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The Food-Related Moral Experiences of Children with Swallowing Difficulties:

A Participatory Hermeneutic Ethnography

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It does not matter how slowly
you go as long as you do not stop.

Confucius

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Abstract

Background: Food is an essential need for everyone. It is a source of sustenance, an occasional indulgence, and a way to define oneself within a culture. Appropriate nutrition is considered a right for every child. Children's experiences—including their food-related experiences—can shape their understandings of themselves and the world around them. Their experiences with food can affect the fulfillment of their nutritional and other eating-related needs. For this reason, it is important to understand how children with swallowing difficulties experience food as well as the factors that influence these food experiences. Sameroff's Transactional Model of Development, which emphasizes the role of environmental factors in a child's development, sees psychological and social development as a dynamic process that results from the interaction between children and their environment. An important influence on children's experiences is the child's relational environment (e.g., between families/caregivers and children). Examining children's relational environment can help advance understandings of children's food-related experiences and help improve services for children with swallowing difficulties since little is known about these experiences.

Research Purpose: To advance knowledge about food-related moral experiences of children with swallowing difficulties.

Objectives: 1) To explore the food-related moral experiences of children with swallowing difficulties; 2) To analyze how interactions with families/caregivers affect these experiences.

Methods: Participatory hermeneutic ethnography was used for this study. This methodology helps identify what is particularly meaningful for these children and other people within the study settings, as well as the local imaginaries and institutional norms, structures and practices. A six-month participatory hermeneutic ethnography was conducted in the city of Genoa and Milan in Northern Italy. The study settings included participants' homes and schools, where these children usually have meals. Eight children with swallowing difficulties from 7 to 11 years old and their families participated in the study. The participatory approach within the chosen methodology promoted the involvement of children and their families, caregivers and healthcare professionals. Multiple data collection methods were used and integrated (e.g., participant observation, interviews, documents analysis). Data collection and interpretation were conducted simultaneously. A Childhood Ethics interpretive framework guided the analysis and interpretation of (a) moral experiences of children, (b) family and caregiver influences on these experiences, as well as (c) the social context of healthcare.

Results: The results showed that food-related moral experiences of these children are strongly *influenced by the context* where they usually eat, including environment, time, space, people, food type and their specific swallowing difficulty. Also, these children need different *levels of support during mealtimes* that is provided mainly by family/caregivers and healthcare professionals or assistants that know these children very well. Children are mostly *aware of their condition* and the help they need and at the same time they have a strong *will to be accepted and included in social activities* with their peers.

Implications: This study helped develop a better understanding of children with swallowing difficulties' food-related moral experiences and the families/caregivers' interactions related to these food-related moral experiences. This research contributed to advancing knowledge related to the food-related moral experiences of this population of children, and understanding of their real needs, which can inform the development of intervention improvements that they require. Also highlighted was the need for specialized healthcare professionals to care for these children within community and hospital settings.

Resumé

Contexte : La nourriture est un besoin essentiel pour chacun. C'est une source de subsistance, une indulgence occasionnelle et une manière de se définir au sein d'une culture. Une alimentation appropriée est considérée comme un droit pour chaque enfant. Les expériences des enfants, y compris leurs expériences liées à l'alimentation, peuvent façonner leur compréhension d'eux-mêmes et du monde qui les entoure. Leurs expériences avec la nourriture peuvent affecter la satisfaction de leurs besoins nutritionnels et autres besoins alimentaires. Pour cette raison, il est important de comprendre comment les enfants ayant des difficultés à avaler vivent la nourriture ainsi que les facteurs qui influencent ces expériences alimentaires. Le modèle transactionnel de développement de Sameroff, qui met l'accent sur le rôle des facteurs environnementaux dans le développement de l'enfant, considère le développement psychologique et social comme un processus dynamique résultant de l'interaction entre les enfants et leur environnement. L'environnement relationnel de l'enfant (par exemple entre les familles/tuteurs et les enfants) a une influence importante sur les expériences des enfants. Une analyse de l'environnement relationnel des enfants peut aider à mieux comprendre leurs expériences liées à l'alimentation et à améliorer les services destinés aux enfants ayant des difficultés de déglutition, car on sait peu de choses sur ces expériences.

Objectif de la recherche : Faire progresser les connaissances sur les expériences morales liées à l'alimentation des enfants ayant des difficultés de déglutition.

Objectifs : 1) Explorer les expériences morales liées à l'alimentation des enfants ayant des difficultés de déglutition ; 2) Analyser comment les interactions avec les familles/aidants affectent ces expériences.

Méthodes : L'ethnographie herméneutique participative a été utilisée pour cette étude. Cette méthodologie permet d'identifier ce qui est particulièrement significatif pour ces enfants et d'autres personnes dans les contextes de l'étude, ainsi que les imaginaires locaux et les normes, structures et pratiques institutionnelles. Une ethnographie herméneutique participative de six mois a été menée dans les villes de Gênes et de Milan, dans le nord de l'Italie. Les contextes de l'étude comprenaient les maisons et les écoles des participants, où ces enfants prennent généralement leurs repas. Huit enfants ayant des difficultés de déglutition âgés de 7 à 11 ans et leurs familles ont participé à l'étude. L'approche participative de la méthodologie choisie a favorisé l'implication des enfants et de leurs familles, des soignants et des professionnels de la santé. Plusieurs méthodes de collecte de données ont été utilisées et intégrées (par exemple, observation participante, entretiens, analyse de documents). La collecte et l'interprétation des données ont été menées simultanément. Un cadre d'interprétation de l'éthique de l'enfance a guidé l'analyse et l'interprétation (a) des expériences morales des enfants, (b) des influences de la famille et des soignants sur ces expériences, ainsi que (c) le contexte social des soins de santé.

Résultats : Les résultats ont montré que les expériences morales liées à l'alimentation de ces enfants sont fortement influencées par le contexte dans lequel ils mangent habituellement, notamment l'environnement, le temps, l'espace, les personnes, le type d'aliment et leur difficulté spécifique de déglutition. De plus, ces enfants ont besoin de différents niveaux de soutien pendant les repas, fournis principalement par la famille/les soignants et les professionnels ou assistants de santé qui connaissent très bien ces enfants. Les enfants sont pour la plupart conscients de leur état et de l'aide dont ils ont besoin et, en même temps, ils ont une forte volonté d'être acceptés et inclus dans les activités sociales avec leurs pairs.

Implications : Cette étude a permis de mieux comprendre les expériences morales liées à l'alimentation des enfants ayant des difficultés de déglutition et les interactions des familles/tuteurs liées à ces expériences morales liées à l'alimentation. Cette recherche a contribué à faire progresser les connaissances sur les expériences morales liées à l'alimentation de cette population d'enfants et à comprendre leurs besoins réels afin qu'il soit possible de

développer les améliorations d'intervention dont ils ont besoin. En outre, cela a mis en évidence la nécessité d’une équipe de professionnels de la santé spécialisés prenant soin de ces enfants à la fois en milieu communautaire et hospitalier.

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Thank you for this generous financial support that allowed me to study on a full-time basis and perform this work.

Contribution to original knowledge

As an innovative study conducted with children with swallowing difficulties exploring their own experiences, this study is a significant contribution to the field of childhood ethics and nursing research. The methodological perspectives developed and implemented to elicit the voices of children, especially those who communicate differently, contribute to research with children. Additionally, the methodological articulation using the frameworks of child health and childhood ethics contributes to the childhood ethics studies field, advancing understandings of the impacts of socio-cultural context and background on these children's everyday lives. This study provides detailed descriptions and interpretations of children's experiences with swallowing difficulties and the social context that influences their everyday lives. These data could improve the understanding of the needs and best interests of children with swallowing difficulties through an ethnographic framework based on their experiences.

Contribution of Authors

As a PhD candidate, I was responsible for developing the study protocol, conducting the fieldwork, data analysis and interpretation, and writing the thesis presented in this document. This thesis represents my original work: I was responsible for the development, conduct (including participant recruitment, data collection, interview transcriptions), interpretation and writing of all of the aspects of this work as doctoral candidate. My thesis supervisor, Dr.

Franco A. Carnevale, and supervisor Prof. Annamaria Bagnasco and thesis committee member, Dr. Milko Zanini, were involved in all the steps, offering ongoing substantive and methodological guidance throughout this process.

Introduction

Over recent years, there has been an increase and improvement in the use of medical technologies and medical care in the neonatology setting, leading to decreased child mortality rates but also to a growing number of children referred to as “children with medical complexity” (Cohen et al., 2011; Lefton-Greif, 2008). The definition of children with medical complexity (CMC) has delineated four domains regarding the health conditions and care requirements of these children: (1) needs (i.e., healthcare services needs such as medical care, specialized therapy, and educational needs), (2) chronic condition(s), (3) functional limitations (i.e., limitations in using body structures and systems for performing and/or participating in community life activities), and (4) usage (i.e., high use of healthcare services, including frequent hospitalizations, surgeries, and involvement with subspecialty services and providers) (Cohen et al., 2011).

Since a portion of CMC have swallowing difficulties (Prasse & Kikano, 2009), the growing number of CMC has consequently led to a rise in the incidence of children with swallowing difficulties (NB: swallowing difficulties is referred to medically as dysphagia) (Kovacic et al., 2020; Lefton- Greif, 2008). This subpopulation of children with swallowing difficulties will be the focus of this study.

The complex care needs within this population have posed significant challenges for children, families, and healthcare professionals (Lefton-Greif et al., 2015; Kuo et al., 2014; Dewan & Cohen, 2013). Due to the heterogeneity of this population, considering the variety of chronic or complex illnesses to which swallowing difficulties could be associated, all interventions for these children should be tailored and based on a multidisciplinary team evaluation and care plan (Zang et al., 2021; Lawlor & Choi, 2020;Lefton-Greif, 2008).

Healthcare for CMC, including those with swallowing difficulties, also raises significant ethical concerns, such as health differences, disparities (e.g., different services availability) and discrimination, barriers to access to care (Lefton-Greif et al., 2015; Craig, 2013), and the exclusion of children from decisions that affect them (Kuo et al., 2014; Carnevale et al., 2006). Problems with healthcare services and interactions with healthcare professionals can also increase challenges in the everyday lives of children and their families (e.g., problems with access to healthcare and social services specifically adapted for them) (Craig, 2013; Carnevale et al., 2006). Children with swallowing difficulties have different access to food compared to their peers or other people without swallowing difficulties in terms of type, taste, consistency, and quantity. Commonly, these children use assistive nutritional devices (e.g., a nasogastric tube, percutaneous gastrostomy). The diet for people with swallowing difficulties usually requires modified food preparation, which can alter the food's taste and consistency (Zanini et al., 2017). In these situations, children can live some disparities and differences meaning that they can have moral experiences that also place a tress on these children's agency.

Research demonstrating that swallowing difficulties can compromise nutrition, health, and experiences has been conducted mainly within adult populations (Zanini et al.,2017). However, the impact of swallowing difficulties on children's food experiences is still unknown, as children with swallowing difficulties are underrepresented in the research literature (Kovacic et al., 2020). Given that food is an essential need in children'severyday life, it is important to understand how swallowing difficulties affect children's fulfillment of this need as well as how they experience food. Therefore, the goal of this study is to explore how children with swallowing difficulties experience food and mealtime.

Research on the food-related moral experiences of this population can provide insights for the development of specific and innovative interventions adapted to how these children experience food while also optimizing their access to nutrition considering that equitable care is an ethical imperative (WHO, 2008). In turn, adapted food interventions can help reduce food-related health inequities within this population (Kovacic et al., 2020). For example, a specific nutritional program with food with different textures for adults with swallowing difficulties has demonstrated positive outcomes on nutritional andhealth status, as well as the food experiences of these patients (Zanini et al., 2017), an approach which has not yet been adapted for children with swallowing difficulties. In short, examining the food-related experiences of children with swallowing difficulties will help generate knowledge that is needed to develop interventions that can help optimize these children's eating experiences.

Background

Children with Swallowing Difficulties

Within the healthcare literature, swallowing difficulties is commonly referred to as dysphagia. The term swallowing difficulties is used throughout most of this proposal to minimize the "medicalization" of these children's health experiences. However, in thesection which describes the more biological aspects of swallowing difficulties, the term "dysphagia" is used, to align with terminology used within this body of literature.

Dysphagia is defined as any disruption in any of four phases of the physiologic swallowing sequence: the preparatory, oral, pharyngeal, and esophageal phases (Dodrill & Gosa, 2015). It occurs in approximately 1% of children (children refers to all young people below the age of 18 years) in the general population and a higher percentage (from 30% to 80%) in at-risk populations (e.g., children who were born prematurely or children with disabilities and medical complexity) (Bhattacharyya, 2015; Prasse & Kikano, 2009), resulting in compromised safety, efficiency, or adequacy of nutritional intake (Lawlor & Choi, 2020; Lefton-Greif, 2008). The increased incidence of dysphagia in children is due to advances in healthcare that improve the survival of extremelypremature infants and children with medical complexity (Lawlor & Choi, 2020).

Dysphagia is a skill-based disorder different from behavioural feeding problems such as oral aversions that may arise in children who have sufficient skills for normal eating and drinking (Dodrill & Gosa, 2015). As stated above, the normal swallow is divided into four phases. The preparatory phase is when food is taken into the oral cavity, moistened with saliva, chewed, and prepared into a bolus using the oral tongue and hard palate. The oral phase is the propulsion of the food bolus into the oropharynx by the oral tongue, triggering the swallow reflex. The pharyngeal phase is the passage ofthe food bolus through the oropharynx and hypopharynx toward the esophagus via coordinated muscle contraction. The esophageal phase begins when the bolus enters the esophagus and ends when it passes into the stomach (Kakodkar & Schroeder, 2013). Forthis reason, dysphagia can be further categorized according to the disordered phase of swallowing: oral dysphagia can present as absent oral reflexes, immature or absent suck,uncoordinated biting/chewing, and poor handling of the food bolus; pharyngeal dysphagia can present as laryngeal penetration, aspiration, choking, pharyngeal reflux and nasopharyngeal reflux; and esophageal dysphagia results from obstruction of the passage of the food bolus through the esophagus or by poor coordination of esophageal muscle contractions (Dodrill & Gosa, 2015).

Dysphagia among children can be caused by a single medical problem. However, causes are often multifactorial (Lawlor & Choi, 2020): physiological (prematurity, neuromuscular disorders, anatomic abnormalities of the aerodigestive tract, disorders fromthe gastrointestinal tract, cardiopulmonary disease), nutritional, behavioural, psychological, and environmental (Kakodkar & Schroeder, 2013). Dysphagia can present with several variations of swallowing impairments, and it can arise in different patient populations: children with cerebral palsy, acquired or traumatic brain injury, other neuromuscular disorders, and craniofacial or airway malformations, as well as those withrespiratory, cardiac, or gastrointestinal disease and on preterm-born children (Dodrill, 2014; Newman et al., 2001; Roden & Altman, 2013). Children with generalized severe motor impairment (e.g., spastic quadriplegia) are likely to experience more significant swallowing difficulties than those with diplegia (a form of paralysis that affects similar body parts on both sides of the body). Still, oropharyngeal dysphagia is prevalent even inchildren with mild cerebral palsy (Aredvson, 2013). This means that most children with dysphagia have divergent levels of disability and/or cognitive impairment.

The signs of swallowing difficulties in children vary depending on their age and the cause of dysphagia. The most common ones that cause a caregiver to seek evaluation for feeding disorders are prolonged feeding time, little interest in feeding, food refusal, posturing (such as back arching and neck extension), failure to thrive, nasal regurgitation,cough, choking, wet respirations during and after feeding, increased work of breathing, orchanges in color with feeding (Duncan et al., 2018; Prasse & Kikano, 2009; Weir et al., 2009). All these signs of swallowing difficulties can harm these children’s pulmonary health through aspiration of food. They can also affect dietary intake, growth, and development and lead to prolonged and stressful mealtimes (Dodrill & Gosa, 2015).

Due to the heterogeneity of children with dysphagia, treatment and management of this problem should be tailored to the clinical characteristics of each child with a thorough assessment and a multidisciplinary approach (Lawlor & Choi, 2020; Lefton-Greif, 2008). The clinical evaluation of dysphagia focuses primarily on evaluating the mechanism and safety of the swallow (e.g., identifying aspiration by radiographic studies or through endoscopic evaluation of swallowing) (Myer et al., 2016). However, these approaches do not provide a thorough assessment of a child’s symptoms, and they do not measure the impact of dysphagia on children’s physical or emotional well-being. Furthermore, there are no validated screening tools for dysphagia in children (Zang et al., 2021; Myer et al.,2016).

Importance of Food

Food is an essential need concern for everyone, a source of sustenance, occasional indulgence, and a way to define oneself within a culture (Rappoport, 2003). Good nutrition is considered a right for every infant, child, and adolescent (UN, 1989). The concept of food perception among children has been examined through a concept analysisusing the evolutionary method by Rodgers (2000). This approach is commonly used to examine concepts that are of great interest within nursing to clarify the key attributes or defining qualities of a concept so that the concept can be used more effectively. From thisinquiry, children and adolescents’ perception of food can be defined as their judgement offood, which is formulated by their recognition of attributes influencing this perception.

This perception is identified in food taste and appearance, sensory appeal, palatability, availability and proximity, cost and convenience, time and effort, food quality, and nutritional value (Ottonello et al., Manuscript in preparation). The antecedents of the concept of food perception that impact the perception itself are parental, social, emotive, and cognitive development influences. The consequences include both positive, such as adequate nutrition, a healthy lifestyle, and growth, and negative ones, such as malnutrition(Ottonello et al., Manuscript in preparation). Given the significance of food and that no previous studies have been done before on this topic with children (Zang et al., 2021; Kovacic et al., 2020; Dodrill & Gosa, 2015; Ottonello et al., Manuscript in preparation), itis necessary to examine the food-related experiences of these children, including an investigation of how interactions with families/caregivers affect these experiences (where caregivers are family members or paid helper who regularly take care of the child)

(Sameroff, 2009). Examining the children's experiences and how interactions influence their experience will advance our understanding of what is meaningful for them and how food is impactful in their lives. Moreover, greater attention is needed to examine the social aspects of mealtimes and eating to help develop well-focused interventions for this population (Chapman et al., 2015; Zanini et al., 2017). This because the social environment also plays a role in the child development process that is rooted in socially contextualized relationships. Healthcare professionals taking care of children with swallowing difficulties, especially in home care practice contexts, have an active role during mealtimes of these children (e.g., feeding them, preparing specific and special meals) to fulfill their nutritional needs. These healthcare professionals should understandhow this population experiences food and mealtimes and how this experience and awareness can influence their food practices.

