for the best for the child. This concept is strongly connected to ethical consideration that are being explored especially in the north American literature in which is suggested to involve parents in the end of life decision

(McGraw et al., 2012). Below some HCW expresses some doubts regarding the treatments whom children with PCCI sometimes are cared with. And some participants state about a limit beyond which they don't wish to go.

when he arrives a D at 18 who weighs 20 kg and every time he comes back we always keep putting on and taking off the mask, putting and removing the tube, in my opinion, a child so you have to leave it alone. The S weighs 17 kg at 18, how is it possible? I think that these children cannot always be intubated (...) there should be a limit IT1_338

But sometimes we went a little too far. Especially with chronic children and I cannot stand the fact of going beyond . Sometimes I would say enough, and I wonder how difficult the situation of life in which they are. Of course, I do not say killing children but there should be a limit, for me there should be IT1_235

When children with PCCI are hospitalized, they are subjected to many treatments, the decision to suspend one of this can become a difficult choice

Sometimes you're very debated between what you're doing, that you can give to them, the point to which you must stop, in the point of view of suffering, when you arrive at a final stage of the disease, where at a certain point you face with difficulty a situation in which you cannot delineate well what is the limit of your assistance, or what is the time to let them go because they are complex children and you say, today I did a lot, because I have to stop here MP5_528

The Parents thought is sometimes really close when they express the will to reduce the child fatigue.

Sometimes I have to say it and I also have to say STOP, enough because it has passed so many. Sometimes you would say, "Lord, that's enough." ... it's not nice to say why a child you miss is hard to bear G1_132

without fury. Because according to me, then it becomes a therapeutic fury . you have to make it live . but do not make it suffer even more . G20_239

we are for life without suffering for the child. because it has always suffered . is to see it attached to the car . I cannot see it attached to a car G20_236

What many participants asserts is the necessity to identify the moment when this is going too far, and the child can't take it anymore.

Help them make them live better in another dimension. Change when they no longer respond to therapy, they need to stop when they are exhausted, when they cannot make it anymore IT1_337

The same opinion be expressed by parents that are exposed to the continuing deterioration of their child.

for us it was a torment to come on every day, to see that it was being consumed. It is being consumed even now but it is a different way of dealing with it. And accept the fact that we have done everything possible G2_31

In both the groups are emerged as relevant the according situation, also regarding this topic. That is to say, when the decision is shared, parents are involved and aware about the decision made on the treatment.

the only thing you will do is give him a painkiller until the heart stops. It has 2 beautiful eyes. and this is enough for me. We have already asked too much, and I live with the knowledge that they have done everything that could be done ... with the awareness that we asked two things: this baby had a full stomach and increased meals. We asked to accompany him, we were told that he will be accompanied. G3_99

they were full of gratitude and there was not a day that they forgot to thank you, but also the accompaniment to the death of this child with his mother, having waited for both parents to be present, then to my mother I given in his arms, we removed all the garrisons, the pipe and washed it together, a sense of liberation, but there was an air of serenity in that room. IT2_386

Smiling and suffering

Many participants observed and gave relevance to the children with PCCI ability to communicate and both parents and HCW are strongly worried about possibility for the child to feel pain.

Will he be aware of having pain ...? perhaps he does not understand that it is pain, but the stimulus is that .. he has pain, does not reassure himself until he is in the arms of a mother but there is a brain damage (...) but it is not me that I can judge if it is worth the penalty or not IT5_466

There was hard because (...) when we woke up (...) we saw all the damage caused by the head injury. it was stiff (...) the eyes fixed, the disconnected sounds, the grimaces of pain .. I lived it poorly poor, in the sense I saw another child, I could no longer see him as before ... The reality, not all the our considerations, the reality of how it ended, is as if they will bring it home.IT1_342

The recognition of child's movements and the possibility to communicate with them is crucial for the most part of interviewed participants. To have the possibility to communicate with a child with PCCI can be for a clinician a good reasons to continue the medical treatments (ex. 591) and can allow parents to feel to be connected with them.

Will he be aware of having pain ..? perhaps he does not understand that it is pain, but the stimulus is that .. he has pain, does not reassure himself until he is in the arms of a mother but there is a brain damage (...) but it is not me that I can judge if it is worth the penalty or not IT5_466

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Children with PCCI parents are aware about the difficulties and the impossibilities of their child related to the underlying condition, for this reason they have low expectations about the ability of their child to do everything. Parents develop during the time, increasing level of confidence and expertise on recognizing every improvement on the child's condition (Gardner, 2014). Moreover they seem to be able to experience more intensely every single gesture and to give it an high value. For example a smile give an unexpected and unknown joy.

his smile is a bit of joy, these things are ... unknown G4_312

Also HCW learn to pay attention to all this little things. This nurse surprises herself about her ability to recognize what a child is feeling. Moreover, she observes this as a confirmation about the mothers competences.

when these children are able to communicate (...) and looked at you with these eyes, the fact of massaging him liked and you say (...) these, however, with your eyes tell you everything and I see him once a year, imagine mom IT6_412

CONCLUSIONS

The lived experiences of children with PCCI parents and HCW is characterized by many factors that determine the relationship among parents, HCW and the child's process of care.

By analyzing the outcomes of the literature review, it is possible to observe the development of multiple lines of research. The phenomenon of children with PCCI, initially examined to comprehend the lived experiences of children who were mostly affected by non-complex conditions, progressively moved to the study of all the elements that have characterized complex chronic conditions over the past three decades.

In the past, chronic children were subjected to extremely high levels of readmission and mortality rates, nevertheless, since the 90s, many authors have observed a substantial decrease of children's death rate without a corresponding reduction in readmission levels (Boyd & Hunsberger, 1998; Gortmaker, 1985; Hostler, 1991; R. E. K. Stein & Jessop, 1982). The trend in chronicity prevalence is still growing, and children with PCCI are increasingly affected by severe chronic multiple-system conditions, functional limitations, and incremented family needs (E. Cohen et al., 2011; Tamara D. Simon et al., 2014; Glader, Plews-Ogan, & Agrawal, 2016). The *children shift* has forced health care institutions to manage the cost increases to provide the necessary care; moreover, in the last few years, the treatment focus on children with PCCI has continuously changed. The criteria used to evaluate patients' outcomes has prompted an evaluation in terms of the growing number of patient-centered outcomes, such as well-being and quality of life in symptom control, in addition to the usual medical endpoints (Bullinger, Schmidt, Petersen, & Ravens-Sieberer, 2006; Kazak, Simms, & Rourke, 2002; Rolland, 2003). Researchers has made many attempts to define a child with a chronic condition during this time of change. After an in-depth review of the literature, the author has concluded that children with PCCI is the better definition of complex chronic children with regard to the ones that were included in this research.

The rapid dissemination of researches conducted between 2000 and today proves that this theme is relevant both for institutions and individuals. It is interesting to observe that, until a few years ago, the most relevant articles were all cost-reduction-oriented. In the late 90s is that many institutions recognized the impossibility of providing an

adequate level of care for children with PCCI. Recently, there have been an increasing emphasis on “improving health care delivery (...) in the context of a family” (Willits, 2013), registered in many countries in attempt to develop health care systems based on home care services and the delegation of care to the families.

Many studies have proved that the presence of a Child with PCCI can have a profoundly negative impact on the economic and social situations of families (D.Z. Kuo et al., 2011; D. Z. Kuo et al., 2013). Despite this, the majority of care for a child with PCCI is provided by families in the home environment (Christian, 1998). The acknowledgment that “a chronic condition affects not only the patient but also the family as a system” has shifted the focus from the child to the overall family system. Due to all the reasons evidenced above, the care transition of a child with PCCI care from hospital to home creates many demands and needs from parents.

Throughout the years, more and more researches were conducted by taking into account the families’ points of view, in the North American context; unfortunately, similar researches in Europe, and particularly in Italy, are lacking.

This study’s aim has been to explore the lived experiences of children with PCCI parents in the Pediatric Intensive Care Unit (PICU), and the related experiences of health care workers.

The results show many interesting themes regarding both groups of participants.