Moreover, to know how children experience food we should consider their own voices and respect their right to be heard. The United Nations Convention on the Rights ofthe Child (CRC) highlighted the fundamental primary principles of (a) protection from harm, (b) provision of required resources, and (c) participation according to their age and maturity, referring to children's right to take part in decisions and matters that affect them (UN, 1989). As time has progressed, there has been growing interest and continued development of interdisciplinary research regarding children and childhood and how children's rights should be better respected (Spyrou et al., 2018; Bluebond-Langner & Korbin, 2007; Carnevale et al., 2008).

It is important to recognize children as active agents in the research process, focusing on their voices and on the recognition that they are capable and active in the construction and determination of their social lives (McNeilly et al., 2020) and in respecting their right to be heard (CRC, 2009). A recent report expressed the need to pay particular attention to children with disabilities (CRC, 2016). The views and experiences reported by children themselves, rather than parents and other adult proxies, have becomemore evident in research as a result (Parsons et al., 2016). Several studies underlined that, to illuminate the multiple facets of children's experiences, healthcare professionals and researchers should draw on frameworks that recognize children's capacity to act as agentswho are able to reason and interpret their own lived experiences (Montreuil & Carnevale, 2018). Within this view, various methodologies have been developed, constituting significant advancement in research with children and in understanding their lives. These advances stress the importance of understanding children's experiences, considering their views and interpretations to provide care that is optimally aligned with their needs (Santoset al., 2020).

In Sameroff's (2009) transactional model for child development, development is seen as a bidirectional interplay between children and the social environment, rooted insocially contextualized relationships. Therefore, an essential role for the child's growthand social and emotional development is played by the relationship between families/caregivers and the children themselves, through social interactions with other people and how these affect children's experiences. Furthermore, since families/caregivers need to navigate different services, frequently with fragmented communication, some expressed feeling lonely and unsure about the consequences of their decisions regarding their child's health (Kuo et al., 2011). Using a research approach that considers the social environment for child development can also help inform the improvement of services for children and their families/caregivers.

Moreover, the nursing profession has a professional, moral, and ethical responsibility to attend to the holistic care of patients, listen to their needs, and provide care that is basedon the best extant evidence and adapted for each individual patient (CNA, 2017;

Keegan, 1987).

A three-fold theoretical framework has been used to guide this study. One of these components is a childhood ethics framework. This childhood ethics framework - whichwill be described in detail below - is a hermeneutic ontological approach to Childhood Studies. It is based on Charles Taylor's philosophy (Carnevale et al., 2021; Carnevale et al., 2013; Taylor, 1971) in which the understanding of social lives is rooted in interpretations of what is morally meaningful or salient for the people within a setting, in light of institutional norms, structures, and practices. Understanding the perspectivesof children with swallowing difficulties, within these institutional norms, structures, and practices, is essential toward addressing the existing knowledge gaps in relation to care for this population (Hunt & Carnevale, 2012). These perspectives, shaped by their sociopolitical contexts, can be framed through the concept of "moral experiences" (Hunt & Carnevale, 2011) that refers to how individuals live the morally meaningful dimensions of their lives (Hunt & Carnevale, 2012). Moral experience is defined as "[e]ncompassing a person's sense that values that he or she deem important are being realized or thwarted in everyday life. This includes a person's interpretations of a lived encounter, or a set of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust" (Hunt & Carnevale, 2011). Thereby, moral experience involves understanding how people interpret notions of right, good, and just concerning what matters most to them (Hunt & Carnevale, 2011). This Childhood ethics framework aims to examine the morally meaningful (i.e., salient) dimensions that affect young people (Carnevale et al., 2020) and broader social and moral backgrounds, since what aperson considers "moral" is embedded in collectively shared understandings within a specific social context (Hunt & Carnevale, 2011; Taylor, 2004).

Given this definition of moral experience—as the perception that what for a person is considered important is realized in their everyday lives —and that food is a concern in our everyday lives, people can have food-related moral experiences. The principal premise for this research is that no studies have examined the food-related moral experiences of children with swallowing difficulties to date, which has impededthe development of interventions that can help optimize these experiences (e.g., development of adapted foods). For this reason, before planning specific interventionsfor children with swallowing difficulties, nurses and other healthcare professionals should better understand this population's food-related moral experiences and promoting children's active participation in this research.

The results from this study can help develop a better understanding of the food- related moral experiences of children with swallowing difficulties. The results will alsoassist to plan future targeted interventions considering the moral experiences of this population and inform the development of specific tools for assessing swallowing difficulties in children, based on the particularly important aspects of their experiences.

Paradigm

This research focused on the food-related moral experiences of children with swallowing difficulties, and, for this purpose, participatory hermeneutic phenomenology was used. The hermeneutic framework, rooted in Taylor's (1971) philosophy, emphasizes understanding the meaning individuals ascribe to their actions and the views of others, aiming to interpret and understand what is particularly salient within people's experiences. The goal of hermeneutic research is to understand and differs ontologically from some other research approaches (e.g., positivism, post-positivism) because it is considered to be within a constructivist paradigm based on a view of truth composed of multiple local and specific realities that can only be subjectively understood (Guba, 1990).

Methodology: Participatory Hermeneutic Ethnography

Participatory hermeneutic ethnography will be used as the methodology for this study. Participatory hermeneutic ethnography (Montreuil & Carnevale, 2018) is a qualitative research methodology that links key aspects of a participatory research approach, hermeneutics, and ethnography. This methodology has been previously used ina study conducted in a child mental health setting (Montreuil et al., 2020) and with children with medical complexity in Brazil (Passos Dos Santos, Macdonald, & Carnevale, 2023). This methodology, which draws on multiple data collection methods, has been used to generate rich data regarding the moral experiences of children in specific healthcare settings while examining the institutional norms, structures, and practices and how they interrelate with these experiences (Montreuil & Carnevale, 2018). The bridging of Taylor's hermeneutics with ethnographic and participatory research approaches represents an innovative aspect highly suitable to vulnerable populations, including children. This methodology has been used to examine experiences and contextual factors through interpretive and iterative processes. Examining the context and experiences will help illuminate priorities for practice changes and strategies that can be used to achieve these changes (Nastasi & Berg, 1999). Participatory hermeneutic ethnography can lead toa more robust articulation of moral life and a deeper understanding of institutional norms,structures, and practices through a collaborative and equitable knowledge-production process.

The analysis of moral experiences, achieved through participatory hermeneutic ethnography is embedded in the context of meanings where the agent's experiences are lived (Hunt & Carnevale, 2011). This means that people's moral experiences can be better understood through analyses of the contexts of people's lives, including social, cultural, and historical influences (Hunt & Carnevale, 2011; Kleinman & Benson, 2006).Examining moral experiences can broaden our understanding of the moral dimensions ofagency and how things are meaningful for children. Participatory hermeneutic ethnography can help advance our understanding of this population of children as moral agents (Carnevale et al., 2020; Hunt & Carnevale, 2011). Using this methodology to understand food experiences (e.g., in children with swallowing difficulties) helped illuminate what is particularly meaningful for these children and the aspects that should be optimized and the negative ones that should be mitigated.

Theoretical Framework

The participatory hermeneutic ethnography methodology used for this study drew on a three-fold theoretical framework to orient this research: Childhood Ethics, participatory research approach, and social model of disability.

Childhood Ethics

Childhood ethics is an ontological approach centered on recognizing children as agents, understanding their experiences, considering their surrounding context and it examines the morally meaningful dimensions of matters that affect young people. It is grounded on hermeneutical ontology of childhood, adapted from Taylor's (1971) hermeneutic framework (Montreuil & Carnevale, 2018) that allows for the examination of"horizons of significance" and "social imaginaries" associated with understandings of norms, structures, and practices and the experiences of a specific group of people (Carnevale, 2013). Taylor's hermeneutics is a human sciences framework in which humanlife can only be understood through interpretation (Taylor, 1971, 1985, 2004).

Hermeneutics has been applied to health sciences to examine and interpret the social contexts of health experiences (Benner, 2004; Carnevale, 2013).

Specifically, horizons of significance represent the broader socio-historical-cultural background in which meaning is rooted (meaningful background) related to the understandings, beliefs, and values shared by a group of people (Taylor, 1991). In this context, human experiences are grounded in a communal background horizon of significance as well as the mutual benefits and exchanges among individuals within a modern society (Taylor, 2004). These experiences are shaped by the different historical and cultural contexts in which people live and are immersed, defining the shared understandingson what is right, good, and just (Taylor, 2004). These understandings orient people's actionstoward what matters most in different societies (Taylor, 2004), whereas social imaginaries are associated with the relational social, historical, and political context and reflect common understandings at the root of collective practices (Carnevale, 2013; Montreuil & Carnevale, 2018). The broader socio-historical-cultural context informs these understandings.

Participatory Research Approach

This study strives to understand and recognize children's voices and experiences by viewing them as active agents with meaningful interests regarding their food-related experiences. Therefore, a participatory research approach will be used to orient children's participation as study partners. Family/caregivers and healthcare professionals were included within this participatory approach as secondary participants who helped me further understand children's experiences (Bergold & Thomas, 2012; Jagosh et al., 2012).That is, this study involved the participation of different actors included in the study asresearch partners who had significant roles in decisions about the study's objectives,data collection, and data analysis and interpretation (Jagosh et al., 2012).

Moreover, a participatory approach promotes the collaboration of people immediately affected by the issues under investigation, creating significant opportunities for creating links between research and practice. This collaboration allows people's voicesto be better heard and taken into consideration (Cargo & Mercer, 2008), and is crucial to developing research with marginalized groups (such as children with swallowing difficulties, who are often marginalized and not fully able to participate in social activities). Such an approach follows the notion of research *with*, not research *about* people (Bergold & Thomas, 2012).

For this study, the participatory approach guided how to address participants' preferences about the research during data collection, analysis, and interpretation. Furthermore, because the exclusion of children from discussions and decisions about matters that affect them is a significant ethical concern, the use of a participatory approach supports an ethical framework for conducting research with children with swallowing difficulties that promotes their participation throughout theresearch process.

Social Model of Disability

Since most children with swallowing difficulties have different levels of disability (which could also include cognitive and communicative differences), this study has been founded on a social model of disability and a sociological understanding of childhood that recognizes the abilities of disabled children as capable research participants (Thomas, 2004). The social model of disability recognizes that disabled children encounter disabling barriers in society that exclude them and minimize their participation.The sociology of childhood recognizes the agency and capacity of children as social actors (James et al.,1998). Within these theoretical approaches, methodological approaches should be adapted to overcome disabling barriers in traditional research to directly engage with disabled children. This implies using inclusive methods to involve children in research processes, from gaining access and consent (and assent) to analysis and utilization of results. Methodological approaches should be reflexive and continuously adapted, following the research questions for each study and children's abilities and preferences (Kelly, 2007).

Study Objectives

This study aims to explore the food-related moral experiences of children (six to

12 years old) with swallowing difficulties during mealtime and to analyze how interactions with families/caregivers affect the food-related moral experiences of these children.

The research questions are: 1) What are the food-related moral experiences of children (six to 12 years old) with swallowing difficulties? 2) How do interactions with families/caregivers affect these experiences?

Methods

Design

This study used a participatory hermeneutic ethnography (PHE) methodology (Montreuil & Carnevale, 2018), using multiple data collection methods with participantobservation (PO) as the principal method. This methodology has been described as particularly well-suited for investigating children's moral experiences in healthcare settings (Montreuil & Carnevale, 2018; Montreuil, 2017; Passos Dos Santos, Macdonald & Carnevale, 2023).

The PHE methodology is rooted in Taylor's hermeneutical framework for humansciences inquiry. Participatory hermeneutic ethnography is an optimal methodology forthis study because of the particular significance of children's local contexts and how these affect their moral experiences. Furthermore, this methodology is well-suited for examining the meanings that a particular group of people may hold regarding their experiences and how they integrate health beliefs and practices into their everyday lives(Montreuil & Carnevale, 2018).

As the first study of this kind with this population, the project was designed flexibly to allow for continuous adaptation of the design, implementation, analysis, interpretation, and knowledge utilization strategies that could be used. These strategies were adapted in consultation with the student's Thesis Committee.

Study Procedures

The study was conducted in three phases in line with a participatory approach (Cargo & Mercer, 2008) (Table 1). The first phase involved the development of the study proposal, drawing from the relevant literature and the specified research questions. The study was submitted for ethical approval to the McGill University Institutional ReviewBoard (IRB) in April 2022 (IRB Review Number A00-B33-22B / eRAP 22-03-044) and to the research ethics committee in Italy (CER Liguria:512/22) in September 2022, where the study was conducted.

The second phase consisted of data collection, analysis and interpretation that were conducted with children involved in the study, with the support of family/caregivers. Decisions were made collaboratively with families participating in the study about the best times and places to conduct PO with children and semi-structured interviews with parents/caregivers and the relevant documents that should be analyzed. The Advisory Committee members provided recommendations to the researcher about these decisions during two meetings. These meetings were performed one before data collection started, one during data collection, analysis, and interpretation. Phase three consisted of preparing the final report, writing of the doctoral dissertation, and initiating dissemination of the study results through articles prepared for peer review journals and presentation in research conferences and forums.

Table 1 *Study Timeline*

Phase 1	**Phase 2**	**Phase 3**
June-December 2021 **Development of the Study Proposal**	**December 2022-February 2023** Recruitment of study participants	**October-December 2023** Writing of doctoral dissertation
January-March 2022 **Comprehensive Examination**	**March- October 2023** Data generation Data analysis and interpretation	**From January 2024** Study dissemination Presentation in research conferences and forums
April-September 2022 **Submissions for ethical approvals**		

Study setting

Data were collected both at home and school settings where participants usually have meals. Specifically, 11 PO sessions were performed at children's homes and 10 at children's schools. Study participants live in two cities of Northern Italy, in different neighborhoods and socio-economic conditions.

School observations were made in two different primary schools. One was called School Center with Special Educational Resources (R.E.S) where children with special needs, that can include physical, cognitive, or communicative impairments and/or swallowing difficulties, are followed and assisted by special and trained staff including a nurse, physical therapists, educators and teachers. Within this school, there are also children with no impairments that share activities with children participating to the study. The other one was not specifically developed for children with cognitive or communicative impairments but has a specific group of educators and assistants that take care and follow these children.

Participants

Participants in this study were children aged seven to 11 years with swallowing difficulties whose families/caregivers consented to their participation in this study and children provided assent throughout all study phases. These children have a clinical diagnosis of swallowing difficulties (i.e., dysphagia).

Distinctions of the types of swallowing difficulties were not considered within the inclusion criteria, because adding further eligibility criteria would have reduced the pool of potential study participants. These children also have different levels of cognitive and/or communicative impairments and they were included in the research ensuring their involvement in the research and decision-making process to the maximum extent possible and ensuring their best interests. This age range has been chosen to ensure a diversity of experiences in light of the characteristics of the eligible population (that can have several forms of communication and/or cognitive impairments); considering participant observation (PO) would be conducted also at schools (in addition to children's homes), this age group has recruitment feasibility advantage in that they are going to be accessiblewithin a common space, that is primary school.

Participants were recruited from two home-care practice (HCP) centers in the city of Genoa and Milan, Northern Italy. Home-care practice centers, in the Italian context, are services connected with the healthcare system that care for children (and adults) with complex and/or chronic diseases in need of healthcare assistance temporarily or long-term at home and at school. The co-supervisor (AB) and thesis committee member (MZ) have research networks that were mobilized to ensure access to the study centers and schools where participants were recruited. The researcher contacted and informed two home-care practice centers in Northern Italy about the possibility of conducting this study and of recruiting children and their families from within to their service. Invitation letters were prepared and sent to these centers after receiving ethical approvals. A presentation online meeting introducing the project to the potentially eligible families was performed, after which families had two weeks to decide to participate with opportunities to ask for additional information from the researcher. Then, parental consent and children's assent to participate in the study were sought.

Following the presentation meetings with families of potential study participants, and their consent in participating to the study, an Advisory Committee of study partners for the study was created and consulted during the whole research process followingthe principles of participatory research. This Advisory Committee consisted of three sections that were consulted twice during the study. These three sections were composed of (a) two children (aged six to 12 years, male and female, with swallowing difficulties and ability to communicate verbally), (b) two parents/caregivers of children with swallowing difficulties (they were primary caregiver of these children that consented to participate in the study), and (c) three healthcare professionals (e.g., two nurses and one speech therapist,)—with 'a' and 'b' living and 'c' working in the study context setting (home and/or schools where these children usually have meals). Children that were members of the Advisory Committee were also included as study participants for PO sessions and they filled out two different consent forms. Adult members of the Advisory Committee were recruited among caregivers of children recruited form the two HCP centers and healthcare professionals working in the study context area with these children. This final composition of the Advisory Committee was slightly different comparing to the planned optimal Advisory Committee composition that consisted of 4 children, 2 parents/caregivers, 4 healthcare professionals. In the study protocol it was anticipated that the final actual composition could vary somewhat from the plan, depending on the availability of potential advisors. One pilot test of PO session was performed with one child member of the Advisory Committee to receive feedback to help improve the PO guide and specific approaches used within the PO, as well as help the researcher become even more familiar with the study context.

Purposive sampling was used within cases considering these three major dimensions: time (e.g., lunchtime, three observations for each participant), people (e.g., age, gender, ethnicity, swallowing difficulties, socio-economic family conditions), and context (e.g., environment, organizational structures, relationships) (Hammersley & Atkinson, 2007). Therefore, maximum variation sampling, according to children's age, gender, family socio-economic conditions, ethnicity, and clinical condition (e.g., swallowing difficulties severity, which were assessed with specific tools determined byclinician opinion and present in children's clinical chart), were used to select participants to help ensure diversified sampling.