Parents’ accounts describe difficulties with relating to the times they lived inside the hospital. The time in question seems to be a non-lived time and, if combined with the strong emotional impact of a Pediatric Intensive Care Unit, results in emotions like abandonment and isolation. Parents feel the uncertainty of the child’s life and perceive the hospital as place where they are forced to stay. What seems to help parents in experiencing the PICU concerns the feeling of being accepted by the professionals and extensively involved in the child’s care process. As the principle caretakers of their children, parents play many roles, and one of the most relevant risk of hospitalization is to lose touch their role. The roles are characterized by many factors: firstly, parents sustain the burden of care and they frequently they play a crucial role of advocacy, because most children with chronic conditions need to be cared for by multiple specialists, and have multisystem impairments (Rafferty & Sullivan, 2017); secondly, they manage the family system and all the hospitalization-related disorders; thirdly, they must deal with the unavoidable comparison with other families and their usually

healthy children. In some cases, a particularly valuable element for parents is the support of professionals who listen to them and pay attention to the patients. Probably, given that they live a life characterized by important differences compared with other families, they sometimes feel that professionals are close to them, and be reassured by the trust that they place on professionals. Some parents observe the importance of being trusted by HCW, and that this trust to be neutral. This is the basis on which a form of partnership can evolve allowing parents to accept what it depending on the child.

Consequently, some critical elements are the impossibility of building a relationship with professionals that is based on trust. This happens when they perceive the self-importance of clinicians or when one or more errors have occurred during past hospitalizations. It should be noted that often times PCCI can be related to one or more mistakes made by professionals, frequently at birth. The feeling of loss caused by the absence of their child after birth is something that parents, especially mothers have difficult time with.

That experience is so traumatizing that after a long time they continue to feel as though the child wasn't born.

With regard to medical errors parents don't voice the necessity for punishment, but rather, for honesty and clarity.

The most stressful situations for them were related to the impossibility of receiving complete information regarding the child's health status. They assert that, when they are involved in the decision-making and aware of all information regarding the child, they have more chances of accepting the disease and everything related.

As observed by many authors (Carnevale et al, 2008; Latour, 2010), communication still remains one of the most critical issues. Parents show the necessity of receiving clear and complete information, and they state that they would be able to manage all information regarding their child. Sometimes they are scared by the communication event but the most crucial aspect for them remains that of being informed.

The healthcare workers perceive the problem of communication from a different point of view, in that they are worried about the impossibility of communicating all the information they possess. This can happen in specific situations: firstly in the diagnostic phase, when they don't have enough information and they must thus wait to be sure with regard to the child's clinical situation; secondly, when they must wait

for a better communication moment, that is to say, an encounter involving a multidisciplinary team. HCW are struggle with their opinions about communication, that ought to be complete and constant, and what they consider as the optimal thing for parents (adequate communication involving, for example experts in communication, such as psychologists).

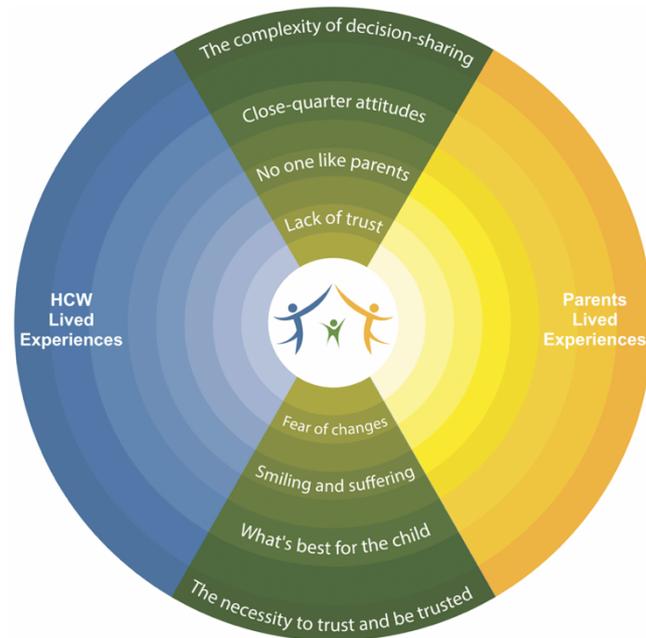
Professionals ask for appropriate training to perform communications and to be able to support parents. Professionals perceive the burden of suffering related to being continually exposed to situations characterized by profound pain. In many cases, HCW narrate about cases that lead them to develop some defense strategies: frequently, these cases are related to a failed communicative event or to an inability to build an effective communicative moment. Sometimes defense strategies are associated with the fear of being involved in the families' lived experiences and of losing the ability to be professional.