For each child participating in the study, we planned for data collection to include three PO and one semi-structured interview, when possible. The sampling goal was to recruit 8-10 children. We were able to recruit 8 children. Three PO were conducted with six of these children, while only two PO were possible for the remaining two children. Interviews and document analysis were conducted for all participants. These datasets enabled "thick" descriptions of participants' experiences (Carnevale, 2005). Considering the multiple data collection methods used, the volume of data that were collected with this number of children was very rich and helpful toward informing the research, to better understand the food-related moral experiences of children with swallowing difficulties.

Children participating had different levels of cognitive and/or communicative impairments and for this reason, data collection methods were adapted to these characteristics. For example, Augmentative Alternative Communication (AAC) was used together with special attention to non-verbal cues, facial expressions, play and artactivities.

Table 2. *Participants*

ID	Age	Gender	Diagnosis	PO sessions	PO setting	Interview	Key Documents
1 C	8	M	Mild-moderate dysphagia due to outcomes of surgery for esophageal atresia	3	Home (2 lunches and 1 snack	Mother	Medical records, speech therapist records, WHO documents*
2 N	9	M	Genetic encephalopathy with moderate cognitive and communicative impairment	3	School Lunch	Mother	Medical nutritional records and food diary, City guidelines on children school inclusion
3 M	10	F	Cerebral palsy with significant motor and cognitive impairments	3	2 School (lunch) 1 Home (snack)	Mother	Medical nutritional records, food diary and school food diary
4 D	7	M	Swallowing difficulty due to mild cerebral palsy	3	1 Home 2 School (lunch)	Mother	Medical records, food diary and school food diary
5 A	8	F	Epileptic encephalopathy with psychomotor delay	3	Home	Babysitter/caregiver	Medical records, food diary, documents from

							HCP** service
6 J	11	M	Mild swallowing difficulty due to oncological disease outcomes	3	School	School Nurse	Medical nutritional records and food diary
7 C	9	F	Psychomotor delay due to genetic encephalopathy	2	Home	Mother	Medical records and food diary
8 P	10	M	Mild swallowing difficulty for surgical outcomes in cardiac patients	2	1 Home 1 School	Mother	Medical records and food diary

** International declarations and conventions. The United Nations Convention on the Rights of the Child (1989) and the World Health Organization Millennium Development Goals (United Nations, 2015)*

***HCP= Home Care Practice*

Data Collection

After participant recruitment, a meeting was planned with parents/caregivers who consented for their children to participate in the study. They were presented with the possibility of writing daily food diaries or sending voice messages about their notes, suggestions, and comments regarding their children's food-related experiences as additional data collection methods.

Children and families participating in the study were involved in deciding the besttimes and places to conduct the PO, who would have been interviewed according to their preferences to personalize and adapt data collection, as well as any consideration of supplementary data collection methods according to the needs and preferences of participants (Montreuil & Carnevale, 2018). Decisions about when, who, what, and where to observe were recorded in field notes to make more explicit the decisions taken in collaboration with the Advisory Committee. The exact number of family/caregivers who were interviewed and the number of interviews were decided and reassessed in light of the quality and relevance of the data collected (Hammersley & Atkinson, 2007), based on addressing the research questions, as judged by the Advisory and Thesis Committees. The research group decided if data collected was properly answering study question or not.

The data collection phase (fieldwork) of the study was six month long. Several data collection strategies (that are described below) have been used concurrently to examine various data types within different settings (Savage, 2006). Since children with swallowing difficulties can also have different levels of cognitive and/or communicative impairment (Dodrill & Gosa, 2015), data collection methods have been adapted for each participant according to the level of cognitive and communication impairment to accommodate children's participation capacities (e.g., use of arts, play, or images or alternative augmentative communication) (Kelly, 2007). This multi-method data collection approach helped ensure rich and diverse data, allowing for an in-depth examination of the food-related moral experiences of childrenwith swallowing difficulties. The involvement of these children was ensured to the greatest extent possible in the decision-making and all research process ensuring that these children's best interests was followed and respected.

Data collection was performed with the following three main methods: PO, semi-structured interviews with parents/caregivers, and examination of key texts. In line with a participatory approach, additional types of data collection methods (e.g., arts and play, food diaries) were used (Cruz & Higginbottom, 2013) to help supporting and describing data collected through PO sessions.

Participant Observation: PO was the primary data collection method, which has been recognized as an optimal method for research with children (Carnevale et al., 2008). Children participating to this study were observed during mealtimes at their homes and/or schools. Since these children have different access to food (in terms of type, taste, quantity and consistency) compared to their peers, they can experience differences, injustice and inequalities during mealtimes. The use of PO allowed to explore children's experiences within their "lived" contexts. This focus would not be as readily possible with other data collection methods, such as structured interviews and quantitative methods (Carnevale et al., 2008). PO, with its inherent flexibility, allowed for the development of a relationship between the researcher and children. This was facilitated by the researcher spending time with children within children's own settings. With this method, the researcher was both a participant and an observer engaged in the research activities. The researcher had informal conversations and interactions with the participants that contributed to a more contextualized data collection process, permitting the collection of information that otherwise could not be as readily accessed (Hammersley & Atkinson, 2007; Phillippi & Lauderdale, 2018).

PO included the collection of verbal and non-verbal data, and this is particularly relevant when conducting research with younger children who may be less verbally articulate but still quite communicative (Carnevale et al., 2008). This aspect is important to consider in light of ethical concerns related to power differentials in research with children. Since children involved in this study have different levels of cognitive and communicative impairments, PO has been particularly relevant in appreciating different forms of children's communication, how they navigate their social worlds, interact with others, and understand their lived experiences (Carnevale et al., 2008).

Importantly, for children who communicate differently (e.g., reduced or absent ability to produce oral speech), there have been implications (e.g., adaptation of data collection methods, techniques for providing study information to these children) for the research process when attempting to listen to the "voices" of those who cannot communicate verbally

(Teachman et al., 2018). Interaction and communication with these children were created following the principles of the Social Model of Disability considering different ways of approaching with these children: augmentative alternative communication; attention to their verbal and non-verbal cues.

PO were conducted in different contexts where the child usually has meals, which include breakfast, lunch, and snacks (home, school). Each child participant was observed at least three times to help ensure the richness of observations. These PO sessions were performed at times chosen by children and families according to their needs and preferences to promote trustworthiness and heterogeneity of the children's food-related moral experiences. Usually, each PO session did not exceed 40-50 minutes to avoid burdening families and children and to help the researcher take time to write field notes as soon as possible. Participants and families were asked to help the researcher specifying the optimal duration of each session. A guide for PO was used (Appendix A). This guide contains questions about what situations will be observed to best understand children's food-related moral experiences and the families/caregiver interactions, social surroundings, and relational contexts. This guide was provisional and, in line with a participatory approach, could have been adapted in consultation with the study partners or according to the specific PO session.

During PO, to help stimulate the child's engagement to share food-related moral experiences, informal interviews and discussions were paired with specific engagement strategies, such as drawing, and play, which have been demonstrated to be effective ways to minimize the power differential between adult researchers and children and contribute to better understanding the "children's worlds" (Kirk, 2007). These strategies were used to elucidate children's interpretations, choices, and preferences (Kirk, 2007), deepen understanding of their experiences and the local meaningful moral context, and help get the researcher involved and familiarized with the environment. The student researcher wrote field notes at the end of each

PO session, recording data from observations and informal interviews, along with reflections relating to the data collected (Muecke, 1994; Mulhall, 2003). The researcher kept a reflective journal in whichpersonal experiences about the fieldwork were recorded (e.g., personal assumptions, feelings, interactions with participants, and reactions) (Lipson, 1991; Mulhall, 2003). This was important strategy to improve self-awareness in collecting, analyzing, and interpreting data, to maximize the researcher's attunement to what is observed, and to foster reflection (Mulhall 2003).

During participant observation sessions, I adopted a participant observer role, in which I did not perform nursing tasks per se (e.g., give medication or providing basic nursing care), but contributed to care like what a volunteer usually does (e.g., playing with children), without taking clinical responsibilities for specific patients. This type of participative role facilitated my integration in the field and provided in-context data that could not have been obtained only with observation (Gerrish, 2003; Muecke, 1994). To improve the use of self in collecting, analyzing, and interpreting data, I kept a journal in which personal experiences were recorded (e.g., personal assumptions, feelings, and reactions) to promote self-awareness, maximize attunement to what was observed and foster reflection (Lipson, 1994; Mulhall, 2003).

Interviews: Semi-structured interviews (Appendix B) with families/caregivers were conducted, sometimes, when possible, before PO to provide the researcher with a detailed understanding ofthe context where the observations would have been conducted. Children were welcome to participate in these family interviews if they wished.

These data collected with multiple methods was included in each child's "unit of analysis" data, which incorporates all information and data collected from each child participating through these different data collection strategies.

Examination of key texts: Normative and clinical documents were reviewed to complement the other types of data (e.g. charts, policies, procedures and clinical tools). The analysis of relevant documents and materials is considered an important source of data in ethnographic studies as it provides rich information that could not be accessed otherwise (Hammersley & Atkinson, 2007). This data contributed to the researcher's understanding of institutional norms, structures, and practices in the setting, and could also be used as a prompt to discuss the meaning for the people in the setting of the explicit norms, rules and procedures in place. Also, this contributed to the development of "*thick description*" of the study context and setting.

The specification of how to use the different data collection techniques were developed in continuous consultation with the study participants throughout the project,considering modifications—if necessary—throughout data collection.

Peculiarities related to the COVID-19 situation

Since during the development of this study we were still within the COVID-19 pandemic, varying levels of social restrictions and distancing, affected study timeline and development delaying data collection of almost six months. This happened mainly because it was not always possible for me to access school or to observe children during mealtimes with their peers because of social restriction measures. Also, some planned PO sessions were delayed because study participants or researcher contracted COVID-19.

Data Analysis and Interpretation

Data analysis was conducted simultaneously with data collection, as a circular and iterative process, so that data was analyzed in an ongoing manner and continuously compared with new data. Through the study, new lines of inquiry and analysis weregenerated based on data collected and Advisory and Thesis Committee feedback and suggestions. Data was analyzed using the processes within Participatory Hermeneutic Ethnography, which draw on Benner (1994), Crist and Tanner (2003), Carnevale (2013).

Benner’s (1994) framework is rooted in interpretive traditions that align with Taylor’s hermeneutics but focuses more explicitly on experiences. Crist and Tanner (2003) laterbuilt on Benner's work to develop more specific guidance for data analysis. Montreuil and Carnevale (2018) drew on Benner and Crist and Tanner to develop participatory hermeneutic ethnography that analyzes the socio-historical-cultural context in line witha hermeneutics framework.

Field notes (i.e., data recorded from PO sessions), interview transcripts, and key texts were analyzed using SAMMSA (Summary & Analysis coding, Micro themes, Meso themes, Syntheses, and Analysis) (Macdonald et al., 2023). SAMMSA is a 5-step-by-step analytic method committed to both clarity of process and rich ‘quality’ qualitative analysis recently developed by a group of researchers of the VOICE (Views On Interdisciplinary Childhood Ethics) project Team (Macdonald et al., 2023).

The five steps are presented as follows: (1) S&A: Summary and Analysis coding;

(2) M1: development of Micro themes; (3) M2: development of Meso themes; (4) S: generation of Narrative Syntheses; (5) A: cross-syntheses Analysis & Interpretation.

SAMMSA process has roots theoretically in hermeneutics and methodologically in ethnography and is attentive to data holism and tries to avoid the data fragmentation that can occur in some versions of thematic analysis. It moves from coding through to synthesis and interpretation of the whole of the data (field notes, interview transcripts and key documents). SAMMSA follows these main characteristics: it uses both deductive and inductive coding strategies; it relies on a thematic-type analysis including Micro followed by Meso themes; it uses a part–whole synthesis technique to ensure the integration of an entire data set remains attentive to the specificities of salient data points.

Specifically, analysis within-case and across-case methods (Montreuil & Carnevale, 2018) with movements between each case (parts) and the totality of data (whole) is essential in hermeneutic analysis to collect relevant statements from each source of data and then compare it with the whole data so as to best understand the "parts" as part of an irreducible "whole," building categories that are congruent with the phenomena. In addition to part-whole analysis, commonalities and differences among the experiences involved in the study were examined (Benner, 1994; Passos dos Santos, Neves, & Carnevale, 2016). Analysis based on hermeneutics is an important strategy in advancing a contextualized understanding of study phenomena, shedding light on otherwise taken-for-granted aspects which may be disregarded when different contextual aspects are not adequatelyconsidered (Benner, 1994). Specifically, children's experiences were analyzed by considering their individual and relational experiences through a comparison of the similarities and distinctions within and among them to better understand the subjective perspective of the people living the phenomenon under study within their local social context, illuminating how these shape people's experiences (Benner, 1994;Crist & Tanner, 2003; Hunt & Carnevale, 2011).

Data collected and preliminary analysis were shared with Advisory and Thesis Committee members as an interactive process to reach a consensus on data interpretationthrough mutual understanding among study partners (Macdonald et al., 2023; Montreuil & Carnevale, 2018). The use of childhood ethics framework guided to examine and interpret the social context of food-related moral experiences following the interpretive framework of hermeneutical analysis in a participatory manner with the study partners.

Children's experiences were analyzed considering their individual and relational experiences and then compared to the others. This allowed to better understand the contextualized and experiential nature of the food-related moral experiences of children with swallowing difficulties. More specifically, the following SAMMSA steps were followed in an iterative, nonlinear manner during and following data collection: (1) the researcher developed detailed interpretive comments while recording and writing field notes and transcribing interviews; (2) the researcher prepared narrative syntheses for each participant based on field notes data, family/caregivers' interview transcripts, data from the documentation review (Appendix C), and interpretive comments, including excerpts from the raw data; (3) the researcher summarized the syntheses for the Advisory and Thesis Committees to identify significant themes, contextualize the data, and derive meanings; (4) the researcher wrote additional syntheses to clarify the initial interpretations based on the comments of collaborators.

The SAMMSA analysis process phases are presented in the table below reporting extracts from data collected and analyzed (Table 3).

Table 3. *SAMMSA Analysis Process*

Fieldnotes Extract	***S Code – A Code***	***Micro Theme***	***Meso Theme***	***Narrative Synthesis***
N. seems impatient to want to start eating, as soon as he smells the food he starts moving his legs and arms upwards and with some vocalizations	S Code: The child, smelling the food, expresses his desire to eat by "moving his legs and arms upwards and making some vocalizations".	Micro theme 4: Communicative characteristics of the child	Role of contextual factors on mealtimes	The other contextual aspect that influences the child's experience concerns the communicative characteristics of the child himself. Nonverbal communication plays an important role for this child in

and smiles he shows his desire to start eating.	A Code: The child shows his desire to eat through sensory stimuli such as the smell of food and non-verbal communication ("moving his legs and arms upwards and making some vocalizations").			expressing his desires and emotions. For example, through sensory stimuli such as the smell of food and non-verbal communication ("moving his legs and arms upwards and with some vocalizations") he manifests his desire to eat.
Mealtime is strictly regulated by school rhythms: it goes from 12pm to 12.30pm after which we proceed	S Code: Mealtime at school is determined by the rhythms and program of school activities. A code:	Micro Theme 7: Meal timing in relation to the school environment	Role of contextual factors on mealtimes	In addition to the people present, the timing of the meal itself in relation to the rhythms of the school program plays an important role in this child's meal experience. In fact, at school,

with recess and afternoon activities. As in every school, the times are marked by the ringing of the bell and the meals arrive already prepared and packaged by the catering company which places them on the children's tables according to their daily menus.	Mealtime at school follows the rhythms and timing of the school calendar and not always the rhythms of children with swallowing difficulties.			time is marked by the ringing of the bell with very precise and structured timing and this, while on the one hand helps the child to understand the sequence of activities, on the other hand does not always follow the needs and rhythms of children with disabilities of swallowing, especially for the duration of the meal. For example, *for the child, taking slower bites and pauses*" help him to have "better control and comfort during

				feeding and this cannot always be guaranteed. It is therefore important to establish a routine for feeding time for these children (context, time, people).

Data collected through additional data collection methods (e.g., arts/play and informal interviews, which were documented within field notes; food diaries which generated additional data documents) were incorporated within the analysis of data generated through the main data collection methods (i.e., PO, interviews, document analysis).

Methodological Rigor

Ensuring methodological rigor in qualitative research is essential so that the research results will have the "integrity" required to impact practice and/or policymaking. Several strategies were used to ensure this study's methodological rigor: personal diary and researcher's reflective notes, use of several complementarydata collection methods, member checking, debriefing, and prolonged engagement with study participants.

Trustworthiness is the degree of confidence in data interpretation and methods used to ensure the quality of a study (Polit & Beck, 2014). It refers to the credibility of the study, transferability, confirmability, and dependability of research findings. Trustworthiness can be ensured using different strategies, such as reflexivity,triangulation, member checking, and others.

Reflexivity is a process by which researchers evaluate and develop an explicit awareness of themselves, defined as positionality, and formulate a statement about the values, beliefs, interests, and ambitions that might shape the research interest and its focus(Shaw, 2010). Being reflexive entails examining the researcher's involvement and awareness of the limits of the researcher's knowledge and how the researcher's behaviourmay influence or affect others. This allows us to look more critically at circumstances andrelationships and help review and revise ways of being and relating (Cunliffe, 2009).

Many factors may be essential to consider when thinking about reflexivity, such as ethnicity, age, previous life experiences, social identity, role, and personality (Jootun et al., 2009). Reflexivity is linked to the quality and credibility of research, as it requires researchers to be willing and able to acknowledge and consider the numerous ways in which they can influence their findings. It implies the ability to be introspective and look at external forces that may shape the study, such as culture, history, politics, the researcherand participant, and their social interactions (Sandelowski & Barroso 2002). Reflexivity does not see the researchers as neutral data-collecting machines. Instead, it allows researchers to understand further their effects on their research and how these might be minimized where possible (Underwood et al., 2010). A reflexive approach does not limit bias but brings it to the forefront so that, rather than attempting to hide ordeny issues that arise, researchers can tackle them and adapt interpretations to bring a more credible and realistic version of participants' accounts to light (Underwood et al., 2010). Within this research project, the researcher needs to be aware of her positionality by conducting a thorough self-analysis and confronting any influence that may affect data collection or analysis. The researcher kept a personal diarywith reflective notes about feelings and perceptions during each PO encounter.