HCW observe the parents' role change and therefore have some difficulties in relating with someone that frequently becomes more competent than they are in taking care of the child. Oftentimes the parents' expertise in evolves in to a 'power struggle' that emerges in this research as a difficulty with assessing respective roles, an outcome that is described in many different ways in the relevant literature (Allshouse, Comeau, Rodgers, & Wells, 2018; Martens et al., 2008). HCW needs to retain control of a child's clinical situation, whereas parents feel that they can't lose their advocating role for the latter (Rafferty & Sullivan, 2017). The former feel like they are involved in difficult decision-making situations, and sometimes they also perceive that they are forced to follow decisions that they don't share.

To be trusted by parents is what professionals are looking to obtain. In many cases they are conscious that multiple critical events could have reduced parents' trust in professionals and this makes the possibility of establishing a relationship based on neutral trust harder. They know that parents are scared of change with regard to the child's clinical conditions and that every change required time for parents to get used to it.

During the process of analysis, the researcher identifies some highly interrelated categories among the health care experiences of parents and HCW. These are grouped in Figure 8. By observing the figure, it is possible to imagine an eye in which a child with PCCI represents the pupil, that is to say, the focus on which all the other elements are centered.

Figure 8 _Analyzed data, Common Point of Views Between Parents and HCW



A system characterized by the lived experiences of HCW (blue, on the left) and parents (yellow side, on the right) respectively has been unequivocally organized around the child. Despite this,

the author observes overlapping experiences between the groups, in some instances. That overlapping is not exclusively related to a personal opinion or an understanding attitude, that rather, it is more like a common thread similar to concept of reciprocal empathy (for the concept of empathy, see p. 86). **The complexity of decision-sharing** emerges when HCW cannot completely and accurately inform parents about the child's conditions, mostly when the communication should be given with communication expert or with other team members. Parents perceive this insecurity and thus remain dissatisfied with the communication event itself. Parents realize that the information is summary, and this makes them feel nervous and unsafe; on the other hand, HCW feel that they are hiding the truth and that they are ineffective.

Close-quarter attitudes are difficult to maintain for professionals who works with CCC and their parents. Due to past critical events that may have modified their level of empathy towards families, professionals sometimes develop defense strategies or establish standard attitudes to manage critical situations.

Parents define the formality as a natural part of the medical profession but, in spite of this, they ask for a quantum of humanity. The relationship between parents and HCP is made up of a significant number of life experiences. As described in literature, CCC

parents experience several stressful situations, during which they are exposed to life-threatening events for their child, as well as and difficult communication events (Morse, 2008, Meert, 2008, Carnevale, 2008). Frequently, HCW are not prepared to manage such complex situations. In these cases, both groups experience traumatic proximity-related events. Nevertheless, it is important to remember that while HCW can choose to avoid proximity, and thus to maintain a professional relationship, for parents this is impossible, seeing as they are forced to accept the professionals chosen path.

At home, parents are the sole experts with regard to the child's illness, but they lose such competence as soon as they enter an intensive-care context. HCP need to look to parents to establish an alliance that may allow them to build trust: in order to do this, they should, first and foremost, accept parents' competence in taking care of their children (**no one like parents**). The strong role played by parents is directly related to the possibility of giving the child the best care they require for the specific evolution of their pathological situation, i.e., the necessity of helping parents understand the decline of their child's health.

Lack of trust probably depends on past events that have had a relevant impact on parents and HCW. Not only have such episodes been felt as traumatic but they have also caused a change in terms of being able to maintain a good relationship between parents and HCW.

This study brings to light the correlation that exists between the episodes of suffering experienced by both groups respectively (parents and HCP) and changes in attitude, as well as diminished possibilities of building a trusting and safe relationship.

Furthermore parents state their difficulties with accepting changes, due to the high probability of changes for the worse. This **fear of change** is based on the awareness of the high complexity of their child's illness, and on the high probability of deterioration, as well as, later on, chronicization of the child's health conditions. Sometimes, this fear of change lift them to fight a lost battle because, even though they know that it is necessary to give the child adequate care, but they nevertheless tend to cause pose an obstacle for the changes that need to be made. The worry for the deterioration of the child's health conditions is constantly on the parents' minds, and HCW in the PICU must frequently inform that the child will require life-sustaining technology or else their health will deteriorate. These situations are directly connected

to the possibility of developing a trusting relationship which represents one of the major challenges for HCW.

Both parents and HCW need to find a way to communicate with the child and are strongly worried about the possibility that the child will feel pain. The importance of the **Smiling and suffering** category emerges if it is understood that, for HCW, the child's ability to communicate is one of the reasons to continue with medical treatments; at the same time, it can allow parents to feel connected with their child.