Triangulation involves using at least two related data sources or researchers to reduce inherent bias associated with a single source, method, or researcher (Long & Johnson, 2000).

For this reason, several complementary data collection methods were used in this research. Member checking refers to checking study findings and conclusions by the respondents from whom the data were initially generated (Long & Johnson, 2000). It aims to ensure the dependability and credibility of qualitative studies. In this study, the researcher shared data and analysis with study participants and advisors for feedback during meetings with the Advisory Committee throughout the data collection and analysisprocess.

Prolonged engagement of the researcher with study participants implies spendingextended time with participants in their everyday life and it is recommended to gain theirtrust and establish rapport and a better understanding of behavior, values, and social relationships. This enabled the researcher to get more in-depth information from the respondents and identify pertinent aspects in the community concerning the issue being studied, allowing for a heightened focus on these aspects and ensuring comprehensive exploration of the research topic (Creswell, 2006). This was achieved through the development of a trusting relationship between the researcher and study participants,

which was facilitated through various familiarization processes (e.g., informal meetings between children and the researcher before PO).

Debriefing was applied throughout the research process between the researchers and experts to ensure trustworthiness of the study. An expert reviewer in this study was one of the supervisors of this research project (FC), an experienced qualitative researcher who can meaningfully question the researcher’s interpretations, provoke critical thinking, and provide alternative/additional perspectives and explanations. In addition, the other members of the Thesis Committee (professors and experienced researchers) were consulted. The word "debriefing" here implies a discussion between the student researcher and the supervisors (along with other members of thesis committee) to discuss the phases of the research process (data collection and analysis methods) with consideration of feedback received from members of the AdvisoryCommittee. Debriefing meetings with them were scheduled when necessary, during data collection and analysis phases, and additional meetings were planned if necessary or required by the researcher.

Finally, providing detailed and thick descriptions promotes transferability of theresults (Long & Johnson, 2000), which elevates the study's credibility. The researcher provided sufficient details about settings, inclusion and exclusion criteria, sample characteristics, and data collection and analysis methods so readers can evaluate the extent to which the conclusions are transferable to other settings, situations, and populations (Creswell, 2006).

Ethical Considerations

Data collection started after the research ethics board of the study setting (regional ethics committee where the study was conducted) and the McGill Institutional Review Ethics Board (IRB) had approved the study. Additional planning and preparation are vital in ensuring that children and young people, especially those with disabilities, can participate in research in a meaningful way and that researchers conduct studies ethically (McNeilly et al., 2020). Ethical Research Involving Children (ERIC) upholds children's rights in research and seeks to safeguard the dignity and promote the best interests of children who take part in research (ERIC, 2019). With children, research ethics boards typically require informed consent from a parent for their child to participatein a study, which is also a common legal requirement (Huang et al., 2016).

This study is based on a participatory design, striving to promote children's right to participate in activities that affect them, as specified in Article 12 of the United Nations Convention on the Child's Rights (UNCRC, 1989). Although the study participants weretoo young to provide consent to participate in the study—so parents consented on their behalf—we sought assent from children whenever they are capable of understanding explanations about the study, which were adapted to their usual ways of communicating, as well as capable of expressing agreement or disagreement.

Consent (Appendix D): Parents were informed about the study by a healthcare professional known to them (e.g., a “care manager,” a term used in Italy corresponding toa case manager in Canada) who works in the study setting. Parents were asked if they agree to share their contact information with the researcher, who contacted them to describe the study and invited them to participate. If the parents agreed, the researcher contacted contact them to explain the study, answer their questions, and seek their consent for their child’s participation. Parental consent was required for all participating children. Assent was sought for children who have the capacity to provide verbal or writtenassent. For a child who has the capacity to provide verbal or written assent, who does notassent to participate, that child did not participate in the study. For children incapable of providing assent (e.g., because of language or cognitive “impairments”), those children participated in the study with only parental consent. This helped ensure the study was inclusive of children with cognitive and communicative “impairments” to help advance knowledge for this specific population. To help ensure that assent from children is valid throughout the study, special attention was paid to children’s verbal and nonverbalcues to continuously assess their willingness to participate.

The provision of accessible information to meet individuals’ diverse needs is vital in helping them make informed decisions about their participation (Graham et al., 2013).

The researcher therefore considered various ways of providing information. Those who agree to participate were provided with a further full description of the study aim, data collection process, and their right to withdraw at any time without consequences for their healthcare received, and their questions were answered by the researcher. Before data collection sessions, the researcher asked the participants how they would like to tell her if they wanted to end the session and implicitly withdraw their assent to participate, as assent is an ongoing process (McNeilly et al., 2020). Particularly for children, their expressions and reactions were observed to detect possible discomfort. This strategy is also considered relevant to minimize the existing power differential between the researcher and children (Carnevale et al., 2008). Families who feel uncomfortable at any time during the research project had the right to withdraw their consent whenever they wish to. Given the challenges these families face in their everyday lives, some families were not able to participate fully in data collection (details stated in the Recruitment section). Data gathered from families and children who may withdraw before data collection is completed were be used, with their consent, as partial or complementary data, as determined through discussions with the Thesis Committee. All these feasibility issues have been discussed with members of Thesis Committee. Given that participants' consent should be assessed in a processual rather thanepisodic manner (Carnevale et al., 2008), informed consent and assent was continuously reaffirmed from participants.

Confidentiality: All identifying information were de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics. Data were de-identified during the initial data analysis. For this reason, identification codes were assigned to all participants (Gallagher, 2009) also including members of the Advisory Committee. All data containing identifying information (interview transcripts and field notes) were confidentially storedby the researcher in a locked file in the co-supervisor's (A.B.) research office in Italy at the Health Sciences Department of the University of Genoa. Computerized data were kept on a password-protected computer. Passwords protect documents containing information about the participants. The student researcher has access to the study data. All data will be destroyed seven years after the publication of the study. Only de-identified data will be shared among partners of the study. These confidentiality protection measures were stipulated in the consent form.

Participant observation: Permission from families were sought to observe different situations as described above (Carnevale et al., 2008). Also, permission to conduct some PO sessions were sought from schools attended by children who participated in the study. These schools were asked to allow access to the researcher in observing the child included in the study during lunchtime. These schools had already allowed healthcare professionals caring for these children to access schools. People who were potentially seen during the PO data collection (e.g., other healthcare professionals,school staff, children at school) were informed about the study and they were excluded from the study's data collection field. Whatever procedures required by schools where PO can take place (e.g., information sheet, researcher contacts for families)were provided. No information was collected from classmates of children participating in the study. If situations arose during PO involving a child's maltreatment or potentially harmful practices in any of the study settings, the researcher discussed these with the study supervisor and co-supervisors, who are experienced nurses and researchers.The situation was analyzed according to the particular facts relating to each situation.

If the situation would have been urgent (e.g., clearly unsafe, and harmful), the Italian law for childprotection would have been followed to intervene, following the child's best interests. This was not necessary for this study since urgent unsafe or harmful situations did not occur.

Results

Study setting- a *"thick description"*

The food-related moral experiences of children with swallowing difficulties are deeply influenced and rooted in the social context where these children and their families live. For this reason, before reporting the results and themes describing the moral experiences of these children during mealtimes, I present a "*thick description*" of the study setting with a local hermeneutical analysis of the social context. This analysis has helped me develop and describe themes that underlie the food-related moral experiences of children with swallowing difficulties and how interactions with families and caregivers influenced children's experiences.

Several primary document sources for hermeneutical analysis were identified in collaboration with study partners as follows (international statements and conventions; medical and clinical records, food diaries and menus; institutional documents for school services):

Table 4. *Documents analyzed*

Source	***Documents Included***	***Access***
International statements and conventions	The United Nations Convention on the Rights of the Child (1989),	Online access
	World Health Organization (WHO) Millennium Development Goals (United Nations, 2015)	Online access
	WHO Social Determinants of Health (WHO, 2008)	Online access
Institutional documents for school services	institutional documents concerning school services and organizations for children with disability	Online access and personal access
Medical and clinical records	Information about hospital discharge, medical diagnoses, and medical certificates for follow-up healthcare assistance	Personal access
Food diaries and menus	They detailed the school menu for everyday lunch at school, specifying the	Personal access during PO sessions

	ingredients they could eat, following personalized nutritional indications	

International statements and conventions: The United Nations Convention on the Rights of the Child (1989), the World Health Organization (WHO) Millennium Development Goals (United Nations, 2015) and the WHO Social Determinants of Health (WHO, 2008) were selected. These documents stress the importance of "*Achieving health equity within a generation is achievable, it is the right thing to do, and now is the right time to do it*". Also, a document stresses the important of having and reaching proper nutrition for all people "*People with adequate nutrition are more productive and can create opportunities to gradually break the cycles of poverty and hunger*" (WHO, 2016).

These sources were considered because of their significant strength in impacting health systems and governances, identifying priorities, setting goals, and prescribing plans and actions toward children's health, including those with swallowing difficulties and other impairments.

Medical and clinical records: Medical reports and certificates specific to the children who participated were analyzed to learn about local practices and institutional norms on how these children are managed. The documents included information about hospital discharge, medical diagnoses, and medical certificates for follow-up healthcare assistance. Also, healthcare professionals working with these children were interviewed to describe barriers and facilitators from the institutional point of view that children and families could encounter in managing the situation.

Food diaries and menus: These documents were provided by families or school nurses, showing what these children should eat according to their swallowing difficulties. They detailed the school menu for everyday lunch at school, specifying the ingredients they could eat, following personalized nutritional indications. Each meal comprised one main plate, one second plate and fruits or dessert.

Institutional documents for school services: Some institutional documents concerning school services and organizations for children with disability, including those with swallowing difficulties, were analyzed. This allowed us to explore and know the contextual organization behind public services provided to these children and families. They contained a detailed description of school requirements and the composition of a professional team dedicated to these children during school activities.

Through the development of this local hermeneutical analysis, the social context in which children with swallowing difficulties are living in Italy could be described as involving multiple horizons of significance that are related to legal perspectives and interpretation of policies according to goals of inclusion and protection of these children, together with biomedical views on healthcare for these children, normalization of childhood, and societal outlooks on the maternal figure, considering the mother as the principal caregiver for children participating in this study.

Given that children with swallowing difficulties can also have cognitive and/or communicative impairments, management and care for these children can have significant ethical and social concerns together with political implications. From an ethical point of view, childhood studies have described the importance of recognizing children as active moral agents, meaning that they can interpret and interact with their social contexts, presenting concerns about matters that affect them (Montreuil & Carnevale, 2016). This ethical view strives to include social and relational perspectives to understand children's experiences (Carnevale, Teachman, & Bogossian, 2017; Carnevale et al., 2015). From a research and practice perspective, to recognize children's moral agency, their views should be included and acknowledged, considering the broader social and relational contexts in which they are embedded (Carnevale, 2020). Because of the relational and contextual perspectives on the experiences of children with swallowing difficulties, authors have suggested an in-depth ethical analysis of the surrounding sociopolitical contexts to better grasp the experiences and voices of these children (Carnevale et al., 2017; Teachman, McDonough, Macarthur, & Gibson, 2018).

This study has been conducted in the Italian context, specifically in two cities situated in Northern Italy where social, healthcare and school services are considered similar together with cultural outlooks and perspectives. Also, it is essential to underline the impact and the perception of food among Italians, where an authentic "culture of food" has been developed through the years and history of this country within the Mediterranean culture (Fonte, 2002). Food is perceived as a moment of pleasure, sensorial experience and sharing with others. For example, when it is lunchtime, Italians take a real lunch break that lasts until one hour, when they stop their activities to enjoy lunch. It is unusual to see workers having lunch while working at their desks or offices (Mascarelllo et al., 2020). This broader social perception and meaning given to food, typical of Mediterranean countries (Monteleone et al., 2009), can significantly impact how children with swallowing difficulties and their families perceive food and mealtime, influencing these children's food-related moral experiences. Also, we can assume that, considering the importance given to food, having challenges and difficulties in eating (e.g., swallowing difficulties) can determine an essential and meaningful impact on the everyday lives of these children and their families.

This study was conducted at home and in school settings of children participating in the research. These children could have other conditions associated with swallowing difficulties that could include cerebral palsy, communicative impairments, cognitive impairments, and encephalopathy of genetic origins, as mentioned in Table 2. Also, some of them had a temporary swallowing difficulty that influenced their experiences and family expectations and approaches to the situation. For example, having swallowing difficulties without cognitive and/or communicative impairments determined different food approaches and support needed, which were different from those children with other impairments.

Schools included in the study setting were two primary schools specifically; one of them is called School with Special Educational Resources, and it is specific for children with impairments, disabilities, and medical complexities that require exceptional support (https://www.miur.gov.it/alunni-con-disabilita). These schools are recognized by the Italian Ministry of Education as specific for these children, satisfying detailed structural, professional, and educational requirements. All children with special needs are followed by a specific and trained team of healthcare and educational professionals such as nurses, physiotherapists, educators, teachers, social assistants, and occupational therapists. The aim of this multi-professional team is to provide education and inclusion of these children in school activities with interventions adapted to their conditions and capacities so that they can be included in school activities with their peers in a safe and protected environment. The school nurse is a figure present at school every day, and she is located in a specific room called a "nursery", where she keeps all medical records, therapy sheets, food diaries and menus specific to these children. The nurse usually takes care of these children for primary everyday fundamental care (e.g., diaper change, oral hygiene, medication administration and emergency and complications management). She collaborates with the other team members and, if necessary, participates in school and playing activities.

Educators take care of these children for the educational aims and school activities involving and adapting educational contents and resources to these children's cognitive and communicative levels. One crucial aspect is the inclusion process that this team, following national ministry requirements, follows to integrate these children with special needs with their peers. During several school and class activities, children participating in this study were integrated and included in the classroom with their peers. During mealtime, children with swallowing difficulties could eat at the same table with one or two classmates without swallowing difficulties. In one school, children in the research had lunch in a dedicated canteen with a personal table with their names and space for educators or assistants who took care of them during mealtimes. In this dedicated room, when possible, children from other classes without special needs usually had lunch with children who needed assistance. In the other primary school, children with swallowing difficulties had lunch at the same table and room together with the other classmates, and they were always supervised by an educator or assistant dedicated explicitly to the child.

While the broader socio-historical context was similar for all participants as described above, home environments differed among all participants (e.g., neighborhoods where children and their families live, dimension and location of the houses, rooms and spaces dedicated to mealtimes). Participants' houses were all city apartments in buildings. None of them lived in independent houses. Some houses had specific requirements for people with disabilities (e.g., structural services available for wheelchairs, wide room spaces, security, and alarm systems). They were also used by some children participants with movement impairments associated with swallowing difficulties and other related conditions (e.g., cerebral palsy, communicative and cognitive impairments).

During observations at children's houses, usually, their mothers were alone or with other siblings, and sometimes, nannies or healthcare professionals were primary caregivers. All participants had dedicated spaces for playing (alone or with other people) and all necessary support systems for movement, mealtime, and hygiene. One outstanding aspect of the study setting was adapting and personalizing tools used for mealtimes according to children's abilities and characteristics (e.g., personalized glasses and cutlery).

Children participating in this research study described and showed cues, their positive experiences of being included in a social group, such as participating in school activities with classmates, siblings, or friends (e.g., a birthday party). These positive experiences shared by children emphasize the importance of participating in communal activities as an experience that indicates good aspects of "normality" in their lives meaning that they could participate and do the same thing as their peers defined as “normal” because they don’t have swallowing difficulties. These views are similar to data from a scoping review on the experiences of children with medical complexity. These showed children's discourses on the good aspects of being included in a group and participating in school activities (Santos et al., 2020).

A study with children with disabilities has described how children expressed feelings of happiness associated with being part of a group and performing the same activities as their school peers. These situations perpetuated the "sameness" of children's experiences and prevented negative feelings (Connors & Stalker, 2007).

This study demonstrated the complex dynamism of children's relationships and interdependence. Some children expressed their preferences concerning what matters to others. Recognizing this relational basis in children's experiences can help expand the understanding of children's voices and perspectives (Spyrou, 2019). As highlighted by Carnevale et al. (2017), a more in-depth understanding of children's interests is more likely to be achieved by acknowledging relational perspectives involved in children's and families' beliefs and values. While children are somewhat dependent on people responsible for making decisions on their behalf (parents or legal representatives), they are not deprived of significant moral views (Carnevale et al., 2017). Adopting research and care approaches that include these relational perspectives could contribute to a better understanding of children's interests and preferences.

In the study's setting, families, healthcare professionals and school teams planned healthcare and educational decisions and actions to reach the dominant view of a "healthy life" and is similar to their peers as defined in views on good pediatric healthcare. To reach a "healthy life," children were expected to match standardized developmental stages. Parallel with this view, Gibson et al. (2015) highlighted that, in traditional pediatrics, deviations from standard development measures are considered problematic, and interventions to re-insert children into standard patterns must be implemented. These attempts to reach the "normal" can cause frustration for children when they are not included in decision-making processes (Phelan, 2011) and when they are judged, considering their functional abilities (Gibson et al., 2015). In line with this dominant view, studies about people with disabilities are primarily focused on biological and physiological differences, resulting in problems around "normalization" and how the bodies of people with disabilities need to be "fixed" to function productively (Fadyl et al., 2020).

Within this view, societal and medical understandings of children with swallowing difficulties are rooted in biomedical notions. Children are primarily regarded in terms of their failures (e.g., what they "can't" do) and their clinical conditions.

Mothers, siblings, and caregivers had essential roles as interlocutors for many children participants. The interlocutor can be defined as someone able to understand the child's expressions and concerns and is ultimately someone with whom the child is confident sharing his/her experiences. For two children, the presence of unfamiliar people became a threat since they were not confident about being assisted during mealtimes by people they did not know well. Having someone known whom children trust made their experiences more positive, helping them disclose their views, wills, and preferences.

The relational perspectives of these children were illustrated in the complex relationship between mothers' (and sometimes other principal caregivers') voices and children's interests. Mothers' interpretations of children's expressions helped understand children's needs. When people responsible for decisions and actions do not consider these interpretations, the children's interests may not be fully represented, sometimes resulting in the child's discomfort. Furthermore, children demonstrated they wanted to care for their mothers and family, trying to avoid burdening them. For example, even if the child did not like the food prepared, he did not tell his mother to avoid making her suffer or increasing her burden. Sometimes, this desire seemed to express a child's caring conscience for their loved ones.

This examination of the institutional norms, structures, and practices for the care of children with swallowing difficulties, combined with an analysis of the moral experiences of children described below, sheds light on critical ethical issues related to childhood and inclusion. Firstly, there are societal attempts for children to "reach" normalized childhood developmental standards and to be compared with those standards. Furthermore, children are sometimes viewed as "incomplete human beings" needing protection, with adults still having a high impact on decisions that affect them. This means that children are not fully considered as active agents. Adopting a view of children as moral agents and learning what is meaningful to them could contribute to developing care practices that are more ethically and respectful of children's experiences and preferences.

During this “thick description” of the study setting, I found several elements that helped describe the context where children participating live and have food-related moral experiences. Notably, the broader socio-historical context of the Italian culture influenced the importance and value given to food by this population. Also, social settings with the inclusion of children (e.g., school activities, parties) helped and influenced their food-related moral experiences and the concept of being part of a group. This can be linked to the concept of a “healthy and normal lifestyle” stressed in the biomedical developmental model and implies the children’s perception of being different from others because of their swallowing difficulty, which moves away from the concept of normality described above. In this vision that could be considered limited, caregivers and mothers play a significant role in these children’s moral experiences in supporting and adapting meals and situations to their condition to ensure safety and inclusion for them. These elements reflect the “local social imaginaries” (Carnevale, 2013a) that reciprocally shape institutional norms, structures, and practices and have been analyzed with an interpretive/analytical framework.

The analysis of the wider background context, the horizon of significance, shed light on what leads to the adoption of different practices, and through the analysis of the local imaginaries, what is the moral order (the values, standards, norms) that are shared by children, families, and caregivers.

Moral experiences of children with swallowing difficulties

Results describing children food -related moral experiences are presented here in a descriptive way divided into major thematic areas that have been developed from data. For each theme a narrative description is presented. Also, some verbatim quotations will be presented as illustrative exemplars.

The food-related moral experiences of children with swallowing difficulties were diversified according to each child’s experience but with a lot of similarities regardless of their clinical conditions or histories. These experiences are strongly influences by contextual factors such as: setting, people, time, swallowing difficulty level, food-type. Children showed and communicated differently to *be conscious of their condition* (both temporary or permanent) and needs that affect their moral experiences. They always expressed (explicitly or implicitly) their *will to be accepted and included in social activities* with other people especially their peers. Finally, all these experiences are determined by children’s *interactions with family/caregivers* and support from them that allowed these children to have food adapted to their conditions and to have safe and proper meals.

The children’s ages ranged from seven to eleven years old, and their clinical diagnoses of swallowing difficulties varied substantially, and were mainly associated with other conditions (e.g., cerebral palsy, cognitive and communicative impairments) as described above. Three of them were able to communicate verbally, with the others communication happened mainly in a non-verbal form through the mediation of the primary caregivers and attentive observation of children's reactions, expressions, non-verbal cues and interactions in everyday situations and participant observations.

The analysis of multiple data sources included in this study enabled to identify four main themes that describe these children's food related moral experiences, with a pivotal role played by the factors determining the context where mealtimes occurred (with space, environment, people, food type, time dedicated for a meal, swallowing difficulties), together with the influence of family and caregivers, children's will to be included in social activities and children's understanding of their conditions.

I need to specify that even though some aspects described herein were particularly relevant for children who communicate differently, the overall findings were not interpreted in relation to the communication differences of the children participating. Therefore, our findings described below refer to the general moral experiences of the participants. For example, the desire to be included in social activities, the role of family and caregivers were not systematically different between children who communicated verbally and those who did not.

In addition, the relational perspectives of children with swallowing difficulties, voices and interests were highly determinant in my understanding of their moral experiences. Decisions regarding food and mealtimes of these children involve multiple actors with various interests and levels of authority. Thus, adults, such as parents and healthcare professionals, are presented as those who were involved in the decision-making processes, of these children's everyday lives, mealtimes, and related treatments.

The dominant views about "*the norm*" (e.g., what is widely considered "normal") were expressed in documents, healthcare professionals' discourses, family and caregivers' conversations and local practices, explicitly or implicitly expressed a dominant view of the "norm". These views determined notions of "good care" rooted in biomedical views on child development (e.g., reaching developmental abilities such as walking, eating, etc.). In addition, the analysis of multiple sources illustrated a construction of good care for the swallowing difficulty conditions based on normal developmental patterns. Specifically, good care is focused on reaching developmental milestones, comprising activities that will enable children to approach normality patterns, specifically to eat "normally" by mouth, or standing up and speaking. Moreover, the background understanding of constantly striving to reach the norm rooted in biomedical views on the healthy child revealed notions around the functionality of the body for children included in this study, including expectations of eating all food consistencies autonomously. Based on these understandings, the local *social imaginaries* around care for children with swallowing difficulties encompass the moral order that children should reach the norm to become healthy children and have a quality of life.

However, the conditions around attempting to reach this norm are poorly addressed and recognized by adults surrounding children with swallowing difficulties. In addition, the interests of healthcare professionals, family, and caregivers responsible for decisions and actions regarding these children's lives are embedded in these notions, perpetuating and mediating dominant values and practices.

Impact and role of contextual factors. The various elements that define the context within which these children's meal experiences took place played an essential role in their food-related moral experiences. They faced unique challenges that could profoundly affect their sense of self, relationships with others, and their understanding of right and wrong. From the observations, it has been identified that the change in the environment in which the meal took place, the people present, and the type of food eaten significantly impacted the type of experience lived by the child.

A familiar, supportive environment, respectful of the child's needs and known to the children themselves, such as their homes, the school canteen, or the same table with his utensils, contributes to ensuring that children experience the meal with a more positive relational climate "*Each table has the child's name on it and it's their own table for the whole school year" (*PO Fieldnotes*).* "*Creating a positive and supportive atmosphere*" during meals by "*encouraging the child to make feelings and preferences understood*" and taking children's time to "*eat the meal at her own pace*" (Interview) were some of the main strategies used to make their experiences as pleasant as possible. "*The child was really happy when he saw his table with his name and his glass and other utensils*" (PO Fieldnotes).

Furthermore, the presence of trusted and known people, especially for children who needed more help and physical support to eat, made the experience more pleasant and calmless. This was because the child felt understood, helped, and not observed or judged, which can unconsciously happen to those who know less about his tastes and preferences "*The child started smiling and moving his hands when she saw her trusted educator that was waiting for her to eat together*" (Po Fieldnotes). In this condition, the impact of the environment and the context of the meal was fundamental. Consuming a meal in calm "*the room is silent and quiet, only the child and his Mom are present*" (PO Fieldnotes), in your own home with your family, and in a serene and welcoming context contributed to ensuring that the children enjoys a meal suited to their needs "*I usually mesh fish and potatoes together to create a creamy consistency*" (Interview) and times as a moment of sharing and socializing and not an activity to satisfy a physiological need. For example, in the presence of the nanny and the observer, a child appeared relatively calm, "*expressing her mood at that moment with vocalizations, upward movements of the arms,* *and lateral movements of the head*" (PO Fieldnotes) differently from when the mother was present. This is because the nanny was a trusted person for the child. She knew her attitudes and preferences well and, simultaneously, had a different perspective and emotional load compared to the mother, "*this is why I can feel calm when I am with her*" (PO Fieldnotes), which brought her to stay calm while working with the baby.

Even in the school context, having a trusted reference attendant influenced the experience of the child who had his preferences. For example, during participant observations, I noticed changes in the children's attitudes about the operator who followed them during the meal. Children's level of interaction changed according to their confidence level with the people in the room during mealtime. When the reference attendant was present (e.g., the person who followed a child since the beginning of the school year), the children usually had a "*higher level of interaction through smiles, vocalization, and active participation"* (Interview) compared to when there was no reference operator "N. *usually is happy when I am with him during lunchtime at school because…you know, I started knowing him at the beginning of schoolyear*" (PO Fieldnotes). In those cases, children seemed less smiling and interacted with the operator only for specific mealtime activities "*The child seems upset and not very happy of having lunch without his trusted operator*" (PO Fieldnotes). However, when the operator with whom children were most familiar was present, they interacted more, observing, and listening to what the operator said, highlighting how children's communication and information about meals are essential for their integration during mealtime "*Today you have tomato sauce pasta, fish with potatoes and…your favorite…chocolate cream"* (PO Fieldnotes). This is why knowing these children well, their habits, preferences and needs is essential to ensure they are comfortable and understood.

Additionally, the menu and the type of food proposed for the meal also played a role in the moral experience of the child. If the food offered respected children's tastes and preferences “*Today, you have tour favorite meal!!”* (PO Fieldnotes), this led them to feel satisfied and consequently accepted and satisfied from the point of view of taste and, therefore, of the sensorial experience of food.

Together with the contextual factors, the clinical characteristics of the swallowing difficulty influenced the children's experience. Children's personal and physiological characteristics greatly influenced their experiences with food and mealtime. Bringing food to their mouth independently gratified these children more by making them feel "*more autonomous*" in something. Furthermore, having a mild swallowing deficit also leads to less worry and apprehension on the part of family caregivers due to a reduced risk of aspiration or inhalation, which means that the meal is experienced more peacefully by all participants. Also, children's food textures must be revisited in terms of "*consistency", "mixed and difficult to distinguish taste",* and the dish was compared to "food for small children" as defined by the child himself. These children, "*not being able to perceive or taste all the consistencies of foods*" (PO Fieldnotes), but only foods with a liquid or soft/creamy consistency, faced sensory problems related to food, which in turn can lead to having aversions towards certain consistencies and flavours and to not having a complete experience with food as can happen for other children without swallowing deficits. This risked leading to a distinction and comparison with other children, which can be perceived by those with swallowing difficulties to the point of feeling "*a difference*" compared to their peers. For example, a child participating compared with her sister, who was starting to wean and therefore began to experience new consistencies. This transition was experienced by the little girl with a certain "*weight*". Therefore, "*she often does not finish the mea*l" and "*has a more closed attitude and less enthusiasm*" than before (Interview).

These children's swallowing difficulties affected the timing and duration of the meal, and this could have an impact on how these children and their family members and caregivers experienced this moment. In this case, supporting the child only in blending the food, being supervised during the meal, and not having moments when the food spills out from the sides of their mouth is important.

Among the contextual aspects, respecting the meal routine and the child's rhythm is essential to ensure that the environment adapts to the child and not vice versa. Following a ritual, a particular sequence of actions *"Fastening the bib or tapping the fork on the cup to let the child understand that food is about to arrive or permanently using the exact arrangement of the plate, glass and cutlery*)" (PO Fieldnotes) helped to make children understand what was about to happen (e.g., "*that he is about to eat"*). This made children aware of the environment and what was happening around them. Specifically, all phases of the meal must follow a particular sequence respectful of the needs of these children, starting from the meal routine with the preparation of the table and food. The table for these children was set with plates, cutlery, glasses, unique utensils, a cup with a lid, and a straw for drinking. And all the elements necessary for the needs of the child and family. Furthermore, the children often needed to follow their routine, such as always eating at the same table and position. "*The table where the child eats at school is always the same and has his name written on it. The cutlery and glass are always the same, personal to the child and specific to his needs*" (PO Fieldnotes).

Another extremely relevant factor determining the context of mealtime is time. Time influences the experience of these children. Time refers to two things: "timing" (e.g., when meals can be eaten); "durations" (e.g., the amount of time allowed for mealtime). A significant difference was noted between the time dedicated to meals at home, without a tight and precise rhythm, in which children had their own time to finish what was proposed to them according to their rhythms and needs, compared to school times where the ringing of the bell marked the rhythms according to the planned school activities "*Time for lunch is finished! The bell has rung!"* (PO Fieldnotes). This needs to consider the time these children take to eat at their own pace and speed. This aspect reflected how children often adapt to the context rather than vice versa.

At home, the duration of the meal varied based on the amount of food eaten and the child's level of appetite, but it was never accelerated or slowed down due to factors that did not depend on them. Sometimes, there were factors involved that could influence the needs of the children, such as the presence of siblings or the little appetite.

In addition to the people present, the timing of the meal and the school program's rhythms played an essential role in this child's meal experience. In fact, at school, time is usually marked by the ringing of the bell with exact and structured timing. On the one hand, this helped the child to understand the sequence of activities; on the other hand, only sometimes followed the needs and rhythms of children with swallowing difficulties, especially for the duration of the meal. For example, for a child, taking "*slower bites and pauses*" helped him to have "*better control and comfort during feeding*"(PO Fieldnotes). It is, therefore, important to establish a routine for feeding time for these children, considering the elements of context, time, and people.

Furthermore, the level and communication characteristics of children (whether verbal or exclusively non-verbal communication) impacted the level of understanding by the people who assisted the children and ate with them, underlining once again the importance of having a trusted and known figure during this such a delicate moment for them, that of the meal.

Nonverbal communication is vital for some children in expressing their desires and emotions. For example, when they perceived through sensory stimuli (such as the smell of food), they showed their desire or refusal to eat with non-verbal communication ("*moving legs and arms upwards and with some vocalizations*") (PO Fieldnotes).

When people who did not know the child well were present during mealtimes, this led to discomfort/distress for the children due to difficulty communicating and being understood, thus leading them not to communicate thoughts and preferences and not make their voices heard.

Children' s understandings of their condition

The type and level of swallowing difficulty of these children and how they understood their conditions played a role in determining their food-related moral experiences. Being aware of having a chronic or, in the worst cases, degenerative swallowing deficit condition led these children not to experience the meal as a moment of pleasure but as a necessary and tiring daily commitment. This perspective was also associated with other conditions and potential limitations associated with the child, increasing the burden for the child himself and the family.

In some cases, children showed conflicting views and reactions regarding mealtimes. For some, it was experienced as a moment of pleasure in which taste and sociability were satisfied; for others, it was seen as a moment of duty without any sensorial or emotional satisfaction.

Instead, in cases where the swallowing deficit was temporary and solvable, the child's and family's attitudes are considerably different. It aims to consider the future, where the situation will be resolved, and the child can "*eat everything again like the others*". For example, when children were aware of their temporary swallowing difficulty, they joked about the timing in which they would be able to eat foods with solid consistency "*after the surgery we can change and I'll eat your pasta and you my creamy food..*" (PO Fieldnotes) even if they knew that "*it will take a long time*", generating a state of displeasure in them and sadness. This temporary swallowing difficulty also affected the outlook and evolution of the children's condition. The fact that it is not a definitive condition determines different attitudes and approaches to the condition of the child and the family. This created relief for the child and the family, but also disappointment and sadness when the resolutive treatment surgery was postponed "*Unfortunately surgery has been delayed again, I hope this moment will come soon, for my son and also for the whole family*" (Interview).

Role and influence from family /caregivers.

Children's interactions with their family members and caregivers during mealtime were essential in influencing their mealtime experiences. A trusted person preparing the food and assisting the child during the meal helped foster more significant interaction and a positive experience. The child felt free to express disappointment or that something was wrong, meeting and respecting his wishes and ensuring that what was right for him was achieved.

In parallel to contextual factors, the children's interactions with their family/caregivers and the people who surrounded them and who shared mealtime with them strongly impacted their experiences. For example, the relationship between children and their siblings is like a "normal" relationship between siblings, even during meals, despite the peculiarities of the child's food, and this denotes the adaptation to the child's swallowing deficit as usual for the two brothers and does not create worry or anxiety for the child himself.

The family strives to make mealtime a "*positive, stress-free experience*". A strong impact is given by the child's interaction with the mother and how the mood of one influenced that of the other. The mothers always tried to do everything possible to adapt the food to their children's needs. When they saw the child sad for not being able to eat the same things as the others, they cheered them up by saying that they had prepared "*snacks especially for him with chopped ham and cheese and blended fruit*" (PO Fieldnotes), so children recognized and appreciated their mothers' effort.

Relationships with family members influenced these experiences, both positively and negatively, when the child perceives directly or indirectly that they were a "*burden*" for the daily family organization due to the modifications and adaptations to his food that must be made concerning the food that is eaten by the rest of the family who does not have swallowing deficits. Adapting the menu to the child's nutritional needs and swallowing difficulties requires the use of time and energy by family members. Furthermore, these children often have other associated conditions and pathologies that significantly impact family organization.

Sometimes, it happens that the children, hearing or perceiving the burden or complaints of their family members (often the mother), "*I hope that having to blend his food will end soon….about the family's difficulty in going out to eat due to the burden it places on her to adapt every meal to her son's needs*" (Interview), caused a situation of disappointment in them, which then evolved into sadness for the child due to the fact of feeling like a burden due to his condition. On the other hand, when the child perceives complaints and the burden expressed by the mother, "*she expresses disappointment and displeasure as if she felt like a burden on the family*".

This characteristic of not being able to taste, eat and swallow all the consistencies of food "he can only swallow soft consistencies" determined the need to receive substantial support/assistance during mealtime "*There must always be someone present to eat with him: both at home and school*". This means that this child was not autonomous in a fundamental aspect of everyday life, namely eating.

For this reason, the type of relationship built between the child and family members/caregivers plays a pivotal role in the moral experiences linked to these children's food. Being perceived as "*different*" compared to others and consequently feeling different causes these children to experience an ethical dilemma in which what is proper and essential for them is not achieved.

As with the presence of parents and caregivers, being surrounded by a support and reference healthcare and socio-health team also influenced the experience of these children.

The overall management of the swallowing deficit requires a "*collaborative effort*", "*multidisciplinary approach, patience, and perseverance*" for the child and the rest of her family members. Managing these children is "*a journey that requires ongoing assessment, adaptation and support from healthcare professionals, therapists and family members*" (Interview).