What's best for the child. Some HCW express doubts regarding the treatments that a child with PCCI is sometimes cared for with, and, every now and then, they state that there should be a limit beyond which they don't go. Parents sometimes follow a similar way of thinking when they express the will to reduce their child fatigue. Identifying the moment when treatment has gone too far, and the child can't take it anymore, represents another challenge that parents and HCW ought to consider. The necessity of sharing decisions emerging as being relevant in both groups, decision involving parents and that make them aware of the choices made with the treatment. This intern leads us directly to the last common thread, **the necessity to trust and be trusted.**

Parents need to trust professionals because this allows them to feel safe. Children with complex chronic conditions are entrusted to their families for their entire lives, and parents are thus those who provide everything for their children. Delegating the care of their child to a third party can be strenuous for parents; despite this, they feel safe when trusting HCP's competences. Parents state that it is necessary to know and communicate with someone in order to trust them. When a relationship is based on trust, it is possible to create an alliance with parents that helps with the child's care; on the other hand, HCP perceive the importance of parents' confidence as an indispensable element to establish an effective relationship with them. Even though HCW strongly assert the need to be trusted, on many occasions they are the once who are unable to trust parents. Despite this, parents are still able to involve HCW in the family system by promoting the development of a relationship based on an alliance, established on the basis of trust, and constituting a significant all-encompassing involvement that is unique to chronic conditions.

Pursuant to the initial research question, this study highlights the many common points of view existing between parents and HCW taking care of children with PCCI. The

same should be taken into consideration when defining policies aimed at involving parents in the process of care, and to promote a more collaborative and communicative environment. Other suggestions emerge regarding the necessity for health care workers to learn specific communication skills, and to develop competences in accomplishing to the role of supporting parents.

Another relevant consideration is the life quality of the children involved in the research: they have been often been described as critically ill, with poor competence in communication, without the possibility to have an effective relationship with parents and HCW. Many participants have raised considerations regarding the child's quality of life and the difficulty of defining a clinical limit beyond which they don't wish to go.

The originality of having collected and analyzed the perspective of parents, physicians and nurses emerged as strongly useful on the comprehension of the phenomenon of chronicity in critical children. The author summarized the lived experiences of both groups through eight interrelated categories that are organized around the child.

What strongly emerged is the importance to involve the parent and the HCW like fundamental core elements to allow the appropriate complete management of the process of care.

This will be one of the most relevant challenges that HCW and parents will have to tackle together. At the end of this research, the results will be shared with the participants and all PICU teamwork.

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APPENDIX

Appendix A: Literature review references listed by thematic areas

Definition of children with chronic conditions (n 26): (McPherson et al., 1998), (J. Neff & al., 2002; J. M. Neff et al., 2002), (Wise, 2004), (Vincer et al., 2006), (MCHB, 2006), (Burns et al., 2010), (David E. Hall, 2011), (E. Cohen et al., 2011), (D.Z. Kuo et al., 2011), (T. D. Simon, Mahant, & Cohen, 2012), (Agrawal, Feudtner, & Hall, 2012), (Dewan & Cohen, 2013), (Brady, Varadarajan, Peterson, Lannon, & Gross,

2013), (P. Namachivayam et al., 2012), (T. D. Simon et al., 2012), (Elias, 2012), (Moura et al., 2017), (Dewan & Cohen, 2013), (E. Cohen et al., 2012), (Russell & Simon, 2014), (J. M. Neff, Clifton, Popalisky, & Zhou, 2015), (Cohen, 2015), (Jay G. Berry et al., 2015), (Ralston et al., 2015), (Mokkink et al., 2008), (Shapiro et al., 2017), (Coller et al., 2016)

The lived experiences of children with chronic conditions (n 4): (Gortmaker, 1985; P.W. Newacheck et al., 1986), (Spirito & Stark, 1994), (Boyd & Hunsberger, 1998), (Marshall, Carter, & Rose, 2009)

The role of nurses (n 10): (Maytum et al., 2004; Wise, 2004), (Lake et al., 2017), (Baird, Rehm, Hinds, Baggott, & Davies, 2016; Lake et al., 2017), (Harbaugh, Tomlinson, & Kirschbaum, 2004), (Graves & Hayes, 1996), (Tomlinson et al., 1999), (Kirk et al., 2005), (O'Haire et al., 2005), (Martens et al., 2008), (Looman et al., 2013)