For the family and the children, "*having professional guidance*" within the team who provides specific and tailored strategies is key to "*adapting the family's approach as needed*". At the same time, "*contacts with support groups or even online communities*" help to share and adapt the management and experience of the child, always taking into consideration the "*specificity and uniqueness of each child*". At the same time, specific reference operators known to the children have an important role.

Both for respecting and carrying out the support therapies necessary to maintain and improve their swallowing deficit and to be a support for the family. In addition to the reference operators, a multidisciplinary team to support the child and the family is also essential for managing the situation. This is especially true at mealtime, when the child "*sometimes feels anxiety or frustration related to eating, especially in social contexts or when trying new foods*" (Interview).

During observations with children, they mentioned several times how important and helpful the support they received from parents, caregivers, and healthcare professionals during mealtimes. They appreciated having their mom (or another family member/caregiver) prepare and adapt food and meals to their preferences and swallowing difficulties. This aspect occurred frequently at home rather than at school, where meals were standardized following specific nutritional requirements for children but without asking everyone what they wanted for lunch. Children also expressed that the relationship with staff members, the support and the empathy they received from them were meaningful in influencing their food-related moral experiences. Children also emphasized that talking with someone during mealtimes was helpful and a way for them to be heard.

Children emphasized the benefits of having the opportunity to share and stay with other children or classmates during mealtime and how it contributed to making them feel good: "*I prefer having my friend from the other class eating lunch next to me, instead of staying only with my assistant*" (Interview). Also, sharing food or snacks with other children and, in the meanwhile, playing with them was considered a valuable aspect by children participating in this study. For example, participating in a birthday party, having a "*personalized cake*" for swallowing difficulties but with the same taste as the other children's cake was considered a beneficial and happy experience of inclusion, "*Finally, I can eat the same taste as the other children, I am so happy, and I want them to taste my cake*" (Interview).

Social relationships and desire for social inclusion

Relational perspectives, voices, and interests of children with swallowing difficulties influenced their eating experience and everyday lives. Parents emphasized the importance of these social relationships. They mentioned it could be "more difficult for their children to be included in activities with others or make close friends at school".

During the observations, children often expressed the desire to be like others, "*to eat the same things as others*", and to share and socialize during mealtime "*to be wholly included with their family members and peers during this experience, sharing the same tastes and textures*" (PO Fieldnotes).

Children sometimes made comparisons between the food they could eat and what others ate "*I am hungry... but my food is not as good as other people's and I only like fruit when blended like this*" (Interview). They highlighted that they "*cannot eat some* *foods*" that other children ate or that the consistency of blended/creamy foods was not the same as other children without swallowing deficits. "*My focaccia (blended) is not as good as what others eat*" (Interview). In these cases, in which their need to eat foods different from those of others became evident, children expressed sadness/melancholy and, in some cases, a strong desire to eat food with the same consistency as that of others, for example, by "*observing a lot the sister's dish*" (PO Fieldnotes).

Children saw mealtime as a moment of sharing where they could spend time with their peers and families. They often showed interest in eating with schoolmates, as a sense of integration within a group during a social moment, even though the school food is not considered good "*even if they say it is not very good*"(PO Fieldnotes). Children often expressed the desire to eat with others and to be included. For example, when children who communicate differently are impatient to eat, they bang their cutleries on the table. They observed their schoolmates eating at the other tables near him. This desire, however, cannot always be satisfied because for organizational and protection issues, the teachers, on the one hand, do not want to have the responsibility of this management, and the mother, on the other, cannot always be present at school during lunch "I have to leave my classmates to have lunch at home".

In some cases, they were happy to eat with their classmates or to have a birthday "*cake*" with the same taste as the one prepared for the other children. This highlighted the need to feel included and feel the same. Furthermore, the children often showed interest in sharing their food and in having others' opinions on his "*revisited*" pasta. This denotes an interest in comparing oneself with others who do not have swallowing deficits, having a discussion and an interaction.

Even in the family context, when the family goes out to eat, the child often eats his food first and "*I go to the restaurant to look at others eating*" (Interview). This highlights the reduced possibility of social sharing for those with swallowing deficits and the poor compliance of restaurants in adapting food for those with swallowing deficits.

Another aspect of inclusion appreciated by the children concerned was being informed about the menu planned for the day with their involvement and participation in the meal based on their possibilities. This gave them a sense of inclusion and involvement that positively contributed to delineating the moral experiences during mealtime. For example, some children interacted more and appeared more satisfied with what they ate when, both at home and at school, they were involved in meal choice and preparation, such as "*mixing, pouring or choosing the ingredients*"; "*she likes it if when you prepare her lunch or breakfast, you share them and explain verbally what you are doing*" (Interview). This gave a "*sense of belonging and happiness*". Even the creation of a relaxed environment, perhaps by playing music, contributed to the development of an inclusive and welcoming environment where children could feel included, accepted and rewarded "*with applause and encouragement when the meal ends*", with the creation of a specific mealtime routine, for example with a personal table for school lunch with their names "*faded label with the child's name*" (PO Fieldnotes).

An important issue that emerged from some participant observations was a case where the child rarely shared meals with peers. This could lead to the risk of further perceived isolation for the child and can also become a reason for food refusal since eating was seen as a moment of "*duty rather than pleasure*". In one observation, the child, feeling observed during the meal due to the difference in the food he can eat compared to others, "*assumed a closed attitude, lowering his gaze and stopping interacting with the surrounding environment*" (PO Fieldnotes).

Not being able to share the meal experience 100% with one's family or peers often gave children a feeling of displeasure and being different from others. Children repeatedly highlighted their desire to share and socialize at mealtime. In a supportive context, these children developed the desire to feel like others, with the need to eat with their classmates and share the meal while participating in other "normal" social situations. The concept of normality is mentioned when children consider themselves as "normal" when they can do things like their peers "*go to a birthday or when he is older*

go out with friends"(PO Fieldnotes), independently and without an overprotective parents' attitude.

The development of these aspects is undoubtedly influenced by the socio-cultural context within which the child lives his experiences. "*The fact of feeling accepted and not observed as someone different certainly helps him to experience mealtime in serenity as a sharing with others, especially with his classmates*" (Interview).

Not feeling socially included could lead these children to feelings of inadequacy and low self-esteem, wondering why they are different from others and resisting the temptation to define themselves based on their condition. "*Often when we are out and about, they look at us and stare when he eats, and he notices this, and now I understand that he suffers a lot*" (PO Fieldnotes). The perception of self and the sense of isolation thus depends on the context, the type of people present during mealtime and the interaction between them and the child. If the environment and context are not "*inclusive and supportive*" for these children, their condition can lead to experiencing stigma and discrimination from peers, other children and even adults who have little knowledge, awareness or understanding of the situation.

In the observations, when people surrounded children, they knew well and did not look at them with a critical attitude, they usually managed to finish meals calmly. Sharing moments with people vital to them creates morally significant experiences for them. These children's moral experiences are deeply intertwined with social interactions and the broader cultural context. They follow a unique path in which their experiences can foster personal growth and contribute to a more inclusive and understanding society if they can gain support from the community.

Discussion

This study highlighted the importance of understanding and exploring children’s food-related moral experiences and how their understanding can be achieved and helped by examining the social, political, and relational perspectives that surround them. By articulating these perspectives and recognizing children’s moral agency, this study demonstrated that children with swallowing difficulties have the capacity to understand their everyday lives and the context where they live their meal experiences, even with different cognitive and communicative capacities.

This study found that children can express their views and feelings within situations in various ways through multiple forms of expression, verbal and nonverbal. This understanding was helped and supported by the articulation of the multiple social dimensions involved in children’s experiences. Children, like adults, are not disconnected from structural forces, meaning that decisions about matters that affect them are affected by social and cultural context (Bluebond-Langer & Korbin, 2007). Therefore, in this study, the moral experiences of children were interpreted within a complex social context that interacts with and affects their experiences. This inquiry has helped advance our ontological understanding of childhood, which includes not only a child-centered orientation, but expands the exploration of contextual issues that help define children and childhood in different realities (Spyrou, 2019).

The integration of children's perspectives in research on childhood sheds light on our ability to understand how children are capable of influencing their social environments, engaging meaningfully with their surroundings (Bluebond-Langer & Korbin, 2007). Despite facing instances of exclusion and a lack of acknowledgment of their voices, the children in this study expressed their desire for inclusion and active involvement in social activities. The nature of their experiences was altered based on whether individuals, especially family members and caregivers, acknowledged their expressions and involved them in decisions related to meals and food.

Some children described their positive experiences with regards to being included in a social group, such as participating in activities with a group in their school or in social encounters with other children (e.g., birthday parties). These positive experiences shared by children emphasized the importance of participating in communal activities as an experience that indicates the good aspects of “normality” in their lives. These views are similar to the findings of a scoping review on the experiences of children with medical complexity that showed children’s discourses on the good aspects related to being included in a group and participating in school activities (Santos et al., 2020). Another study with children with disabilities described how children were expressing feelings of happiness associated with being part of a group and performing the same activities as their school peers. These situations perpetuated the “sameness” of children’s experiences and helped prevent negative feelings (Connors and Stalker, 2007).

Food-related moral experiences can involve complex ethical considerations. For example, parents and caregivers may have challenges with decisions about what is best for the child's well-being, balancing nutritional needs with the child's desire for a sense of normalcy. This can lead to moral dilemmas related to feeding methods, dietary restrictions, and the child's autonomy in food choices.

This study demonstrated the dynamic complexity of children’s interdependence and relationships. For instance, some children mentioned that they want to see their parents (especially mothers) happy, without perceiving their burden in managing their swallowing difficulties. The acknowledgement of this relational basis in children’s experiences can help expand understandings of children’s voices and perspectives (Spyrou, 2019). A more in-depth understanding of children’s interests is more likely to be achieved by acknowledging the relational perspectives involved in the beliefs and values of both children and parents (Carnevale et al., 2017). While children may be dependent on people responsible for making decisions on their behalf (e.g., parents or legal representatives), they still have their own significant moral views (Carnevale et al., 2017). Incorporating relational perspectives into research and care methods can help enhance our comprehension of children's interests and preferences.

Implications and Contribution to Nursing

The implications outlined above carry particular significance for nurses and other healthcare practitioners. Nurses, who play a pivotal role in making decisions that influence the experiences of children living with swallowing difficulties, need to extend the focus of healthcare beyond biomedical processes aimed at achieving developmental milestones. Efforts should be directed towards enhancing children's experiences by considering their perspectives and individualized notions of well-being, fostering moments of joy and contentment. Healthcare professionals, including nurses, bear a crucial responsibility in attentively listening to the voices of both children and caregivers, to grasp the child's preferences and interests. In the pursuit of strategies to optimize children's experiences with food and mealtime, nurses can explore alternative approaches, such as utilizing play and arts for communication and interaction, as well as creating a supportive and tailored environment, to enhance the care provided to this population.

The encounters with healthcare professionals shaped the experiences of children differently. In this context, nurses, and other healthcare professionals and caregivers, in the setting were considered as having an important role in how these children and their families navigate mealtime experiences. Some mentioned their understandings about the care for these children with regards to how they feel responsible for helping them to have their needs met. Other caregivers were more focused on performing procedures and giving food in a safe manner with little contextual or individual considerations (e.g., only considering how to avoid risk of aspiration, how to make the child eat everything on the plate). This situation led healthcare professionals to seek ways of reducing the child's distress, actively changing the child's experiences. These different levels of engagement both of healthcare professionals and caregivers resulted in different understandings about the results of their actions on children's wellbeing (Santos et al., 2018). These different understandings can have impacts on how nurses are enacting their moral agency. Lack of understanding can lead to unintentional exclusion or the perpetuation of stereotypes. It is essential to raise awareness and educate the community about the challenges these children face to foster a more inclusive environment. The acknowledgment of the moral dimension in nursing practice can therefore help nurses to engage with more ethical practices that are focused on the best interests of the child. Further investigations are necessary to understand how nursing practice can be optimized by educating nurses toward the inclusion of children's interests and preferences in decision-making process.

The pivotal role played by healthcare professionals, particularly nurses, significantly influences the daily experiences of children coping with swallowing difficulties. The prevailing notion of being normal" or "being like the others", as perceived by these children, is largely grounded in biomedical and developmental models. Children facing swallowing difficulties often deviate from the established norms of these models. By recognizing these children's views and interpretations, we can foster approaches that better incorporates their active participation in decision-making processes. This perspective and approach require practice adaptations, with a call for incorporating knowledge about the interests and agency of children with swallowing difficulties into the educational training of healthcare professionals who work with this population.

Furthermore, it is imperative to extend this awareness to individuals beyond the healthcare realm who may interact with this population, such as schoolteachers and other educators.

One strategy, specifically for the Italian context, could be developing specialized educational programs for nurses that can better prepare them to acquire the competencies and skills required for taking care of these children, both in hospital and home settings, in the ways described within this thesis.

Also, the study results underlined the importance of having a team specialized in the management of children with swallowing difficulties and with communicative impairments so that they can effectively understand and communicate with these children. Understanding these children’s needs is a necessary condition for providing care that responds to their needs.

From a research perspective, the choice of a participatory hermeneutic ethnographic design in this study has profound implications for how the food-related moral experiences of the children were delineated and articulated. The decision to involve children in the research process, along with the focus on the social and relational dimensions of their experiences, aligns with what Spyrou (2019) characterizes as the ontological turn in childhood studies. This shift signifies a departure from viewing children as isolated entities and instead emphasizes inquiries that recognize meaningful connections and the ways in which we comprehend children and childhood (Spyrou, 2019). This shift necessitates acknowledging children as both vulnerable beings and moral agents. This nuanced understanding can shed light on the situations and contexts influencing children's food-related moral experiences, providing insights into how to understand and navigate potentially challenging ethical situations that may arise during mealtimes for these children (Carnevale, 2020; Spyrou, 2019).

Child-focused research within epidemiological frameworks may overlook specific aspects of children's experiences, hindering a comprehensive understanding of their rights and best interests. This gap arises when these perspectives inadvertently neglect the unique facets of children's lives, hindering a more comprehensive understanding of children's rights and best interests.

Developing methodologies that center on researching with children and are grounded in their moral experiences can facilitate the elicitation of children's lived interests. This, in turn, can inform how healthcare professionals and decision-makers can formulate individualized approaches to promote children's best interests, particularly in the context of food and mealtimes.

The conventional understanding of best interests, as presented in the literature, is often abstract and involves navigating multiple, potentially conflicting interests. By employing the moral experiences framework to understand children's interests, there is an opportunity to generate empirically individualized knowledge about their experiences and preferences. This approach is firmly rooted in relational, social, historical, and cultural perspectives. To foster more child-centered approaches, these perspectives should be scrutinized on a case-by-case basis to determine the individual best interests of each child. By creating approaches for researching with children and based on their moral experiences, we can help elicit children’s lived interests and inform how healthcare professionals and people responsible for decisions and actions can develop individualized plans to promote children’s best interests related to food and mealtimes.

The use of participatory hermeneutic ethnography as a methodology has implications for data analysis and interpretation, resulting in knowledge production that can demonstrate how social contexts can impact the moral experiences of participants.

Family members and caregivers' insights on children's experiences were a central methodological strategy to ascertain the interpretations of children's lived experiences.

By employing a Childhood Ethics framework to understand the food-related moralexperiences of children with swallowing difficulties and how interactions with families/caregivers affect these food-related moral experiences, this study helped advance our understanding of these children as moral agents and has illuminated how mealtimes are impactful in their lives; highlighting what is particularly meaningful for them, which positive aspects of their food experiences should be optimized, and which negative ones should be mitigated.

The results of this research provided insightful information to plan intervention improvements with this population that align with children's best interests, optimizing these children's experiences with food in light of their individualized needs, goals, and aspirations. For example, developing a school mealtime duration that is adapted to these children's needs and times; creating specific food with different textures and the similar taste as other children's food consistency (e.g., pasta, bread, sweets) following similar studies conducted with adult populations (Zanini et al., 2017).

This study, anchored within the VOICE Childhood Ethics Research Program (Carnevale et al., 2015), facilitated and promoted the engagement of children and families within the research process through a participatory framework. This international and interdisciplinary project has the main aim to identify, investigate and develop strategies for addressing ethical concerns relating to children and youth following Childhood Ethics principles of best interests and participation of children as active agents. Furthermore, engaging children in the research process can help advance methods used for better hearing and acknowledging children's perspectives and integrating their participation. Before starting data collection, it was anticipated that potential participants would have navigated numerous barriers to full participation in this project, given the complex demands of their daily lives. I was attentive to participants' interests in being part of the research process, offering opportunities for participating that were adapted to their availability and convenience. Involving families in the research process further informed our understanding about matters that affect children and family/caregivers, helping create strategies for ethical care and care coordination (e.g., developing care approaches that are respectful of children needs, preferences and expectations) and acknowledging essential sources of support. These strategies could help empower families to care for these children and improve nurses' and other healthcare professionals' sensitivity to ethical care. The family's involvement as a research partner helped ascertain that these strategies were feasible, as well as meaningful and valuable, for these families. The knowledge generated by this research can help inform policymakers and healthcare providers and thus may help improve access to care, care coordination, and availability of services concerning nutrition focused on the needs of these children and families.

Given that this study has helped promote the active involvement of children and families through participatory hermeneutic ethnography, it is imperative to extend this engagement to knowledge mobilization activities. In doing so, children can contribute their insights, ensuring that their priorities play a crucial role in the application of the new knowledge. Study partners will be invited to participate in developing a dissemination plan that can include the presentation of a study report to the health services and organizations where children receive care. This report could encompass recommendations for practices that prioritize the needs of children and families, along with strategies for influencing institutional policies and structures.

Furthermore, the study findings will be shared in health-related seminars, congresses, and conferences to disseminate the knowledge generated to diverse stakeholders, including healthcare providers, educators, parents, grandparents, and children. The results will also be published in academic and professional journals. Finally, further research can be built from this work to enable the development of better- adapted meals for these children, such as introducing meals with different food textures specific for this population, as has been done with older adults (Zanini et al., 2017).

The results of this study can provide useful information to foster the development of care approaches and interventions attentive to children's voices and to what is meaningful to them, including the advancement of Children's Nursing practice (Randall, 2017). Children's Nursing, which orients care for children, young people, and their families, requires that nurses have a well-developed understanding of the health, psychological, developmental, communication, and cultural context of their patients' health practices. This study contributed to the ongoing development of Children's Nursing for children with swallowing difficulties. Children's Nursing is an increasingly recognized approach within Italy.

The multiple approaches designed for this study generated rich data that informed in-depth analyses of the food-related moral experiences in this specific subpopulation and that provided contextualized and relevant knowledge for nurses and other healthcare professionals who provide care for children with swallowing difficulties. Study results fostered valuable insights to inform practices and improve ethical care for this population. By promoting the recognition of children as moral agents and elucidating what is meaningful to them, this study has contributed to the development of care practices that are more respectful of children's own experiences.

With reference to future research, this thesis raised certain concerns that would be important to address. Recognizing the agency of children with swallowing difficulties and including their multiple forms of expression toward understanding their voices has enabled a deeper understanding of their experiences and best interests. The examination of additional approaches to include these children's views in research processes may help to advance clinical practice for this frequently excluded population.

In addition, this study showed the significant effects of social contexts and collective views on the experiences of children with swallowing difficulties.

Finally, the field of childhood studies would benefit from bridging the gaps between social contexts and health experiences and advancing the understanding of how societies significantly influence children's health outcomes from a more inclusive perspective. Considering that this study has been conducted in the Italian context, where food culture, food availabilities and food options are numerous and specific for this setting, further participatory research with children with swallowing difficulties in different socio-cultural and economic contexts would be important to understand how we can move toward care approaches that provide better health outcomes for children worldwide.

Limitations

One of the limitations of this study is related to the level of participants' participation. Even if different strategies were used to engage with study partners throughout the research process, it was difficult to know the extent to which they would participate (Carnevale et al., 2008) and the nature of the collaborative process of the participatory framework (Cargo & Mercer, 2008). Data elicited with some participants could be limited. Due to this concern, several data collection adaptations were used, as described above, to optimize data collection.

Since the study was conducted in a single setting, there may be a limitation in the diversity of data that could be collected compared to a multicenter study. Future studies are planned in different cultural settings to address this limitation. Being a single-setting study, it inherently has limitations in capturing the multiple sociocultural contexts in which children with swallowing difficulties may reside. Research conducted in diverse social-political contexts has the potential to unveil new nuances and perspectives in children's experiences that were not explored in this study. Consequently, it is recommended that further research include in-depth analyses within various settings to enhance our understanding of the experiences of children with swallowing difficulties across different contexts.

Despite the limitations mentioned above, the approaches designed for this study ensured an in-depth analysis of the food-related moral experiences of children with swallowing difficulties, advancing crucial knowledge for nurses and other healthcare professionals. Study results provided important insights that can inform practices and improve care for this population.

Conclusions

This study has provided an account of the moral experiences of children with swallowing difficulties in Italy. It describes how multiple *social imaginaries* influence and determine children’s food-related moral experiences, focusing on the influence and role of contextual factors and the social environment, the importance and role of family/caregivers’ support and on children’s desire to be part of a social group and being included in social activities and events.

By using inclusive ways of understanding children’s moral experiences and being attentive to their multiple forms of communication, this study can help reimagine children’s actual lived interests and lead healthcare professionals and people responsible for decisions and actions to more ethical practices. Adopting participatory hermeneutic ethnography as a methodological framework for research with children offered rich data and discussions related to children's moral experiences in specific healthcare settings (and other social agents when present), while also examining the institutional norms, structures, and practices and how they interrelate with experiences. Finally, the use of the moral experiences' framework helped to reveal less recognized interests and how children experience certain interests.

Results from a participatory hermeneutic ethnographic study always involve an interpretation of the data and do not offer a complete and definitive account, which is not an aim of this type of inquiry. Through a participatory hermeneutic ethnographic study, important ethical issues can be highlighted and examined in light of social/local imaginaries and horizons of significance, to address some of the ethical concerns that can be present in a specific setting. In addition, the use of a participatory research approach allows people directly affected by the study to be part of the research process, leading to a study that is more attuned to and inclusive of their perspectives (Cargo & Mercer, 2008).

The various participatory discussions led to a deeper understanding of the participants' experiences, as well as the social and local imaginaries that reciprocally shape institutional norms, structures, and practices.

The rich contextual focus of this design generated results that offer an in- depth analysis of the food-related moral experiences in this specific population, which can then also inform practices in other settings. By promoting the recognition of children as moral agents and learning what is meaningful to them, this study can contribute to the development of care practices that are better informed by and more respectful of children's own experiences.

Future work could explore the ethical implications of research conducted within this methodological framework. This exploration may include considerations related to consent and assent processes, as well as the involvement of children in participatory research. Given the richness of the data generated by participatory hermeneutic ethnography, potential users of the knowledge can evaluate the relevance of the results in their specific settings. Furthermore, it has the potential to stimulate reflection and discussion among healthcare workers. Examining the application of knowledge derived from this type of study in practical scenarios would be valuable. Such an analysis could shed light on how this knowledge contributes to addressing ethical concerns in specific settings.

Finally, the study results provided a rationale and a support underlining the need for nurses specialized in taking care of children with swallowing difficulties through specific and standardized educational paths that can provide competencies, knowledge, and skills for taking a personalized and holistic care for these children both in a hospital and home care settings.

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To be a study participant for participant observation:

Parental Information/Consent Form—Child ParticipationChild Assent
Form—Participant Observation
Participant Information/Consent Form—Adult Participation FamilyMember

To be a study participant for the interview:

Participant Information/Consent Form—Adult Participation FamilyMember

To be a study participant as a member of the Advisory Committee:

Parental Information/Consent Form—Child ParticipationChild Assent
Form
Participant Information/Consent Form—Adult Participation FamilyMember
Participant Information/Consent Form—Adult ParticipationHealthcare
Professional

Appendix A: Participant Observation Guide

This guide is an adaptation of two previous hermeneutically focused ethnographies with a participatory approach conducted in a child mental health setting (Montreuil, 2017) and with children with medical complexity in Brazil (Passos Dos Santos, unpublished VOICE Research Protocol) respectively. The main dimensions that will be observed are time, people, and context. In line with the participatory approach used in the study, the specific decisions about when, who, where, and what to observe will be made in collaboration with the study partners. This is a provisional version of the guide. Modifications will be considered in collaboration with study partners and the Thesis Committee and adapted for different study contexts. The various questions guiding participant observation (PO) refer specifically to activities, practices, actions, interactions, and relationships related to children with swallowing difficulties' mealtimes.

Context

What is the general atmosphere for the moment of mealtime of children and their families (contemporaries if PO occurs at school)?

How is the environment structured (e.g., physical setting, sitting arrangement)?What is the organizational structure?

What are the explicit and implicit norms/rules and routines related to mealtime of the child(e.g., prayers, etc.)?

What is the structure of the relationships?

People

Who is present during the child's mealtime? What are the different roles? What arethe characteristics of the people attending?

How many people are there?

What are the interactions between people (e.g., nature of interactions, reasons they occur, emotions expressed)?

What are people saying and doing?What are the nonverbal messages?

Time

How do mealtimes vary over time? (Referring to the days and weeks when observations maytake place)

What are the routines of the children and their families during mealtimes? How are activities related to the moment of the child's mealtime?

Which actions vary over time? Which remain similar?How are actions related to mealtime situations?

What are the events during children's and families' mealtimes (e.g., interactions with environments and other people)?

What events or patterns are related to changes in activities? What is the relationship betweentime, space, and people?

Examples of guiding questions for informal interviews

What do you think of [specific situation, interaction]?When [specific situation, interaction] happened:

How did you feel?

What did you think?

What did you do?

Who was involved?

What happened after that?

Appendix B: Interview Guide

Interview Guide: Family Member/Caregiver

This guide is adapted from two previous hermeneutically focused ethnographies conducted with children in a mental health setting (Montreuil, 2017) and children withmedical complexity in Brazil (Passos Dos Santos, unpublished VOICE Research Protocol). The questions described are numbered; however, they can be addressed differently, allowing participants to share their experiences freely.

1. Introduction

Mention that their comments will remain strictly confidential. Specify that the interviews will be audio-recorded, if they agree, for the student researcher to remember what is being said.

Specify that they can withdraw at any time.

Mention that, by accepting to participate in this project, they are not waiving any of their legal rights nor discharging the researchers or the institution of their civil and professional responsibility. Ask about the relationship with the child with swallowing difficulties. We would like you to tell us about the food-related experiences of a child with swallowing difficulties and hear about your experience within this situation.

2. Family General Information

Information about the clinical health condition and history of the child:

- What is the clinical health condition and history of the child?
- How do you deal with his/her swallowing difficulties? What are the problems and approaches?

Information about care management of the child within the family environment:

- What resources are available for the care of your child?

- How are services for your child financed?
- Who lives in the house with the child?
- Who cares for the child at home?
- Does the child have access to any particular services?
- What are the public policies that you refer to when seeking healthcare?

Information about the socio-economic status of the family:

- How are family finances affected by your child's health?
- How many people contribute to the family's income?
- How many people depend on the family's income?

3. ***Everyday child's eating experiences.***

- What is a typical day for your child?
- What is the best time for your child's eating experience?
- What would you like to see?
- What are the needs for the care of your child during mealtimes?

Appendix C: Document Analysis Plan

The questions are related to analyzing key institutional documents (e.g., policies, procedures, code of conduct, and clinical tools) and family records (e.g., notes of parents, food diaries, drawings). The specific documents will be identified in collaboration with the Advisory Committee members.

Guiding Questions for Review of Institutional Documents

What structures and practices are reported in the text? How are the structures andpractices described? What is their meaning?

How are the care and the mealtime for children with swallowing difficulties documented in institutional documents? What are the similarities and differences with otherdocuments? Who is involved? What is each person doing? What do the documents describefor mealtimes during hospital and home care?

How is the child referred to? Is the perspective of the child included in thedocuments? Is the perspective of family members included in the documents?

Appendix D: Consent and Assent Forms

Consent and Assent Forms (English Versions)

To be a study participant for the participant observation:

Parental Consent Form: Child ParticipationAssent Form: Child

Consent Form: Adult Family Member

Participant Information/Consent Form—Adult Participation Family Member: Interview

To be a study participant for the participation in the Advisory Committee:Parental Consent Form: Child Participation

Assent Form: Child

Consent Form: Adult Family Member Consent Form: Healthcare Professional

McGill | Ingram School of Nursing | École des sciences infirmières Ingram

Università di Genova | DISSAL | Dipartimento di Scienze della Salute

Parental Information/Consent Form — Child Participation Participant Observation

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

Title of Project: Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Sponsor(s): 2020 VOICE (Views on Interdisciplinary Childhood Ethics), McGill Student Awards

We are inviting you to participate in a research project. Before accepting, please take the time to read the information about the study in this consent form. We encourage you to ask any questions you may deem necessary about the research process or any unclear information.

Purpose of the Study: This study is about the food-related moral experiences of children with swallowing difficulties in Italy. The aim is to understand people's experiences about what is good, right, and just concerning the everyday food experience of children with swallowing difficulties. We are also interested in how healthcare practices and community contexts influence people's experiences. Children with swallowing difficulties have different access to food (in terms of type, taste and consistency) compared to their peers, and for this reason during mealtimes these children can experience injustice and/or inequalities living moral experiences.

Study Procedures: The primary way the student researcher is going to collect data is through observing and speaking with your child. This will happen at places you and your child consider important in your everyday lives between June and November 2022. The student researcher will be present with your child during mealtime at the moment and setting that you prefer—for example, at home or school during a regular mealtime. The student researcher will not be present if you consider it not a good moment for you and your child. The student researcher will record information in a study file. It is expected to do three observations with your child with maximum one hour duration each.

Voluntary Participation: Your child's participation in this research is voluntary. You are free to refuse to have your child as a study participant and withdraw from the study at any time, for any reason, by informing the researcher in charge of the project or one of the members of the research team. There will not be any loss of benefit or impact on the quality of care and services for you and your child in case you choose not to participate in the study.

If you decide to withdraw, information collected about your child will be destroyed unless you give permission otherwise.

Potential Risks: Risks to your child by participating in this research are minimal and should be no greater than those experienced in their everyday life. This refers to the possibility of emotional or psychological distress caused by discussing sensitive topics related to their situations. If this happens, the student researcher will take all measures necessary to support your child. These measures include pausing or stopping the discussion or talking about what is bothering them. Also, the student researcher will constantly encourage your child that there is no “right” answer, answering any questions arising during the participant observation and addressing any concerns they may have. If your child feels sad, frustrated, or any other uncomfortable feelings, he or she can talk to a family member or a caregiver with whom he or she is comfortable.

Potential Benefits: Participating in the study might not benefit your child, but we hope the research will contribute to the advancement of understanding the mealtime experience of children with swallowing difficulties by illuminating what is particularly meaningful for them, the aspects that should be optimized, and the negative ones that should be mitigated.

Compensation: Your child will receive a small toy or gift as a token of appreciation for his/her time in participating in this project. If you withdraw your child from the project or your child is withdrawn before it is completed, your child will still receive the toy or gift.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you and your child in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. A code will be assigned to your child’s name to protect their identity and confidentiality. The student researcher will preserve the key linking the code to your child’s name. This information will be stored in a locked cabinet in the hospital setting of this study, accessible only to the student researcher.

All information collected by this study will be used only for research purposes. These data will be kept by the researcher in charge of the project for seven years following the publication of the results and will then be destroyed in conformity with the rules in effect. The data could be published in specialized scientific magazines or shared during scientific conferences; however, identifying your child will not be possible.

The only exception to confidentiality is when a child or another person is currently at risk of harm or it is reported that child abuse has occurred. In this case, the proper authorities and professionals would be notified to keep the child or person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your child's research information will remain confidential, although the reason for concern will be shared.

Questions: If you have questions concerning the research project or feel there is a problem related to your child's participation in the research project, you can communicate with the student researcher, Giulia Ottonello, at the following number: 3475131828.

If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the Regional Ethics Committee at 010/5554213 or comitato.etico@hsanmartino.it. or McGill Institutional Review Board: Ms. Ilde Lepore, Ethics Officer, McGill Faculty of Medicine and Health Sciences Institutional Review Board: 514-398-8302 or ilde.lepore@mcgill.ca.

Please sign below if you have read the above information and consent to your child's participation in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you, and the researcher will keep a copy.

I have read the above information and consent to participate in this study.

Participant's Name: (please print)

Participant's Signature:

Date:

Name of the minor child

Name and signature of the legal representative (parent or guardian)

Date: _

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Università di Genova | DISSAL Dipartimento di Scienze della Salute

Child Assent Form—Participant Observation

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

Title of Project: Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Why are we doing this study?

We want to understand what you think about your mealtime and food experiences. We also want to know how your family, the healthcare people, and their practices affect how you feel about your experience of mealtimes.

What will happen during the study?

The research student will come to your home or school, places where you usually have mealtimes. This will happen between June and November 2022. She will be observing, talking to people, and taking notes. You can talk to her about things you consider important, such as good and bad feelings you have and situations that you think are fair or unfair.

Are there good things and bad things about the study?

You might like participating in this project, or you might not. If you do not, you just have to tell your parents or the research student that you want to stop. Whether you participate or not will not affect your care at home or at the hospital. You also do not have to answer any questions if you do not want to. Sometimes, talking about sensitive things might make you feel sad or angry. The research student will do her best to help you feel better and will ask you if you wish to talk about how you feel or if you wish to pause or stop the discussion. You can also talk to one of your family members or caregivers about feeling sad or angry. To thank you for your participation, you will receive a small toy or gift at the end of the study.

Who will know what I say?

No one but the researchers will know what you said, and the things we talk about will not be shared with your parents, nurse, teachers, or friends. The only exception is if you or another person is currently in danger of getting hurt or we find that you or another person has been hurt in the past.

Do I have to do this?

If you do not want to be part of this study, that is okay. No one will be upset or disappointed. If you say yes now but change your mind, you can tell the research student at any time, and that will be okay. Your parents have also read some information about this study. They can talk to you about it. Ask any questions that you may have at any time.

Assent of the child able to understand the nature of the research project

Date

Verbal assent of the child unable to sign but able to understand the nature of the project:

yes___no___

____

Name of and signature of the person who obtained the child’s assent

Date

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Università di Genova DISSAL Dipartimento di Scienze della Salute

Participant Information/Consent Form—Adult Participation Family Member: Participant Observation

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences **Title of Project:** Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Sponsor(s): 2020 VOICE (Views on Interdisciplinary Childhood Ethics), McGill Student Awards

We are inviting you to participate in a research project. Before accepting, please take the time to read the information about the study in this consent form. We encourage you to ask any questions you may deem necessary about the research process or any unclear information.

Purpose of the Study: This study is about the food-related moral experiences of children with swallowing difficulties in Italy. The aim is to understand people's experiences about what is good, right, and just concerning the everyday food experience of children with swallowing difficulties. We are also interested in how healthcare practices and community contexts influence people's experiences.

Children with swallowing difficulties have different access to food (in terms of type, taste and consistency) compared to their peers, and for this reason during mealtimes these children can experience injustice and/or inequalities living moral experiences.

Study Procedures: The primary way the student researcher is going to collect data is through observing and talking to your/this child. This will happen at places you and your/this child consider important in your everyday lives between June and November 2022. The student researcher will be present with your/this child during mealtime at the moment and setting that you prefer—for example, at home or school during a customary mealtime. The student researcher will not be present if you consider it not a good moment for you and your/this child The student researcher will record information in a study file.

Voluntary Participation: Your participation in this research is voluntary. You are free to refuse to have your/this child participate in the study, as well as to withdraw from the study at any time, for any reason, by informing the researcher in charge of the project or one of the members of the research team. There will not be any loss of benefit or impact on the quality of care and services for you and your/this child in case you choose not to participate in the study. If you decide to withdraw, information collected about your/this child will be destroyed unless you give permission otherwise.