Costs (n 9): (Berman et al., 2005), (Glader et al., 2016), (Perkins & Agrawal, 2018), (Vincer et al., 2006), (Burns et al., 2010), (E. Cohen et al., 2012), (Casey et al., 2011), (Jay G. Berry et al., 2011), (Jay G. Berry et al., 2015)

Institutions and organizations (n 26): (Burns et al., 2010), (Gordon et al., 2007), (Guertin, Cote-Brisson, Major, & Brisson, 2009), (Kirk, 1999), (Morris, Gard, & Kennedy, 2005), (J. Neff & al., 2002), (J. M. Neff et al., 2015), (T. D. Simon et al., 2010), (E. Cohen et al., 2010), (Luca et al., 2011), (Casey et al., 2011), (Adams et al., 2013), (Bogetz, Ullrich, & Berry, 2014), (Ryan J. Coller et al., 2014), (Russell & Simon, 2014), (Ananth et al., 2015), (Ralston et al., 2015), (Thomson & Shah, 2015), (Noritz et al., 2017), (Olson, 2017), (Gold et al., 2016), (Palfrey et al., 2004), (R. J. Coller et al., 2014), (Breneol et al., 2017), (Friedman & Norwood, 2016), (Nelson et al., 2016)

End of life or palliative care (n 10): (Feudtner et al., 2002), (McGraw et al., 2012), (Kelly Nicole Michelson, Patel, Haber-barker, Emanuel, & Frader, 2013), (R. Boss et al., 2014), (Bogetz et al., 2014), (Schwantes & Brien, 2014), (Baker et al., 2015), (Hakanson et al., 2017), (DeCoursey, Silverman, Oladunjoye, Balkin, & Wolfe, 2018; Feudtner et al., 2002), (F.A. Carnevale, 2012)

The role of doctors (n 5): (Neha, 2018), (Sadof, Gortakowski, Stechenberg, & Carlin, 2015), (Alexander et al., 2011; Sadof et al., 2015), (Van shaik, 2016), (Shan, 2018)

Algorithms or Scale (n 7): (Simon et al., 2014), (Chan et al., 2016), (Glader et al., 2016), (Adams et al., 2017), (C. Feudtner et al., 2001), (Shapiro et al., 2017), (Simon et al., 2018)

Communication between parents and health care staffers (n 13): (Pollak et al., 2007), (D. S. Morse, Edwardsen, & Gordon, 2008), (Meert et al., 2008), (Carnevale, 2008), (Bransetter, 2008), (Quigley et al., 2014), (Kelly N. Michelson et al., 2016), (Bry et al., 2016), (F.A. Carnevale, 2008), (F.A. Carnevale et al., 2016), (Altman, Zurynski, Breen, Hoffmann, & Woolfenden, 2018), (Rafferty & Sullivan, 2017), (Wocial et al., 2017)

Generical papers prior to 1998 (n5): (Hill, 1949), (P. Boss & Greenberg, 1984), (M.M. Pollack et al., 1987), (Batshaw, 1991), (McPherson et al., 1998)

Parent's experience of CCC caring (n 36): (Heaton, Noyes, & Sloper), (Kirk et al., 2005), (Fawcett, Baggaley, Wu, Whyte, & Martinson, 2009), (Maltby, Kristjanson, & Coleman, 2003), (Gibson, 1999), (Johnson, 2000), (Monsen, 1999), (Balling, 2001), (Ray, 2003), (Salfors, 2003), (Sullivan-Bolay, 2003), (Trollvik, 2004), (Goble, 2004), (Nuutila & Salanter, 2006), (MacDonald & H. Callery, 2007), (Hagstrom, 2016), (Dickinson, Smythe, & Spence, 2006), (George, Vickers, Wilkes, & Barton, 2006), (Mulvaney, Schlundt, & Mudasiru, 2006), (Green, 2007), (Mu & Tomlinson, 1997), (Cashin, Small, & Solberg, 2008), (Waite-Jones & Madill, 2008), (Swallow, Allen, & Williams, 2012), (Bowes, Lowes, Warner, & Gregory, 2009), (Huang et al., 2011), (Miller et al., 2009), (Graham et al., 2009), (Kimura & Yamazaki, 2013), (Oxley, 2015), (Hayles, 2015)