Potential Risks: Risks associated with your participation in this research are minimal and should be no greater than those experienced in your everyday life. This refers to the possibility of emotional or psychological distress caused by discussing some sensitive topics. If this happens, the student researcher will take all measures necessary to support you. These measures include pausing or stopping the discussion or talking about what is bothering you. You can also talk to a healthcare professional with whom you feel comfortable.

Potential Benefits: Participating in the study might not benefit you, but we hope the research will contribute to the advancement of understanding the mealtime experience of children with swallowing difficulties by illuminating what is particularly meaningful for them, the aspects that should be optimized, and the negative ones that should be mitigated.

Compensation: You will receive a small lump sum (20 €) in compensation for costs incurred and for constraints.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you and your/this child in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. A code will be assigned to your/this child name to protect their identity and confidentiality. The student researcher will preserve the key linking the code to your your/this child's name. This information will be stored in a locked cabinet in the hospital that is the setting of this study, accessible only to the student researcher.

All information collected by this study will be used only for research purposes. This data will be kept by the researcher in charge of the project for five years following the publication of the results and will then be destroyed in conformity with the rules in effect. The data could be published in specialized scientific magazines or shared during scientific conferences; however, identifying your/this child will not be possible.

The only exception to confidentiality is when a child or another person is currently at risk of harm or it is reported that child abuse has occurred. In this case, the proper authorities and professionals would be notified to keep the child or person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your/this child's research information will remain confidential, although the reason for concern will be shared.

Questions: If you have questions concerning the research project or feel there is a problem related to your/this child's participation in the research project, you can communicate with the student researcher, Giulia Ottonello, at the following number: 3475131828.

If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the Regional Ethics Committee at 010/5554213 or comitato.etico@hsanmartino.it. or McGill Institutional Review Board: Ms. Ilde Lepore, Ethics Officer, McGill Faculty of Medicine and Health Sciences Institutional Review Board: 514-398-8302 or ilde.lepore@mcgill.ca.

Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you, and the researcher will keep a copy.

I have read the above information and consent to participate in this study.

Participant's Name: (please print) Participant's Signature:

Date:

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Participant Information/Consent Form—Adult Participation Family Member: Interview

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences **Title of Project:** Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Sponsor(s): 2020 VOICE (Views on Interdisciplinary Childhood Ethics), McGill Student Awards

We are inviting you to participate in a research project. Before accepting, please take the time to read the information about the study in this consent form. We encourage you to ask any questions you may deem necessary about the research process or any unclear information.

Purpose of the Study: This study is about the food-related moral experiences of children with swallowing difficulties in Italy. The aim is to understand people's experiences about what is good, right, and just concerning the everyday food experience of children with swallowing difficulties. We are also interested in how healthcare practices and community contexts influence people's experiences.

Study Procedures: Maximum two in-person interviews will be conducted for each family member consenting to participate to these interviews. Each interview will last maximum one hour. Questions about family general information and child's everyday eating experiences will be asked. Interviews will be audio-recorded to allow the researcher to analyze what is being said during the interviews. The student researcher will record information in a study file. These interviews will be performed between June and November 2022, and they will take place where and when the participants prefer.

Voluntary Participation: Your participation in this research is voluntary. You are free to refuse to have your/this child participate in the study, as well as to withdraw from the study at any time, for any reason, by informing the researcher in charge of the project or one of the members of the research team. There will not be any loss of benefit or impact on the quality of care and services for you and your/this child in case you choose not to participate in the study. If you decide to withdraw, information collected about your/this child will be destroyed unless you give permission otherwise.

Potential Risks: Risks associated with your participation in this research are minimal and should be no greater than those experienced in your everyday lives. This refers to the possibility of emotional or psychological distress caused by discussing some sensitive topics. If this happens, the student researcher will take all measures necessary to support you. These measures include pausing or stopping the discussion or talking about what is bothering you. You can also talk to a healthcare professional with whom you feel comfortable.

Potential Benefits: Participating in the study might not benefit you, but we hope the research will contribute to the advancement of understanding the mealtime experience of children with swallowing difficulties by illuminating what is particularly meaningful for them, the aspects that should be optimized, and the negative ones that should be mitigated.

Compensation: You will receive a small lump sum (20 €) in compensation for costs incurred and for constraints.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you and your/this child in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. The student researcher will preserve the key linking the code to your/this child's name. This information will be stored in a locked cabinet in the hospital that is the setting of this study, accessible only to the student researcher.

All information collected by this study will be used only for research purposes. This data will be kept by the researcher in charge of the project for five years following the publication of the results and will then be destroyed in conformity with the rules in effect. The data could be published in specialized scientific magazines or shared during scientific conferences; however, identifying your/this child will not be possible.

The only exception to confidentiality is when a child or another person is currently at risk of harm or it is reported that child abuse has occurred. In this case, the proper authorities and professionals would be notified to keep the child or person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your/this child's research information will remain confidential, although the reason for concern will be shared.

Yes / No: You consent to be audio-taped.

Questions: If you have questions concerning the research project or feel there is a problem related to your/this child's participation in the research project, you can communicate with the student researcher, Giulia Ottonello, at the following number: 3475131828.

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Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you, and the researcher will keep a copy.

I have read the above information and consent to participate in this study.

Participant's Name: (please print)

Participant's Signature:

Date:

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Parental Information/Consent Form—Child Participation as a Member of the Advisory Committee

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

Title of Project: Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Sponsor(s): 2020 VOICE (Views on Interdisciplinary Childhood Ethics), McGill Student Awards

We are inviting you to participate in a research project. Before accepting, please take the time to read the information about the study in this consent form. We encourage you to ask any questions you may deem necessary about the research process or any unclear information.

Purpose of the Study: This study is about the food-related moral experiences of children with swallowing difficulties in Italy. The aim is to understand people's experiences about what is good, right, and just concerning the everyday food experience of children with swallowing difficulties. We are also interested in how healthcare practices and community contexts influence people's experiences. Children with swallowing difficulties have different access to food (in terms of type, taste and consistency) compared to their peers, and for this reason during mealtimes these children can experience injustice and/or inequalities living moral experiences.

Study Procedures: We are going to collect data through inviting your child to be a member of the Advisory Committee for this research study. The Advisory Committee is composed by three sections of study partners (children, parents/caregivers, healthcare professionals) that can be consulted in different meetings during the whole research process. This means that you child will be invited to join meetings together with other children (3-4) with swallowing difficulties. The student researcher will meet with your child together with other children and ask questions about the everyday experience of living with swallowing difficulties and about feedback on how this study will be conducted to help improve the research study process (observation guide, approaches used). For example, the student researcher will ask your child to describe a good day in their lives and situations where they felt something was right or wrong. There could be only one meeting and interview, or there could be more than one if you agree. Each meeting and interview will last a maximum of one hour and will be recorded. If you or your child disagrees with the audio recording, the student researcher will write notes to remember what is discussed, and the interview will not be recorded.

Voluntary Participation: Your child's participation in this research is voluntary. You are free to refuse to have your child participating in the study, as well as to withdraw from the study at any time, for any reason, by informing the researcher in charge of the project or one of the members of the research team. There will not be any loss of benefit or impact on the quality of care and services for you and your child in case you choose not to participate in the study. If you decide to withdraw, information collected about your child will be destroyed unless you give permission otherwise.

Potential Risks: Risks to your child by participating in this research are minimal and should be no greater than those experienced in their everyday life. This refers to the possibility of emotional or psychological distress caused by discussing sensitive topics related to their health conditions. If this happens, the student researcher will take all measures necessary to support your child. These measures include pausing or stopping the discussion or talking about what is bothering them. Also, the student researcher will constantly encourage your child that there is no "right" response, answering any questions and addressing any concerns they may have. If your child feels sad, frustrated, or any other uncomfortable feelings, he or she can talk to a healthcare professional with whom he or she is comfortable.

Potential Benefits: Participating in the study might not benefit you, but we hope to learn about the field and advance the healthcare provided for children with swallowing difficulties in Italy.

Compensation: Your child will receive a small toy in compensation for participating in this project. If you withdraw your child from the project or your child is withdrawn before it is completed, your child will still receive the toy or gift.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you and your child in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. The student researcher will preserve the key linking the code to your child's name. This information will be stored in a locked cabinet in the hospital that is the setting of this study, accessible only to the student researcher.

All information collected by this study will be used only for research purposes. This data will be kept by the researcher in charge of the project for five years following the publication of the results and will then be destroyed in conformity with the rules in effect. The data could be published in specialized scientific magazines or shared during scientific conferences; however, identifying your child will not be possible.

The only exception to confidentiality is when a child or another person is currently at risk of harm or it is reported that child abuse has occurred. In this case, the proper authorities and professionals would be notified to keep the child or person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your child's research information will remain confidential, although the reason for concern will be shared.

Yes / No: You consent to your child being audio-taped.

Questions: If you have questions concerning the research project or feel there is a problem related to your child's participation in the research project, you can communicate with the student researcher, Giulia Ottonello, at the following number: 3475131828.

If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the Regional Ethics Committee at 010/5554213 or comitato.etico@hsanmartino.it. or McGill Institutional Review Board: Ms. Ilde Lepore, Ethics Officer, McGill Faculty of Medicine and Health Sciences Institutional Review Board: 514-398-8302 or ilde.lepore@mcgill.ca.

Please sign below if you have read the above information and consent to your child's participation in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you, and the researcher will keep a copy.

____

I have read the information above and consent to my child's participation in this study.

Name of the minor child:

Name and signature of the legal representative (parent or guardian):

Date:

Child Assent Form: Participation as a Member of the Advisory Committee

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

Title of Project: Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Why are we doing this study?

We want to understand what you think about your mealtime and food experience. We also want to know how the healthcare people and their practices affect how you feel about your experience of mealtimes. Children with swallowing difficulties have different access to food (in terms of type, taste and consistency) compared to their peers, and for this reason during mealtimes these children can experience injustice and/or inequalities living moral experiences.

What will happen during the study?

You are invited to participate as a member of the Advisory Committee for this study. This is a group of people that will be consulted in in-person meetings during the whole research process to have feedback and advice about phases of this study. The student researcher will meet you together with other children and ask questions about your everyday experience of living with swallowing difficulties and about your feedback on how this study will be conducted to help improve the research study process (observation guide, approaches used). This will happen between June and November 2022. She will be observing, talking to people, and taking notes. You can talk to her about things you consider important, such as good and bad feelings you have, and situations that you think are fair or unfair. She will audio-record times that you speak together. You can tell the research student if you do not want to be recorded, and she will take notes to remember the things you talked about. You can meet with her one or more times if you want to talk more.

Are there good things and bad things about the study?

You might like participating in this project, or you might not. If you do not, you just have to tell your parents or the research student that you want to stop. Whether you participate or not will not affect your care at home or at the hospital. You also do not have to answer any questions if you do not want to. Sometimes, talking about sensitive things might make you feel sad or angry. The research student will do her best to help you feel better and will ask you if you wish to talk about how you feel or if you wish to pause or stop the discussion. You can also talk to your nurse or one of the healthcare workers if you feel sad or angry. To thank you for your participation, you will receive a small toy at the end of the study.

Who will know what I say?

No one but the researchers will know what you said, and the things we talk about will not be shared with your parents, nurse, teachers, or friends. The only exception is if you or another person is currently in danger of getting hurt or we find that you or another person has been hurt in the past.

Do I have to do this?

If you do not want to be part of this study, that is okay. No one will be upset or disappointed. If you say yes now but change your mind, you can tell the research student at any time and that will be okay. Your parents have also read some information about this study. They can talk to you about it. Ask any questions that you may have at any time.

Assent of the child able to understand the nature of the research project

Date

Verbal assent of the child unable to sign but able to understand the nature of the project: yes_/no

Name and signature of the person who obtained the child assent

Date

Participant Information/Consent Form—Adult Participation Family Member: Participation as a Member of the Advisory Committee

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

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Study Procedures: We are going to invite you and other parents/caregivers (4) to be member of the Advisory Committee. The Advisory Committee is composed by three sections of study partners (children, parents/caregivers, healthcare professionals) that can be consulted in different meetings during the whole research process. This means that you will be invited to join in-person meetings together with other parents/caregivers of children participating to the study. Each meeting and interview will last a maximum of one hour and will be recorded. If you disagree with the audio recording, the student researcher will write notes to remember what is discussed, and the interview will not be recorded.

Voluntary Participation: Your participation in this research is voluntary. You are free to refuse to have your/this child participate in the study, as well as to withdraw from the study at any time, for any reason, by informing the researcher in charge of the project or one of the members of the research team. There will not be any loss of benefit or impact on the quality of care and services for you and your/this child in case you choose not to participate in the study. If you decide to withdraw, information collected about your/this child will be destroyed unless you give permission otherwise.

Potential Risks: Risks associated with your participation in this research are minimal and should be no greater than those experienced in your everyday lives. This refers to the possibility of emotional or psychological distress caused by discussing some sensitive topics. If this happens, the student researcher will take all measures necessary to support you. These measures include pausing or stopping the discussion or talking about what is bothering you. You can also talk to a healthcare professional with whom you feel comfortable.

Potential Benefits: Participating in the study might not benefit you, but we hope the research will contribute to the advancement of understanding the mealtime experience of children with swallowing difficulties by illuminating what is particularly meaningful for them, the aspects that should be optimized, and the negative ones that should be mitigated.

Compensation: You will receive a small lump sum (20 €) in compensation for costs incurred and for constraints.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you and your/this child our child in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. The student researcher will preserve the key linking the code to your/this child's name. This information will be stored in a locked cabinet in the hospital that is the setting of this study, accessible only to the student researcher.

All information collected by this study will be used only for research purposes. This data will be kept by the researcher in charge of the project for five years following the publication of the results and will then be destroyed in conformity with the rules in effect. The data could be published in specialized scientific magazines or shared during scientific conferences; however, identifying your/this child will not be possible.

The only exception to confidentiality is when a child or another person is currently at risk of harm or it is reported that child abuse has occurred. In this case, the proper authorities and professionals would be notified to keep the child or person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your/this child's research information will remain confidential, although the reason for concern will be shared.

Yes / No: You consent to be audio-taped.

Questions: If you have questions concerning the research project or feel there is a problem related to your/this child's participation in the research project, you can communicate with the student researcher, Giulia Ottonello, at the following number: 3475131828.

If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the Regional Ethics Committee at 010/5554213 or comitato.etico@hsanmartino.it. or McGill Institutional Review Board: Ms. Ilde Lepore, Ethics Officer, McGill Faculty of Medicine and Health Sciences Institutional Review Board: 514-398-8302 or ilde.lepore@mcgill.ca.

Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you and the researcher will keep a copy.

I have read the information above and consent to participate in this study.

Participant's Name: (please print)

Participant's Signature:

Date:

McGill | Ingram School of Nursing École des sciences infirmières Ingram
Università di Genova | DISSAL Dipartimento di Scienze della Salute

Participant Information/Consent Form—Adult Participation Healthcare Professional: Participation as a Member of the Advisory Committee

Student Researcher: Giulia Ottonello, RN, MSc, Doctoral Student, McGill University, University of Genoa

Supervisors: Franco Carnevale, RN, PhD, Professor, McGill University, Ingram School of Nursing

Annamaria Bagnasco, Full Professor, University of Genoa, Department of Health Sciences

Title of Project: Moral Experiences with Food Among Children with Swallowing Difficulties: A Participatory Hermeneutic Ethnography

Sponsor(s): 2020 VOICE (Views on Interdisciplinary Childhood Ethics), McGill Student Awards

We are inviting you to participate in a research project. Before accepting, please take the time to read the information about the study in this consent form. We encourage you to ask any questions you may deem necessary about the research process or any unclear information.

Purpose of the Study: This study is about the food-related moral experiences of children with swallowing difficulties in Italy. The aim is to understand people's experiences about what is good, right, and just concerning the everyday food experience of children with swallowing difficulties. We are also interested in how healthcare practices and community contexts influence people's experiences. Children with swallowing difficulties have different access to food (in terms of type, taste and consistency) compared to their peers, and for this reason during mealtimes these children can experience injustice and/or inequalities living moral experiences.

Study Procedures: We are going to invite you and other healthcare professionals (4) to be member of the Advisory Committee. The Advisory Committee is composed by three sections of study partners (children, parents/caregivers, healthcare professionals) that can be consulted in different meetings during the whole research process. This means that you will be invited to join in-person meetings together with other healthcare professionals working with children that can be potential study participants. Each meeting and interview will last a maximum of one hour and will be recorded. If you disagree with the audio recording, the student researcher will write notes to remember what is discussed, and the interview will not be recorded.

Voluntary Participation: Your participation in this research is voluntary. You are free to refuse to participate in the study, as well as to withdraw from the study at any time, for any reason. There will not be any loss of benefit for you in case you choose not to participate in the study. If you decide to withdraw, information collected about you will be destroyed unless you give permission otherwise.

Potential Risks: Risks associated with your participation in this research are minimal and should be no greater than those experienced in your everyday life. This refers to the possibility of emotional or psychological distress caused by discussing some sensitive topics. If this happens, the student researcher will take all measures necessary to support you. These measures include pausing or stopping the discussion or talking about what is bothering you. You can also talk to a manager at the hospital with whom you feel comfortable.

Potential Benefits: Participating in the study might not benefit you, but we hope the research will contribute to the advancement of understanding the mealtime experience of children with swallowing difficulties by illuminating what is particularly meaningful for them, the aspects that should be optimized, and the negative ones that should be mitigated.

Compensation: No compensation will be provided for your participation in this study.

Confidentiality: During your participation in the study, the student researcher will collect and record information about you in a study file. Only information necessary to reach the study goal will be collected.

Information will be kept strictly confidential to the extent prescribed by the law. All identifying information will be de-identified to remove all direct identifiers from the data, but keeping indirect identifiers such as age, gender, ethnicity, region of residence, and other unique characteristics to protect their identity and confidentiality. This process will be done during data transcription and fieldnote writing. The student researcher will preserve the key linking the code to your name. This information will be stored in a locked cabinet in the hospital that is the setting of this study, accessible only to the student researcher.

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Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you and the researcher will keep a copy.

I have read the information above and consent to participate in this study.

Participant's Name: (please print)

Participant's Signature:

Date:
