

Moral experiences of crisis management in a child mental health setting:

A participatory hermeneutic ethnographic inquiry

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## **Abstract**

The use of restraint and seclusion to manage crisis situations in mental health settings is being widely challenged, but is still common. The rates of restraint and seclusion episodes on child mental health units are of particular concern, as they have been reported to be significantly higher than on adult units. A growing body of literature has highlighted the misuse of these control measures and the serious harms that can result from these practices (e.g. traumatization, death of the child). The use of such measures poses ethical challenges to nurses and other staff members who aim to act in the best interests of children and ensure their safety, while promoting children's capacity to manage their behavior and recognize children's agency. This study sought to examine the institutional norms, structures, practices, and corresponding moral experiences of children, parents and staff members around crisis management and the related use of control measures in order to develop care approaches that promote an optimal reconciliation of ethical concerns in child mental health. A novel methodological framework drawing on Taylor's hermeneutic philosophy—participatory hermeneutic ethnography—was developed to conduct this study, which enabled an in-depth examination of the concept of children's agency. A five-month participatory hermeneutic ethnography was conducted in a Canadian child mental health setting providing care to children aged 6 to 12 years old. Data collection involved participant observation, interviews, and documentation review. An interpretive framework was used for data analysis. The results show how the strict structure in place both prevented and contributed to crisis situations. Children were expected to comply, conform and acquiesce with staff and were generally perceived as the objects of care; and not as active agents involved in care processes. Children perceived control measures as helpful in exceptional cases when there was an imminent risk to someone's safety, and largely disagreed with their use as a consequence for bad behavior.

This perspective contrasted with most of the staff members who considered control measures contributed to help the child feel safe, learn the limits in the setting, and form a trusting relationship. Parents were not part of the everyday experiences in the setting, and were confident the staff would use control measures as a last resort. The results suggest that the prevalent view of the child shared by staff members as *incomplete human becomings* led to the adoption and legitimization of authoritative norms, structures and practices guided largely by a behavioral approach, which sometimes led to an increased use of control measures for reasons other than imminent harm. Children experienced these controlling practices as abusive and hindering the development of trusting relationships with the staff, which impeded the implementation of a more collaborative approach that staff members sought to put in place to prevent the use of control measures. Changes in conceptions of children from objects to agents by the staff and seeking a *rapprochement* with children, by getting to know what is meaningful to them and try to bridge these horizons, could help build more authentic trusting relationships that might be more conducive to the implementation of collaborative approaches.

## Résumé

Le recours aux contentions et à l'isolement pour gérer les situations de crises en santé mentale est largement remis en question, mais pratique courante. Les taux d'épisodes de contentions et d'isolement sur les unités de soins de santé mentale avec les enfants est particulièrement préoccupant, ayant été rapportés comme étant significativement plus élevés que sur les unités de soins aux adultes. Un nombre croissant d'écrits scientifiques a mis en lumière l'utilisation abusive de ces mesures de contrôle et les dommages graves qui peuvent résulter de ces pratiques (par ex. : trauma et mort de l'enfant). L'utilisation de telles mesures pose des défis éthiques aux infirmières et aux autres membres du personnel qui visent à agir dans le meilleur intérêt des enfants et à assurer leur sécurité, tout en favorisant la capacité des enfants à gérer leur comportement et en reconnaissant leur agentivité. Cette étude a examiné les normes institutionnelles, structures, pratiques et expériences morales des enfants, parents et membres du personnel en lien avec la gestion de crise et l'utilisation des mesures de contrôle afin de développer des approches de soins qui favorisent une conciliation optimale de préoccupations éthiques en santé mentale de l'enfant. Un nouveau cadre méthodologique s'appuyant sur la philosophie herméneutique de Taylor – l'ethnographie herméneutique participative – a été développé pour mener cette étude, ce qui a permis un examen approfondi de la notion d'agentivité chez les enfants. Une ethnographie herméneutique participative de cinq mois a été menée dans un établissement canadien de santé mentale offrant des soins aux enfants âgés de 6 à 12 ans. La collecte de données incluait l'observation participative, des entrevues et une analyse documentaire. Un cadre interprétatif a été utilisé pour l'analyse des données. Les résultats révèlent comment la structure stricte en place jouait le double rôle de prévenir les situations de crise et d'y contribuer. Les enfants devaient respecter, se conformer et acquiescer au personnel

soignant et étaient généralement perçus comme des objets du soin, et non comme des agents actifs impliqués dans les processus de soins. Les enfants percevaient les mesures de contrôle comme étant nécessaires dans des cas exceptionnels lorsqu'il y avait un risque imminent pour la sécurité de quelqu'un. Ils étaient largement en désaccord avec leur utilisation comme conséquence d'un mauvais comportement. Cette perspective contrastait avec la plupart des membres du personnel qui considéraient que les mesures de contrôle contribuaient à aider l'enfant à se sentir en sécurité, à connaître les limites et à établir une relation de confiance. Les parents n'étaient pas présents au quotidien dans le milieu de soins et étaient confiants que le personnel soignant utiliserait les mesures de contrôle en dernier ressort. Les résultats suggèrent que la vision dominante de l'enfant par les membres du personnel comme des *êtres incomplets en devenir* a conduit à l'adoption et à la légitimation de normes, structures et pratiques guidées principalement par une approche comportementale qui a parfois entraîné une utilisation accrue des mesures de contrôle pour des raisons autres qu'un préjudice imminent. Les enfants considéraient ces pratiques comme étant abusives et empêchaient le développement d'une relation de confiance avec le personnel, entravant la mise en œuvre d'une approche plus collaborative que les membres du personnel cherchaient à mettre en place pour diminuer l'utilisation des mesures de contrôle. Un changement dans les conceptions de l'enfant par le personnel soignant – d'objets du soin à agents actifs – ainsi que la recherche d'un rapprochement avec les enfants, en apprenant ce qu'ils considèrent comme significatif et en essayant de faire le pont entre ces horizons, pourrait contribuer à créer des relations de confiance plus authentiques et propices à la mise en œuvre d'approches collaboratives.

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doubtful. Merci Jean LU pour ta relecture de mes résultats; tes commentaires méticuleux m'ont beaucoup aidé. I'm looking forward to future collaborations!

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## Preface

### Thesis Format

This thesis follows a manuscript-based format, in accordance with regulations from McGill University's Graduate and Postdoctoral studies. I chose this format to facilitate the publication process and foster the development of the skills necessary to present research in a succinct manner amenable to dissemination in scholarly journals. The thesis includes four original manuscripts, compiled into a unified, cohesive document. At the beginning of each chapter composed of a manuscript, I included a short introductory text to situate it in the broader document. Here is an overview of the structure and content of the thesis:

- The **Introduction** to the thesis includes an overview of the rationale for the study, including relevant knowledge gaps and the specific aims of the study.
- **Chapter I** includes relevant background information and a comprehensive literature review of alternatives to the use of control measures for crisis management in child mental health, as well as of the experiences of children, parents and staff members related to the use of control measures in this setting.
- **Chapter II** presents a conceptual analysis of a key concept guiding this study, children's agency. This analysis, which constitutes **Manuscript 1**, contributes to clarify the conceptual framework in which this thesis is grounded. The concept analysis, published in the *Journal of Child Health Care*, is limited to the health-related literature, examining evolutionary trends of the concept, as well as its attributes within the scientific health literature.
- **Chapter III** presents in more depth the conceptual as well as methodological framework developed for this study: participatory hermeneutic ethnography. This framework,

detailed in **Manuscript 2**, bridges different approaches drawing on Charles Taylor's hermeneutic framework, in which human agency is a key concept. It builds on the concept analysis in chapter II to bring *children's* agency into Taylor's hermeneutics and apply it to health ethics research with children. This manuscript is currently under review by the journal Qualitative Health Research. Additional details related to the participatory research process are in Appendix A.

- **Chapter IV** comprises the study results and discussion, which are included in **Manuscripts 3 and 4**. Each manuscript includes a summary of the literature review, conceptual framework and methodology, to help situate the reader before the presentation of the results and discussion. Manuscript 3 addresses the thesis main research questions concurrently, while Manuscript 4 focuses specifically on children's moral experiences. Manuscript 4 complements Manuscript 3 by highlighting children's experiences, a research area that has been scarcely studied.
- **Chapter V** provides a discussion of the implications of the thesis for clinical practice, research and education, as well as directions for future research and a conclusion that summarizes how the main research aim was met and the principal contributions of the thesis.

### **Contributions of Authors**

This thesis represents my original work: I was responsible for the conceptualization, 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 thesis committee members, Drs. Linda McHarg and Catherine Thibeault were involved in all the steps, offering ongoing substantive and

methodological guidance throughout this process. I am the primary author of the four manuscripts included in this thesis. Throughout the thesis, I use the first-person singular, since the thesis represents my independent doctoral work.<sup>1</sup> The specific contributions per manuscript are detailed here:

- **Manuscript 1—A concept analysis of children’s agency within the health literature<sup>2</sup>**

The first author, Marjorie Montreuil, conceived the intellectual content of the article and was involved in all of its steps: elaborating the guiding questions, choosing the methods, conducting the article searches, collecting, analyzing and synthesizing the data, writing the first draft of the manuscript, and revising the subsequent versions. The second author, Franco A. Carnevale, provided extensive background knowledge for the conduct of this analysis; he was involved in the choice of method and elaboration of the questions to guide the analysis, and reviewed the subsequent versions of the manuscript. Both authors have read and approved the final manuscript as well as the supplementary files.

- **Manuscript 2—Participatory hermeneutic ethnography: A methodological framework for health ethics research with children**

The first author, Marjorie Montreuil, conceived the intellectual content of the manuscript and was involved in all of its steps: conceptualizing the framework, writing the manuscript, and revising subsequent versions. The second author, Franco A. Carnevale, provided input throughout the conceptualization and writing process. Both authors approved the final version of the manuscript. Thesis committee members, Drs. Linda

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<sup>1</sup> For the publication of the manuscripts, the first-person plural is used to acknowledge the role of thesis committee members.

<sup>2</sup> Thesis committee members are not co-authors on this manuscript as it was completed before the finalization of the committee. They have read and approved the text as presented in this thesis.

McHarg and Catherine Thibeault, provided feedback on drafts of this manuscript and approved the final version. Their contribution to this manuscript is acknowledged.

- **Manuscript 3—Moral experiences of crisis management in a child mental health setting: A participatory hermeneutic ethnographic study; and Manuscript 4—Children’s moral experiences of crisis management in a child mental health setting**

The first author, Marjorie Montreuil, led the conceptualization of the study, in close collaboration with the thesis supervisor (Franco A. Carnevale) and committee members (Linda McHarg and Catherine Thibeault). Marjorie Montreuil implemented the study, collected the data, transcribed the interviews, wrote the narrative syntheses, performed and led the analysis/interpretative process, wrote the first draft of the two manuscripts and revised subsequent versions. The thesis supervisor and committee members were involved in these different steps, offering substantive feedback. All authors have read and approved the final version of the two manuscripts.

### **Original Contributions of the Thesis**

This thesis constitutes an original contribution to the field of child mental health and childhood ethics. It makes 5 key methodological and substantive contributions to research and clinical practice with children.

#### **Methodological Contributions**

1. In Manuscript 2, the development of a methodological framework for empirical ethics research with children is a contribution to the field of childhood ethics. The use of Charles Taylor’s hermeneutic philosophy to bridge key aspects of ethnography, participatory research and hermeneutics led to the development of an innovative methodological framework that allows for an in-depth examination of the local imaginaries, of what is morally meaningful to the people

in the setting, in addition to institutional norms, structures and practices. This methodological framework is highly suitable to study ethical issues within healthcare settings.

### **Substantive Contributions**

2. Within child health research, the concept of children's agency was not clearly defined in the scientific literature. This contrasts with other disciplinary fields, notably social sciences, in which advances have been made in developing this concept. By examining the concept of children's agency more closely and retracing its evolution within health research, Manuscript 1 articulates a definition of the concept that is essential to improve communication among health researchers and clinicians working with children. This manuscript provides a conceptual foundation on which further inquiry and discussion can be based.

3. Through the examination of norms, structures, practices, and moral experiences within a child mental health setting, the study conducted as part of this thesis sheds light on ethical concerns related to common practices with children, such as the use of behavioral and controlling approaches that run counter to collaborative approaches due to a view of children as the objects of care, in contrast to moral agents who should actively take part in decisions affecting them. Very few studies had empirically examined these questions, which had been addressed mostly in theoretical texts and commentaries. My study offers rich descriptions and interpretations of both the experiences and the context of child mental health care—with a particular emphasis on crisis management—important to improve services offered to this vulnerable population. Since nurses are the ones offering ongoing care to children in mental health settings and are commonly in charge of managing crisis situations, Manuscripts 3 and 4 on the study results directly contribute to the field of child mental health nursing and nursing ethics.

4. Also, as highlighted in the literature review, very few studies have been conducted on children's experiences of crisis management within child mental health settings. My thesis represents a distinct contribution to knowledge by examining, in addition to staff's, children's moral experiences, which highlights their capacity to act as moral agents and offers a unique perspective into their daily experiences (Manuscript 3 and main focus of Manuscript 4).

5. The discussion in terms of the staff and children's local imaginaries presented in Manuscript 3 is also a novel contribution to research. The use of Taylor's framework within empirical research illuminates what is meaningful to children and staff members and furthers our understandings of their moral lives. It allowed for an in-depth analysis of the data while providing a framework to seek to bridge different perspectives in light of local/social imaginaries and horizons of significance.

## Introduction

Before the 1990s, behavioral techniques were largely recognized practices in mental health institutions, including the use of restraints and seclusion for behavior and crisis management. The use of these practices are being increasingly questioned by healthcare professionals, policy makers, managers, researchers, and community members (e.g. see AGIDD-SMQ, 2014<sup>3</sup>; Johnson, 2010<sup>4</sup>; MSSS, 2015<sup>5</sup>), but are still commonly being used. In child mental health settings, the prevalence of the use of control measures (i.e. seclusion and restraint) is often higher than in adult settings, and an increasing body of literature is highlighting the harms resulting from using these practices, including traumatization, physical injuries and death of the child (Hert et al., 2011; Lebel et al., 2004; Nunno, Holden, & Tollar, 2006). Despite these potential harms, the literature related to alternatives to control measures in child mental health setting is highly limited (Valenkamp et al., 2014).

In Quebec, ministerial orientations have been adopted in 2002 on the use of control measures in health care services, with the expressed goal to change institutional practices to decrease their use, as they are described as being in direct opposition to human rights (MSSS, 2002/2015). Since 2002, various professionals, including nurses, can now decide on the use of control measures in institutions where a protocol is adopted, as opposed to having only the physician being responsible for the decision (L.Q. 2002 c.33; L.Q. 2009 c.28<sup>6</sup>). The rationale mentioned by policy makers for this change is that by sharing the responsibility of the decision

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<sup>3</sup> This publication is used here as a local example of the view of the community on the use of control measures, as it is the position statement of a community group.

<sup>4</sup> This paper presents a recent integrative review of 46 initiatives to reduce the use of control measures in psychiatric settings. It is used as an example of the growing interest in finding alternatives to control measures in psychiatric settings.

<sup>5</sup> This document from the Quebec Government is the *plan d'action* to reduce the use of control measures in healthcare services, which highlights the will from policy makers to reduce the use of these measures.

<sup>6</sup> These laws are the ones that stipulate which healthcare professionals can now decide on the use of control measures and delimits the scope of their practice.

related to the use of control measures, it will result in a decrease of their use as people are not following orders, but are accountable for the decision made (Trudeau, 2014<sup>7</sup>). Laws and policies in Quebec thus strive to reduce the use of control measures; there is an agreement that they should be avoided. However, control measures are still part of daily clinical practice in child mental health, and the experiences related to how crises are managed and how control measures are used with children have not been studied in depth, in contrast to adult settings.<sup>8</sup>

Control measures are supposed to be used only to prevent the person from harming him/herself or others, and should be minimal and exceptional (CQLR.c.S-4.2 118.1). With children, the best interests standard should apply, as is common in child medicine (CMA, 2004). However, the concept of children's best interests is not clearly articulated. For example, authors have questioned whether or not the interests that are served are those of the children themselves or those of adults, since the concept of best interests is defined by adults who have decisional authority (Freeman, 2007). It is also unclear how children's perspectives are included in defining what is in their best interests, and how the concept of children's agency is taken into account when discussing best interests (Carnevale et al., 2015). This raises ethical questions in relation to the use of control measures with children that calls for further inquiry.

In this context, the goal of this thesis was to examine some of the ethical and moral concerns around conflict and crisis management and the use of control measures in a child mental health setting. The use of such measures poses ethical challenges to nurses and other staff members who aim to act in the best interests of children and ensure their safety, while promoting

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<sup>7</sup> This view was shared by a representative of the *Collège des médecins* during a conference, in response to many people's questions as to why professionals other than physicians can decide on the use of control measures. He emphasized that the goal is really to reduce their use through shared decision-making.

<sup>8</sup> Through my own clinical practice as a child mental health nurse, I have also witnessed some of these situations first-hand and have been called to manage crisis situations. These experiences triggered a profound interest in understanding such issues, as well as studying possible solutions to address them.

children's capacity to autonomously manage their behavior and recognize their agency. In order to perform this study, the concept of children's agency needed to be clarified, and a methodological framework suitable to examine these concerns was developed, based on Taylor's hermeneutic philosophy. The study allowed for the examination and discussion of the institutional norms, structures, and practices related to conflict and crisis situations in a child mental health setting, as well as the study of the moral experiences of the different people involved, including the children themselves. Nurses are often the ones who are called to manage crisis situations in mental health settings (Riahi et al., 2016); the implications of the study for clinical practice, research and education are addressed.

### **Definition of certain terms**

The term *children* is used in this thesis to refer to all minors aged 0-17 years old, which is the age range used by the United Nations to refer to children (UNCRC, 1989).

The term *staff members* is used to refer to any person working on the unit directly with children, such as nurses, psychoeducators, psychologists, therapists, social workers and educators.

To be consistent with Quebec Government's orientations, the term *control measures* is used to refer to the different types of measures that are used in healthcare settings to limit a person's freedom of movement. These measures include human or mechanical restraints (i.e. using human force or a mechanical mean to limit or prevent a person from moving freely), seclusion (i.e. to confine a person in a setting from which he/she cannot go out freely), and chemical restraints (i.e. to limit a person's capacity to act by administering a medication to him/her) (MSSS, 2015<sup>9</sup>). In Quebec, only seclusion or human restraint can be used with children

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<sup>9</sup> In Quebec healthcare settings, because of the adoption of the ministerial orientations on control measures, the term *control measures* is the one currently used by professionals and speaks to the study participants. Considering that

aged 12 years and younger, the latter being commonly called a therapeutic hold or physical hold (Douglas Mental Health University Institute, 2015; Mohr, 2010).

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this study uses a participatory research approach, I consider important that the term used reflects the common way to refer to such measures in local settings, despite the wider use of *coercive measures* or *containment measures* in the scientific literature. This is why a local reference is used to support the choice of wording and related definition.

## Chapter I

### Literature Review<sup>10</sup>

Clinicians routinely use control measures with children for behavior management in institutional settings (Hert et al., 2011; Lebel et al., 2004<sup>11</sup>). The rates of restraints and seclusion episodes on child mental health inpatient units are of particular concern, as they have been reported to be 5 to 6 times higher than on adult units (Lebel et al., 2004), with 25% of children inpatients having at least one seclusion episode during the hospitalization period and 29% at least one restraint episode (Hert et al., 2011). These numbers highlight the vulnerability of children who are more likely to be physically controlled than adults in mental health settings. Moreover, in most cases, restraints and seclusion are reported to be used with children in response to non-compliance with a request, and not because of safety issues (Nunno et al., 2006). This situation can result in wrongful treatment for children that can cause serious harms; measures such as restraints, including physical holds, can even result in the death of the child (Nunno et al., 2006<sup>12</sup>). Still, there is an underdeveloped commitment to advancing knowledge related to alternatives to control measures with children, exemplified by the lack of research literature on the topic. The following section reviews the literature related to alternatives to the use of control measures in child mental health settings, as well as the experiences of children, parents and staff members of the use of these measures.

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<sup>10</sup> Parts of this review are included at the beginning of Manuscript 4, but are presented here within the wider context of the study to offer an overview of the literature on the topic addressed in this thesis and help situate the reader.

<sup>11</sup> No research literature specific to Quebec or Canada was found in regards to control measures in child mental health settings. The literature reviewed reflects the Western perspective on institutional practices in mental health settings, mainly from the United States. It is acknowledged that the use and perspective of control measures can vary from one country to another, but the literature reviewed is still highly informative (e.g. see Steinert, Lepping, Bernhardsgrütter et al., 2010, for a comparative review of the use of control measures in 12 countries).

<sup>12</sup> This study is a quantitative descriptive chart review of 45 deaths of children following the use of human or mechanical restraints in the United States between 1993-2003. It was the only study found that described the abuse and misuse of using restraint (both human and mechanical) with children and the direct relationship with cases of children's death. The authors suggest that institutions reinforce the application of the principle after which restraints should be used only in cases of harm to self or others, and highlight that all restraint positions, mechanical or human, have a lethal potential.

## Review Method

In order to conduct this review, an interpretive synthesis approach was used in which both quantitative and qualitative studies were included (Dixon-Woods et al., 2006). The review initially focused on the use of alternatives to control measures within child mental health settings. The aim of this review was to provide a thorough understanding, as well as a critique, of the current research literature available on the topic. However, due to the highly limited literature available, it was decided to also include studies related to the experience of the use of control measures, in addition to the ones related to alternatives, from all possible perspectives (e.g. staff members, parents, children) to provide a more thorough review of the available literature. The interpretive synthesis approach encouraged the adoption of an iterative process in which the aim was reviewed in light of the search results and findings (Dixon-Woods et al., 2006), which allowed for a richer understanding of the research literature related to the topic of interest.

A rigorous search was conducted in 2015, with reruns conducted in 2017, using the main health-related computerized databases: CINAHL, EMBASE, PsychINFO, PubMed, and Social Work Abstracts<sup>13</sup>. Different combinations of the following keywords were used in order to identify a wide range of studies related to the evolving aim of this review: child\*, adolesc\*, psychiatr\*, mental health, pediatric\*, restrain\*, seclusion, family, nurse\*, health\* professional\*, crisis, aggress\*, intervention, alternative\*, perspective, and experience. Additional studies were identified based on a screening of the reference lists of selected articles resulting from the computerized searches, as well as from ancestors and offspring searches performed in Google Scholar. To be included, articles had to address alternatives to control measures with children (0-18 years old) in mental health settings or the experience of the different people involved, and be

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<sup>13</sup>A librarian working at the Douglas Mental Health University Institute, Benoît Cameron, was consulted to identify relevant databases and keywords, as well as assist with the computerized searches.

written in English or French. Articles related to the use of control measures in settings other than child mental health were excluded, as each setting has particular norms and practices that can vary considerably and, even though it might have provided a richer review, would not have contributed to address the specific aim of the current review. A total of 26 studies were included in the final review: 19 were related to alternatives to control measures, and seven to the experience related to the use of control measures.

Each paper was read in full and specific information was entered into an Excel file: type of study, study aim, setting, country, definition of key concepts used, theoretical basis, methodology/methods, sample, findings, and relevance/critique.

## **Synthesis**

Of the 19 studies retained related to alternatives to control measures with children, two were review papers. One offered a critique of the literature published from 1995 to 2005 related to the reduction of the use of control measures in child mental health settings (Delaney, 2006), and the other was a follow up to the 2006 review that included papers published on the same topic between 2006-2013 (Valenkamp, Delaney, & Verheij, 2014<sup>14</sup>). The 2006 review included studies with both adults and children (the total number of studies included is not mentioned, but almost all of the studies were from adult settings), while the 2014 review was limited to empirical studies in a child or adolescent setting, which resulted in the inclusion of only three papers published within seven years. The authors concluded that the reduction of the use of control measures in child mental health settings is a largely underdeveloped area of research, which they consider “particularly distressing given the negative outcomes that are correlated with the use of these measures both in patients and staff” (Valenkamp et al., 2014, p. 173). They

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<sup>14</sup> These reviews were used to identify additional articles that will be discussed in more depth in the following paragraphs.

emphasized the need for more research, both empirical and qualitative, to better understand the experiences of the child, family, and staff members of using control measures as well as the institutional implications of implementing alternatives.

**Alternatives to control measures.** Based on the studies reviewed, four different approaches have been identified as forming the basis of control measure reduction programs: (a) a behavioral approach; (b) a relational approach; (c) a cognitive-behavioral approach; and (d) an approach based on trauma-informed and strengths-based care. All of the studies were conducted in the United States of America (USA), except for one that was done in Australia (Dean et al., 2007). Independent of the approach used, the studies all used comparable quality indicators as outcome measures collected from chart reviews, and reported similar limitations such as the inability to know with certainty if the effects were the result of the alternatives or not. The four approaches will first be presented, followed by a discussion of the strengths and limitations of the studies and related approaches.

Two articles were found reporting on a behavioral management program. One was based on a standardized framework for managing behaviors, in which behaviors considered appropriate by the staff members were reinforced (e.g. through sticker charts and verbal encouragements) and the behaviors deemed inappropriate discouraged through the use of a hierarchy of interventions, based on the principle of least restrictive methods (ranging from quiet time to seclusion) (Dean et al., 2007). The implementation of the behavioral program led to a decrease in episodes of aggression, as well as use of restraint and length of time of seclusion episodes. However, the number of episodes of seclusion did not decrease, and is described by the authors as being necessary as a high level intervention. In the other study, de-escalation techniques were the main alternatives used (Paccione-Dyszlewski et al., 2012). As part of this project, a training

program was developed based on adult crisis management programs, and the training was offered to 734 healthcare workers in a child mental health hospital, offering services to about 500 children (up to 23 years old) per day. The implementation of this behavioral program is reported to have led to better quality care, seen in a decrease in patient time spent in restraint and seclusion, a decrease in patient and staff injury, as well as an increase in patient satisfaction, measured by a decrease in parental complaints.

Another approach, called ABCD (an initialism for autonomy, belonging, competence, and doing for others), was based mainly on positive relationships and autonomy. The implementation of this relational approach in a child mental health hospital (children aged 5 to 18 years old), led to a decrease in the number and length of restraint and seclusion episodes, but an increase in the number of patient injuries and use of *pro re nata* (PRN) medication (Donovan, Siegel, et al., 2003; Donovan, Plant, et al., 2003).

Four articles were also found on studies using a collaborative problem-solving approach, which is largely based on principles from cognitive-behavioral therapy. Within this approach, the goal is to help children develop cognitive skills considered necessary to reduce aggressive behaviors, through the use of individualized plans (Greene et al., 2006; Martin et al., 2008). One study was conducted on a unit with children aged 3 to 14 years (Greene et al., 2006), and the other with children aged 4 to 12 years (Martin et al., 2008). The results of both studies showed a decrease in the number of episodes and duration of control measures, but a temporary increase in injuries to staff in the study by Martin et al. (2008).

Another approach was based on trauma-informed and strength-based care, focusing primarily on practice recommendations from the National Association of State Mental Health Program Directors (NASMHPD, 2000). This collaborative approach is based on prevention

principles, de-escalation techniques, and a focus on positive behaviors (Masters, Bellonci, & Bernet, 2002). Four articles were identified using this approach. One was a state-wide initiative conducted in Massachusetts, in which there was a dramatic reduction in the use of control measures on the eight participating child units (5-12 years old) with a total reduction of 72.9% in the use of restraint and seclusion following the implementation of the program and a reported reduction in injuries to both staff and patients (Lebel et al., 2004). The other articles presented the results from studies performed in child and adolescent mental health hospitals, where healthcare workers received training based on the NASMHPD recommendations (Azeem et al., 2011; Azeem et al., 2015; Caldwell et al., 2014). There was a marked reduction in the use of restraints and seclusion in the years following the implementation of the program.

Recent research highlights various strategies that can be used to help prevent aggressive behaviors in child mental health settings, for example a “feelings thermometer” to help children indicate how they are feeling and offer interventions to help them become calmer before there is a crisis (Andrassy, 2016), the use of sensory modulation rooms where children can go if feeling agitated (Bobier et al., 2015), or the use of mindfulness-based interventions to reduce stress (Hallman, O'Connor, Hasenau, & Brady, 2014).

All of the studies presented suggest that it is possible to significantly reduce the use of control measures in child mental health settings. These studies reflect a growing interest in adopting less coercive and more collaborative practices with children. Despite the encouraging outcomes reported in these studies, there are multiple limitations that should be addressed. First, the use of PRN medication was only reported in two of the studies; its use had increased in one of the studies following the implementation of the new program, suggesting that medication might have become an alternate strategy to control measures (Donovan et al., 2003), but was

reduced in another one (Dean et al., 2007). An over-reliance on PRN medication to control behaviors is considered as hindering recovery by limiting the person's capacity to take part in the treatment. These medications (e.g. sedative-hypnotics such as benzodiazepines or sedative-hypnotic-like drugs such as diphenhydramine) typically result in drowsiness and difficulty concentrating, which can significantly interfere with daily activities (Lehne, 2007). A careful and limited use of such medication is warranted (Donat, 2005).

Furthermore, many restrictive practices such as holds and time outs were not measured in these studies; there might have been a significant increase in the use of these practices that are also coercive. In the study by Dean et al. (2007), the use of time out and seclusion are presented as necessary within a behavioral management approach. The necessity to use time out and seclusion highlight the limit of these interventional programs that are based on a hierarchy of restrictive methods to be used in response to children's "non-compliant behaviors", independent from the specific context and child. This use of a hierarchy of restrictive methods has been critiqued for more than 20 years as contributing to the behaviors it is supposed to prevent, through the creation of an aggression-coercion cycle in which the restrictive environment contributes to an escalation of the methods used. These critiques are prevalent in the nursing literature (e.g. see Delaney, 2006; Goren, Singh & Best, 1993; Mohr, 2010). In addition, the practice of seclusion has been criticized as being counter-therapeutic and potentially resulting in trauma and harm (Finke, 2001).

An increase in injuries has also been reported in three studies (Donovan, Siegel, et al., 2003; Donovan, Plant, et al., 2003; Martin et al., 2008). The authors are unsure how to explain this increase, and call for additional research that would explore the perceptions of children, families, and staff in regards to the new approach. Moreover, it is unclear if the outcomes

resulted from the implementation of the approach or if they were due to other factors (e.g. to a change in staff members or managers, to children's different treatment plans, etc.). The sustainability of the practice change was scarcely documented: only one follow up study was conducted to examine if the changes remained over time (Azeem et al., 2015). In this study, the restraint and seclusion reduction program was successful; the authors emphasize the culture change that was needed to implement this new program at all levels of care and management in the hospital to reach this goal, ranging from extensive staff training to the adoption of family-centred care with open visiting hours and family activities. This study suggests that important changes targeting multiple factors are required to lead to practice change.

Of particular importance, the perspective of children, families and staff members was almost absent from these studies; it is unknown if the people involved in and affected by the practice change considered that the care quality had improved. Information on the experiences—including the moral experiences—of using control measures as well as using alternative measures would have contributed to the understanding of the high prevalence of the use of control measures and coercive practices with children, as well as what they consider as relevant and ethical practices. Only the study by Caldwell et al. (2014) included consultations with youths and families, who highlighted the need for crisis preventative measures and the importance of trusting relationships between patients and staff members.

**Experiences related to control measures.** The literature on the experiences related to the use of control measures in child mental health settings is scarce. Besides the study by Caldwell et al. (2014) that referred to consultations with youths and families, only seven articles were identified, of which four were published in the 1980s and 1990s<sup>15</sup>. Five articles included

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<sup>15</sup> Articles related to the perspective, attitudes, and beliefs of children, family members and staff members were also included to inform on their experience related to control measures.

the perspective of children, and five the perspective of healthcare workers<sup>16</sup> and two included the perspective of family members. All the studies were conducted in the USA except for the most recent that was conducted in Finland, which included only adolescents and no school-aged children (Hottinen et al., 2012). The five most recent studies were all from the nursing literature.

Allen (2000) conducted a literature review on nurses' beliefs and rationales related to the use of control measures in child mental health settings (Allen, 2000<sup>17</sup>). This review included only one study specifically related to children in mental health settings (Goren & Curtis, 1996). The author of the review emphasized a common trend in the articles related to the positive attitude of nurses toward the use of control measures, mostly in relation to the necessity to use such measures for safety purposes. The author commented on the lack of research on the effectiveness of control measures, as well as the ethical questioning related to their use, and underlined the need for additional research that explores alternatives to control measures.

In the studies that included children's perspective, there was an emphasis on the coercive nature of control measures. For example, Mohr et al (1998), in a qualitative descriptive study of 19 former inpatients from a mental health institute who were aged between 3.9 and 18 years old while they were hospitalized, have identified different types of trauma that children have experienced as a result of being restrained or secluded, and highlight the "lack of understanding by the children of why given interventions were used" (p. 95). Similarly, in a study conducted by Miller (1986), children from 5 to 13 years old who had been secluded in a mental health facility were asked to draw and/or write about their seclusion experience, and the punitive nature of seclusion was emphasized by children who also expressed feeling helpless. Children from 3 to

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<sup>16</sup> Some of the articles included the perspective of both children and staff members, and of both children and family members.

<sup>17</sup> This article reviews the literature from 1987 to 1998, and a total of eight studies was included. Except for one study, all were related to control measures in pediatric settings other than mental health or in adult mental health settings.

12 years old who had experienced physical holding while in a residential or day center also stressed their fear for their personal safety and anger while being restrained (Lundy & McGuffin, 2005). Seclusion is only supposed to be used as a last resort, to prevent a person from harming him- herself or others, in his/her best interests, which was not how children reported their experience.

In two of the studies, the findings related to the child's perspective were shared with healthcare workers who were surprised to hear that children expressed not feeling secure while being physically restrained or secluded (Miller, 1986; Lundy & McGuffin, 2005). The authors mentioned that healthcare workers subsequently asked for alternatives to control measures that would be more therapeutic from the child's perspective; this would call for further research.

Only two studies included the perspective of family members, one of which co-analyzed the perspectives of both children and parents (Mohr et al., 1998). The sole study in which the perspective of parents was analyzed separately is by Kazdin (1984), in which children and parents were asked to rank the level of acceptability of different practices: time out, PRN medication, and seclusion. The author concluded that children and parents were able to identify the acceptability of different treatment options and that their opinion should be taken into account in clinical decisions. As this was the only study exploring the perspective of family members separately, there is a great need for additional research on family's perspective of the use of control measures with children in mental health settings, which would be more recent and explore additional aspects than solely acceptability of behavioral practices.

In the study by Hottinen et al. (2012), adolescents and healthcare workers were also asked about their opinion related to different containment measures (including PRN and intramuscular medication, different types of restraints and seclusion, and constant and

intermittent observation). Here again, there was a contrast in perspectives. For example, healthcare workers had a positive attitude related to the use of mechanical restraints, but not adolescents. In these studies, the different interventions participants had to rate were all coercive; no information was provided on what alternatives children or family members might suggest. It is assumed that the coercive measures were necessary, which is coherent with an approach based on a hierarchy of restrictive methods.

From the review of these articles, it is clear that there is a significant lack of studies on the experience of control measures in child mental health settings, particularly in relation to the voice of the child and family. The moral implications of using such practices are also absent from the literature. These measures, when justified, are based on the notion of the best interests of the child, but this notion is inconsistently defined and the agency of children is not addressed<sup>18</sup>. While research on the use of control measures with children is in short supply, the literature on alternatives to control measures with adults hospitalized in mental health settings is vast. Various reviews have been conducted, in which there is a great emphasis on the need to limit the use of control measures because they are considered unethical and against human rights (e.g. see reviews by Goulet, Larue, & Dumais, 2017; Johnson 2010; Muskett, 2014; Scanlan 2010). Studies on the perception of control measures by adult patients and healthcare workers have also been conducted; for example, an integrative review of 12 qualitative studies on the experience of adults being physically restrained highlights the unethical aspects related to using control measures (Strout, 2010), and a systematic review of 37 articles on the perceptions of violence prevention from both adult patients and staff has been conducted (Hallett, Huber, & Dickens, 2014). From the staff's perspective, moral distress has been described by nurses

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<sup>18</sup> The notion of children's agency is somewhat controversial, in that there is no agreement between researchers related to the recognition of children as having agential capacities (see Montreuil & Carnevale, 2016). This concept of children's agency is discussed in more detail below.

working in adult mental healthcare settings as resulting directly from using control measures (Bigwood & Crowe, 2008; Moran et al., 2009; Olofsson & Norberg, 2001).

In summary, studies about the use of control measures with children are limited in scope and number. It is commonly suggested that the good nurse/healthcare worker needs to use certain forms of coercive measures in order to protect the best interests of the child. These practices have often become routine and expected, and form institutional norms that supersede the person's individual moral stance (Bray et al., 2014). The use of control measures is currently not framed as a moral issue, but does have moral implications for children and families, as well as for staff members.

## **Preface to Chapter II**

Chapter II presents a concept analysis of children's agency within the health literature, a key concept guiding the thesis study. Clarifying this concept in relation to children was essential considering the framework used is Taylor's hermeneutics, in which human agency is a key concept. This first manuscript, published in the *Journal of Child Health Care*, ends by offering a tentative definition of children's agency, which is the definition used in the remainder of the thesis. This concept guided the development of the specific methodology employed, data interpretation, and discussion of the results.

## Chapter II

### **Manuscript 1—A Concept Analysis of Children’s Agency Within the Health Literature**

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Supplementary File 2 (published online) includes the summary of the characteristics of the articles included in the concept analysis, categorized by trends, which is in Appendix B to this thesis.

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### Abstract

The capacity of children to act as agents is being increasingly recognized and has important implications for health research and practice. However, there are various discrepancies in how children's agency is defined in the literature. The aim of this analysis was to examine the concept of children's agency within the health-related literature, using Rodgers evolutionary method. The following questions were addressed: (a) How did the concept of agency become associated with children in the health-related literature?; (b) What are the sociocultural and legal contexts that surround the concept of children's agency?; (c) What is the meaning of children's agency? A total of 45 articles were included in the analysis. An inductive approach was used to identify the attributes of children's agency, as well as the temporal, disciplinary, and paradigmatic trends in its conceptualization. The concept of children's agency first appeared in the health literature in the 1980s, and was defined as an ability children could gradually develop. Later on, children's agency was used to refer to the capacity of all children to influence their own and others' health care needs, and is now increasingly used to refer to children as active agents who reflect on and construct their social worlds.

*Keywords:* Agency, agent, child, concept analysis, health, pediatric, Rodgers evolutionary method

## A Concept Analysis of Children's Agency Within the Health Literature

Since the 1970s, the idea of children as having agency is increasingly discussed in the research literature, particularly in the interdisciplinary field of childhood studies (James, 2009). From an ethical standpoint, agency is often presented in direct opposition to the best interests standard, in that children are considered in need of protective measures in their best interests, until they gain the capacity to act as agents. Recently, the need to reconcile these views in favor of a framework in which children's agency and best interests can both be recognized and coexist has been put forward (Carnevale et al., 2015). From this perspective, children are perceived as having highly varied agential capacities, which should result in a broad conception of children's agency that recognizes this wide range of agential capacities.

This article places itself in this context, aiming to clarify the concept of children's agency specifically in the health-related literature. A significant body of literature has examined and developed agency in childhood (for example in philosophy and the social sciences), but this concept has not been clearly articulated in relation to children within the health literature. This lack of conceptual clarity has important implications in a health context, as the way children's agency is conceptualized will have important implications for how health care will be decided upon and provided, as well as deeply affect how health research will be designed and conducted. Clarifying the characteristics of children's agency and retracing its evolution can contribute to the knowledge development process for this concept, by improving communication among users of the concept, as well as providing a conceptual foundation on which further inquiry could be based.

This analysis sought to explore how children's agency is conceptualized in the health-related literature from an evolutionary perspective. The following questions guided the analysis:

(1) How did the concept of agency become associated with children in the health-related literature?; (2) What are the sociocultural and legal contexts that surround the concept of children's agency?; (3) What is the meaning of children's agency?

### **Rodgers Evolutionary Method**

The method used in this concept analysis is based on an evolutionary view developed by Rodgers (2000), which is mainly grounded in the philosophical views of Toulmin and Wittgenstein. Following this philosophy, concepts are perceived as being dynamic in that they do not remain stable over time and context, but “change, grow, and develop (and need to be developed) in an evolutionary manner” (Rodgers, 2000, p. 100). Using this method is not expected to result in a finite, universal definition of the concept, but rather to clarify the attributes of the concept in order to promote its understanding and facilitate communication.

### **Data Sources**

#### **Concept of Interest**

Children's agency is the concept of interest for this analysis. The term *children* is used here to refer to minors from 0 to the age of majority, which is usually defined as 18 years old (United Nations Convention on the Rights of the Child [UNCRC], 1989). The term *agency* has multiple usages, and is usually employed in the social sciences to refer to self-determination or the ability to act independently (O'Leary, 2007). In this analysis, the focus is on agency as it relates to humans—specifically children—as agents who have the capacity to act (Carnevale et al., 2015).

#### **Setting and Sample for Data Collection**

The time period examined for this concept analysis ranges from 1951 to 2014, to analyze the development of the concept over time. Since the focus of this analysis is on children's agency

within the health-related literature, articles from multiple fields were screened for potential inclusion in the analysis, with no limitation regarding the disciplinary orientation of the authors or journals, as long as the article was related to health. Health is a highly multi- and interdisciplinary field, and the selection of specific disciplines could have discarded important views on the concept (Rodgers, 2000). Searches were performed using CINAHL (Cumulative Index of Nursing and Allied Health Literature) and PubMed (free access version of MEDLINE), which are the two primary computerized databases indexing health-related literature.

The searches combined yielded a total of 2901 articles, from which 45 were retained for inclusion in the analysis (see Supplementary File 1 for the details regarding databases searches).

*Supplementary File 1. Details regarding databases searches*

| Search terms <sup>19</sup>                          | Total number of articles | Number of articles retained |
|-----------------------------------------------------|--------------------------|-----------------------------|
| agen* or autonom* and child* in title <sup>20</sup> | 2582                     | 36                          |
| adolesc* or autonom* and child* in title            | 291                      | 9                           |
| self-determination and child* or adolesc* in title  | 18                       | 0                           |

Duplicates were first removed, and titles and abstracts were screened for relevance to the present concept analysis: articles related to a pharmacological *agent* or institutional *agency*, were by far the most prevalent and have not been retained. Conference abstracts and book reviews were also excluded, since these writings did not provide an elaborate enough view of the concept. In accordance with Rodgers' concept analysis method (2000), additional searches were performed while analysing the initial articles to include surrogate and related terms (e.g.: adolesc\* and self-determination). Considering the multiple usages of the words agency and agent, identifying the

<sup>19</sup> All the searches were performed in November 2014, and were limited to the French and English literature.

<sup>20</sup> The concept of autonomy had been identified as a possible surrogate term for agency (Carnevale et al., 2015), and was thus included in the initial searches performed.

relevant literature was quite challenging. Olli et al. (2012) have also highlighted this difficulty in their review of factors affecting agency in children with disabilities: through different computerized searches in seven databases yielding abundant results, they could identify only two articles of relevance to their study.

### **Data Management and Collection**

Each text was first read in full to “identify the general tone of the work and to gain a sense of the writer’s use of the concept” (Rodgers, 2000, p. 93). The following questions were asked for each text and recorded on an Excel worksheet: (a) Why was this document published?; (b) How does it relate to children’s agency?; (c) What are the surrogate and related terms that are used?; and (d) How is children’s agency defined? In addition to these questions, the year of publication and the primary author’s disciplinary and country affiliations were recorded to allow a comparative analysis based on these contextual criteria. A second reading of each article was then performed, in order to identify and organize the data into the three specific categories: attributes, contextual basis, and references (see Supplementary File 2 for more details related to data collection, which can be found in Appendix B to this thesis).

In addition to the Excel worksheet, a record was kept of the researchers’ thoughts and perceptions throughout the analysis process. This document was used to help the researchers identify major themes and keep track of the analytic process. This also provides an audit trail that can be used to retrace the steps of the analysis, contributing to the credibility of the inquiry (Rodgers, 2000).

### **Data Analysis**

An inductive analysis was conducted to identify the different themes related to the three categories: attributes of children’s agency, contextual basis, and references. As suggested by

Rodgers, labels were first identified, followed by an exploration of areas of agreement and disagreement in how children's agency is conceptualized, looking at disciplinary, temporal, and paradigmatic trends. Rodgers does not mention specifically the analysis of paradigmatic trends, but mentions that concepts may be viewed through various contextual bases. The framework used to analyze the paradigmatic orientation is the one developed by Lincoln and Guba (2000), who identified five paradigms labeled as: positivism, postpositivism, critical theory, constructivism, and participatory. The paradigmatic analysis was valuable in highlighting the perspective from which the research was conducted, and related view of children and childhood (e.g.: the child as the object of research in positivism).

## **Results**

The data was grouped to emphasize the trends in how the concept of children's agency has evolved over time in the health literature, to provide greater insight into the contextual elements that contributed to its development (Rodgers, 2000). The distinctive attributes of the concept are based on the temporal, disciplinary, and paradigmatic analyses<sup>21</sup>.

### **Appearance of the Concept within the Health Literature: Orem's Self-care Agency**

The concept of agency in children within the health literature first appeared in the late 1980's in the American nursing literature, with different articles being published referring to Orem's self-care theory as their main framework<sup>22</sup>. In Orem's theory, each person is considered as a self-care agent. Self-care agency is defined as one's ability to engage in self-care in order to enhance treatment and prevent illness (Orem, 1976). However, in Orem's initial theoretical framework, self-care agency did not apply to children; parents and other adults were considered

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<sup>21</sup> Due to space limitations, not all the references are included here. Please refer to Supplementary File 2 for descriptions of the characteristics of the articles included in the concept analysis, as well as a complete listing of the references.

<sup>22</sup> No articles were identified that referred to children's agency prior to the 1980s, despite the inclusion of articles from 1951 to 2014 in the literature searches.

to be fully responsible for children's self-care. This view was present in a study by Gaffney and Moore (1996), in which adults were considered the "dependent care agents" for children who were described as having no self-care agency.

In order to apply Orem's self-care theory to children, different authors provided an altered view of agency that was related to children's developmental abilities: they assumed that there is a transition process in which children progressively acquire a greater ability to perform self-care agency. Children were referred to in these articles as the recipients of care, who were slowly *becoming* self-care agents as they moved into adulthood.

### **Developmental Perspective**

From the beginning of the years 2000 onwards, several articles were published referring to children's agency from a developmental perspective, mainly from American authors working in various health-related fields such as communicative disorder, nursing, occupational therapy, and nutrition, as well as psychology and philosophy. In most of these articles, agency was explicitly or implicitly defined as being the causal agent in one's own life. For example, in a study examining factors affecting agency in adolescent mothers, DeSocio et al. (2013) defined agency as "the positive expectation of personal control over one's future" (p. 160). Agency was used to refer to the child who exists as a person and gradually develops greater agency related to his or her self.

The specific attributes of children's agency identified from the literature adopting a developmental perspective are: (a) ability to attend to one's self needs, (b) ability to direct future possibilities (e.g. through decision-making), and (c) confidence in ability to organize and perform certain health behaviors. Also, the idea that agency is part of the child's identity was beginning to appear. In these later articles, agency was described as the result of cognitive

processes through which children gradually build their identity. Younger children were described as lacking agency since they cannot retain memories of experience and do not have a sense of self (Baker, 2013). As children develop and gain a greater sense of self, they are presented as acquiring greater agency.

In these studies, as in the studies referring to Orem's self-care theory, agency was considered to be an empirically measurable concept; positivist or postpositivist frameworks were adopted. Different scales were used to measure various factors presented as constituting agency.

### **Children as Health Change Agents**

Beginning in 2005, increasing research has been published in which health educational interventions were provided to children who were described as "health change agents". Most of these studies were conducted with schoolchildren considered vulnerable, many of which were conducted in developing countries, such as Kenya, Tanzania, India, and Ethiopia. This body of literature is highly varied in terms of disciplinary orientations, but public health research was the most prevalent discipline. In these articles, children were presented as having the potential to be health-promoting actors who can act in larger societal structures, and are not only passive recipients of care.

For the attributes of agency, these articles present children's agency as (1) having the capacity to engage with health knowledge and skills, (2) playing an active role in meeting their own health needs, and (3) influencing the choices of others regarding health behaviors – mainly of their family and community. In contrast to the views of agency presented in previous sections, children were referred to as not only having the ability to attend to their own health needs, but to play an active role in meeting those needs, as well as influence the choices of others. In accordance with this latter view, school-aged children were considered as having the capacity to

act as change agents, which led to children being the agents of health-promoting interventions designed by the researchers.

Most of these articles on children as health change agents have been analyzed as adhering to a postpositivist paradigm. However, in contrast to previous views of children's agency, the developmental view was absent in these articles; school-aged children of all ages were included in the studies with no reference to their developmental capacity to act as change agents.

Moreover, a few articles were identified as constructivist, mainly because of their methodological approach. In these articles, the authors presented a slightly different view of children's agency in which an additional attribute was present: the ability to propose solutions to address problems and act on them to promote health. As a result, these authors considered that children's views should be included in the research process by using means such as photovoice or focus groups to help children express their views more freely.

### **Agency in Childhood Studies**

Starting around the year 2010, various authors situated their work in what is presented as the growing field of childhood studies, and was mainly seen in articles from authors in social sciences, with a few articles from medical anthropology and nursing. This literature was almost exclusively from authors based in the UK and Scandinavian countries, and they situated their work in the context of the UNCRC (1989), which stipulates in articles 12 and 13 that children have participatory rights and that their views should be "given due weight". Children were considered in this literature as active social agents involved in shaping their own lives, as well as the lives of others. Agency was presented as not being related to age or other personal/social characteristics, but being present in all children.

The specific attributes of agency that were common in these articles were analyzed as the capacity to: (a) act; (b) shape one's life; (c) have an influence on other human beings; and (d) "actively reflect on and construct their social worlds" (Hampshire et al., p. 702). Olli et al. (2012), in their literature review of agency in children with disabilities, mentioned that agency exists even in cases when the child's self-expression is misunderstood or the child is not allowed to have an influence. From this perspective, agency is not something that develops over time as described in the developmental view, but is seen as being always present in children. Consequently to this view, children were perceived as active agents during clinical encounters, in which they can speak for themselves and be an integral part of the health decisions that are made, as well as processes related to health decisions.

Of all the articles sharing this conception of children's agency, none adhered to a postpositivist paradigm; most drew on a constructivist and/or participatory paradigm. In research adopting a participatory approach, studies were conducted as to involve children in the research, with different levels of children's involvement.

## **Discussion**

The clinical and research implications of adopting a particular view of children's agency are addressed here, aiming to answer the questions outlined in the introduction of the paper. The questions are addressed concurrently in the following discussion, concluding with a tentative definition of agency.

### **Implications of Children's Agency in Research Inquiries**

**Children as objects of research.** The manner in which children's agency is conceptualized has a significant impact on how children will be considered in a scientific inquiry. When looking at Orem's self-care theory, children were initially perceived as having no

agency at all, and research that aimed to study children focused on parents as the dependent care agents fully responsible for the children's health and well-being. Gradually, this view began to shift, as more authors published articles in which children were perceived as gradually acquiring agency. Initially, only adolescents were considered in these studies, since they were perceived as having more agential capacities—defined in terms of autonomy and cognitive abilities—than younger children. James (2009) considers that this view is the result of the dominance of developmental psychology over a century until the 1970s-80s, a field in which “children were studied predominantly as representatives of a category whose significance lay, primarily, in what they revealed about adult life” (p. 35). Children were thus studied, and still are by certain researchers, to discover the universal stages of development that characterize the passage from children—defined as incomplete and dependent *becomings*—to adults who are full beings with individual agency and rational capabilities. In the health-related literature, this view was prevalent from the appearance of the concept of children's agency in the late 1980s, until the arrival of the concept of children as health change agents in the years 2000. In studies adopting a developmental view, children were described as the *object* of research and it was assumed that children's agency could be studied in an objective manner, through the measurement of factors associated with agency. Consistent with the tenets of positivism, the results of these studies were considered applicable to all children, independent of context.

**Children as actors.** In the studies referring to children as health change agents, the authors considered that children could play a role in influencing health care behaviors and bring about change at the personal, familial, and community levels. Children were described as active agents and not only as passive recipients of the care of others. However, in the articles identified for this analysis as adhering to a positivist/postpositivist paradigm, children were assumed to

need adults to guide the change process, and children's views were not included in the identification of issues and solutions. This perspective contrasts with the dominant view in childhood studies related to children as agents. For example, Dedding et al. (2014), in an article reporting on a participatory-action research study conducted with children with diabetes, concluded: "In fact, if we think that children can only participate when they are invited and facilitated by adults or in specially designed projects, we might even be contributing to the reification of the child as passive recipient of care" (p. 8). Consistent with this latter view, using the term *actor* might be more reflective of the role children had in the postpositivist studies of children as health change agents, in the sense that they could do something (i.e. act) and influence others, but were not authentically agential in that they were not actively *reflecting* on their lives and *shaping* their worlds and the worlds of others. Children were mainly included in the research process as actors who, with adequate education, could bring about change.

**Children as agents.** In the articles adopting a constructivist or participatory paradigm, children were significantly more involved in the research process and there was a stated recognition of the role children can play in constructing their social worlds. In a participatory paradigm, there is a political participation described as a right of people to participate in the different steps of the research that aims to generate knowledge about them. This right is deemed a basic human right (Heron and Reason, 1997), which is considered applicable to children in these studies in accordance with the UNCRC (1989). Consistent with this perspective, researchers need to find ways to involve children directly in the research process, and co-create knowledge of relevance to the children themselves. Dedding et al. (2014) used such an approach and involved children as co-researchers who developed and evaluated interventions.

### **Agency: a “Fuzzy” Concept**

While performing the data collection and analysis, multiple types of agency were identified in relation to children, and it was questioned whether all these variations should be included or not. Considering the limited amount of articles addressing children’s agency within the health literature, it was decided to include all the variations, since they were all related to the concept of interest. As presented above, some articles referred to self-care or change agency, while others referred to personal, human, social, or moral agency, as well as agency alone. The inclusion of all these variations is consistent with Rodgers’ view that the same idea can be worded differently, and that exploring these different terms can provide valuable information on the concept of interest (2000).

Also, the concept of autonomy was included in this analysis as it was considered a possible surrogate term for agency. However, after having performed the analysis, it appeared that autonomy would be more a related than a surrogate term for agency, in the sense that it shares some similarities with agency, but not the same attributes. Autonomy was used to refer almost exclusively to the capacity to make an informed decision, often in a legal context related to the child’s capacity to consent. In contrast, agency widely referred to the ability to attend to one’s self needs, in addition to the capacity to make an informed decision.

### **A Tentative Definition of Agency**

An attempt has been made to develop a definition of children’s agency that would reflect the evolution of the concept within the health literature. It was noticed that agency was initially defined in terms of abilities and later of capacities. These terms were not explicitly defined in the articles, but a common distinction between the two is that abilities are learned, while capacities are inborn (Grammarist, 2014). This change in vocabulary might reflect the distinction between

agency as a learned ability in line with the view from developmental psychology, and agency as applying to all children independent of their developmental status, as seen in studies referring to children as health change agents and from the field of childhood studies.

Based on the analysis performed, children's agency could be defined as children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others. This definition entails that multiple forms of expression can be used to speak for oneself, including speech and bodily expressions, and that the capacity of children to enact agency is not dependent on adults as facilitators of agency. This definition is only tentative in that concepts are seen as dynamic in nature, changing with time and context (Rodgers, 2000). It is closely linked to the definition of researchers from the field of childhood studies, which is the latest trend in the evolution of the concept, and represents a more social view of agency.

It is hoped that this exploration of the concept of children's agency will help advance the understanding of how the health literature engages with this concept. An exploration of children's agency within different bodies of literature such as in education, law, history, anthropology, and sociology, would be particularly interesting as it could examine paradigmatic differences in how agency is conceptualized, and explore disciplinary similarities and differences. In addition, this broader exploration might allow for a more in-depth comparison of the different variations of agency that were seen in this analysis, particularly the difference between the concepts of social and moral agency in children. An examination of the practical implications of children's agency could also be highly relevant; the ethical consequences of agency in relation to the best interests standard have not been formerly addressed here and would need to be investigated further.

### **Preface to Chapter III**

Chapter III presents the methodological framework developed for the study conducted as part of this thesis, participatory hermeneutic ethnography. This second manuscript first details the philosophical framework on which this methodology draws—Taylor’s hermeneutics—and follows by a description of its operationalization for health ethics research with children. Appendix A presents additional methodological details related to the participatory research process.

### **Chapter III**

#### **Manuscript 2—Participatory Hermeneutic Ethnography:**

##### **A Methodological Framework for Health Ethics Research with Children**

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### Abstract

When conducting ethics research with children in healthcare settings, studying children's experiences is essential, but so is the context in which these experiences happen and their meaning. Using Charles Taylor's hermeneutic philosophy, a methodological framework for health ethics research with children was developed that bridges key aspects of ethnography, participatory research and hermeneutics. This qualitative methodology has the potential to offer rich data and discussions related to children as well as family members and healthcare workers' moral experiences in specific healthcare settings, while also examining the institutional norms, structures, and practices and how they interrelate with experiences. 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 healthcare setting.

*Keywords:* Qualitative methodology, hermeneutic ethnography, participatory research, health ethics, children

## Participatory Hermeneutic Ethnography:

### A Methodological Framework for Health Ethics Research with Children

Children's own experiences are being increasingly studied, especially in the interdisciplinary field of childhood studies. Within this field, children are seen as active agents and not as passive objects to be examined. They are considered as having the capacity to engage actively in research and be involved through participatory approaches. Consistent with this view, different methodological approaches have been developed focusing on research *with* or *by* children as opposed to research *on* children (e.g. Freeman & Mathison, 2009; Greene & Hogan, 2005; James & Prout, 2015). These methodologies mark a great advancement in doing research with children and fostering our understanding of children's lives. When conducting research with children regarding ethical issues, paying attention to their own experiences and drawing from approaches in which children are seen as active agents can foster our understanding of children's own moral lives. However, these approaches tend to focus either on interviews to explore children's experiences, with little consideration of the context and social relationships in which children are situated, or the context and social interactions through ethnographic approaches, with a lesser focus on children's experiences. While designing a study on crisis management in a child mental health setting, I considered important studying these different aspects; researching children's experiences is essential, but so is the context in which these experiences happen and the meaning—the moral significance—for the different parties involved. I turned to Charles Taylor's hermeneutic philosophy to develop a methodological approach to ethics research with children that bridges key aspects of ethnography, participatory research and hermeneutics. Some aspects of Taylor's work have already been included in a methodological approach for health research (Benner, 1994), but key concepts developed by Taylor that address the broader context,

such as social imaginaries as well as his ideas on moral agency, have not been included in a specific methodological framework. Principles of participatory research—to engage children within the research process itself and foster their inclusion in key decisions—had also not been bridged with existing hermeneutic methodologies. I first present the conceptual framework on which the proposed methodological framework is based, followed by a discussion of the specific methodological implications of adopting such a framework and how it could be applied to health ethics research with children.

### **Conceptual Framework**

The foundational conceptual framework is Taylor's hermeneutics, which includes the central concepts of horizons of significance and social imaginaries. These concepts are presented here, as well as the concept of local imaginary that was developed to apply the concept of social imaginaries to a specific study setting.

### **Hermeneutics**

Charles Taylor's hermeneutics is part of a human sciences framework, in which human life can only be understood through interpretation (Taylor, 1971; Taylor, 1985)<sup>23</sup>. This view contests a reductionist and objectivist view of human phenomena as adopted in empiricist or positivist research that is based on a natural sciences framework, in which interpretation is evacuated. Taylor has critiqued the use of natural sciences frameworks in the study of human phenomena, particularly in behaviorism and cognitive psychology (Taylor, 1983; Taylor, 1985). He considers that using such frameworks leads to a misunderstanding of human life. In contrast

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<sup>23</sup> Charles Taylor (1931- ) is a philosopher from Montreal, Quebec, who has developed a contemporary view of hermeneutics. His work has been widely recognized internationally. Even though his work does not relate directly to health research, it has been used as a guiding framework to address health related inquiry, including nursing (e.g. Carnevale, 2013a; Carnevale, 2013b; Hunt & Carnevale, 2011). Taylor has also collaborated on a special issue of the *Journal of Medicine and Philosophy* (2011) on a hermeneutical conception of health research based on his philosophical work.

to natural phenomena (e.g. physical, chemical or biological) that are considered constant and independent of interpretation, “human beings are self-interpreting animals ... our interpretation of ourselves and our experience is constitutive of what we are, and therefore cannot be considered as merely a view on reality, separable from reality” (Taylor, 1985, p. 45-47). Taylor argues for an ontological shift from a reductionist conception of human phenomena to an interpretive conception based on concepts such as human agency, personhood, and selfhood. This ontological shift is paired with an epistemological shift in how knowledge related to human phenomena can be acquired (Carnevale & Weinstock, 2011; Taylor, 1971). This understanding is embedded in a broader socio-historical-cultural background in which meaning is rooted. This meaningful context or background is called by Taylor (1991) a *horizon of significance*, which represents the meaningful understandings, beliefs and values within a group (e.g. a society) that orient what is considered moral, referring to how right, good, or just is imagined (Hunt & Carnevale, 2011).

Relating to human experience, a conception of moral experience based on Taylor’s philosophy has been developed, on which the proposed methodology builds. From this view, moral experience is defined as follows:

Moral experience encompasses a person’s sense that values that he or she deems 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 the spectrums of right-wrong, good-bad or just-unjust (Hunt & Carnevale, 2011, p. 659)

Moral experience refers to how things matter, or to what things mean, to a specific person; this is embedded in and informed by a particular context and background (i.e. horizon of significance) (Hunt & Carnevale, 2011; Carnevale, 2013a). Even though moral experience is defined here in

more individualistic terms, it is always within a significant background or meaningful context that things make sense, and thus does not mean that moral experience is defined in relativistic terms. In his discussion of the concept of moral ideal, Taylor warns against moral relativism, in that it leads to an atomism/individualism in which people have no socially-defined moral grounds on which decisions are made (Taylor, 1991). In contrast with other conceptions of hermeneutics that focus predominantly on personal individual experiences, Taylor's conception of hermeneutics is socially based; a person's self-understanding is always situated within a horizon of significance that orients what is considered as moral. Hence, the particular choices made by a person are enacted within a specific context in which meaning is rooted, which means that in a specific study using this framework, both the personal experience and socio-historical-cultural background are of importance.

The conceptualization of the term *meaning* from a hermeneutical perspective is different from a linguistic perspective. In hermeneutics, meaning refers to the "experiential significance of a thing for a subject or group of subjects" (Carnevale, 2013a, p. 87). In contrast, linguistic meaning refers to the attributes that are used to designate a thing, and not to the expressive meaning. To exemplify this difference, Carnevale (2013a) contrasts the linguistic and hermeneutic meanings of the term *photograph*: there are agreed-upon characteristics or attributes that lead to call an object a photograph, which represents its linguistic meaning; on the other hand, the hermeneutic meaning of a photograph refers to the meaningful expression that is conveyed by the object, such as remembering a significant event in life. A specific meaning is interdependent with other meanings, and is constructed in an intersubjective manner (Taylor, 1971). It is this intersubjective meaning that is at the root of our own self-understandings as well as shared understandings, and these meanings and understandings are informed by the socio-

historical-cultural context. In a specific group or society, the *moral order* is defined by Taylor (2004) as a shared understanding of what is good or right, which emanates from what he calls a *social imaginary*:

By social imaginary, I mean something much broader and deeper than the intellectual schemes people may entertain when they think about social reality in a disengaged mode. I am thinking, rather, of the ways people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations (p. 23)

Taylor highlights major differences between social theory and social imaginary. For instance, in contrast to social theory, social imaginary is “not expressed in theoretical terms”, but can take any form that conveys this imaginary, such as stories or images (2004, p. 23). This concept is largely influenced by Benedict Anderson’s imagined communities, in reference to nations as constructed entities (Anderson, 2002/1983). A social imaginary is “shared by a large group of people” and not only a restrained group as with theories, which allows within a society for a “common understanding that makes possible common practices and a widely shared sense of legitimacy” (Taylor, 2004, p.23). Taylor considers that background understandings and practices mutually inform each other: a group sharing a common understanding will share collective practices, but the practices also inform the understanding of our social existence, as well as our sense of moral order (Taylor, 2004).

To apply the concept of social imaginary to a study in a specific setting, I have developed the concept of *local imaginaries*, which refers to local understandings, to the “ways people imagine their social existence” (Taylor, 2004, p. 23), but within the limits of the specific social

space being studied. In a specific local imaginary, people share foundational goods and values founded on qualitative distinctions (see section below for a discussion of this concept); this imaginary is perceived as “the only possible one, the only one that makes sense” (Taylor, 2004, p. 17). It is shaped and informed by broader social imaginaries and horizons of significance. By referring to Taylor’s concept of *hypergood*, which he defines as the most important good from which to judge other goods or ends (Taylor, 1989), we can examine what is of most value to children and analyze how it is related to specific institutional norms, structures, and practices in a specific setting, including how they mutually inform each other.

In sum, in line with a hermeneutic moral framework, every human being is shaped by both subjective personal experiences and the local meaningful moral context in which he/she resides (i.e. horizon of significance). The moral order shared by a group, which refers to how right, good, or just is collectively imagined, is rooted in the group’s local imaginary. Personal experiences and horizons of significance both inform each other through a dynamic process and can be better understood through hermeneutical interpretation (Hunt & Carnevale, 2011).

***Children’s agency.*** A concept that is central to Taylor’s hermeneutics is human agency. He considers that: “to be a full human agent, to be a person or a self in the ordinary meaning, is to exist in a space defined by distinctions of worth” (Taylor, 1985, p. 3). These distinctions of worth refer to the meaningfulness of things, to the expressive meaning, which is a qualitative distinction that is morally grounded. Taylor discusses the notion of strong evaluation that is at the root of qualitative distinctions, which is characterized by “a distinction between desires as to worth” and is guided by morality (1985, p. 17). He explores the notion of self, of what distinguishes responsible human agents from animals. However, he does not address agency specifically in relation to children.

The capacity of children to act as moral agents is largely unrecognized (Carnevale et al., 2015). Children are often expected to passively comply with norms decided on by others, who are usually people in a position of power (e.g. healthcare workers *in charge of* children). The benefits of reconciling the concept of best interests with moral agency has been discussed, in order to recognize both children's need for protective standards as well as their capacity for moral reasoning as human agents (Carnevale, 2013a). Wall (2010), in his book *Ethics in Light of Childhood*, developed a framework in which children's experiences should be considered in how morality is defined. He explores the concept of moral agency in children, and argues for a reconciliation of moral agency and vulnerability, the latter being the rationale on which the concept of best interests is generally based. As he argues (2010): "What is needed in light of childhood is a deeper sense of the connection between human agency and human vulnerability. These should be understood not as polar opposites, but as intertwined for all human beings in a dynamic and creative tension" (p. 39). I adopt a view of agency in which children are perceived as both vulnerable and agential, which calls for a form of protection in their best interests, as well as their inclusion in processes affecting them. For example, children's inclusion in research processes can be beneficial or detrimental to them depending on how it is performed (James, 2007) and the dual perspective of children as vulnerable and agents contributes to keep these issues at the forefront to address them reflectively.

This concept of agency in children is increasingly discussed in the research literature, particularly in the interdisciplinary field of childhood studies (James & Prout, 2015). To clarify the characteristics of the concept specifically within the health-related literature, I conducted a concept analysis of children's agency using an evolutionary framework (Montreuil & Carnevale, 2016). This analysis is consistent with a hermeneutic framework, as it provides a deeper

understanding of the historical evolution of the concept and moral outlooks on children in our society; it informs on the disciplinary views, sociocultural context and meaning of the concept within this research area. Children's agency is defined as:

Children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others. This definition entails that multiple forms of expression can be used to speak for oneself, including speech and bodily expressions, and that the capacity of children to enact agency is not dependent on adults as facilitators of agency (Montreuil & Carnevale, 2016, p. 510).

There is a lack of full consideration of the notion of children as having agency. For example, children's agency is not always recognized within the field of developmental psychology or is defined primarily in terms of moral failure to comply with pre-established norms, as opposed to considering children as having the capacity to actively contribute to define the norms (Montreuil et al., 2017). Also, within anthropology, Lancy emphasized the lack of attention to defining the concept of children's agency, and critiqued research referring to children's agency as being ethnocentric and hegemonic (Lancy, 2012). The way children's agency is depicted by Lancy is different from the conceptualization of agency as described here. For example, children's agency is described by Lancy in individualistic (autonomy-centred) terms, as opposed to a more socially based conception that is adopted here.

### **Participatory Hermeneutic Ethnography as a Methodological Framework**

When applying the above conceptual framework to research methodologies, it calls for a qualitative approach that would be interpretive, iterative and allow for the examination of both experiences and contextual aspects. Methodologies based on empiricist frameworks would be in direct opposition to Taylor's framework. Drawing on methodological principles from

hermeneutic, ethnographic and participatory research traditions allowed for the elaboration of a methodological framework in line with the work of Taylor, based on the examination of horizons of significance and social/local imaginaries that contribute to understandings of norms, structures, and practices as well as the moral experiences in a specific group (Carnevale, 2013a). In addition, which is of importance to health research, examining the context and experiences helps illuminate priorities for practice change and strategies for achieving those changes (Nastasi & Berg, 1999).

Traditionally, ethnographic methodologies were described as aiming to uncover what is implicit, as well as what is explicit, in order to understand a specific culture (Germain, 2001). In contrast, within hermeneutic ethnography, it is not the culture, but the social and local imaginaries that are studied. As mentioned by Carnevale (2013b): “SI [social imaginaries] enable hermeneutical qualitative research to examine the broader social context surrounding a research concern (i.e., in addition to the presenting immediate context), which would bring a valuable innovation to hermeneutical empirical qualitative research” (p. 189). This type of methodological framework is suitable to address a specific issue within a single context—it is *focused* in scope—and is therefore more closely related to the principles of focused ethnography as opposed to classical anthropological ethnographies in which the whole culture is explored. A focused ethnography is time-limited and centers on a particular problem within a specific context (Muecke, 1994).

I also consider hermeneutic ethnography gains from being bridged with a participatory research framework. Participatory research is defined as a “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change” (Green et al., 1995, Definition section, para. 1). It is considered an

*approach* to research or an *orientation* to inquiry—as opposed to a methodology—and different research methodologies and methods can therefore be used employing this approach (Cargo & Mercer, 2008). The participatory research tradition that most readily allows for a bridging with hermeneutic conceptions is the Southern tradition inspired greatly by the work of Paulo Freire, related to issues of social justice and addressing questions of empowerment and agency (Wallerstein & Duran, 2008). By purposefully working with people with less power the goal is to give attention to their voice and help them create power through their involvement in the research process (Veale, 2005). With children, their participation in the study process can promote their empowerment by having a say in institutional practices directly affecting them. However, this involvement has to be performed in an authentic manner to be meaningful and prevent children from being used to promote, for example, the researcher’s pre-defined research agenda (James, 2007). Moreover, research results are not considered to be more true or more real if children are involved in the research process; I consider their inclusion will lead to a *different* research orientation and interpretive account that informs on children’s experiences in light of their own diverse perspectives, taking into account what they consider as meaningful.

According to Taylor (2004), what is moral (i.e. what is good, right, or just) is rooted in *shared* meaningful understandings and practices. The use of a participatory research approach, through a collaborative and equitable knowledge production process, can lead to a stronger articulation of moral life and deeper understanding of the social and local imaginaries that shape institutional norms, structures, and practices. The term *equitable* is used in contrast to the term *equal*, in the sense that partners to the project are provided with equal opportunities to engage in the research process, but are free to choose their level of involvement (Salsberg et al., 2015). Thus, different partners can have different levels of involvement, even though they have the

same (i.e. equal) opportunities to be involved. Collaborators on a participatory research project can, for example, contribute to refine the research questions, decide what data is relevant to collect from their perspective, contribute to interpreting the data and be involved in developing the dissemination plan. Different types of collaborators can be involved, such as patients (including children), families, healthcare workers, managers, and decision-makers. There are some challenges to the use of a participatory research approach, for instance related to the shared decision-making process that can lead to delays in the realization of the study in case of disagreements, or to changes to the initial plans since decisions are made collaboratively. However, despite these challenges, the adoption of this approach generally leads to more contextualized, relevant and practical knowledge that contributes to bridging the research-practice gap (Green, 2008), and provide potential benefits to the study itself as well as to the people involved.

In the study I conducted using this framework, children who were collaborators in the participatory research process were consulted to decide if meetings with children would be held separately or with the adult collaborators. Children mentioned preferring having separate meetings, in order to share their perspectives more freely. Most of the adult collaborators were authority figures to children in the setting, which resulted in a pre-established power differential in place. As Carnevale et al. (2008) mention, researchers need to be aware of these power dynamics when performing studies with children and find ways to address them. Instead of imposing preconceptions related to power differentials, I consider consulting with children regarding their participation is more coherent with a view of children as agents, while recognizing their vulnerable status.

## Data Collection

To conduct a participatory hermeneutic ethnography, various data collection strategies can be used concurrently to allow for the examination of various types of data within clinical settings (Savage, 2006). Similar to strategies used within traditional ethnographic studies, participant observation, interviews (both formal and informal), and documentation review are especially suitable (Knoblauch, 2005; Muecke, 1994). These three strategies combined offer rich data that lead to a deeper understanding of the moral experiences, as well as the institutional norms, structures, and practices in a specific setting. Collaborators can be involved in deciding when are the most appropriate times to be present in the setting for the participant observation, who will be interviewed, and what are key institutional documents to analyze.

**Participant observation.** Participant observation has been described as a strategy that may provide richer and more thorough data than other data collection techniques when conducting research with children in healthcare settings (Carnevale et al., 2008). When conducting participant observation, the researcher is both a *participant* and an *observer* who is engaged in the activities in the setting and has informal conversations with the participants that contribute to data collection that is more contextualized (Hammersley & Atkinson, 2007). In line with Taylor's framework, both moral experiences and the local meaningful moral context shape human beings and mutually influence each other; data from both conversations and observations are thus central to answering a specific research question as they provide necessary information to document these aspects. In contrast, doing solely observation without being involved with the people in the setting would not provide the data required to understand the experiences, social imaginaries, and horizons of significance, as these are also conveyed in spoken language and interactions. This involvement from the researcher allows for the unfolding of in-context

discussions that provides information that could otherwise not be accessed. By being continually present in the setting for an extensive period of time, the aim is to capture the daily experiences and be able to observe the norms, structures, and practices that are present. Muecke (1994) argues, “the more complete the researcher’s participation in the life-space of the people studied, the greater the value of the study because of the researcher’s greater exposure to a variety of situations” (p. 203-204). Moreover, the collection of both verbal and non-verbal data is particularly relevant when conducting research with younger children who may be less articulate, but still quite communicative (Carnevale et al., 2008). In addition, participant observation is more flexible than other data collection strategies, such as structured interviews, and allows for the development of a relationship between the researcher and children as the researcher spends time with them in the setting; this aspect is important to consider in light of the ethical concerns related to power differentials in conducting research with children, especially children receiving healthcare services who are often considered as highly vulnerable (Carnevale et al., 2008).

**Interviews.** Semi-structured interviews can be conducted in conjunction with participant observation to provide richer data that could not be collected through informal conversations. For example, discussing certain sensitive topics with participants might require meeting in a space that would provide confidentiality. In addition to formal interviews with study participants, key informants can also be interviewed to provide additional contextual information. Key informants should be chosen based on their experience and knowledge of the issue of interest (Muecke, 1994). As is common in ethnographic studies, the exact number of informants who will be interviewed, as well as the number of interviews that will be conducted, is reassessed in light of the quality and relevance of the data collected (Hammersley & Atkinson, 2007). The process is

iterative: the data from the participant observation informs the content of the interviews, and the data from the interviews in turn informs the participant observation.

**Documentation review.** Normative and clinical documents can also be reviewed to complement the other types of data (e.g. charts, policies, procedures, unit rules, 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 contributes to the researcher's understanding of institutional norms, structures, and practices in the setting, and can 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.

### **Data Analysis and Interpretation**

While the data collection strategies presented above are largely consistent with ethnographic research, the analysis process described here is more closely related to hermeneutics. As expressed by Hunt & Carnevale (2011):

Hermeneutical interpretation seeks clarity by identifying the object in which clarity is sought, distinguishing this underlying clarity from its presenting expression and specifying the subject for whom the underlying clarity is meaningful (p. 659).

This type of interpretation is performed through an examination of part-whole relations, in which meaning-making is established by going back and forth between partial expressions and the whole through a hermeneutical circle (Taylor, 1971). In a hermeneutical circle, expressions are always interpreted in relation to others and to the whole, and are not interpreted in isolation, as is common practice in positivist/empiricist research. Taylor presents the hermeneutical circle as the relations between partial expressions with other partial expressions, as well as to the whole, since

partial expressions “only make sense or not in relation to others” (1971, p. 6). For example, when doing hermeneutic research analysis, narrative syntheses are “examined simultaneously with the emerging interpretation, never losing sight of the informant’s particular story and context” (Crist & Tanner, 2003, p. 203). The analysis continuously relates what is meaningful to the context, and also examines the collective moral experiences of certain groups (e.g. children, nurses, and families) (Hunt & Carnevale, 2011). Groups such as families or healthcare professionals working in a specific social space can share a moral experience, which can be explored through hermeneutical interpretation (e.g. by looking at the similarities and differences within the personal experiences, as well as the shared meanings and collective social experience) (Hunt & Carnevale, 2011).

The data collection strategies presented above typically result in the collection of a large amount of data, which can become overwhelming if not analyzed in an ongoing and iterative manner along data collection (Emond, 2005). A large amount of data is considered by Benner as actually facilitating the interpretive process by leading to “richness and redundancy” that contribute to make meanings clear and visible (1994, p. 107). The interpretation can be performed in a participatory manner with the study collaborators. The involvement of a team that includes both researchers and people who are affected by the phenomenon under study is considered highly valuable when conducting a hermeneutic study, as it leads to a shared understanding of what is significant and meaningful, which is consistent with Taylor’s hermeneutic framework (Crist & Tanner, 2003).

The following analytic/interpretive steps build on Benner’s (1994), as well as Crist and Tanner’s (2003) interpretive framework. Benner developed a hermeneutical framework called interpretive phenomenology that draws on Heidegger as well as Taylor’s philosophies. Crist and

Tanner built on Benner's work to clarify how to concretely perform a hermeneutic analysis. However, Benner's interpretive framework does not include an explicit examination of the broader social context. Therefore, this framework is combined here with a local/social imaginaries framework to guide data analysis and interpretation (Carnevale, 2013a). This analytic/interpretive framework was refined while conducting the study in a child mental health setting, and followed the following steps in an iterative process along data collection (these processes were continuously oriented by the research question for the study): (a) while recording field notes and transcribing interviews, I developed detailed interpretive comments along the notes; (b) for each study participant as well as for the context, I prepared a narrative synthesis based on field notes data, key informants' interview transcripts, data from the documentation review, and interpretive comments, including excerpts from the raw data; (c) I presented a summary of the syntheses to the study collaborators to identify important themes, contextualize the data, and make-meaning of the data; (d) I then wrote additional syntheses to clarify the initial interpretations. Throughout this process, exemplars were identified to enhance understanding (Benner, 1994). Exemplars can be textual excerpts that illustrate *ways of being* and increase the understanding of patterns, similarities, and differences. Collaborators contributed to the interpretation of data by providing contextual information and enhancing the background understanding. This process fostered a shared understanding of what is significant and meaningful to the people in the setting and informed on the meaningful moral context in which the agents reside. What children or staff members considered was good or right was analyzed by taking both the local and broader moral contexts into account. Taylor argues that understanding is always part of a reciprocal engagement with others, and not performed in a disengaged manner. In this sense, interpretation of data was performed in an intersubjective manner as part

of the participatory research process. Divergent views as to how to interpret the data were reported and examined, to further the interpretive process.

### **Implications**

Adopting participatory hermeneutic ethnography as a methodological framework for research with children has the potential to offer rich data and discussions related to children as well as healthcare workers' 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. The results from a participatory hermeneutic ethnographic study are always an interpretation of the data and do not offer a complete and objective account, which is not one of the aims of this type of inquiry. Adopting a different framework would yield a different interpretation by focusing on aspects that vary from the ones included here, which could offer valuable complementary or contrasting perspectives. 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 lead to a deeper understanding of the participants' experiences, as well as the social and local imaginaries that reciprocally shape institutional norms, structures, and practices.

An important concern related to ethics research is to address what ought to be from an ethical standpoint (Spielthener, 2017). Through participatory hermeneutic ethnographic research, we can study moral experiences and institutional norms, structures and practices (i.e.

“what is”), but understanding these various aspects does not mean they are right, just or good. Taylor’s hermeneutic philosophy offers a rich framework highly suitable to address these ethical questions, for example by seeking a *rapprochement* between differing outlooks to foster reciprocal understandings in light of corresponding social imaginaries. These understandings do not provide a final say on what “ought” to be, but can open-up and foster discussions of important ethical concerns while being attentive to a plurality of experiences and related local/social imaginaries, reflecting on shared assumptions and values, and seeking to bridge different conceptions.

Future work could examine the ethical implications of research with this methodological framework, for example in relation to consent and assent processes and to children’s involvement within the participatory research process. Due to the richness of the data provided by a participatory hermeneutic ethnography, potential knowledge users can assess the relevance of the results for their specific settings and it can foster reflection and discussion among healthcare workers. It would be helpful to study how the knowledge resulting from this type of study is applied in practice and how it can potentially help to address ethical concerns in specific settings.

### **Preface to Chapter IV**

Chapter IV presents the study results and discussion, which constitutes Manuscripts 3 and 4. An overview of the literature review, conceptual and methodological frameworks are first presented in each manuscript, followed by the results and discussion. Manuscript 3 addresses the thesis main research questions concurrently, examining the institutional norms, structures and practices in the setting, as well as the moral experiences of children, parents and staff members. Manuscript 4 offers a more focused examination of children's moral experiences that complements the account presented in Manuscript 3, highlighting what children consider meaningful and helpful in relation to crisis situations, which is an area that has not been studied in depth.

The specific timeline followed in the study is presented in Appendix C, and more information on how the participatory research approach was operationalized is in Appendix A.

## Chapter IV

### Manuscript 3—Moral Experiences of Crisis Management in a Child Mental Health

#### Setting: A Participatory Hermeneutic Ethnographic Study<sup>24</sup>

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<sup>24</sup> For the publication of this manuscript, most footnotes will be removed. They are included here to provide more depth in relation to the study and the discussion, as is required of a doctoral thesis.

### Abstract

Restraints and seclusion are routinely used in child mental health settings for conflict and crisis management, but raise significant ethical concerns. These practices are often presented as being part of routine care and necessary for safety purposes, despite the associated risks for both children and staff. Contrary to the literature on adult mental health, the perspectives of children on these control measures are almost absent. This study explored the institutional norms, structures, practices and corresponding moral experiences around conflict and crisis management in a child mental health setting, with the aim to address certain ethical concerns. A five-month participatory hermeneutic ethnography was conducted in a child mental health setting offering care to children aged 6 to 12 years old in Montreal, Quebec, Canada. Data collection involved participant observation, interviews, and documentation review. An interpretive framework was used for data analysis. The results show how the strict structure in place both contributed to and prevented crisis situations. Children were expected to comply, conform and acquiesce with the staff and were generally perceived as the objects of care and not as active agents involved in care processes. Children perceived control measures as helpful in exceptional cases when there was an imminent risk to someone's safety, and largely disagreed with their use as a consequence for bad behavior. This perspective contrasted with most of the staff members who considered control measures contributed to help the child feel safe, learn the limits in the setting, and form a trusting relationship. I argue that the prevalent view of the child shared by staff members as *incomplete human becomings* led to the adoption and legitimization of authoritative norms, structures and practices guided largely by a behavioral approach, which sometimes led to an increased use of control measures for reasons other than imminent harm.

*Keywords:* child, mental health, inpatient, crisis management, hermeneutic ethnography,

participatory research, Canada

## Moral Experiences of Crisis Management in a Child Mental Health Setting:

### A Participatory Hermeneutic Ethnographic Study

Within mental health hospital settings, clinicians routinely use control measures with children for crisis management (Hert et al., 2011; Lebel et al., 2004). The rates of restraints and seclusion episodes on child mental health inpatient units are of particular concern, as they have been reported to be 5 to 6 times higher than on adult units (Lebel et al., 2004), with 25% of child inpatients having at least one seclusion episode during the hospitalization period and 29% at least one restraint episode (Hert et al., 2011). These numbers highlight the vulnerability of children who are more likely to be physically controlled than adults in mental health settings. An increasing body of literature is highlighting the harms resulting from using these practices, including physical and psychological trauma (Hert et al., 2011; Nunno et al, 2006; Lebel et al., 2004). This situation—which raises significant ethical and moral concerns—calls for an in-depth examination of the use of control measures with children in mental health settings and how crises are managed. This article presents the results of a participatory hermeneutic ethnography conducted within a child mental health setting focusing on crisis management, with a discussion of key ethical concerns within child mental health.

### **Control Measures in Child Mental Health Settings**

The term *control measures* refers to the different types of measures that are used in healthcare settings to limit a person's freedom of movement. These measures include human or mechanical restraints (i.e. using human force or a mechanical means to limit or prevent a person from moving freely), seclusion (i.e. to confine a person in a setting from which he/she cannot go out freely), and chemical restraints (i.e. to limit a person's capacity to act by administering a medication to him/her) (MSSS, 2015). Control measures are supposed to be used in exceptional

cases, to ensure the physical safety of the person or others, when “less restrictive measures have proven ineffective” (APNP, 2014, p. 4).

With children, in most cases, restraints and seclusion are reported to be used in response to non-compliance with a request, and not because of safety issues (Nunno et al., 2006). This situation can result in wrongful treatment for children that can cause serious harms; measures such as restraints, including physical holds, can result in trauma and physical harms—cases of children’s death have also been reported (Nunno et al., 2006). Still, knowledge related to alternatives to control measures for crisis management with children is limited. Certain alternatives have been studied, such as the use of collaborative problem-solving (Bonnell, Alatishe, & Hofner, 2014; Pollastri, Lieberman, Boldt, & Ablon, 2016) or trauma-informed and strength-based approaches (Azeem, Aujla, Rammerth, Binsfeld, & Jones, 2011; Azeem et al., 2015), but the literature is limited in scope and number. In a review of the empirical evidence on control measures reduction efforts conducted in 2014, Valenkamp et al. concluded that the reduction of the use of control measures in child mental health settings is a largely underdeveloped area of research, which they consider “particularly distressing given the negative outcomes that are correlated with the use of these measures both in patients and staff” (Valenkamp, Delaney, & Verheij, 2014, p. 173). This situation contrasts with the literature related to alternatives to control measures with adults, an area in which extensive research has been conducted, as shown in various reviews conducted on the topic (e.g. see reviews by Goulet, Larue, & Dumais, 2017; Hallett, Huber, & Dickens, 2014; Johnson, 2010; Muskett, 2014; Scanlan, 2009).

Literature on the experience of control measures in child mental health settings is also limited, particularly in relation to the child and family’s experiences. From children’s

perspectives, there is an emphasis on the coercive nature of control measures and a feeling of fear, anger and helplessness in being restrained or secluded (Lundy & McGuffin, 2005; Miller, 1986; Mohr et al., 1998). From the staff's perspective, it is commonly suggested that the good nurse/healthcare worker needs to use certain forms of coercive measures in order to protect the child's safety (Allen, 2000; Goren & Curtis, 1996; Hottinen et al., 2012). These practices have often become routine and expected, and are said to form institutional norms that supersede the person's individual moral stance (Bray et al., 2014).

In this context, this study sought to examine the institutional norms, structures, practices, and corresponding moral experiences around the use of control measures in order to develop care approaches that promote an optimal reconciliation of ethical concerns in child mental health. This was done in partnership with children receiving care in a mental health setting, as well as parents, nurses, and other staff members.

### **Conceptual Framework**

A hermeneutic moral framework was used in this study, in line with the philosophical work of Charles Taylor.<sup>25</sup> According to Taylor, a person's identity is rooted in one's own understandings of oneself and cannot be known outside of interpretation. This understanding is embedded in a horizon of significance, which represents the broader socio-historical-cultural background in which meaning is rooted (Taylor, 1991). Meaning refers here to the "experiential significance of a thing for a subject or group of subjects" (Carnevale, 2013a, p. 87) and is at the root of our own self-understandings, as well as shared understandings. These understandings are informed by the broader socio-historical-cultural context. The moral order in a group or society

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<sup>25</sup> See manuscript on Methodology for a full description of the conceptual framework and methodology that were developed for this study.

is defined by Taylor (2004) as a shared understanding of what is moral, of what is good or right.

This shared understanding emanates from a social imaginary:

By social imaginary, I mean something much broader and deeper than the intellectual schemes people may entertain when they think about social reality in a disengaged mode. I am thinking, rather, of the ways people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations (p. 23)

A social imaginary reflects common understandings at the root of collective practices; conversely, practices convey the understandings that are shared (Taylor, 2004). Since this study was performed in a specific setting where there were locally shared imaginaries, the term *local imaginaries* will be used to refer to the shared imaginaries in this specific social space, which are informed by horizons of significance and social imaginaries. Groups such as children or nurses can share a moral experience, which can be explored through hermeneutical interpretation, for example by looking at the similarities and differences within the personal experiences, as well as the horizons of significance and collective social experience (Hunt & Carnevale, 2011). Institutional structures are defined in this article as social constructions that reflect the practices that occur in the setting and are based on shared meanings, rooted in the shared horizon of significance and social imaginaries. The institutional structures exist through the practices and shared meanings of material resources and social roles.

### **Methodology**

The specific methodological approach used was focused ethnography, adapted to Taylor's hermeneutic framework (Montreuil & Carnevale, 2017). The use of Taylor's

hermeneutics as a methodological framework allowed for the examination of horizons of significance and local imaginaries that contribute to understandings of norms, structures, and practices as well as the experiences in a specific group (Carnevale, 2013a), in the present case as it relates to child mental health within an institutional setting in Canada. In addition, the hermeneutic focused ethnography was conducted as part of a participatory research framework. According to Taylor (2004), what is moral (i.e. what is good, right, or just) is rooted in *shared* meaningful understandings and practices. The use of a participatory research approach led to a stronger articulation of moral life and deeper understanding of the institutional norms, structures, and practices, through a collaborative and equitable knowledge production process. Participatory ethnography has been recognized as an effective methodology to address health-related issues and foster public and policy engagement (Hansen, Holmes, & Lindemann, 2013).

### **Data Collection, Analysis, and Interpretation**

The main data collection strategies were (1) participant observation, (2) interviews with key informants and (3) documentation review, three strategies frequently used when conducting a focused ethnography (Knoblauch, 2005; Muecke, 1994). This multi-method approach offered rich data and allowed for an in-depth examination of the moral experiences as well as the institutional norms, structures, and practices related to crisis management in the study setting. Data collection began following approval of the Institute's Review Ethics Board.

Access to the field—a mental health day-hospital offering services to children aged 6-12 years old and their family—was granted by the administration and also supported by the staff members. Data collection strategies were operationalized in collaboration with an advisory committee, which included 4 children, 2 parents, and 4 staff members (including 2 nurses, one of which was also a manager). The iterative nature of ethnographic research entailed concurrent

data collection, analysis, and interpretation. I began consultations with partners 5 months before the start of data collection, and continued the consultations throughout the remainder of the study process. I performed fieldwork over a 5-month period, from February to June 2016, going in the setting 3 to 5 days every week. Participant observation was the main research strategy (see Appendix D for observation guide), as is often the case in ethnographic studies (Denzin & Lincoln, 2005) and recognized as a key strategy in researching children's experiences (Greene & Hogan, 2005). I was engaged with the participants and collected data through informal conversations in combination with observations, which allowed for the collection of rich verbal as well as non-verbal data in-context and contributed to contextualize and make-meaning of the data.

I sought written informed consent from staff member participants, as well as from parents for their child's participation, along verbal assent from child participants (see Appendix E for the English version of the consent and assent forms). All parents were approached for their child to participate in the study through written and phone communications (see Appendix F for an example of letters sent to parents), with twelve parents consenting to their child's participation on a total of 24 children enrolled in the program. This high participation rate allowed for an in-depth examination of children's moral experiences. I wrote field notes at the end of each day of fieldwork, recording data from observations and informal interviews, along with reflections relating to the data collected (Muecke, 1994). Data from informal interviews were central to deepen the understanding of personal experiences and the local meaningful moral context. Data were analyzed in an on-going manner and were compared and contrasted with new data continuously. 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 develop care plans), but

contributed to care similar to what a volunteer would do (e.g. play games with children), without taking full 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 by doing solely 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). Sampling was done along three major dimensions: time, people, and context (Hammersley & Atkinson, 2007). It was a process in which decisions about when, who, what, and where to observe were recorded to make more explicit the decisions that were taken in collaboration with the advisory committee.

Using purposive sampling in collaboration with the advisory committee, key informants were identified to provide insight into the phenomenon of inquiry (7 children; 4 parents; 7 staff members). Children from 7 to 12 years old participated in the study. The language used in the interviews was adapted to each child; for example, if children said they did not know what fair or unfair meant, other words were used such as just/unjust or good/bad. Key informants were chosen based on their experience and knowledge of the program (Muecke, 1994). I conducted between one and four individual semi-structured interviews with each informant (lasting between 15 minutes and 1,5 hours each); the number varied depending on the depth and richness of data from each interview (see Appendix G for interview guides). The interviews were conducted in a private room. With the children, a specific room with different types of mattresses, cushions, fidgets (i.e. small toys children can play with), and a small tent was used, which was conducive to a more informal type of interview instead of a formal office with a table and chairs. Children

could move freely around the room, and it was emphasized that what they would share would remain confidential, which was important considering the power differentials between staff members and children on the unit. Drawing and play were also used to maximize children's opportunities to share their experiences, to contribute to the understanding of the "children's worlds" (Kirk, 2007, p. 1251). The semi-structured interviews started 2 months after the beginning of fieldwork, in order for children to familiarize themselves with my presence before meeting with them individually.

For documentation review, I consulted the clinical charts of children participants as well as normative and clinical documents related to the program chosen in collaboration with the advisory committee (see Appendix H for the documentation review guide). This review informed on how crisis situations were documented and contributed to the understanding of institutional norms, structures, and practices in the setting.

The interpretive frameworks of Benner (1994) and Crist and Tanner (2003) were used to guide data analysis and interpretation; these frameworks were combined with the analysis/interpretation of the broader socio-historical-cultural context as described by Carnevale (2013a). The following analytic/interpretive steps were followed, in an iterative, non-linear manner during and following data collection: (1) I developed detailed interpretive comments while recording field notes and transcribing interviews; (2) I prepared narrative syntheses for each participant and for the environment, based on field notes data, key informants' interview transcripts, data from the documentation review, and interpretive comments, including excerpts from the raw data; (3) I presented a summary of the syntheses to the advisory committee and researchers involved in the study to identify important themes, contextualize the data, and make-

meaning of the data<sup>26</sup>; (4) I wrote additional syntheses to clarify the initial interpretations. Throughout this process, exemplars were identified to enhance understanding (Benner, 1994). Since data collection, analysis, and interpretation followed an iterative process, the analysis of the field notes helped identify key informants and questions to ask, which in turn helped identify what to observe and when to do subsequent participant observation sessions, as well as inform on what documents to analyze.

## **Results**

This ethnographic study sought to answer the following questions: (1) What are the institutional norms, structures, and practices related to conflict/crisis management? (2) What are the moral experiences related to conflict/crisis management—both favorable and unfavorable—from the perspectives of children, parents, and staff members? (3) What are care approaches that optimally reconcile ethical concerns in child mental health in relation to conflict/crisis management? Questions 1 and 2 are addressed here concurrently, starting with a broader presentation of the program, followed by an examination more specific to conflict and crisis situations. The children and staff's perspectives are compared and contrasted throughout the text. Parents' perspectives are limited, as parents were not present on the unit; they have the legal authority to consent for their child's care, but were not part of the everyday experiences in the setting. The analysis of the wider background context, the horizon of significance, shed light on what leads to the adoption of different practices, and also, through the analysis of the local imaginaries, what is the moral order (the values, standards, norms) that are shared by children,

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<sup>26</sup>In order to protect participants' confidentiality, the syntheses were not shared in full with the advisory committee, as identification of the participants could not have been fully prevented. A summary of the syntheses, in the form of a text from a single person's perspective was created and shared with the staff partners. For the child partners, a summary of the syntheses was shared verbally with them. No consultation has been performed with the parents after 3 months of data collection, as the parents mentioned not having the time to be involved in the study.

staff members, and parents. Question 3 is addressed in the Discussion, examining the “ought” implications related to the optimal reconciliation of ethical concerns in child mental health, taking this context into account.<sup>27</sup> More details on the moral experiences of children specifically is included in a separate article (Montreuil, Thibeault, McHarg & Carnevale, 2017).

### **Study Setting: The Day Program**

The study took place in a mental health day-hospital program for children aged 6-12 years old with behavior problems located in Montreal, Quebec, Canada. Examples of diagnoses present in children’s charts included attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), disruptive mood dysregulation disorder (DMDD) and conduct disorder. Children were usually referred to this third-line of care program through their school, when it was considered the child and family needed additional support that schools and services through 1<sup>st</sup> and 2<sup>nd</sup> lines of care could not offer, and that the child needed specialized and ongoing care throughout the day.

The program offered care to 24 children at a time: 12 children aged 6-9 and 12 children aged 9-12, both divided in 2 groups. Each group of 6 children shared a room and was assigned a primary worker, who was either a specialized educator or a psychoeducator<sup>28</sup>. The targeted length of stay in the program was 6 months, but many children remained in the program for most of the school year. The children attending the program were going to the day hospital instead of going to their school, following the school calendar. They had school activities in small groups

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<sup>27</sup> Considering the limited number of children on the unit, specific information related to the characteristics of the child participants are not included to enhance confidentiality. Also, some of the participants’ identifying information has been modified to enhance confidentiality (e.g. the masculine form is used to refer to the children, as only 1 girl participated in the study and she could be more easily identifiable as there were only 3 girls out of 24 children in the program). French quotes have been translated in English. Thesis committee members reviewed the translations to ensure the meaning was consistent between the two languages.

<sup>28</sup> In Quebec, Canada, where the study was conducted, specialized educators are workers who have earned a professional degree in this field, while psychoeducators must hold a Master’s degree in psychoeducation and be registered with a professional Order. They are both trained in the field of psychosocial adaptation difficulties.

with teachers 2 hours per day; the remainder of the day was shared between various activities following a weekly schedule, including individual and group sessions with nurses, psychiatrists, psychoeducators, psychologists, social workers, or specialized educators. At least one nurse was continually present in the setting. Nurses offered physical care to the children as needed and monitored medication effects and side effects. When a crisis situation occurred, nurses were often called to help manage the situation and use control measures if deemed necessary. The only control measures used with children were seclusion and human restraint, in accordance with local legislation. The seclusion room was about 2 by 1 meters, totally empty, with concrete walls and a window covered with a protective screen. Human restraint was usually performed in the hallway. If a child was restrained in a room, he was carried in a hold in the hallway. There was also a calm room, about 3 times bigger than the seclusion room, in which there were different types of mattresses and cushions, a small tent, soft chairs, fidgets and stuffed animals.

There was a token system in place, with a large map on the wall in each group divided by levels on which each child had a small doll to indicate the level they were at. Each level had specific behavioral goals and objectives (e.g. I follow the rules; I do my activities, transitions and activities calmly). Each child had a booklet with a table listing the expected behaviors for the level they were at. Every day, the teacher and primary worker filled out the table and the children received tokens based on the points from the table. They could also receive tokens spontaneously during the day when doing certain behaviors that fit the behavioral objectives outlined in the token system, or had consequences for not respecting them such as sitting in time-out at an empty desk or on a bench outside the room. With the tokens, children could buy rewards (e.g. bring a toy home for the weekend or take a candy from a candy box). Staff members described that relational rewards necessitated fewer tokens than material rewards, to encourage children to

choose relational rewards such as going in another group for lunchtime, play with a staff member or tell the rules to the other children. When discussing with the children, they generally described the token system in positive terms and referred to it as being similar to programs in their previous schools (e.g. “it’s like in all the schools”). The punitive consequences were sometimes considered by children as being “deserved” (i.e. having something bad happen to you for doing something considered bad by the staff) and sometimes unjust, especially when not knowing the reason for having a consequence. For instance, a child shared with me that when he was warned not to do a certain behavior, he found it helpful as he then knew what to do or not, but that staff members did not always do it and then he had a consequence without knowing the reason, which he found unfair. Children also mentioned not knowing what the score would be in their behavior booklet. As one child described: “Well, we say the number; they [the staff] fix it. They fix it right... Like, they give different numbers”. When asked what the scores meant, most of the children emphasized the scores meant they were “good” or “bad”, and being good meant “listening to adults”, which was one of the expected behaviors.

The staff said they tried to recreate the school environment and expectations since children will go back to their schools when leaving the program. The staff expected the children to comply with their requests and with the rules in place, and children were rewarded or had consequences/punishments if not conforming or acquiescing, both individually and as a group. Staff members also offered positive reinforcements in the form of praise to children. They mentioned it is a way to show children what they are doing is right. Some children mentioned they often liked being praised and it made them feel good, but it depended on how it was done. For example, one child said in relation to positive reinforcement: “Some teachers are really authentic, they mean it. It’s obvious it’s authentic. Others they do it too much. Some children,

like Jim, like when they get praised. It depends on the child”. Certain staff members mentioned offering positive reinforcement brought them a good feeling: “It’s fun also to have the feeling to be reinforcing the child! You know, I mean, to have this effect, positive. For the staff, that’s cool”. However, other staff members considered the interventions should be done in an emotionally neutral way, and enforced “like the police. Ok, you will have a consequence, you have been impolite”. The rules were the same for all the children, with rare individual accommodations. Here is an example I observed of the staff’s consistency in applying the rules:

A child asked a staff member, if he could go see the nurse because his foot hurt. The nurse heard what he said and mentioned she could help him; they went to the nursing office. When the child came back, he started to eat his lunch, but there was not much time left for lunchtime. When he was about half way done, the staff member told him he only had 3 minutes left. The child asked if he could have more time since he was at the nursing office. He added, looking directly at the staff member:

- If I don’t eat everything I have to bring it home and then my mom forces me to eat it all before supper. I don’t want that. Can I take more time to finish it?
- You decided to go see the nurse, now you have less time to eat.

The child continued eating in silence in a hurry and did his after-lunch routine when told to. (field notes)

All staff members shared they were acting in the child’s best interests, as a way for children to reintegrate the school system more easily. They emphasized there were different normative implications expected of children because they are children, notably to respect adult authority and to attend school, including all the different activities it involves. All the children mentioned

listening to adults is “good”, and certain children mentioned disliking school, but having to attend. As one child said, shrugging his shoulders: “everywhere we go, there’s school”.

## **Conflict and Crisis Situations**

**The role of institutional norms, structures and practices in conflict and crisis situations.** The environment and organization of the unit were described by staff members as contributing to prevent crisis situations by making children feel safe. They mentioned that in a more “loose” setting, children do not know the limits, which makes them feel insecure. As a staff member mentioned: “A staff who does not provide structure contributes to the insecurity of the child who becomes anxious and acts out”. Children considered having rules in place on the unit as generally positive. One child stated the rules on the unit help to learn “to be better”, and another one stated that when a setting is “more loose”—with fewer limits—certain children have a hard time and escalate, having more frequent crises. Even though children emphasized the importance of rules, all of them said they would change certain rules, especially the use of group consequences that was described by many children as unfair (e.g. one child stated: “You shouldn’t be consequenced [sic] for the behavior of others. That’s not how life works”) and the use of time-out. For example, one child mentioned he hates being in time-out, and would like to have a limit on the amount of time someone has to be in silence at the “think desk”, which he said makes him depressed and would be even worse for people who are already depressed, as is the case of certain children on the unit. Some of the children considered they should share their opinion in relation to rules and then adults would decide what they are. One child compared the rules to country laws: “if everyone agrees that something is not right, the laws would change”. He suggested it should be the same on the unit. Also, most children emphasized it was important for them to understand why a certain rule was in place, and considered some rules would never

change since, as one child stated, “that’s what humans have been doing for centuries”, giving the example of removing your hat inside. They considered sharing their perspective with the staff would not lead to changes on the unit.

If a child did not conform with the rules or requests, it could lead to a conflict with the staff, who then imposed consequences that were referred to by some children as “new rules” that sometimes they reported made them more angry and led to crisis situations (i.e. when the child continued to refuse to comply with a request or acquiesce, or became aggressive). In this sense, the structure contributed to both prevent and lead to conflicts, as it was setting the limits of what was considered right or not from the staff’s perspective. I observed different situations in which not following a rule resulted in a crisis and the use of control measures, for example with a child who was asked to remain in silence by the primary worker while playing a game. She explained to a co-worker that the child did not like the directive, threw his chair, and hit the bench in the hallway when asked to sit. I then observed the nurse and another staff member ask the child to sit closer to the seclusion room. The child yelled, and they carried him in a physical hold to the seclusion room, where the nurse was holding the door shut. The child was yelling from inside the room:

The staff shared they know when this child is not well he yells, so they put him right away in the seclusion room, so as not to disturb the other children on the unit. They said as soon as they’ve asked him to sit closer to the seclusion room, he started yelling, so they carried him to the seclusion room. The timer rang after the child had been in the room for 5 minutes, and the nurse opened the door. The child was sitting cross-legged on the floor; his eyes were puffy and red. He looked at the staff members and expressed feeling depressed, frustrated and stressed in relation to his behavior. They closed the door

saying it was the same discourse as always, adding 5 minutes to the timer. When the time was up, the nurse opened the door and asked if he was calm enough to come out and eat his lunch. He nodded and came out calmly to sit on the bench after being told to.

The child later told me in relation to the staff on the unit: “I have a good relationship with them, but I get frustrated at them. I asked for clarifications, and he explained that they are nice to him, which he said has not always been the case elsewhere, but ‘they get me in silence for things I didn’t do’ ” (field notes).

Some of the staff members described the use of control measures as an effective way to decrease the frequency and duration of disruptive disorders, as in this child’s case.

In the year before I conducted the study, the team had developed a protocol for crisis management, which included a de-escalation approach. This normative document described that if a child does not conform to a directive from the staff, the directive is mentioned again and “we ensure the child understands it”. If the child does not conform, the staff member offers him or her the choice to conform or “withdraw from the group” (e.g. at the time-out desk or in a calm corner in the room). If the child still does not conform, he sits outside the room, a pacification approach is used (e.g. listening to the child, offering reassurance and providing clear directives) and the seclusion room or physical hold (“arrêt d’agir”) is used if pacification fails in ending the crisis.

One staff member described how before the development of the new protocol, “it was really the staff who was taking all the power over the child”. Now, they mentioned changing their practice to leave some power to the child, but take it all if the child does not behave as expected from them. Examples of power they now let the child have included “to let him make the right decisions” (i.e. by not interfering with the child’s behavior), and “to let him decide the

amount of time he will be in the seclusion room”, which they said helps the child feel “safer”. I have observed children ask for 5 minutes to calm down, and one child asking angrily for 50 minutes, which they respected, telling the child they would check in every 5 minutes to make sure he did not change his decision. The staff explained to me this was a way to give more power to the child. On some occasions, control measures were also used as a threat, which the staff explained was to show children what the consequence of their behavior would be, and help them use the power they have to make the “right” choice. For example, a staff member once told a child who was lying prone on the bench outside the room, banging the bench with his feet: “Stop banging or I will put you in the time-out room, that’s for sure”.

Specific environmental conditions could also lead to more crisis situations, as I have observed during lunchtime. The level of noise and activity was much higher during this time as opposed to other activities (e.g. school or therapy sessions). Both the children and staff (as in my observations) reported there are more crisis situations during that time.

**Moral experiences related to crisis and conflict management.** Some staff members mentioned the seclusion room and physical hold provided security to the child, as they contributed to identify the limits in the setting and the child would know he would be stopped if he was having a crisis. Some of the children shared this view to a certain extent, mentioning for instance that the use of control measures contributed to making the unit safe for them, as it prevented other children from being aggressive toward them or from injuring themselves. For example, one child said he felt good when another child who was aggressive was in the seclusion room, because he could continue to play with his friends. Another child emphasized: “if you’re running in a wall and bleeding, thank God they stop you”. The staff agreed they don’t want to

take chances that children might hurt themselves or others, and said they stop them beforehand, as they consider they know when the child will escalate.

On the other hand, when children referred to their experiences of having been secluded or restrained, it was usually presented in a negative way, for example reporting it was making them “angry” or it was “painful”. Children agreed that the seclusion room was a punishment for “bad” behavior, for example hitting others and saying “bad words”. Some children mentioned it was so bad to be in the seclusion room they stopped being aggressive to get out. Others said they feared they would hurt themselves while in the room, or that they would be physically restrained. A few children described physical holds as “painful”; they reported changing their behavior in fear of being restrained again. I have observed different situations in which children were being restrained, for example:

A child wanted to go to an activity the next day, but the primary worker had put as a condition that he had to participate in a certain activity he disliked. The child was lying prone on the bench in the hallway, banging the bench with his feet and repeating he wanted to go to the activity the next day. The nurse and another staff member asked him to take a tool (e.g. a fidget) to calm down. The child refused, saying “I hate adults!” Then, the two staff members put on disposable gloves and came back in front of him. The child asked them if they were putting gloves on to hit him. They explained he was sick (he had a cold), and they could get sick too if they had to touch him. The child then asked for 5 minutes on the timer to calm down. The nurse agreed and set the timer for 5 minutes. The child was sniffing and lying down on the bench calmly, remaining silent. After the timer rang, the nurse asked the child if he was ready to go to the activity. The child said no, and started banging the bench with his feet. The two staff members sat on each side of him on

the bench and did a physical hold (i.e. each person was holding one of the child's arms that were crossed on his chest). The child said he could not breathe (his nose was running, the mucous going to the floor). He started to scream that he could not breathe. Another nurse brought a facecloth to blow his nose. After a few minutes, the staff members released the hold. The child did not say anything (he was frowning, teeth clenched, looking at the floor, catching his breath). One of the staff members asked him if they could trust him to participate in the activity. He nodded, looking at the floor. When told to, he went with the group to participate in the activity. The staff members who restrained the child later told me they disagreed with the condition the primary worker had set, but had to respect it since it had been shared with the child and they could not go back on the decision made, as it would make the child feel insecure and lead to more crises (field notes).

The staff emphasized control measures were used in a benevolent manner, so as to prevent the child from hurting himself or others or, as mentioned by certain staff members, a punishment so the child can learn what is right or wrong. In the example presented above, the staff said he was too agitated, so they decided to restrain him. One of the staff members once explained that using physical restraints can decrease the number of disruptive situations during the day, which is then positive for both the child and staff. Children considered some of the staff members "abused their power" by resorting to coercive measures when the child and others were not in danger. In the example above, the child expressed to the staff what could be interpreted as a fear of being hit, of being hurt. Certain children also described having been in the seclusion room or restrained without knowing the reason, which they found was not right.

Certain staff members mentioned emotions were sometimes involved in decisions to use control measures or not, in that they could become angry that a child repeated a behavior that was prohibited and for which they had already intervened in the past. The use of control measures was also largely described as emotionally demanding: “It’s just that it’s the process, it’s not fun... you don’t want to use force with them, but sometimes we don’t have the choice”. Restraint was also described as more emotionally charged than the use of the seclusion room, as the staff is restraining with their own body and have to emotionally disengage from the situation. As the nurse mentioned: “Whether you want it or not, even if you know the child is wrong, well, it gets to me. I think emotionally, it’s somewhat normal. But here again, I put myself in my little nurse’s shoes when it happens, and try to detach a little emotionally from the situation”. Some children considered staff members had emotions when physically restraining a child (e.g. one child said: “For sure some people it disturbs them. You see it in their eyes, the adults too”), while others considered staff members were neutral, acting in a manner detached from the situation. The use of time-out was also described by the staff as a way for them to manage their own emotions during a crisis situation, not solely for the child to calm down.

Parents were glad they would not be called in case of a crisis and the team would handle the situation. For example, a mother said: “calling the parent is used as a last resort after many attempts to resolve the situation, and I’m fine with it”. Parents described the use of control measures as necessary when other interventions failed, and mentioned consenting to their use, being confident the staff would use them as a last resort. Parents were very rarely present on the unit, and shared feeling relieved the team would be in charge of their child’s care during the day, as most of them were working full time jobs and previously had to miss work when their child had a crisis at school.

***The role of the staff.*** Staff members described their role on the unit primarily as authority figures who set limits to children as a group (“mettre le cadre”) and teach them how to behave socially, through the use of the behavioral approach and the social skills workshops. They mentioned focusing on group interventions. Individual care was offered almost exclusively by therapists, who typically met with children individually in their office once a week, as well as weekly with the family. The staff mentioned being in transition to using a more collaborative approach with children, listening more to them before “stopping the behavior” (i.e. using the de-escalation approach, ranging from verbal request to restraint) and “set the limits”. For example, a staff member once told me he previously would have asked a child to go sit at his place while reading, but did not and let the child read in the reading corner to accommodate for his preference. I have sometimes observed abrupt changes in the staff’s approach, highlighting the tension between the behavioral and collaborative approaches, especially in the case of a conflict. The staff was alternating between “listening” and “stopping the behavior”, sometimes shutting the door of the seclusion room as the child was speaking to them if not saying what was expected of him. One staff member mentioned needing “a balance between structure-control-security and listening openly, knowing when it’s the right timing, when it’s not”. She said that if using exclusively an authoritative approach, it could impede the caregiving relationship with the child and prevent the attainment of the therapeutic goals.

However, other staff members mentioned the fear of losing control of the group if individualizing care and not using a uniform authoritative approach. They contrasted the interests of the group with the interests of the individual child, and mentioned they had to find a balance between these competing interests. In practice, this justified for example putting a child in time-out if considered as disturbing the group. Most staff members considered using a uniform

authoritative approach helped in the development of a trusting relationship with the child, as the child could trust they would be firm and consistent, and they would be stopped if not behaving according to the rules or requests. They said children then collaborated more because they trusted the staff would put a limit. During participant observation, one child who was new to the program had been secluded for extensive periods of time during his first week in the program, with 4 episodes lasting up to 3 hours. The staff explained they were setting limits, as they reported he had been verbally aggressive with a staff and had kicked a bench, and they “could not let him do everything”. The staff said they were using control measures because they didn’t have a trusting relationship with him, so they had to help him feel secure first by setting a firm structure in place, and then he would trust them and participate in the program.

From the children’s perspectives, staff members played a variety of roles on the unit, which I have also observed. For example, consistent with the staff’s view, children described them as authority figures, who decided what the rules were and ensured they were respected. They were also often implicitly referred to as omniscient, especially by younger children who considered the staff would know if they did something bad and they would be “punished”. Children also referred to the staff as educators and caregivers, who helped them learn anger management and social skills—which they found helpful—the nurse being present to offer physical care if needed. Some children also described them as playmates; children sometimes played board games with the staff and playing with an adult was a reward that could be bought with the token system. Children generally considered the staff was “nice”, but it changed when there was a crisis situation. One child described this change: “When people [i.e. children] get mad, he [the staff member] starts to act like the kids doing that. When the kids get bad, he starts

being mean and puts them in places and that.” This view reflects in a way the tension described above between the authoritative and collaborative approaches from the staff.

***What children consider helpful.*** During the interviews with children, I asked them what helped the most when experiencing a crisis. Children mentioned the calm corner or calm room helped them become “calmer”, as there were soft cushions and fidgets, as opposed to going in time-out or in the seclusion room where it was “boring” and “empty”. Children also considered it was more the relationship with staff members, the skills they learned, as well as their own decision to change that helped to change their behavior, in contrast to rewards, consequences and the use of control measures. Children also emphasized that having the opportunity to talk with someone was helpful and more desirable than other behavioral or coercive strategies. Here is an example of a child describing how he said he decided to change:

The child said the program helped him, as before he was throwing chairs and biting teachers, and doesn’t do that now. I asked what he thinks led to this change, he replied that he knows it is not safe what he was doing, and it is illegal. He added: “I just decided that if I want a good chance in life, I have to change”. (interview, child)

Another child mentioned he didn’t like how he was feeling when angry, and decided he wanted to feel good and not be angry all the time, so he changed his behavior. He said at first he found the adults on the unit were “mean”, but that he likes the program now as the adults helped him to learn ways to control his anger and he made friends on the unit.

Children emphasized the benefits of having free time to play with other children, and how it contributed to make them feel good. Many mentioned finding it easier making friends on the unit compared with school, as “we’re all the same, we’re here for a reason”. The importance

of these social relationships was also emphasized by the parents, who mentioned their child often had difficulties making friends at school, and some of the staff members.

### **Discussion**

In the previous section, I presented the role of institutional norms, structures and practices in conflict and crisis situations, as well as the moral experiences of children and staff members (and to a lesser extent parents) related to these crisis situations. These results are discussed here in terms of local imaginaries of children and staff in the setting, and put in context within broader horizons of significance and social imaginaries.<sup>29</sup>

In short, I argue that the prevalent view of the child shared by staff members on the unit as *incomplete human becomings* led to the adoption and legitimization of authoritative norms, structures and practices guided largely by a behavioral approach, which sometimes led to an increased use of control measures for reasons other than imminent harm to self or others. Children experienced these controlling practices as abusive and hindering the development of trusting relationships with the staff, which impeded the implementation of more collaborative approaches that staff members sought to put in place to prevent the use of control measures. I then discuss the study results in light of conceptions of children as moral agents, addressing the “ought” implications for clinical practice.

#### **Children as Incomplete Human Becomings: Staff’s Perspectives**

On the unit, children were described by the staff as needing to develop specific socialization and rational thinking skills following a staged process, in their best interests, in light of their future participation in society. The different stages were embedded within the token system and various strategies were used so children would progress through these stages. This

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<sup>29</sup> Refer to section on Conceptual Framework for a definition of the terms local imaginaries, social imaginaries and horizons of significance.

view of children in light of what they will become and their future contribution to society is consistent with what Lee refers to as a dominant framework within child psychology in which children are perceived as incomplete human becomings, in contrast to full human beings, seeing children in terms of what they will become as adults (Lee, 2001)<sup>30</sup>. In line with this dominant framework, children are described in terms of “investments for the future”; children’s worth is assessed by their potential contribution to society as future adults and citizens (Hendrick, 2015, p. 34)<sup>31</sup>. The staff shared that there were certain practices they would not use with adults, as well as activities they would not force adults to participate in, in contrast to children who were described as needing to follow this staged process. For example, the strong belief in children needing to attend school served to justify imposing activities and practices that were considered as normal within schools for children (e.g. washing their hands, not running down the stairs) and it was expected children would conform with what was described as a school norm. For example, going to the gym was a request considered by some of the staff as legitimate since it is an activity required at school, and once led to the use of a physical hold so the child would comply. Staff members were using practices they considered necessary to bring the child to the last stage of the token system, which meant he could go back to his neighborhood school. Some of the staff referred to these practices as investing in the child, referring to teaching and modeling them how they should behave. They emphasized this could only happen once children were conforming with the program and ready to listen to adults. Once the child conformed and the staff invested in

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<sup>30</sup> Lee (2001), in his book *Childhood and society*, examines largely accepted conceptions of children as “incomplete beings”, who are perceived as needing to be socialized to become adult “complete human beings” and challenges these established perspectives. He uses predominantly the term “human becomings” to refer to children as developing, incomplete beings. The term *incomplete human becomings* is used here to emphasize that within this dominant perspective, there is a perceived complete state, which is adulthood.

<sup>31</sup> This book chapter is part of James and Prout (2015, 3<sup>rd</sup> ed.) seminal book in the interdisciplinary field of childhood studies. Hendrick examines the historical western constructions of childhood, and explains how the view of children as sites of investments became dominant.

a child, the child was described as being on the right path to becoming a future “good” member of society, i.e. a complete responsible adult being.

In line with this view of children as incomplete human becomings, there was an expectation of children’s compliance, conformity, and acquiescence with established norms and structures, as well as adults’ requests. These expectations could be interpreted as representing the *hypergood* for most of the staff, i.e. a standard, the most important good from which to judge other goods or ends (Taylor, 1989). As staff members mentioned, their practices were guided by a benevolent aim; they sought to help children so they could have better chances of “success” later in life, which was described as being closely related to success at school. When asked what was “good”, children often mentioned “listening to adults” (i.e. acquiescence), following the rules (i.e. comply), and following group norms (i.e. conform), which mirrors the staff’s expectations in the setting. Consistent with this view, staff members defined their role predominantly as authority figures, and children were expected to respect adults’ authority in all circumstances. When a child expressed disagreement with a request or rule—either through verbal or non-verbal means—the staff intervened so as to stop the discussion or behavior and express their authority over children. From this view, the child was perceived as not knowing what is true or right, and his perspective was rarely sought or recognized.

Within this perspective, children were not seen by the staff as moral agents, in reference to children’s “capacity to act in the light of considerations of right and wrong” (Carnevale, Campbell, Collin-Vézina, & Macdonald, 2015, p. 519). The staff’s view could be interpreted as being consistent with a dominant perspective within developmental psychology on moral development in childhood, notably theories building on the works of Piaget and Kohlberg, in which children gradually develop a capacity for moral judgment through the development of

cognitive and reasoning capacities, as well as teachings from adults (Montreuil, Noronha, Floriani & Carnevale, 2017)<sup>32</sup>. Larcher (2017), in a philosophical analysis of conceptions of children within medicine, states this view is still widely prevalent within western thinking and seemed to be part of the local imaginaries of the staff in relation to their view of children as described above. The staff considered children, especially younger ones, did not have the capacity to reflect on what is right or wrong due to their incomplete state, and needed adult teaching and modeling to know how to act. However, staff members did not consider they were providing moral education to children, but teaching them emotional and social skills to help them live in society, to become good citizens. Various values were nonetheless shared with children on the unit, even if they were implicit. Kohlberg considers there is a moral component to teaching that is often covert, for example “obedience to authority” that was largely “espoused” by both staff members and children (Kohlberg & Hersh, 1977, p. 54)<sup>33</sup>. Kohlberg & Hersh (1977) consider this type of institutional structure as being consistent with punishment and reward based morality, as well as law and order within their moral development framework; this type of structure is described as not conducive to children’s sharing of what they experience as morally significant. Within this firm environment, staff members were authority figures controlling both the group and individuals, using mainly a behavioral approach to guide their practices.

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<sup>32</sup> This manuscript submitted for publication is an interdisciplinary scoping review that I conducted on moral agency in children that examines the predominant views present in the literature from 2000 to 2016.

<sup>33</sup> In this article, the authors review the moral development framework and discuss teaching practices they consider hinder the development of moral judgment in children. Kohlberg’s framework has been largely critiqued for claiming there is a single universal staged process of moral development in children, but still predominates the field of moral development within psychology. It is included here as I consider it reflects the practices in the setting and the view shared by the staff (e.g. consistent with Kohlberg’s framework, they mentioned younger children needed more consistence and guidance because of their less developed cognitive capacities, which I have also observed).

Staff members referred to the behavioral approach as evidence-based and necessary to achieve their aim in the best interests of the child. Some of the staff members referred to operant theories of behavior modification, in which children are externally rewarded or given consequences with aiming to increase their motivation to comply with expected behaviors. From this perspective, the child's behavior can be shaped through external interventions provided by adults; adults identify what behaviors need to change, and use a set of rewards and consequences to lead to these changes. There is some empirical support for these practices, but it is more limited than previously thought (Eyberg, Nelson, & Boggs, 2008; Frensch & Cameron, 2002; Mohr & Pumariega, 2004)<sup>34</sup>. From this view, children are perceived as the *objects* of the interventions and not as *agents* who have the capacity to act, reflect and take part meaningfully in the social world around them. Taylor (1966)<sup>35</sup> critiques behavioral approaches for reducing actions to responses to external stimuli, with no consideration for the purposes of actions, for the interpretations from the person who is acting. By employing such approaches, the staff focused on finding strategies to get the child to act the way they considered was appropriate and would lead them to develop into complete adults, largely discounting children's experiences and moral lives.

### **Limited Parental Support**

Children had highly limited parental support while on the unit. Both children and parents described this as normal, as this is how it would be in their neighborhood schools. Some parents also shared not wanting to intervene with what was happening on the unit, not to send the

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<sup>34</sup> The articles referenced are all reviews of the effects of behaviorist systems in institutional child settings. They highlight some of the limits of the evidence and of the programs, especially the lack of long-term effects and issues related to using uniform approaches.

<sup>35</sup> This is Charles Taylor's first published book, which presents a critique of behaviorism. He developed the concept of human agency in more depth in subsequent publications such as *Human Agency and Language* (1985).

message to their child that they might disagree with some of the norms or practices in place, which they said could lead to their child being opposed to the program. This view led to children being prevented from receiving parental support while in the setting. For example, a child once asked the staff to call his mom because he was not feeling well, which was refused. These practices sharply contrast with other hospital settings in which parents can be present 24 hours a day. It is now widely recognized that parental support is beneficial to children in hospital settings (EACH, 2016; Foster et al., 2016; Harrison, 2010; Power & Franck, 2008)<sup>36</sup>. Within the mental health day hospital, the view of the setting as a replacement for school led to a different way to imagine the parental role, which raises questions related to how decisions were made on behalf of children by the staff.

In daily practices, the staff had to make multiple micro decisions related to children's care. For example, decisions related to the interventions to use, disclosing information regarding one child with the group, or access to food, among others. Children could not give consent for themselves while in the setting, leaving the staff members in charge of these decisions that would be taken by parents in other types of hospital settings. There was a distancing of parents from everyday care, choices and actions, who are the ones legally supposed to make decisions and provide ongoing consent for their child's care. This situation, which parallels the school context,

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<sup>36</sup> Power and Franck conducted a systematic review of parent participation in the care of their hospitalized child and highlight that parents are now largely expected to actively participate, which is beneficial for all the parties involved. The concept of family-centered care is examined in the other two articles by Foster et al. and Harrison, emphasizing the numerous benefits resulting from using such an approach to care, but difficulties nurses experience in implementing this approach. Within international law, the European Association for Children in Hospital (EACH) charter was adopted in 2006. It is mentioned in article 2 of the EACH charter: "Children in hospital shall have the right to have their parents or parent substitute with them at all times", which highlights the broad recognition of the benefits of parental support. Within the mental health day hospital, I believe it was more the conception of the staff's role in this specific setting, as well as parents' expectations that the staff would be in charge during the child's usual school hours, that prevented parents from being more involved, rather than implementation difficulties.

transfers decision-making capacities to the adults in charge in the institution. This leads to certain ambiguities related to the ethical standards that apply in the day hospital setting, and how care and control are practiced. Children did not share any concerns related to their parents not being present on the unit; as with the imposition of rules decided by adults, children described the unit as a school setting where parents are not present and the adults within the institution make the decisions for children. Decisions were in fact often referred to by children as being rules, which could be related to the decisions being taken unilaterally and the children having to comply with them, as with a rule. Children mentioned finding some of these rules unfair, but having to respect them or otherwise have a consequence.

### **The Use of Control Measures**

Within this authoritative setting oriented by a behavioral approach, control measures were seen by the staff as necessary interventional strategies to be used as a last resort when compliance, conforming and acquiescence (i.e. the hypergood) were challenged. This is a common view within de-escalation approaches for crisis management, which was normalized on the unit as was demonstrated for example in the setting's documentation. This de-escalation approach reinforced the view of staff as authority figures. Children expressed for instance their fear of being restrained again, and described the de-escalation approach as impersonal, making them angry and sometimes being unfair.

In addition to the use of control measures as part of the de-escalation approach, staff members used control measures to contribute to set limits for new children so they would feel safer and would trust that the staff would stop them. Within the literature, this perspective is controversial as there are very few studies on the experiences of children being secluded or restrained, and the emphasis from children is on the coercive nature of the interventions in

contrast to a feeling of safety (Lundy & McGuffin, 2005; Mercer, 2013; Mohr, Mahon, & Noone, 1998). The view that control measures lead to a feeling of safety and trust could be interpreted as a form of rationalization, drawing on an apparently consequentialist ethics whereby the behavioral outcomes justify the controlling means. On the unit, to reach the ends of children's compliance, conformity, and acquiescence, the staff legitimized the use of control measures with children, sometimes for extensive periods of time (e.g. hours), including when the child was calm and did not pose an imminent risk of harm to self or others (e.g. I observed children asking to go to the bathroom while in seclusion, who walked calmly to the bathroom and back to the seclusion room). Control measures were thus not only used in case of imminent risk of harm to self or others, which is locally legally required for adults, but also as an authoritative intervention so the child would comply with the institutional structure in place. The dominant perspective of children as incomplete, developing beings—in contrast to active moral agents—justified the use of these controlling practices in the best interests of the child. This view of children led to what could be interpreted as the adoption of different ethical standards with children as compared to adults, in which it is justified to enforce what are considered established social norms through behavioral, controlling and sometimes punitive approaches.

Children shared examples of what they considered legitimate uses of control measures; all of them were related to imminent risks to self or others. Adopting a view in which it is recognized that children have moral experiences would likely lead to similar conclusions as the ones from the literature on alternatives to the use of control measures with adults<sup>37</sup>, in which they are viewed as harmful, but permissible as an *exceptional* measure that is time-limited, in case of *imminent* harm to self or others (MSSS, 2015; Muir-Cochrane et al., 2013). In a study reporting

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<sup>37</sup> By this statement, I do not mean children are “mini-adults” and have all the rights and responsibilities adults would have, but that children are agents with moral experiences and are entitled to receive care that is ethically-sound as adults would receive.

on the implementation of a restraint and seclusion reduction program on a youth psychiatry unit, Azeem et al. (2015) stated a culture change was needed to reduce the use of control measures based on primary prevention. I would add that a change in conceptions of children is needed in the staff's local imaginary in order to allow for more collaborative practices to be implemented.

### **Conceptions of Children and Collaborative Frameworks**

While I was performing fieldwork, staff members sought to use a more collaborative approach with children and decrease the use of control measures, referring in particular to the Collaborative-Problem-Solving approach developed by Greene et al. (2006)<sup>38</sup>. However, the prevalent view of children as incomplete human beings created many tensions and challenges in using a more collaborative approach; the staff believed they knew what was right for children in light of what they would become, without recognizing children's moral agency and authentically including them in discussions and decisions affecting them. In fact, the exchanges between children and staff were almost exclusively oriented by the behavioral system in place. For instance, the staff gave tokens or offered praise when children respected the rules, reminding children of the program's expectations, warning them of the potential consequences of their behavior, and telling directives to which they were expected to comply without discussion. There were few exchanges between children and staff outside of this structure, except during certain individual meetings, occasional informal conversations or the social skills workshops. The staff considered a more collaborative approach was challenging to implement because care had to be individualized, which they said was not always possible in the current context with the staff resources they had on the unit. They thus mentioned they privileged a group approach in

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<sup>38</sup> This approach has received increasing attention in recent years. Various papers have been published in support of this approach, and workshops are offered to train staff members in using this approach. Staff members on the unit had participated to such a workshop the year before I conducted the study. More information on this approach can be found on their website: <http://www.thinkkids.org/>

which the interests of the group were described as superseding the interests of children as individuals. They said they tried to be more collaborative within this group approach, for example by letting children decide the amount of time they would be in the seclusion room or asking them to identify crisis management strategies after a situation occurred. The staff presented this approach as leaving some power to the child, in contrast to imposing authoritative interventions unilaterally. However, privileging a group approach does not preclude the adoption of a view of children in which they would be recognized as agents. On the unit, behavioral practices, which are well-suited to group contexts through its uniform responses to children's behaviors and limited recognition of agency, were favored. These practices led to a vision of collaboration in which children did not fully take part in their care, but were allowed a limited participation within strict limitations.

The staff emphasized the importance of having a trusting relationship with children, which is often a key aspect of collaborative approaches (Berg & Danielson, 2007). Most of the staff's perspectives of a trusting relationship referred to the child's trust that the adult would enforce limits through the behavioral system and be firm and consistent, which was described by the staff as contributing to making the child feel safer. It also entailed trusting the child would comply with the norms and acquiesce with staff. For example, I observed a staff member asking a child who was secluded to tell the truth, referring to corroborating what an adult had said, in order to be able to trust him and let him out to help him. As mentioned above, the effectiveness of these approaches has been challenged, and they are also considered as negatively impacting the relationship between staff and patients by emphasizing power differentials (Ryan, Hart,

Messick, Aaron, & Burnette, 2004)<sup>39</sup>. Some of the children in the study also highlighted that the use of praise was inauthentic and not helpful when applied systematically or out-of-context.

Within collaborative frameworks, the trusting relationship refers to a different concept than what was described by the staff in the study. For example, trust has been defined in a concept analysis as a process in which patients expect that the person providing care is competent, has good intentions, and is attentive to their needs, and in which the provider recognizes patients' vulnerabilities and acts so as to minimize their "fears of harm" (Dinç & Gastmans, 2012, p. 235). This different ontology was shared by one of the staff members who referred to the trusting relationship as a relationship in which children can share their opinion and what is important for them, knowing the adult is there to discuss with them. This perspective is also consistent with more collaborative approaches (e.g. Pollastri et al., 2013), but was uncommon on the unit.

The staff's adoption of the collaborative approach was expected to ultimately decrease the use of control measures on the unit. However, when a crisis occurred, the staff's expectations of compliance, conforming and acquiescence increased and were enforced using control measures if necessary. This dynamic, combined with the behavioral approach orienting most exchanges and the staff's predominant conception of a trusting relationship as the child's trust in the adult being firm and consistent, is interpreted here as preventing the establishment of an authentic collaboration between children and staff. Children emphasized their submissive role in the setting as well as the extent of adults' authority on them. For example, one child mentioned that if they did not comply, there were always other things the staff could do to children to force them to comply, in addition to being put at the desk to remain silent and being secluded or physically restrained. He added in a fearful tone that he did not want to think about these things,

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<sup>39</sup> In this study, the authors examined staff's assaults by patients on child and adolescent mental health inpatient units, and noticed that most assaults followed a comment from the staff related to enforcing a rule in relation to a behavioral token system.

emphasizing children's vulnerability in the setting and limited implementation by the staff of collaborative approaches.

### **Further Thoughts on Children's Local Imaginaries**

There was a certain fatalism in how children disclosed that they had to comply, conform and acquiesce with the norms and structures in place. During the interviews, when I asked children about the program, the rules were often the first thing they mentioned, adding it was the same as in other schools, in that adults decide and children are expected to do as they are told by adults. Children did not consider they could bring about changes to the program, saying for example that sharing concerns with the staff would not change anything, so it was useless. The staff sometimes told the children they had the "power" to decide if they would remain with the group or be in time-out, and they lost this power if not conforming with a directive. The children thus had limited opportunities to discuss or share ideas with the staff, which many of them considered the norm within school settings.

The hypergood for the staff was an expectation of children's compliance, conformity, and acquiescence, which the children mentioned were "good" to do. However, children also shared and expressed what they considered as meaningful, which could be interpreted as the hypergood for them, which was having friends and having fun. They all enthusiastically shared enjoying free playtime and time outside, some suggesting to "put more fun time like recess", explaining that it's good to be able to go outside and play "especially when many people have ADHD". Children said these activities were "fun" and made them "feel good". Children also expressed what was meaningful to them through various other means. For instance, a child once started making dance moves when the educator was not looking to make other children laugh, while he had just been told by the educator to stop acting this way. Also, most children were running

down the stairs when the staff was not looking (which was against the rules), discreetly smiling at each other. Some of the children mentioned in the interviews that they liked running down the stairs as “it is fun” and “good for your health”, and enjoyed doing it. One child explained children needed to learn when to do certain things or not, so as not to have a consequence, in order to be able to do things they found fun (e.g. going high on the swing or making jokes during lunchtime). Most children referred to the social skills workshops as helpful to learn to get along with others, which can help to have friends.

Children showed they navigated the system in place: they agreed with some of the norms, structures and practices, but did not perceive them all as meaningful for them. Seeking a *rapprochement*<sup>40</sup> with children, by getting to know what is meaningful to them and try to bridge these horizons could help build more authentic trusting relationships that might be more conducive to the implementation of collaborative approaches.

### **Strengths and Limitations**

I want to first highlight that the research results presented here are an interpretation of the data; conducting the study and analyzing the data using a different framework would have resulted in a different account. This study does not seek to provide the only possible interpretation, but is one possible interpretation among many. Other frameworks such as critical theories would have yielded a different analysis, exploring for example in more depth power differentials and the subordinate role of children in the setting. Foucault, for example, has been highly critical of psychiatric institutions with adults and this type of framework could have been applied in this context with children, using for instance a discourse analysis (Hook, 2007). In a

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<sup>40</sup> The term *rapprochement* is used by Taylor to refer to a process of reciprocal understanding between divergent moral horizons, e.g. in reference to different cultural outlooks (Taylor & Gutmann, 1992). It is based on Gadamer’s concept of *fusion of horizons*. It is used here in reference to bridging horizons and social imaginaries between the different views present in the mental health setting, seeking reciprocal understandings of what is significant and meaningful to the different people involved.

similar way, using institutional ethnography would have changed the focus to the empirical mapping of social relations based mainly on an analysis of texts, in contrast to examining meanings through participant observation and interviews, as in hermeneutic ethnography (DeVault, 2006). Each framework has its strengths and limitations. One of the advantages of using a moral experiences framework informed by Taylor's hermeneutics is the in-depth examination of the local imaginaries, of what is morally meaningful to the people in the setting, in addition to institutional norms, structures and practices. It allowed for the collection of rich data through my presence in the setting and ongoing dialogue with children and staff, on both experiences and context. Through this active participation (the *participant* aspect of participant observation), data could be contextualized and the interpretive process was highly iterative, which was also enhanced through the use of the participatory research framework.

As with any research conducted in one particular setting, the data is not expected to represent all child mental health settings. However, it offers an in-depth analysis of this particular setting, which can inform practices in other settings with similar programs. Due to the richness of the contextual data provided, potential knowledge users can judge how the results of this study can apply to their specific settings.

### **Conclusion**

This examination of the institutional norms, structures and practices in a child mental health setting, combined with an analysis of the moral experiences of children and staff members, sheds light on important ethical issues related to childhood and mental health. Children are largely viewed as incomplete human becomings, which legitimizes certain institutional norms, structures and practices that situate adults as having a highly authoritative role oriented by a behavioral approach. Within this behavioral approach, children are perceived

by the staff as the objects of care and not as agents. Children view themselves as having to comply, conform and acquiesce with the norms, structures and practices in place—as is expected by the staff—which they sometimes agree with and sometimes not, but stated are obliged to do. The use of a behavioral approach, combined with a de-escalation approach for crisis management, led to an increased use of control measures with children for punitive reasons, which can be abusive and harmful to children. By adopting a view of children as moral agents and getting to know what is meaningful to them could contribute to the development of care practices that are more ethically-sound and respectful of children's own experiences.

**Manuscript 4—Children’s Moral Experiences of Crisis Management  
in a Child Mental Health Setting**

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### Abstract

The experiences of children related to conflict and crisis management in child mental health settings, especially those aged 12 and below, have been scarcely studied. This study examined the moral experiences of children related to conflict and crisis management and the related use of restraint and seclusion in a child mental health setting. A 5-month focused ethnography using a participatory hermeneutic framework was conducted in a day hospital program for children with severe disruptive disorders within a mental health institute. Children considered restraints and seclusion could help them feel safe in certain instances, for example if another child was being aggressive towards them or in exceptional cases to prevent self-injury. Their own experiences of being restrained was however predominantly negative, especially if not knowing the reason for their use, which they then found unfair. Some of the children emphasized the punitive nature of the use of restraint and seclusion, and most children disagreed with these practices when used as a punishment. Children's perspectives also highlighted the limits of the use of a uniform de-escalation approach by the staff to manage crises. Children considered discussing with the staff and developing a relationship with them as more helpful in case of a crisis than the use of a de-escalation approach or coercive strategies.

*Keywords:* Child, hermeneutics, inpatients, mental health, violence

## Children's Moral Experiences of Crisis Management in a Child Mental Health Setting

Increasingly, policies are being adopted by mental healthcare institutions worldwide to reduce the use of coercive practices such as restraint and seclusion (WHO, 2017). These practices are typically used in case of a crisis situation in which the patient becomes aggressive and there is an imminent risk of harm for the person or others. However, these practices are still commonly used within mental health settings, and the rates of restraints and seclusion are considered to be higher in children's mental health settings than in adult settings. This is the case despite the extent of the risks associated with using these practices, including trauma, physical injuries and death of the child (Hert et al., 2011; Lebel et al., 2004; Nunno, Holden, & Tollar, 2006). Still, there is an underdeveloped commitment to advancing knowledge related to crisis management with children, exemplified by the lack of research literature on the topic. Information on the experiences of children—including the moral experiences—of crisis management is highly limited. In this study, I used a participatory hermeneutic ethnographic framework to examine children's moral experiences of crisis management and the related use of control measures such as physical restraint and seclusion within a child mental health setting.

### **Background**

The literature on children's experiences related to conflict and crisis situations and the use of restraint and seclusion in child mental health settings is scarce. Through searches conducted in the main health-related databases (CINHAL, EMBASE, PsychINFO, PubMed, and Social Work Abstracts) only five studies were identified on this topic. Within these studies, there was an emphasis from children on the coercive nature of control measures. For example, Mohr et al (1998), in a qualitative descriptive study of 19 former inpatients from a mental health institute who were aged between 3.9 and 18 years old while they were hospitalized, have

identified different types of trauma that children have experienced as a result of being restrained or secluded, and highlight the “lack of understanding by the children of why given interventions were used” (p. 95). Similarly, in a study conducted by Miller (1986), children from 5 to 13 years old who had been secluded in a mental health facility were asked to draw and/or write about their seclusion experience, and the punitive nature of seclusion was emphasized by children who also expressed feeling helpless. Children from 3 to 12 years old who had experienced physical holding while in a residential or day center also stressed their fear for their personal safety and anger while being restrained (Lundy & McGuffin, 2005). Seclusion and restraint are supposed to be used as a last resort, to prevent people from harming themselves or others, which is not always how children reported their experiences in these studies.

In two of the studies, children were asked about their opinion on different practices to manage crises. In the study by Kazdin (1984), children were asked to rank the acceptability of time out, *pro re nata* medication, and seclusion. The author concluded that children were able to identify the acceptability of different treatment options and that their opinion should be taken into account in clinical decisions. In the study by Hottinen et al. (2012), adolescents were asked about their opinion of different containment measures, including PRN and intramuscular medication, different types of restraints and seclusion, and constant and intermittent observation. In these studies, the different interventions children had to rate or comment on were all coercive; no information was provided on what alternatives children might suggest. It was assumed that the coercive measures were necessary in case of a crisis, and did not examine children’s perspectives and experiences of these measures from a moral standpoint.

From the review of these articles, it is clear that there is a significant lack of studies on the experiences of conflict and crisis management in child mental health settings, particularly in

relation to the perspective of children. The moral implications of using such practices are absent from the literature, as well as examination of what children consider helpful in case of a crisis. This situation contrasts with the adult mental health population in which multiple studies on the perception and experiences of crisis management interventions have been conducted. For example, reviews on the experiences of adults being physically restrained or secluded have been conducted (Strout, 2010; Van Der Merwe, Muir-Cochrane, Jones, Tziggili, & Bowers, 2013) and a systematic review of 37 articles on the perceptions of violence prevention from both adult patients and staff has been performed (Hallett, Huber, & Dickens, 2014).

In summary, studies about the experiences of control measures with children in mental health settings are limited in scope and number. It is commonly suggested that the good nurse/healthcare worker needs to use certain forms of coercive measures in order to protect the best interests of the child. However, knowledge related to children's perspectives of the use of control measures, how they experience them, as well as their moral outlooks on their use in daily practice remains to be studied in more depth.

### **Study Aim**

In this context, this study examined the moral experiences of children related to conflict and crisis management and the related use of restraint and seclusion in a child mental health setting. The results presented here are part of a broader ethnographic study that examined the institutional norms, structures and practices, as well as the moral experiences of children, parents and staff members around crisis and conflict management in a child mental health setting. The focus in this article is specifically on the moral experiences of children to provide more depth into their own experiences, which have only been scarcely studied to date in the literature.

### Conceptual and Methodological Framework

A participatory hermeneutic framework was used drawing on the philosophy of Charles Taylor. Within this framework, knowledge is perceived as the result of a hermeneutic, interpretive process, and is informed by the social, historical, and cultural context (Taylor, 1971; 1985; 2004). Children in a specific social space can share moral experiences, which refer to the moral significance of what they experience daily, of what they consider “right-wrong, good-bad or just-unjust” (Hunt & Carnevale, 2011, p. 659). These moral experiences are informed by *local imaginaries*, which are the shared meanings and practices that are present in a specific setting (Montreuil & Carnevale, 2017). Taylor’s philosophy was adapted to a focused ethnographic methodology, combined with a participatory research framework.

After receiving research ethics approval, fieldwork was performed for 5 months in a day hospital program for children with severe disruptive disorders. This 3<sup>rd</sup>-line-of-care program was offered at a mental health institute, and children attended the program every weekday. Of the 24 children enrolled in the program, 12 children participated in the study, which allowed for the collection of rich data related to children’s experiences. Children’s diagnoses varied, but often included attention-deficit/hyperactivity disorder, oppositional defiant disorder, disruptive mood dysregulation disorder and conduct disorder, with many children having multiple diagnoses. An advisory committee composed of four children receiving care in the program where the study was conducted were consulted throughout the research process to contribute to make key decisions: they were involved in refining the study question, making decisions related to data collection, interpreting the data, and deciding who to share the study results with. Their participation in these different steps enhanced the interpretive process and led to the co-creation of knowledge more attuned to the setting and what they considered important.

The main data collection strategy was participant observation (for 5 months) that included the writing of field notes, combined with interviews with seven children as key informants and a review of key clinical documents through an iterative process. Interviews lasted between 15 minutes and 1,5 hours; the number of interviews per informant varied based on the richness and depth of each interview, and ranged from 1 to 4 interviews with each child. Throughout data collection and analysis/interpretation, a reflexive journal was kept to record personal experiences and interpretations and promote self-awareness (Lipson, 1994; Mulhall, 2003).

For data analysis, an interpretive framework was used that combined the works of Benner (1994), Crist and Tanner (2003) and Carnevale (2013a). Data from field notes, interview transcripts and documentation review were analyzed concurrently: detailed interpretive comments were written throughout the process. Narrative syntheses were written for each participant, which were then synthesized as a group and presented to the advisory committee to foster the interpretive process. Additional syntheses were written subsequently to clarify initial interpretations.

## **Results<sup>41</sup>**

### **The Day Program**

Children attended the day program during school hours. They had different activities throughout the day following a weekly schedule, including different types of group therapy (e.g. music therapy, recreational therapy), schoolwork, and social skills workshops. Most children also met with a therapist for individual sessions once a week. Care was offered by an

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<sup>41</sup> French quotes have been translated in English by the primary author, and verified by other members of the research team to ensure the meaning remained the same. Also, to enhance confidentiality, all children are being referred to in the masculine form, as there were only 3 girls in the program out of 24 children, and they could thus more easily be identified.

interdisciplinary team including nurses, specialized educators, psychoeducators<sup>42</sup>, psychologists, social workers, therapists, teachers and a psychiatrist. Behavioral approaches largely guided the program, with a token system in place. In case of a crisis, most often nurses were called to assist or lead the crisis management situation since they were not assigned to a specific group of children.

The team had developed a crisis management protocol based on a de-escalation approach, which managers expected staff members to apply in case of a crisis. This de-escalation approach included the use of pacification, with interventions such as listening to and reassuring the child, and providing clear directives. It included different steps to follow depending on the child's behavior, with interventions ranging from saying a directive to the child (e.g. asking the child to sit outside the room) to the use of seclusion or physical restraint if the child did not comply with the directive. Staff's experiences are not included here, but highlight the challenges staff members faced while working in this setting; they aimed to offer care in what is referred to as the child's best interests, while addressing conflict and crisis situations with the limited resources available. We will focus here on children's moral experiences related to crisis situations in this specific setting.

### **Children's Moral Experiences**

Some of the children shared what they considered led to a crisis, which included environmental and social factors (e.g. an event that happened, a request from the staff, or something other children did). A child mentioned that sometimes it's "a small thing that accumulates", and gave the examples: "the teacher saying 'go outside', or when you spill your juice box", or someone annoying them. During fieldwork, different situations were observed in

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<sup>42</sup> In the province where the study was conducted, specialized educators hold a professional degree and psychoeducators a graduate degree. They both work in the field of psychosocial adaptation difficulties.

which a request from the staff led to intense reactions from children. For example, a child was once asked to share a situation that had happened when the primary worker was absent, and the child started yelling because he did not want to share this personal situation with the group, resulting in the use of the de-escalation approach. The staff highlighted needing to react “the same way”, uniformly, for each child, using this approach. Children considered it led to the addition of new rules (in reference to staff’s requests), which many said made them angrier. A child described what he referred to as a “big crisis”, exemplifying the de-escalation approach used on the unit in which requests are made to the child by the staff, presenting his perspective of the child and staff’s feelings:

The teacher, she tells you to go to the think desk and the child says: “No!” Then, the teacher would say to go to the think desk or the calm corner, but the child still refuses to go. Then, the child would be brought to the seclusion room and “they hold him tight, like this (he crossed his arms on his chest as in a physical hold), he’s hurt.” I asked how he knows the child is hurt; he said: “I see them cry. They say threats and bad words”. He added: “The educator is angry, or doesn’t like their behavior”. When I asked if he thought this was just or unjust, he said: “I find it so-so. It’s just because he didn’t respect a rule [...] It hurts others and it’s sad”.

The use of a de-escalation approach in which additional requests were made to children by the staff could therefore lead to the use of restraint or seclusion from children’s perspectives.

**Listening to adults.** Children described the adults as being the authority figures in the setting, and they were expected to respect what was being asked of them, as they said is the case in schools. Otherwise, they could have a consequence (e.g. not being able to participate to an activity they like, be in time-out or in the seclusion room, in concordance with the de-escalation

model in place). During fieldwork, a child was once being carried in the hallway in a physical hold by two staff members because he did not respect a request:

As the child was carried outside the room to the bench by two staff members, one of them told him: “I’ve told you to do something, you didn’t do it. You stay here until you’re ready to come back in”. The staff went back with the other children. On the bench, the child lifted his legs, holding his knees in his arms. Once in a while he was crying silently. A nurse who was busy with another child asked another staff if she could try to discuss with him. That person went to sit beside the child, but said he was closing up even more when she tried to talk to him. After a few minutes, the child started hitting his head on the wall. The nurse asked another staff member to go see him. The staff member who had carried him outside the room told him he has to listen when asked to do something and asked if he was ready to eat his lunch. The child said yes and went calmly inside the room to eat.

Consistent with this example, children were sometimes told they had the “power” to decide if they would remain with the group or be in time-out or secluded/restrained, and they lost this power if not conforming with a directive. For example, the following situation was observed:

A child was sitting outside the class and staff members were discussing what they would do as an intervention. The child raised his hand, one of the staff members told him: “Put your hand down. You cannot decide. You let the adult decide for you [in reference to how he behaved]. You have no power anymore”. The child put his hand down, looking intensely at the wall in front of him.

When asked about the program rules, children agreed the most important one was to listen to adults (i.e. respect their authoritative role), as otherwise, as one child stated: “you will be

physically stopped or have a consequence”. He added children needed to know when to do or say certain things, “like when you won’t get in trouble”.

**Being good or bad.** Some of the children emphasized that control measures were used when children were “bad”, and that the measures were used until the children became “good”. Being bad was described as being violent, saying bad words or not respecting a rule or request. In line with this view, certain children referred to control measures as a punishment, as something bad happening for something bad having been done. These consequences—or punishments in children’s perspectives—were referred to by children as sometimes being fair when they were doing something bad, and sometimes unfair. For example, a child said that sometimes they “go in the seclusion room for no reason”, which he considered was unfair. He explained that when staff members do not explain the reason for the use of control measures, it is not right. This perspective was also shared by other children who said it was making them “escalate” when they did not know the reason a control measure was used.

Certain children shared the use of restraint and seclusion sometimes contributed to making them feel safe, as it was preventing other children from potentially harming them or from harming themselves. For example, a child said in reference to other children being put in time-out or in the seclusion room: “I feel good that I’m safe here, but I don’t feel good that people are getting bad.” Some children mentioned that in certain cases being physically stopped could also help prevent a self-injury, but that the actual experience of being restrained can be painful. A child mentioned he had checked on the Internet and learned that a physical hold can dislocate the person’s shoulder and lead to a cycle of pain, screams, and tighter holding. He said that with time he got used to being stopped, but sometimes it makes him “really pissed off”, especially if not knowing the reason. In reference to the seclusion room, another child mentioned: “I HATE it...

It makes me mad”. Other children said they hated it at first and now calm down to get out of the seclusion room. Children agreed control measures should be used only in case of harm to self or others. For example, a child described in detail a situation that happened to one of his friends who was being hit by other children. He compared what his friend did (a karate move), with “what the staff does” (he made the movement of a physical hold), and he said that violence is “ok if it’s self-defence”, but that otherwise it’s “bad”.

**What helps.** Many children considered it was more the relationship with the staff and the opportunity to talk with someone that helped to become calmer when experiencing a crisis, as well as being in a soothing environment. One child described how the calm room was making him feel good, comparing it to his home: “it’s like my home because here [the big mattress], it’s like my bed, there, my chair; there is a tool (e.g. a fidget) and I can swing”. He said that when angry or sad, he would like to go there alone or with someone, adding: “I would feel happy, I could hide there”. Another child said: “Before going to the think desk, [I prefer] to talk with them about my frustrations. Or go to the calm corner and calm down, and they tell me ‘come talk to me when you’re ready’.” A child stated: “I wouldn’t say [the seclusion room] is nice therapy; here [the calm room] is therapy”. Another child mentioned how the calm corner helped him a lot in not using violence, as it was giving him some time alone: “you can go around and it is not a punishment”. On the other hand, some children described the calm room/corner as “too nice” for when a child is angry, as they consider it is supposed to be a punishment, which is more consistent with the staff’s perspective. Learning and applying the social skills learnt during the workshops was also presented as helpful by the children, especially in the case of a conflict with other children.

Certain children said that when going in time-out they do not always talk with the staff, but find it helps when they do, and helps more than sitting in silence at a desk (i.e. in time out at the “think desk”). A child also said playing a game while talking with the staff helps the most. A few children mentioned not remembering what happened after having a crisis that resulted in the use of control measures, and feeling exhausted after; they said the use of the think desk is then useless. As a child described:

“If I throw a fit, I’m tired after and I don’t remember what I did. I’m supposed to think about what I did [at the think desk]”. He liked that with certain staff members, before being in silence “we could also discuss and like decide”. He considers “stressful” to be in silence at the desk, and is unsure if it helps.

Children considered staff members should help children to “find a solution” when a situation happens. A child gave the example that if you spill your juice box and become angry, the person should explain that you can clean it up and say you are sorry. He said the staff should “help children with that”.

### **Discussion**

Similar to the few studies on children’s experiences of the use of restraint and seclusion within mental health settings, the punitive and coercive nature of these measures was largely emphasized by children in this study (Lundy & McGuffin, 2005; Miller, 1986; Mohr, Mahon, & Noone, 1998). Children also mentioned how it could help them feel safe when other children were being aggressive, but their own experiences of being restrained or secluded were largely negative. It was highlighted that the reason for the use of control measures should be shared with children, as otherwise they considered it is not right to use them. Many children stated what was most helpful to them during a crisis situation was to have the opportunity to talk with someone

and be in a calm environment, in contrast to the use of a de-escalation approach that is applied uniformly and in which requests are made to children. This approach is discussed in more detail here, followed by a discussion of the contrast between the adult and child mental health settings in relation to the use of restraint and seclusion.

### **De-escalation Approach**

Support for the use of de-escalation approaches in mental health settings is currently limited (Spencer & Johnson, 2016), and even more so with children (Chun et al., 2016). There might be benefits for the staff (e.g. in their confidence to manage crises), but for children it is unclear if these approaches reduce for example the use of control measures and if they find these interventions helpful. In the setting where the study was conducted, normative documents stated that within the de-escalation approach, the staff needed to give a clear directive to the child and the child was expected to comply with it. In the face of non-compliance, interventions from the staff became more coercive, leading to the use of seclusion and restraint if considered necessary. Certain children mentioned how these directives during crisis situations became in their perspective new rules and often did not help with the crisis situation.

The use of a de-escalation approach has been critiqued in the literature as being reductionist since it presents aggressive behaviors as following a linear model for which there is an appropriate intervention that can match each behavior, independent of the staff's judgement in the decision-making process. Delaney (2006) reviewed the evidence related to different crisis management approaches in child and adolescent mental health inpatient settings. She highlights the lack of evidence to support the benefits of de-escalation approaches, as well as the practice of physical holding. Despite these limits, these practices are widely used and training is offered to staff members to learn how to use them. Similar to most behavioral approaches, the staff then

tends to implement these standardized interventions uniformly to children without considering individual or contextual aspects. Studies on the experiences of healthcare workers using control measures with adults also suggest that there is a moral component related to making the decision to use coercive measures or not (e.g. see Moran et al., 2009); it is not the result of an objective process as espoused in certain approaches based on de-escalation models, as the one used on the unit.

### **Comparison Child-Adult**

Within the adult mental health literature, it is now widely recognized that control measures should be used as a last resort because of its associated risks of physical and psychological harms for both patients and staff, limited evidence of safety and effectiveness, and violation of the person's integrity (APNP, 2014; MSSS, 2015; Muir-Cochrane, Jones, Tziggili, & Bowers, 2013; Nelstrop et al., 2006; Nunno et al., 2006; Van Der Merwe et al., 2012)<sup>43</sup>. In the study conducted here, children critiqued the use of control measures when employed as a punishment, a threat, a way to show adults' authority, when not knowing the reason or when physically painful. This view parallels studies on adults' experiences of being restrained or secluded within mental health settings. For example, in a review of adults' perceptions of being secluded in a mental health setting, Van Der Merwe et al. (2012) mention how patients reported feeling punished or trapped, and perceived negatively not knowing the reason for being put in seclusion. Similarly, in a review conducted by Strout (2010) on adult patients' experiences of being physically restrained in a mental health setting, negative experiences prevailed, with recurring themes such as feelings of "anger, fear, humiliation, demoralization, dehumanization, degradation, powerlessness, distress, embarrassment, and feeling that their integrity as a person

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<sup>43</sup> Both professional guidelines and literature reviews are referenced here highlighting the potential harms resulting from the use of control measures in relation to the adult population in mental health settings.

had been violated” (p. 423). It was also mentioned that restraints were perceived as an unethical practice when used as a punishment. In both reviews, the seclusion or restraint episode was predominantly described in negative terms by patients who had experienced these measures, as was the case in the study presented here.

Based on these studies on patients’ experiences and the serious potential harms that can result from the use of control measures, various alternatives to control measures with adults have been developed and studied (e.g. see reviews by Goulet, Larue, & Dumais, 2017; Hallett et al., 2014; Johnson, 2010; Muskett, 2014; Scanlan, 2009). In contrast, the literature on alternatives to control measures with children, especially children aged 12 and below, is highly limited (Valenkamp, Delaney, & Verheij, 2014). This situation raises questions related to how children’s experiences—including moral experiences—are taken into account in how clinical care is performed in child mental health. In the setting where the study was conducted, children’s moral experiences were largely discounted from daily clinical decisions and practices. Staff members mentioned they were acting in the child’s best interest, but how these decisions were taken and how best interest was defined remains unclear and did not include children’s perspectives. Children were not recognized as moral agents who can actively take part in decision-making processes. Adopting care approaches that are more attuned to children’s moral experiences, based on an open discussion in contrast to a set of pre-established directives, could contribute to foster the development of a trusting relationship between children and staff that is often presented as key in helping manage a crisis (Caldwell et al., 2014; Chun et al., 2016).

### **Limitations**

This study presents one interpretation of the data that was performed using a participatory hermeneutic ethnographic approach in collaboration with an advisory committee composed of

children, and would have yielded a different account if performed using a different approach, framework, or if performed in a different context. A description of the program is provided to help situate the reader who can judge the extent to which the results can be adapted to a different context. In this article, only the perspectives of children are shared, which allows to examine their perspectives in more depth, but does not include the perspectives of staff members which could have provided a contrasting view. For an examination of the perspectives of staff, children and parents, please refer to the broader ethnographic account in Montreuil (2017).

### **Conclusion**

In sum, this study provides an account of children's moral experiences related to conflict and crisis management and the related use of restraint and seclusion in a child mental health setting. It shows how children see control measures as both beneficial and detrimental depending on the context of their use, and how the use of a de-escalation approach to crisis management has the potential to lead to the use of control measures when applied uniformly by increasing children's feeling of anger. By being attentive to children's moral experiences and opening up a discussion with them instead of applying an approach in a decontextualized manner, it might lead to more ethical clinical practices to help children during conflict and crisis situations. In terms of future research, examining alternative approaches to crisis management with children as is currently done in the adult literature would contribute to advance clinical practices in child mental health. Conducting a longitudinal study to examine children's experiences following discharge from a mental health day program would also contribute to deepen our understanding of these children's lives and inform on their perspectives of the care received.

## Chapter V

### Implications and Conclusion

There are key clinical, research, and educational implications related to the thesis conducted, some specific to child mental health and others related more broadly to approaches to performing research or working with children. Some of these implications have been detailed in the different manuscripts, but are re-discussed here, including a discussion more specific to nursing practice and directions for future research.

#### Clinical Implications

Children receiving mental health care are doubly vulnerable from (a) being children and (b) having a mental health diagnosis. To prevent them from being excluded from ethical advances in disciplines such as childhood studies and adult mental health, we need to be more attentive to children's inclusion within child mental health decisional processes and conceive children's best interests as being informed by children's own experiences and perspectives.

I consider a shift in horizons (or in conceptions) in how children and childhood are perceived might be required—about the assumptions related to children—in order to be able to adopt a clinical approach to care that is more collaborative. This would need to be a substantive shift, broader than a “technique” shift, rooted in conceptions of childhood. A similar shift occurred within the field of childhood studies in social sciences (James, 2007; James & Prout, 2015), but its implementation in practice is limited and was not part of the staff's local imaginary in the setting; conceptions of children as *incomplete human becomings* were predominant. The non-recognition of children as human agents prevented the adoption of practices that could authentically involve children in their care. Perceiving children as both moral agents with meaningful thoughts and lives, and vulnerable, (Wall, 2010), could be the premise to change the

practices in the setting and lead to children being listened to and included authentically. The use of a behavioral approach brings with it a set of assumptions related to the child, and these assumptions led in the setting to practices that were potentially harmful to children, most notably the use of control measures in punitive ways as a behavioral strategy. The extent of the risks related to the use of control measures—for instance the risks of physical harm or psychological distress—does not justify the use of these practices for reasons other than an imminent risk to physical safety.

Defining *trusting relationship* as being attentive to children's needs and having trust in children's capacities could also contribute to provide care that is more ethically-sound. A balance between a focus on the group and on individuals could be sought, without resorting predominantly to behavioral techniques to guide the exchanges. For example, instead of using standardized protocols for crisis management, children mentioned they could be asked in advance for what they consider would be helpful for them in case of a potential crisis. There were some examples of this type of practice observed on the unit, but were not shared between all staff members and were implemented within the behavioral framework; this led to children's suggestions being used within the de-escalation approach and not pursued authentically. Since staff members sought full authority over children, it sometimes resulted in a form of detached application of the norms and impeded an authentic collaborative approach.

Children could also be involved in the process of deciding on the norms, structures, and practices used in mental health settings, for example through a consultant role. Within adult settings, patients as partners within clinical, educational, research and organizational contexts is now highly valued (Pomey et al., 2015)<sup>44</sup>. There are also examples of youth participation in

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<sup>44</sup> Pomey et al. present the Montreal Model, arguing patients should be actively involved in all the different sectors related to health care, considering the uniqueness and richness of their experiences.

initiatives for policy and service development for mental healthcare (e.g. Kutcher & McLuckie, 2010)<sup>45</sup>. Younger children as in the day hospital could also contribute to these decisions, in particular by sharing their experiences and what is meaningful to them. They would thus contribute to create “worlds in concert with others” and not solely be part of “worlds other created for them” (to borrow expressions from Bluebond-Langner & Korbin, 2007, p. 245)<sup>46</sup>. Within the study, the children who were part of the advisory committee contributed to shape the research question, guide data collection, interpret the data and decide who to disseminate the research results with. A similar process could be implemented at the clinical and policy levels to lead to more child-inclusive norms, structures and practices.

**Implications for nursing practice.** The implications described above are of particular importance for nursing practice, considering nurses’ close work with children within mental health settings. Nurses provide ongoing care throughout the day and are the ones in contact with family members. In the setting, since nurses were not in charge of a specific group of children, they were the ones being called to help when there was a crisis situation and often became in charge of managing the situation since they could offer one-on-one care. However, nurses were often applying the de-escalation approach following the protocol, with little contextual or individual considerations. Changing conceptions related to children and the use of a behavioral approach would lead to changes in nurses’ daily practices.

The scope of nurses’ practice in the setting was limited. Nurses’ roles in the setting were mainly to address children’s physical care, be in contact with family members for medication follow-up and intervene in case of a crisis. Especially with regards to family nursing, nurses

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<sup>45</sup> This framework for child and youth mental health in Canada was developed in collaboration with youth consultants.

<sup>46</sup> The authors discuss in this article some of the potential benefits and challenges of recognizing children as agents for anthropological and social sciences research.

could have been in charge of providing an accompaniment to family members beyond an assessment of medication effects. Within child mental health settings, there are multiple interventions children and parents have reported as being important and helpful to them, such as caring for the child as a special person, being available to children and parents, working in partnership with them, offering teaching related to mental health, and creating a safe space where they can share concerns and questions (Montreuil, Butler, Stachura, & Pugnaire Gros, 2015)<sup>47</sup>. These could be other roles nurses might play in the setting to improve the care provided, taking children and parents' perspectives into consideration.

In regards to crisis management, nurses mentioned a certain emotional discomfort related to restraining a child with their own body, as opposed to putting a child in the seclusion room, as you are actively preventing the child from moving with your own body. One of the nurses mentioned needing to emotionally disengage from the situation, which some of the other staff members described as a normal practice in child mental health. Perhaps recognizing the moral significance of these emotions and examining how they are meaningful could contribute to fostering more ethical care. These emotions could be interpreted as a form of moral distress from the staff—a sign some aspects of the unit's environment and practices compete with one's own values and might not be entirely beneficial to the patients (Musto & Rodney, 2016).

### **Research Implications**

The study conducted shows that the use of participatory hermeneutic ethnography as a methodological framework has the potential to lead to rich data and in-depth analyses/interpretations that foster discussions of important ethical concerns related to children's health. This type of methodological framework drawing on Taylor's philosophy is thus highly

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<sup>47</sup> I co-supervised this study that was conducted with two master's students on helpful nursing interventions from the perspectives of children receiving mental health care and their parents.

suitable for the conduct of ethics research with children. The use of a participatory research approach can also greatly enrich each step of the study process, making it more attuned to the collaborators' perspectives and leading to a deeper understanding of the moral experiences and imaginaries that are present in a specific setting.

### **Educational Implications**

The shift in conceptions related to children would also need to be reflected in the training of future professionals and other staff working with children. Course curriculum for child-related workers should include recent advances in working with children and families, referring to frameworks in which children are recognized as both moral agents and vulnerable. The benefits and harms of adopting different conceptions of childhood should also be discussed. Concepts that could be addressed can include children's assent to interventions or care. The concept of consent is typically discussed, but with younger children the concept of assent—referring to children's inclusion in the decision-making process while recognizing their potential limits in terms of responsibility—is less prevalent, but could be valuable (Carnevale et al., 2015).

### **Future Research**

In light of future research, this thesis raises certain issues that would be relevant to address. First, it opens up avenues for reflections in terms of ethical care provided to children within mental health settings. Examining alternative approaches to care in which children would be recognized as both vulnerable and moral agents could help advance clinical practice. For example, the concept of assent could be explored to assess how it could foster (or not) children's inclusion in decision-making processes related to mental health care. This type of research could include a knowledge translation component in which these alternate approaches would be shared with the staff, and children's perspectives could be sought in both the development and

implementation of these new approaches. The study presented here focused on crisis management and the use of control measures, but other concerns present in child mental health related for example to involuntary treatment, consent, and privacy could also be addressed. Questions related to how having a diagnosis of mental illness influences the conception of children's moral agency would also be relevant, as well as how children could be involved in governance processes within mental health institutions and the related political implications linked to recognizing children as moral agents.

Second, while conducting the study, staff members highlighted that no follow up care was provided to almost all of the children upon discharge from the program. Moreover, there is no research or clinical data examining children's long-term experiences (or outcomes) following completion of mental health day hospital programs. Conducting a longitudinal study to examine children and family members' experiences following discharge from the program would contribute to deepen our understanding of these children's lives and inform on the specific types of mental health services needed.

Third, the blurred boundaries of the setting as a school and a hospital—for children, parents, and staff—would call for a clarification of the program's objectives that would be informed by children and parents' experiences and expectations, which could be researched further in terms of the offering of services for child mental health. For example, would having more resources directly within school settings be more or less beneficial to children? What contributions could nurses with advanced practice in child mental health bring? Since the role of nurses on the unit was limited, it would be highly valuable to study the potential contributions of nurses both within the community and specialized services. If nurses were practicing to their full

scope of practice, using child-inclusive and family-oriented approaches, it might lead to different children and parents' experiences and outcomes related to accessing child mental health services.

### **Overall Conclusion**

The main aim of this thesis was to examine moral experiences, norms, structures and practices related to conflict and crisis management in a child mental health setting, in order to address some of the key ethical concerns that are present in this setting, drawing on Charles Taylor's hermeneutic philosophy. In order to conduct this research, a deeper articulation of the concept of children's agency was required as it had not been specifically addressed by Taylor in relation to children, and is a key concept of his hermeneutical framework. Its meaning thus required clarification. The concept analysis performed represents a contribution to the field of childhood ethics by retracing the evolution of the concept within the health literature and articulating a definition based on the current state of the literature. Building on this conceptual analytic work, a methodological framework for health ethics research with children was developed, which contributes to advance qualitative research methodologies for health ethics research with children. This methodological framework, which bridges key aspects of focused ethnography, participatory research and hermeneutics, guided the study on the moral experiences of children, staff and family members in a child mental health setting, as well as of the norms, structures and practices in place. Important ethical issues related to crisis management were highlighted and examined in light of social/local imaginaries and horizons of significance, such as the use of behavioral and controlling approaches that run counter to collaborative approaches due to a view of children as the objects of care, in contrast to moral agents who actively take part in decisions affecting them. These study results and related discussion address the principal aim of this thesis and contribute to advance knowledge in the fields of child mental health and childhood ethics.

In sum, this work deepens our understanding of the moral lives of children and staff in a mental health day hospital in light of the broader context in which they are situated—with a specific focus on conflict and crisis management—while offering a novel conceptual and methodological framework for the conduct of health ethics research with children. It is hoped that future research will build on this work to foster the development of care approaches that will be attentive to some of the key ethical concerns present in child mental health. This will be my aim for future research!

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## Appendix A

### Details Related to the Participatory Research Process

#### Advisory Committee

An advisory committee was created to foster engagement of local partners in the study, in which there was shared decision-making related to different steps of the research process. This type of engagement from partners led to the co-creation of knowledge that was more anchored in the local context and more attuned to the experiences of the people in the setting. This type of co-created knowledge is deemed more likely be put in practice by end users and bring about more sustainable change (Cargo & Mercer, 2008). The different partners and consultants engaged in the study process are listed in Table 1.

Table 1

#### *Advisory Committee Members and Consultants*

| Committee members              | Reasons for inclusion                                                                                                                                                                                                                                                                              |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Children                       | End beneficiaries<br>Marginalized group                                                                                                                                                                                                                                                            |
| Parents                        | Legally responsible agents for their child, who give explicit/implicit permission for the practices used in the healthcare setting<br>Child's support network: considered key in participatory research projects aiming to increase empowerment in people deemed vulnerable (Cargo & Mercer, 2008) |
| Nurses and other staff members | End users<br>Service providers who are responsible for patients in the setting                                                                                                                                                                                                                     |
| Consultants                    |                                                                                                                                                                                                                                                                                                    |
| Managers and decision-makers   | Involved in institutional practice change                                                                                                                                                                                                                                                          |

The advisory committee was open to children who were receiving care at the Institute and to their parents, as well as to staff members and managers from the day hospital program (children aged 6 to 12 years old). A flyer explaining the study was sent to the parents of children

enrolled in the program, and they could return a form with their name and phone number if interested in being part of the committee or for their child to participate (see Appendix I for the flyer and forms that were sent). Four parents were interested, but only two agreed to be part of the committee due to time constraints; they all agreed for their child to be part of the advisory committee, resulting in four children being partners to the study. Children were also asked verbally for their assent to participate. With parents, it was agreed that meetings could be over the phone to facilitate their participation. Four staff members were also part of the advisory committee (with a fifth member joining for data interpretation). The program coordinator had agreed to offer release time for staff members' participation to the advisory committee meetings.

The members of the advisory committee were involved in key steps of the study process: refining the research question (e.g. the focus on crisis management changed to conflict and crisis management after the initial meeting); making decisions related to data collection (e.g. choosing when to do participant observation; identifying key informants; selecting the documents to review); interpreting the data and deciding who to disseminate the results with. One decision-maker also had a consultant role on the study. She was kept informed and updated on the study's progress through email and given the opportunity to provide her input at the different phases of the study.

The meetings were conducted with children, parents, and staff members separately. This allowed for the partners to express themselves more freely, especially for children who might have felt a power imbalance to their disadvantage (Veale, 2005). Also, it facilitated the establishment of a rapport between the children and me. The establishment of a trusting relationship with the researcher is considered as particularly important with younger children in

order for them to “get to know” the researcher and express their thoughts and opinions freely (Butler, 2012, p. 69).

With the staff, there were four meetings held between November 2015 and September 2016 (lasting approximately one hour each). With the children, there was an initial meeting before the start of data collection to discuss the research question and data collection strategies, and another meeting to discuss data interpretation and dissemination. The meetings with children occurred during their time spent at the hospital, as agreed to by the unit manager. Considering the children’s busy schedule that differed between groups, it was challenging to schedule meetings with them and find a time when they were all available. Meetings were thus held with children individually or with two children at the time, and the perspectives of other children were shared with them. With parents, individual phone meetings were conducted before the start of the study and during data collection. However, the two parents had limited availabilities and did not participate to the data interpretation and dissemination.

### **Ethical Considerations Related to the Participatory Research Process**

One of the main ethical concerns in relation to the participatory process was about power differentials, particularly in relation to children. Meetings were thus conducted with children, parents, and staff separately to try to decrease this power imbalance. Since the different members could not discuss ideas together, I shared the perspectives of different members with one another to foster an exchange of ideas. This process led to rich discussions with the different members. For example, in relation to data collection, children and staff members had shared whom they considered as potential key informants, and I discussed the different perspectives with them and the final decisions reflected the views of the different partners involved. For data interpretation, perspectives related for example to the punitive nature of the use of control measures differed:

during the meeting with the staff, when I shared that many children perceived control measures as punitive, most staff members were surprised and explained it was not the case, with one staff member strongly arguing it was punitive. Through the discussion of the diverging perspectives, staff members agreed control measures were sometimes used as a punishment, which some preferred to call a consequence, in that the aim was to have something “not enjoyable” happen to the child in consequence for having done something wrong.

### **Partnership Sustainability**

Different strategies were used to help foster the sustainability of the partnership. For example, as I was working at the Institute as a clinical nurse specialist while I was performing fieldwork, I could informally go on the unit to remain in contact with the staff partners. I also had support from the managers, which fostered the continued participation of the partners from the Institute, since they had release time to participate. Discussion and negotiation were used as the main strategies to resolve conflict (as shown in the example above), with the aim to reach consensus through mutual understanding. Successful resolution of disagreement is considered key in enhancing trust and respect between the partners, leading to a stronger partnership and more successful project outcomes (Jagosh et al., 2012). This discussion process was key in exploring diverging perspectives and making specific decisions.

### **Strengths and Limitations of the Participatory Research Process**

Within a participatory research study, it is challenging to know the extent to which the partners will be involved and how the study will unfold, as key decisions are taken collaboratively throughout the study process. Multiple opportunities for participation were offered throughout the project, and special attention was given to respecting partners’ availability and interest in being part of the research process. This led to different levels of involvements

from partners, aiming for an equitable participation and the co-creation of knowledge that was more contextualized. This type of knowledge is deemed more likely to be put into practice by staff members and increases the likelihood that the research products will be sustained over time (Cargo & Mercer, 2008). For the research process itself, involvement of the partners led to a better fit of the research activities with the local context, more appropriate and relevant data collection procedures, an enriched interpretation of data, and enhanced recruitment as people were already aware of the study before the start of data collection. Access to the field was thus greatly enhanced by being in contact with key people in the setting before the start of the study. Also, for research ethics approval, support from people in the setting was needed; since they were already involved in the project, it expedited the process.

These benefits have also been highlighted in the literature on participatory research (Cargo & Mercer, 2008; Jagosh et al., 2012), along additional benefits for the partners, some of which are listed in Table 2. These benefits were not studied specifically within this thesis. However, anecdotal accounts shared by some of the advisory committee members highlight their positive experiences of being engaged in the research process. Involving parents was challenging, considering their limited availabilities, but offered an interesting perspective as to what data would be relevant to collect (e.g. in relation to parents' involvement in the program).

Table 2

*Potential Benefits to Partners*

| Partners                       | Potential Benefits of Engagement for the Partners                                                                                     |
|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
| Children                       | Empowerment: By giving attention to their voice and acting upon it                                                                    |
| Parents                        | Empowerment: Through their involvement in creating knowledge that aims to develop better care for their child                         |
| Nurses and other staff members | Capacity-building, ownership, and credibility to the results: By being involved in creating knowledge of direct relevance to them and |

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|                              |                                                                                                                                                                                      |
|------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                              | contributing to improve their own practice                                                                                                                                           |
| Managers and decision-makers | Practice change, credibility to the results, sustainability: By being engaged, it will facilitate the knowledge translation process to improve practices related to control measures |

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The advisory committee was not involved in the writing of the thesis, but will be offered to participate in the elaboration of the final report that will be submitted to the Institute during the summer 2017. This report will include recommendations as to practices that could be used in child mental health settings, and could guide the development of norms, practice standards, policy, and research priorities at the institutional level. Moreover, priorities for an educational program targeting staff members will be identified.

## Appendix B

## Details Related to Data Collection for Manuscript 1

Summary of the characteristics of the articles included in the concept analysis, categorized by trends<sup>48</sup>

*Appearance of the concept within the health literature: Orem's self-care agency*

| First Author             |         |            |                  | Agency                                                                             |                                                                                                    |                                                                  |            |
|--------------------------|---------|------------|------------------|------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|------------------------------------------------------------------|------------|
| Study                    | Country | Discipline | Label            | Antecedents                                                                        | Attributes                                                                                         | Consequences                                                     | References |
| Canty-Mitchell (2001)    | USA     | Nursing    | Self-care agency | Self-care agency is a learned ability that is linked to health outcomes and risks. | Ability to engage in practices for self-care. Measured with Denyes Self-Care Agency Questionnaire. | Adolescents can increase their performance in self-care agency.  | Ados       |
| Gaffney and Moore (1996) | USA     | Nursing    | Self-care agency | Children require complete care or assistance to maintain health and well-being.    | Being responsible to maintain health. Measured with Denyes Self-Care Agency Questionnaire.         | Children are 'dependent self-care agents'.                       | Children   |
| Gaut (1988)              | USA     | Nursing    | Self-care agency | The capacity to engage in self-care agency is related to                           | Ability to care for one's self in relation to health: includes the                                 | Children should be active participants in the care they receive. | Ados       |

<sup>48</sup> For data collection, the attributes of the concept were first identified by asking the question: 'What are the characteristics of children's agency in this paper?' (Rodgers, 2000, p. 91). Second, the contextual basis of the concept was analyzed through an exploration of the interdisciplinary, situational, sociocultural, and temporal contexts, categorized as the antecedents and consequences of the concept. The antecedents are the assumptions, values, and beliefs about children and agency, while the consequences refer to the implications of adopting a particular view of agency. Here are some examples of guiding questions that were used to help identify and collect the data: What are the author's assumptions, values, and beliefs about children's agency?; What happens as a result of children's agency?; Is children's agency used differently in different situations?. Third, references were identified, defined as 'the actual situations to which the concept is being applied' (Rodgers, 2000, p. 92), which helped define the scope of the concept.

|                |     |         |                  |                                                                                                                                    |                                                                                                                                                                     |                                                                                                                                                                              |                                |
|----------------|-----|---------|------------------|------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|
|                |     |         |                  | the child's growth and maturation. The responsibility for healthcare gradually shifts from the family to the child and adolescent. | power to determine the actions leading to a state of health and the power to accomplish these actions. Measured with Denyes Self-Care Agency Questionnaire.         | Children are recipients of care, and the actions required of the child are determined by adults. Transfer of healthcare responsibility to children can be successful or not. |                                |
| Moore (1987)   | USA | Nursing | Self-care agency | Children transition into the independent care role as they develop.                                                                | Ability to perform activities on one's own behalf that promote health, prevent illness, and augment treatment. Measured with Denyes Self-Care Agency Questionnaire. | Increased self-care as children leads to increased self-care autonomy as adults.                                                                                             | 5 <sup>th</sup> grade students |
| Slusher (1999) | USA | Nursing | Self-care agency | There are universal requisites to develop self-care agency.                                                                        | Ability for a person to meet his or her own health requirements.                                                                                                    | Adolescents can have self-care agency, but their ability is limited.                                                                                                         | Ados                           |

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*Developmental perspective*

| First Author                |         |            |                                | Agency                                                                                                                                    |                                                                                                                                                |                                                                                                                              |                                         |
|-----------------------------|---------|------------|--------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------|
| Study                       | Country | Discipline | Label                          | Antecedents                                                                                                                               | Attributes                                                                                                                                     | Consequences                                                                                                                 | References                              |
| Baker et al. (2003)         | USA     | Psychology | Agency                         | Effort and self-discipline leads to a greater agency.                                                                                     | Personal perception that specific, attainable means could be used to achieve a certain outcome.                                                | Interventions can be used to modify adolescents' behaviors.                                                                  | Ados                                    |
| Baker (2013)                | USA     | Philosophy | Agency                         | Sentience is a precondition to developed agency. Children before 4 years old lack the brain structures to retain memories of experiences. | Ability to describe one's life in a narrative way, with reference to certain key concepts.                                                     | People who have mature agency can consent to treatment. Adolescents and children above 4 years old could have mature agency. | Children                                |
| Beacham and Deatrick (2013) | USA     | Nursing    | Health care autonomy or agency | Developmental construct instrumental in the transition from childhood to adulthood. Typically present in late adolescence.                | Ability to evaluate options, make a decision, define a goal, be confident to stand by those decisions, develop strategies to meet those goals. | Children need to develop autonomy within different domains. Autonomy can be increased following interventions.               | Children with chronic health conditions |
| Contento et al. (2010)      | USA     | Nutrition  | Personal agency                | Motivational and skill building activities can enhance personal                                                                           | Sense of ability to exert personal influence over one's environment and                                                                        | Interventions to enhance motivation and self-regulation leads to behavior                                                    | Ados from low income neighborhood       |

|                               |     |            |              |                                                                                                                             |                                                                                                                    |                                                                                                                                              |                             |
|-------------------------------|-----|------------|--------------|-----------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------|
|                               |     |            |              | agency.                                                                                                                     | personal behaviors. Characterized by: forethought, intentionality, self-efficacy, and self-regulation of behavior. | changes.                                                                                                                                     |                             |
| DeSocio et al. (2013)         | USA | Nursing    | Self-agency  | Develops within adolescence and is influenced by social and cognitive elements.                                             | Ability to direct future possibilities. Measured via personal control beliefs.                                     | Interventions done in adolescence targeting control beliefs can affect the level of self-agency and related health outcomes.                 | Unmarried ado mothers       |
| Helgeson and Palladino (2012) | USA | Psychology | Agency       | Related to the existence as an individual, which is a male principle.                                                       | Ability to attend one's self needs via a positive focus on the self.                                               | A gender-based approach should be used for adolescent health.                                                                                | Ados with diabetes          |
| Hyman (2013)                  | USA | Medicine   | Agency       | Self-control is increased by the use of stimulant drugs.                                                                    | Control over one's own thoughts and behaviors.                                                                     | Stimulants allow the child to control impulses, thus increasing agency.                                                                      | Children with ADHD          |
| Iglesias (2003)               | USA | Psychology | Agency       | When children's opinions are not taken into account in the decisions involving them, it can lead to uncontrolled behaviors. | Ability to freely decide to do or not a certain behavior.                                                          | If the child is more aware of the uncontrolled behavior and have more control in the decisions that are made, it will change their behavior. | Ados with trichotillomania. |
| Mameli (2007)                 | UK  | Philosophy | Moral agents | Critical reflection occurs only at a                                                                                        | Responsibility for one's own actions.                                                                              | A child can choose from an array of                                                                                                          | 'Genetically-engineered     |

|                               |        |                         |              |                                                                                     |                                                                             |                                                                                                                               |                                      |
|-------------------------------|--------|-------------------------|--------------|-------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|--------------------------------------|
|                               |        |                         |              | certain age.                                                                        |                                                                             | life plans independently from genetic make-up.                                                                                | children'                            |
| Peny-Dahlstrand et al. (2012) | Sweden | OT                      | Autonomy     | Autonomy develops gradually throughout childhood within the family context.         | Ability to be the causal agent in one's own life.                           | Issues of autonomy should be discussed with the individual. Autonomy is vital for independence and life participation.        | Children with spina bifida           |
| Rose (2013)                   | UK     | Neuro-science           | Moral agency | In front of authority figures, children's autonomy and agency might be compromised. | Capacity to critically reflect on the norms.                                | When conducting research, the presence of authority figures should be taken into account.                                     | Children with ADHD                   |
| Singh (2013)                  | UK     | Social Science          | Moral agency | The child is a moral agent capable of reason and reflection.                        | Ability to meet normative expectations.                                     | Stimulants improve the children's capacity to meet normative expectations, and thus improves their capacity for moral agency. | Children with ADHD                   |
| Wang et al. (2014)            | USA    | Public Health           | Agents       | Each child is an agent who follows the norms in their social network.               | Ability to maximize one's utility.                                          | A derivation from the norm is the result of a misperception of the norms.                                                     | Children                             |
| Weiss (2004)                  | USA    | Communi-cative disorder | Change agent | As children grow, higher responsibility as change agent can be taken up.            | Responsibility for changes related to oneself. Having the locus of control. | If children recognize they are change agents, therapy will work                                                               | Children with phonological disorders |

|                                  |     |                   |                 |                                                                                                                |                                                                                                                                                                                                            |                                                                                                                                                     |      |
|----------------------------------|-----|-------------------|-----------------|----------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|------|
| Williams<br>and Merten<br>(2014) | USA | Social<br>Science | Human<br>agency | Agency is a<br>component of<br>resilience, an<br>individual-level<br>factor that develops<br>as children grow. | The ability, capacity,<br>and willingness to<br>actively construct<br>one's life course and<br>self-reflect on one's<br>goals. Measured by<br>observed<br>planfulness, self-<br>efficacy, and<br>optimism. | better. Therapists<br>should facilitate<br>behavior change.<br>A high level of<br>agency is related to<br>a drive to continue<br>despite adversity. | Ados |
|----------------------------------|-----|-------------------|-----------------|----------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|------|

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*Children as health change agents*

| First Author                    |         |                    |                      | Agency                                                                                                                                                                                                                            |                                                                                                                                                                      |                                                                                                   |                         |
|---------------------------------|---------|--------------------|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|-------------------------|
| Study                           | Country | Discipline         | Label                | Antecedents                                                                                                                                                                                                                       | Attributes                                                                                                                                                           | Consequences                                                                                      | References              |
| Davó-Blanes and La Parra (2013) | Spain   | Public Health      | Health agents        | Children are aware of the role they play to make health changes for them, the school environment and the wider social context, but consider it challenging to have an active role in the context of adults not listening to them. | Ability to identify one's own health problems, the health problems of others and of the immediate environment. Ability to propose solutions to address the problems. | Children's participation in research and health promotion initiative should be promoted.          | Spanish school pupils   |
| Deepthi et al. (2014)           | India   | Community Medicine | Health change agents | Children are not passive recipients of other people's care and interventions, but can bring about changes in their and community.                                                                                                 | Capacity to bring about change in one's own family and community in relation to health behaviors.                                                                    | Participatory health education programs in schools can be effective in changing health behaviors. | Schoolchildren in India |

|                                      |                      |                         |                        |                                                                                                                |                                                                                                       |                                                                                                                                                             |                                |
|--------------------------------------|----------------------|-------------------------|------------------------|----------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|
| Dickman and Melek (2013)             | USA                  | Public Health           | Agents of change       | Children can be change agents.                                                                                 | Capacity to act to improve one's own health, educate family and bring about changes in the community. | Children can bring about changes related to their health and the health of others through education programs.                                               | Children in Ethiopia           |
| Mwanga et al. (2008)                 | Tanzania and Denmark | Education and Sociology | Agents                 | Children are agents and not passive recipients.                                                                | Action competence and active role in facilitating concrete change for oneself and others.             | An action-oriented and participatory health education project in which genuine participation is adopted should be used in which children are change agents. | Schoolchildren in Tanzania     |
| Montgomery-Andersen and Borup (2012) | Sweden               | Midwifery Public Health | Health promoting agent | Children are not the receivers of health but promoters. They are independent and co-interdependent entities.   | Capacity to shape one's own health and promote the health of family.                                  | Children are an important actor as health promoting agent within their family.                                                                              | Children in the Arctic (Inuit) |
| Onyango-Ouma et al. (2005)           | Kenya and Denmark    | Anthropology            | Agents of change       | Children can engage with health knowledge and skills and are social actors part of larger societal structures. | Capacity to find strategies and space to manage different situations.                                 | A health education intervention provided to children can lead to health behavior and environmental changes in their family and school.                      | Schoolchildren in Kenya        |

|                                |              |                |                  |                                                                             |                                                                                           |                                                                                                                                        |                                           |
|--------------------------------|--------------|----------------|------------------|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| Silberschmidt and Rasch (2001) | Denmark      | Public Health  | Social agents    | Adolescents are active social agent.                                        | Deliberately taking action in relation to someone else.                                   | Health education can lead to increased maturity in decisions related to health and relationships.                                      | Ados in developing countries              |
| Simovska and Carlsson (2012)   | Denmark      | Education      | Agents of change | Children are agents of health-promoting changes.                            | Capacity to be meaningfully involved in bringing about changes for a healthier lifestyle. | With sufficient guidance, children can act as health-promoting agents at the school and community levels.                              | Schoolchildren                            |
| Smyth et al. (2011)            | Australia    | Social Policy  | Active agents    | Agency is constrained by the structure.                                     | Active participants within their families and communities.                                | Infrastructures should be developed to support young carers.                                                                           | Young people who provide informal care    |
| Wingert et al. (2014)          | USA          | Public Health  | Change agents    | Children can develop their own positive health practices.                   | Capacity to influence the choices of others, particularly the family.                     | Children can be trained to serve as change agents for health promotion in their family and community.                                  | Ados                                      |
| Winsor and Skovdal (2011)      | UK and Kenya | Social Science | Agency           | Having a sense of agency can affect the children's psychosocial well-being. | Capacity to actively cope with adversity and mobilize resources to meet one's own needs.  | Children should be encouraged to actively exercise agency and engage in activities to create their own health-enhancing circumstances. | Orphaned and vulnerable children in Kenya |

*Agency in childhood studies*

| First Author                    |              |                |               | Agency                                                                                |                                                                                                           |                                                                                                                    |                                           |
|---------------------------------|--------------|----------------|---------------|---------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| Study                           | Country      | Discipline     | Label         | Antecedents                                                                           | Attributes                                                                                                | Consequences                                                                                                       | References                                |
| Atkins et al. (2010)            | USA          | Nursing        | Health agents | Adolescents are responsible for their own health.                                     | Capacity to make decisions for health actions and be involved in health care decisions.                   | Adolescents should be part of the research process.                                                                | Adolescents from low income neighborhoods |
| Clavering and McLaughlin (2010) | UK           | Sociology      | Agency        | Agency is not dependent on age. All children are social actors who have agency.       | Being engaged in one's own world and involved in shaping it.                                              | Research should explore children's experiences from their own perspective.                                         | Children                                  |
| Clayton (2013)                  | UK           | Sociology      | Agency        | Children are social actors with agency who can deal with complex social worlds.       | Capacity to act, to interact, to make choices, to influence, to shape one's life and the lives of others. | Children have the ability to influence the social world around them.                                               | British Chinese children                  |
| Dedding et al. (2014)           | Netherlands  | Social Science | Agency        | Children are social actors. They give their own meaning and direction to their lives. | Strategies used to realize one's own personal goals. Includes emotions and practical logic.               | During clinical encounters, children should have the opportunity to speak for themselves to exercise their agency. | Children with diabetes                    |
| Hampshire et al. (2011)         | UK and Ghana | Anthropology   | Agency        | Children are not passive recipients of adult care. Children are                       | Capacity to affect one's own life chances and those of others. Capacity to                                | Agency can be demonstrated by engaging in treatment seeking.                                                       | Children in Ghana                         |

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|                       |         |           |        |                                                                                                                            |                                                                                         |                                                                                                                                    |                                        |
|-----------------------|---------|-----------|--------|----------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|
|                       |         |           |        | strategizing agents.                                                                                                       | play a role in the formation of the social realities in which human beings participate. |                                                                                                                                    |                                        |
| Holmila et al. (2011) | Finland | Sociology | Agency | Minors are individuals with their own rights. Children are active agents in their own lives.                               | One's own capacities and resources.                                                     | Children should be active participants in the processes aiming to find solutions.                                                  | Children with problem drinking parents |
| Olli et al. (2012)    | Finland | Nursing   | Agency | The realization of agency is dependent on interactions with other people. Agency is a feature present in all human beings. | To have an influence on other human beings through communication.                       | The realization of agency can lead to increased self-confidence, and a feeling of control over one's own life and of being valued. | 'Disabled children'                    |

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*Autonomy: A related concept*

| First Author                 |         |            |          | Agency                                                                                                                                                        |                                                                                           |                                                                                                              |                                                                   |
|------------------------------|---------|------------|----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------|
| Study                        | Country | Discipline | Label    | Antecedents                                                                                                                                                   | Attributes                                                                                | Consequences                                                                                                 | References                                                        |
| Arribas-Ayllon et al. (2008) | UK      | Sociology  | Autonomy | Children become more competent over time. There is a need to balance parental responsibility and child autonomy, as well as child autonomy and best interest. | To let the children decide if they want or not to disclose certain sensitive information. | Autonomy has relational and temporal consequences for others. It is not a rational, individualistic concept. | Children in the context of genetic testing for potential diseases |
| Drake (2001)                 | UK      | Nursing    | Autonomy | Children differ in their level of maturity to consent. Health care professionals know what the best decision is.                                              | Ability to make an informed decision.                                                     | Children can be competent to consent depending on their level of maturity.                                   | Ados                                                              |
| Godkin (2006)                | Canada  | Medicine   | Autonomy | Sedation and age affect autonomy.                                                                                                                             | Ability to exercise one's choices.                                                        | Best interest should prevail over autonomy in cases in which the child is sedated.                           | Children facing imminent death                                    |
| Lowes (1996)                 | UK      | Nursing    | Autonomy | Nurses should support the child's autonomy. This autonomy evolves in stages.                                                                                  | Ability to participate in making an informed decision.                                    | Children have a right to relevant information and should be fully informed of their                          | Children                                                          |

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|                         |    |          |          |                                                                             |                                                                   |                                                                                                                                            |                                |
|-------------------------|----|----------|----------|-----------------------------------------------------------------------------|-------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|
|                         |    |          |          |                                                                             |                                                                   | health condition and treatment.                                                                                                            |                                |
| Rose (1997)             | UK | Nursing  | Autonomy | Children develop differently based on their life experience.                | Ability to take part in health care decisions.                    | The child's view should be taken into account as an individual separate from the family.                                                   | Children                       |
| Timms and Lowes (1999)  | UK | Nursing  | Autonomy | As children develop, they become more competent in making health decisions. | Capacity to make a decision related to long-term health outcomes. | Adolescents are not ready to be autonomous to manage their health. Health care professionals know what the best outcomes are for children. | Adolescents                    |
| Vince and Petros (2006) | UK | Medicine | Autonomy | Being a person leads to the benefit of autonomy.                            | Ability to consent.                                               | Autonomy is dependent on experiences and values, not on chronological age.                                                                 | Children facing imminent death |

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OT = Occupational Therapy; Ados = Adolescents; ADHD = Attention deficit hyperactivity disorder

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## Appendix C

## Study Timeline

Table 3

*Timeline followed in conducting the study\**

| Phase 1:<br>Oct 2014-Feb 2015           | Phase 2:<br>Feb-July 2016  | Phase 3:<br>July-Oct 2016                           | Phase 4:<br>Oct 2016-June 2017         |
|-----------------------------------------|----------------------------|-----------------------------------------------------|----------------------------------------|
| Comprehensive examination               | <b>Data collection</b>     | Data analysis and <b>interpretation</b> (continued) | Writing of doctoral thesis (continued) |
| <b>Creation advisory committee</b>      | Data analysis              | Writing of doctoral thesis                          | <b>Writing of final report</b>         |
| Submission for research ethics approval | <b>Data interpretation</b> |                                                     | <b>Dissemination</b>                   |

\* The steps in bold are the ones in which the partners from the advisory committee were involved.

## Appendix D

### Participant Observation Guide

The main dimensions guiding participant observation are time, people, and context. The specific decisions related to when, who, what, and where to observe are made in collaboration with members of the advisory committee.

Considering that the study is focused in scope (as opposed to a classical ethnography), the different questions guiding participant observation refer specifically to activities, practices, attitudes, events, interactions, relationships, norms, and rules related to the study aim, which is to examine the institutional norms, structures, practices, and corresponding moral experiences related to conflict and crisis management in order to develop care approaches that will promote an optimal reconciliation of ethical concerns in child mental health.

#### Time

- How do activities vary over time?
  - What is the routine on the unit?
  - How are activities related to crisis situations?
- How do attitudes vary over time?
  - How are attitudes related to crisis situations?
- What are the events on the unit?
  - For example: interdisciplinary meetings, family meetings
- What events or patterns are related to changes in activities or attitudes?
- What is the relationship between time, space, and people?

#### People

- Who is present on the unit?
  - What are the different roles?
  - What are the characteristics of the people?
  - What is the number of people?
- What are the interactions between people?
  - E.g. nature of interactions, reason they occur, emotions expressed
- What are people saying and doing?
- What are the non-verbal messages?
- Who is present and what are people doing before, during, and after a crisis situation?

#### Context

- What is the general atmosphere on the unit?
  - How does it differ when there is a crisis situation or not?
- How is the environment structured?
  - E.g. physical setting, sitting arrangement
- What is the organizational structure?

- What are the explicit and tacit norms/rules on the unit?
- What is the structure of the relationships?
- What are the contextual elements before, during, and after a crisis situation?

### **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 E

### Consent and Assent Forms (English Versions)

To be a study participant for the participant observation and/or chart review:

Parental Consent Form: Child Participation

Assent Form: Child

Consent Form: Healthcare Worker

To be a study participant for the interview as key informant:

Parental Consent Form: Child Participation

Assent Form: Child

Consent Form: Adult Family Member

Consent Form: Healthcare Worker

## **Parental Information/Consent Form – Child Participation Participant Observation and Chart Review**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
PhD Candidate, McGill University

**Funding**

Fonds de Recherche du Québec – Santé  
Richard and Edith Strauss Fellowship in Nursing  
Social Sciences and Humanities Research Council of Canada

**Preamble**

We are soliciting the participation of your child or the child that you represent in a research project. However, before accepting that he participates in the project and signing the information/consent form, take the time to read, understand and carefully examine the following information.

This form may contain words that you do not understand. We are inviting you to ask any question that you may deem useful to the researcher in charge of the research project or the student researcher, and ask them to explain to you any word or information that is unclear.

**Nature and objectives of the research project**

This project is about how challenging situations are managed with children receiving services from the Day Hospital program for children aged 6-12. The purpose of this project is to gain a better understanding of the practices, structures, and rules that are in place in child mental health. We are also interested in people's experiences related to these services, including the perspective of children, parents, and healthcare workers. All the children receiving care at the Day Hospital will be approached to participate to this study.

**Procedures of the research project**

The main way the student researcher is going to collect data is through observing and talking with your child at the Pediatric Day Hospital. The student researcher will be present a few days a week at the Day Hospital between January and June 2016. The student researcher will not disrupt any of the planned activities. She will collect data related to her observations and her discussions with your child. She will ask the healthcare workers before interacting with your child to ensure the timing is good. Here are examples of questions the student researcher may ask: What do you think of the Day Hospital? How did you feel at the beginning of the activity? Who was involved? What happened after that?

If you give authorization, the student researcher will also collect information from your child's medical file. This information will be related to how crisis situations are documented in the medical file. The study will occur during your child's normal schedule at the Day Hospital.

**Risks associated to the research project**

Risks to your child are minimal and should be no greater than those experienced in his everyday life. For some children, discussing sensitive topics might cause them to become emotionally upset or anxious. If this happens with your child, the student researcher will take all measures necessary to support your child, such as pause or stop the discussion, or talk about what's bothering him. Your child can also talk to a

healthcare worker at the Day Hospital with whom he is comfortable.

The student researcher will provide ongoing support and encouragement to your child and explain that there is no “right or wrong” answer to the questions. The student researcher will gladly answer any questions or address any concerns that you or your child may have at any time during the study. Discussion with your child of having been under control measures will not be initiated by the student researcher.

### **Disadvantages associated with the research project**

Possible disadvantages to your child in participating in the project include anxiety, stress, or frustration related to the topics that could be discussed. The student researcher will pay special attention to your child’s verbal and nonverbal cues to continuously reassess his willingness to participate.

### **Advantages**

You or your child will not get any personal benefit from your participation in this research project. However, the study results may assist in the advancement of knowledge in this field.

### **Voluntary participation and possibility to withdraw**

Your child’s participation in this research project is voluntary. You are therefore free to refuse to have your child participate. You can also withdraw your child from the project at any moment, without giving any reason, by informing the researcher in charge of the project or the student researcher.

Your decision not to have your child participate in the research project or to withdraw from it will not have any impact on the quality of care and services to which you and your child are entitled. It will also not have any impact on your relationship with the researcher in charge of the project, the student researcher and the caregivers.

The researcher in charge of the research project, the research ethics committee, or the granting agency could put an end to your child’s participation, without your consent, if new findings or information indicate that your child’s participation is no longer in his interest or for administrative reasons that would force ending the project.

If you withdraw your child or your child is withdrawn from the project, the information that was already collected in the course of the project will be destroyed and not used by the research team.

Any new findings obtained during the course of the research project that may have an impact on your decision to continue to have your child participate in the project would be transmitted immediately to you orally and by writing.

### **Confidentiality**

During your child’s participation in this project, the student researcher will collect and record the information concerning your child in a study file. Only the data required to meet the scientific goals of the project would be collected.

This data could include information contained in your child’s medical files concerning his past and present health condition and lifestyle. Your child’s file could also contain other information such as his name, sex/gender, date of birth and ethnic origin. The specific data that will be collected will be related to your child’s age, sex/gender, primary caregiver, living arrangements, reason for hospitalization, and time

since admission in the program. This information will only be used to describe the participants as a group and will not allow the identification of your child specifically.

All this information collected during the research project will remain strictly confidential to the extent prescribed by the law. In order to protect your child's identity and the confidentiality of this information, only a code number will identify him. The key to the code linking your child's name to your child's study file will be kept by the student researcher. The information and data will be stored in a locked cabinet in a locked office accessible only to the project researcher and his team. All the computerized information will be kept on a password-protected computer in password-protected files, which will be accessible only to the project researcher and his team.

The researchers would use this data for research purposes, in order to achieve the project scientific goals, described in the information/consent form. This data would be kept by the researcher in charge of the project for 7 years following publication of the results, and will then be destroyed in conformity with the rules in effect. Coded data might be used for possible future research studies with your consent. However, no identifiable information would be used in future research.

The data could be published in scientific specialized magazines or shared by other individuals during scientific meetings; however, it would not be possible to identify your child. For surveillance and control purposes, your child's study file as well as your child's medical files could be examined by a person mandated by the Ethics Research Board, if necessary. All these individuals agree with the privacy policy. You have the right to consult your child's study file in order to verify the information gathered and to rectify it if necessary, as long as the project researcher or the institution holds this information.

The only exception to confidentiality is in the case where 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 in order 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.

### **Funding of the research project**

The researcher in charge of the project received funding from a Granting Agency, the Social Sciences and Humanities Research Council of Canada for the successful completion of the research project. The student researcher received funding from a Granting Agency, the Fonds de recherche du Québec - Santé, and from the Richard and Edith Strauss Foundation, for the conduct of this project as part of her doctoral studies.

### **Rights of the research participant**

By accepting to have your child participate in this project, you are not waiving any of his or your legal rights nor discharging the researchers or the institution of their civil and professional responsibility.

### **Compensation**

Your child will receive a small toy or book (about 10\$ value) in compensation for participating to this project. If you withdraw your child from the project, if your child withdraws, or your child is withdrawn before it is completed, your child will still receive the toy or book.

### **Identification of contact persons**

If you have questions concerning the research project or if you feel you have a problem related to your participation in the research project, you can communicate with the researcher in charge of the project,

Franco Carnevale (nurse) at the following number: xxx-xxxx. You can also contact the student researcher, Marjorie Montreuil (nurse) at the following number: xxx-xxxx. For any questions concerning your own rights or your child's rights as a research participant participating in this research project or if you have comments or wish to file a complaint, you can communicate with the Service Quality Commissioner at the following number: xxx-xxxx.

### **Control of the ethical aspects of the research project**

The Research Ethics Board approved this research project and guarantees the follow-up. In addition, it will first approve any review and amendment made to the information/consent form and to the study protocol.

### **Consent**

A dated and signed copy of the present information/consent form will be inserted in my child's medical file. Therefore, I understand that this information will be available to any person or company to whom I will authorize to access his medical file.

### **The Legal Representative's consent**

In my capacity as legal representative, I took notice of the information/consent form. I acknowledge that the research project was explained to me, that my questions were answered and that I was given sufficient time to make a decision.

After consideration, I agree that my child participate in this research project according to the conditions stated above. A dated and signed copy of the present information/consent form was given to me\*.

---

Name of the minor child

---

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

Date

### **Future use of data**

Do you accept that coded data be used for possible future research projects, subject to the approval of the research project by the Research Ethics Board?

YES ☐ NO ☐

---

Signature of the legal representative

### **Signature of the person who obtained the consent if different from the researcher in charge of the research project**

I have explained to the legal representative (parent or guardian) the terms of the present information/consent form and I answered all his questions.

---

Name and signature of the person who obtains the consent

Date

### **Signature and commitment of the researcher in charge of the project**

I hereby certify that we have explained to the research participant's legal representative the terms of the present information/consent form, that we have answered the questions that the legal representative had in that respect, and that we have clearly indicated that he remains free to put an end to the participation of the research participant without suffering any prejudice.

---

\* See attached for the Assent Form signed or verbally agreed to by the child.

I hereby certify that we have explained to the research participant in an adapted language that he can comprehend the research project\*. He understood and did not oppose. I hereby commit myself to respect any refusal. I commit myself, as well as the research team, to respect what was agreed upon in the information/consent form and to give a signed copy of this form to the legal representative.

---

Name and signature of the researcher in charge of the research project

Date

**Child Assent Form  
Participant Observation and Chart Review**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
Doctoral Student, McGill University

**Why are we doing this study?**

We want to better understand what you think of the Pediatric Day Hospital. We also want to better understand how the program works.

**What will happen during the study?**

The Research Student will be present at the Day Hospital a few days a week between January and June 2016. She will be observing and talking with the group and taking notes. You can come talk to her about things related to the program or share how you feel about different situations. She might ask you questions about what you think of the Day Hospital. She might also ask you about situations you think are fair or unfair. She will also read your medical file.

**Are there good things and bad things about the study?**

You might like participating in this project or you might not. If you don't, 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 the Day Hospital. You also don't have to answer any question if you don't 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. She 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 or book at the end of the study (10\$ value).

**Who will know what I say?**

No one but the researchers will know what you said. The things you talk about with the Research Student will not be shared with your parents, nurse, healthcare workers, teachers or friends. No one at the Day Hospital will know what you said. 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. However, even if we need to share some information, it will be about the reason why we are worried for you or someone else, and not about all that you have discussed with the Research Student.

**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. You can also ask the people at the Day Hospital. Ask any questions that you may have.

---

Assent of the child able to understand the nature of the 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 obtains the assent Date

## **Participant Information/Consent Form – Adult Participation Healthcare Worker: Participant Observation**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
Doctoral Student, McGill University

**Funding**

Fonds de Recherche du Québec – Santé  
Richard and Edith Strauss Fellowship in Nursing  
Social Sciences and Humanities Research Council of Canada

**Preamble**

We are soliciting your participation in a research project. However, before accepting to participate in this project and signing the information/consent form, take the time to read, understand and carefully examine the following information.

This form may contain words that you do not understand. We are inviting you to ask any question that you may deem useful to the researcher in charge of the research project or the student researcher, and ask them to explain to you any word or information that is unclear.

**Nature and objectives of the research project**

This project is about how challenging situations are managed with children receiving services from the Day Hospital program for children aged 6-12. The purpose of this project is to gain a better understanding of the practices, structures, and rules that are in place in child mental health. We are also interested in people's experiences related to these services, including the perspective of children, parents, and healthcare workers. All the healthcare workers at the Day Hospital will be approached to participate to this study for the participant observation.

**Procedures of the research project**

The main way we are going to collect data is through observing and talking with children, as well as healthcare workers, at the Pediatric Day Hospital. The student researcher will be present a few days a week at the Day Hospital between January and June 2016. The student researcher will not disrupt any of the planned activities. She will record data related to her observations and discussions. She will talk with you only during "down times", to collect information related to the rules, structures, practices and your experience at the Day Hospital. The study will occur during your normal work schedule at the Day Hospital.

**Risks associated to the research project**

Risks associated to your participation to this research project are minimal and should be no greater than those experienced in your everyday life. For some people, discussing sensitive topics might cause them to become emotionally upset or anxious. If this happens to you, we will take all measures necessary to support you, such as pause or stop the discussion, or talk about what's bothering you. You can also talk to a manager or colleague at the Day Hospital with whom you feel comfortable.

The student researcher will gladly answer any questions or address any concerns you may have at any time during the study.

### **Disadvantages associated with the research project**

Possible disadvantages to your participation to the study include anxiety, stress, or frustration related to the topics that could be discussed.

### **Advantages**

You will not get any personal benefit from your participation in this research project. However, the study results may assist in the advancement of knowledge in this field. The discussions with the student researcher may help you reflect about the rules and practices used at the Day Hospital.

### **Voluntary participation and possibility to withdraw**

Your participation in this research project is voluntary. You are therefore free to refuse to participate. You can also withdraw from the project at any moment, without giving any reason, by informing the researcher in charge of the project or the student researcher.

Your decision not to participate in the study or to withdraw from it will not have any impact on your work or your relationship with the researcher in charge of the project, the student researcher, and your manager.

The researcher in charge of the research project, the research ethics committee or the granting agency could put an end to your participation, without your consent, if new findings or information indicate that your participation is no longer in your interest or for administrative reasons that would force ending the project.

If you withdraw or are withdrawn from the project, the information that was already collected in the course of the project will be destroyed and not used by the research team.

Any new findings obtained during the course of the research project that may have an impact on your decision to continue to participate in the project would be transmitted immediately to you orally and by writing.

### **Confidentiality**

During your participation in this project, the project researcher and the student researcher will collect and record the information concerning you in a study file. Only the data required to meet the project scientific goals would be collected.

All the information collected during the research project will remain strictly confidential to the extent prescribed by law. In order to protect your identity and the confidentiality of this information, only a code number will identify you. The key to the code linking your name to your study file will be kept by the student researcher. The information and data will be stored in a locked cabinet in a locked office accessible only to the project researcher and his team. All the computerized information will be kept on a password-protected computer in password-protected files, which will be accessible only to the project researcher and his team.

The project researcher would use this data for research purposes, in order to achieve the project scientific goals, described in the information/consent form. This data would be kept by the researcher in charge of the project for 7 years following publication of the results, and will then be destroyed in conformity with the rules in effect. Coded data might be used for possible future research studies with your consent. However, no identifiable information would be used in future research.

The data could be published in scientific specialized magazines or shared by other individuals during scientific meetings; however, it would not be possible to identify you.

For surveillance and control purposes, your study file could be examined by a person mandated by the Research Ethics Board, if necessary. All these individuals agree with the privacy policy.

You have the right to consult your study file in order to verify the information gathered and to correct them, if necessary, as long as the project researcher or the institution holds this information.

### **Funding of the research project**

The researcher in charge of the project received funding from a Granting Agency, the *Social Sciences and Humanities Research Council of Canada* for the successful completion of the research project. The student researcher received funding from a Granting Agency, the Fonds de recherche du Québec - Santé, and from the Richard and Edith Strauss Foundation, for the conduct of this project as part of her doctoral studies.

### **Rights of the research participant**

By accepting to participate in this project, you are not waiving any of your legal rights nor discharging the researchers or the institution of their civil and professional responsibility.

### **Compensation**

No compensation will be provided for your participation to this study.

### **Identification of contact persons**

If you have questions concerning the research project or if you feel you have a problem related to your participation in the research project, you can communicate with the researcher in charge of the project, Franco Carnevale (nurse) at the following number: xxx-xxxx. You can also contact the student researcher, Marjorie Montreuil (nurse) at the following number: xxx-xxxx.

For any question concerning your rights as a research participant participating in this research project or if you have comments or wish to file a complaint, you can communicate with the Service Quality Commissioner at the following number: xxx-xxxx.

### **Control of the ethical aspects of the research project**

The Research Ethics Board approved this research project and guarantees the follow-up. In addition, it will first approve any review and amendment made to the information/consent form and to the study protocol.

### **The research participant's consent**

I took notice of the information/consent form. I acknowledge that the research project was explained to me, that my questions were answered and that I was given sufficient time to make a decision.

I agree to participate in this research project according to the conditions stated above. A dated and signed copy of the present information/consent form was given to me.

---

Name and signature of the research participant

Date

**Future use of data**

Do you accept that coded data be used for possible future research projects, subject to the approval of the research project by the Research Ethics Board?

YES ☐      NO ☐

---

Signature of the research participant

**Signature of the person who obtained the consent if different from the researcher in charge of the research project**

I have explained to the research participant the terms of the present information/consent form and I answered all his questions.

---

Name and signature of the person who obtains the consent

Date

**Signature and commitment of the researcher in charge of the project**

I hereby certify that we have explained to the research participant the terms of the present information/consent form, that we have answered the questions that the participant had in that respect and that we have clearly indicated that he remains free to withdraw from the study, without suffering any prejudice

I commit myself, as well as the research team, to respect what was agreed upon in the information/consent form and to give a signed copy of this form to the research participant.

---

Name and signature of the researcher in charge of the research project      Date

## **Parental Information/Consent Form – Child Participation Interview as Key Informant**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
Doctoral Student, McGill University

**Funding**

Fonds de Recherche du Québec – Santé  
Richard and Edith Strauss Fellowship in Nursing  
Social Sciences and Humanities Research Council of Canada

**Preamble**

We are soliciting the participation of your child or the child that you represent in a research project. However, before accepting that he participates in the project and signing the information/consent form, take the time to read, understand and carefully examine the following information.

This form may contain words that you do not understand. We are inviting you to ask any question that you may deem useful to the researcher in charge of the research project or the student researcher, and ask them to explain to you any word or information that is unclear.

**Nature and objectives of the research project**

This project is about how challenging situations are managed with children receiving services from the Day Hospital program for children aged 6-12. The purpose of this project is to gain a better understanding of the practices, structures, and rules that are in place in child mental health. We are also interested in people's experiences related to these services, including the perspective of children, parents, and healthcare workers. We are aiming for the recruitment of a maximum of 4 children to participate to the interviews as key informants.

**Procedures of the research project**

We are going to collect data through an interview with your child. The student researcher will meet with your child to discuss his experience related to the Pediatric Day Hospital. The interview will take place at the Pediatric Day Hospital, at a time that is convenient to you and your child. There could be only one interview, or more than one if you agree. Each interview will last a maximum of one hour and will be recorded. If you or your child disagrees to the audio-recording, the student researcher will write notes to remember what is discussed and the interview will not be recorded. The student researcher will ask questions related to the everyday experience of your child at the Pediatric Day Hospital. For example, the student researcher will ask your child about what happens at different times of the day and to describe a situation in which your child felt a situation was fair or unfair.

**Use of audiotaped interviews**

The goal of the audiotaped interviews is to allow researchers to review the interview to improve data analysis. We also plan, with your consent, to use the transcription of these recordings for other purposes such as teaching and research during scientific conferences.

### **Risks associated to the research project**

Risks to your child are minimal and should be no greater than those experienced in his everyday life. For some children, discussing sensitive topics might cause them to become emotionally upset or anxious. If this happens with your child, the student researcher will take all measures necessary to support your child, such as pause or stop the discussion, or talk about what's bothering him. Your child can also talk to a healthcare worker at the Day Hospital with whom he is comfortable.

The student researcher will provide ongoing support and encouragement to your child and explain that there is no "right or wrong" answer to our questions. The student researcher will gladly answer any questions or address any concerns that you or your child may have at any time during the study. Discussion with your child of having been under control measures will not be initiated by the student researcher.

### **Disadvantages associated with the research project**

Possible disadvantages to your child in participating in the study include anxiety, stress, or frustration related to the topics that could be discussed. The student researcher will pay special attention to your child's verbal and nonverbal cues to continuously reassess his willingness to participate.

### **Advantages**

You or your child will not get any personal benefit from your participation in this research project. However, the study results may assist in the advancement of knowledge in this field.

### **Voluntary participation and possibility to withdraw**

Your child's participation in this research project is voluntary. You are therefore free to refuse to have your child participate. You can also withdraw your child from the project at any moment, without giving any reason, by informing the researcher in charge of the project or the student researcher.

Your decision not to have your child participate in the study or to withdraw from it will not have any impact on the quality of care and services to which you and your child are entitled or your relationship with the researcher in charge of the project, the student researcher and the caregivers.

The researcher in charge of the research project, the research ethics committee, or the granting agency could put an end to your child's participation, without your consent, if new findings or information indicate that your child's participation is no longer in his interest or for administrative reasons that would force ending the project.

If you withdraw your child or your child is withdrawn from the project, the information that was already collected in the course of the project will be destroyed and not used by the research team.

Any new findings obtained during the course of the research project that may have an impact on your decision to continue to have your child participate in the project would be transmitted immediately to you orally and by writing.

### **Confidentiality**

During your child's participation in this project, the project researcher and his team will collect and record the information concerning your child in a study file. Only the data required to meet the scientific goals of the project would be collected.

All this information collected during the research project will remain strictly confidential to the extent prescribed by the law. In order to protect your child's identity and the confidentiality of this information,

only a code number will identify him. The key to the code linking your child's name to your child's study file will be kept by the project student researcher. Only the written transcripts of the audio recordings will be kept. The audio recordings will be destroyed immediately following transcription, by deleting the audio file and any potential copies. All the information and data will be stored in a locked cabinet in a locked office accessible only to the project researcher and the student researcher. All the computerized information will be kept on a password-protected computer in password-protected files, which will be accessible only to the project researcher and his team.

The researchers would use this data for research purposes, in order to achieve the project scientific goals, described in the information/consent form. This data would be kept by the researcher in charge of the project for 7 years following publication of the results, and will then be destroyed in conformity with the rules in effect. Coded data might be used for possible future research studies with your consent. However, no identifiable information would be used in future research.

The data could be published in scientific specialized magazines or shared by other individuals during scientific meetings; however, it would not be possible to identify your child.

You have the right to consult your child's study file in order to verify the information gathered and to rectify it if necessary, as long as the project researcher or the institution holds this information.

For surveillance and control purposes, your child's study file could be examined by a person mandated by the Research Ethics Board, if necessary. All these individuals agree with the privacy policy.

The only exception to confidentiality is in the case where 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 in order 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.

### **Funding of the research project**

The researcher in charge of the project received funding from a Granting Agency, the Social Sciences and Humanities Research Council of Canada for the successful completion of the research project. The student researcher received funding from a Granting Agency, the Fonds de recherche du Québec - Santé, and from the Richard and Edith Strauss Foundation, for the conduct of this project as part of her doctoral studies.

### **Rights of the research participant**

By accepting to participate in this project, you are not waiving any of his or your legal rights nor discharging the researchers or the institution of their civil and professional responsibility.

### **Compensation**

Your child will receive a small toy or book (about 10\$ value) in compensation for participating to 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 book.

### **Identification of contact persons**

If you have questions concerning the research project or if you feel there is a problem related to your child's participation in the research project, you can communicate with the student researcher, Marjorie Montreuil, at the following numbers: xxx-xxxx.

For any questions concerning your own rights or your child's rights as a research participant participating in this research project or if you have comments or wish to file a complaint, you can communicate with the Service Quality Commissioner at the following number: xxx-xxxx

### **Control of the ethical aspects of the research project**

The Research Ethics Board approved this research project and guarantees the follow-up. In addition, it will first approve any review and amendment made to the information/consent form and to the study protocol.

### **Consent**

A dated and signed copy of the present information/consent form will be inserted in my child's medical file. Therefore, I understand that this information will be available to any person or company to whom I will authorize to access his medical file.

### **The Legal Representative's consent**

In my capacity as legal representative, I took notice of the information/consent form. I acknowledge that the research project was explained to me, that my questions were answered and that I was given sufficient time to make a decision.

After consideration, I agree that my child participate in this research project according to the conditions stated above. A dated and signed copy of the present information/consent form was given to me\*.

---

Name of the minor child

---

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

Date

### **Use of audiotaped interviews**

Do you accept that your child be audiotaped during interviews?

YES ☐ NO ☐

---

Signature of the legal representative

Do you accept that the transcription of these recordings could be used for teaching and research purposes, and during scientific conferences?

YES ☐ NO ☐

---

Signature of the legal representative

### **Future use of data**

Do you accept that coded data be used for possible future research projects, subject to the approval of the research project by the Research Ethics Board?

YES ☐ NO ☐

---

Signature of the legal representative

---

\* See attached for the Assent Form signed or verbally agreed to by the child.

**Signature of the person who obtained the consent if different from the researcher in charge of the research project**

I have explained to the legal representative (parent or guardian) the terms of the present information/consent form and I answered all his questions.

---

Name and signature of the person who obtains the consent

Date

**Signature and commitment of the researcher in charge of the project**

I hereby certify that we have explained to the research participant's legal representative the terms of the present information/consent form, that we have answered the questions that the legal representative had in that respect, and that we have clearly indicated that he remains free to put an end to the participation of the research participant without suffering any prejudice.

I hereby certify that we have explained to the research participant in an adapted language that he can comprehend the research project\*. He understood and did not oppose. I hereby commit myself to respect any refusal.

I commit myself, as well as the research team, to respect what was agreed upon in the information/consent form and to give a signed copy of this form to the legal representative.

---

Name and signature of the researcher in charge of the research project

Date

## Child Assent Form Interview as Key Informant

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
Doctoral Student, McGill University

**Why are we doing this study?**

We want to better understand what you think of the Day Hospital. We also want to better understand how the program works.

**What will happen during the study?**

The Research Student will talk with you about what you think of the Day Hospital. You could also share how you feel. She might also ask you about situations you think are fair or unfair. She will make an audio recording of the times that you speak together. This will make it easier for her to remember what you talked about. If you don't want to be recorded, you can tell her and I will take notes instead. You can meet her only once, or more often 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 don't, 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 the Day Hospital. You also don't have to answer any question if you don't 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 or book (10\$ value).

**Who will know what I say?**

No one but the researchers will know what you said, and the things you talk about with the Research Student will not be shared with your parents, nurse, teachers or friends. No one at the Day Hospital will know what you said. 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. However, even if we need to share some information, it will be about the reason why we are worried for you or someone else, and not about all that you have discussed with the Research Student.

**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. You can also ask the people at the Day Hospital. Ask any questions that you may have.

---

Assent of the child able to understand the nature of the 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 obtains the assent

Date

**Participant Information/Consent Form – Adult Participation**  
**Family Member: Interview as Key Informant**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
 Professor, McGill University  
 Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
 Doctoral Student, McGill University

**Funding**

Fonds de Recherche du Québec – Santé  
 Richard and Edith Strauss Fellowship in Nursing  
 Social Sciences and Humanities Research Council of Canada

**Preamble**

We are soliciting your participation in a research project. However, before accepting to participate in this project and signing the information/consent form, take the time to read, understand and carefully examine the following information.

This form may contain words that you do not understand. We are inviting you to ask any question that you may deem useful to the researcher in charge of the research project or the student researcher, and ask them to explain to you any word or information that is unclear.

**Nature and objectives of the research project**

This project is about how challenging situations are managed with children receiving services from the Day Hospital program for children aged 6-12. The purpose of this project is to gain a better understanding of the practices, structures, and rules that are in place in child mental health. We are also interested in people's experiences related to these services, including the perspective of children, parents, and healthcare workers. We are aiming for the recruitment of a maximum of 4 family members to participate to the interviews.

**Procedures of the research project**

We are going to collect data through interviews with children, family members and healthcare workers. The student researcher will meet with you to discuss your experience related to the Pediatric Day Hospital. The interview will take place at the Pediatric Day Hospital, at a time that is convenient to you. If you prefer, the interview can also be over the phone. There could be only one interview, or more than one if you agree. Each interview will last a maximum of one hour and will be recorded. If you disagree to the audio-recording, the student researcher will write notes to remember what is discussed and the interview will not be recorded. The student researcher will ask questions related to your experience with the Pediatric Day Hospital. For example, the student researcher will ask you to describe situations in which you felt a situation was fair or unfair.

**Use of audiotaped interviews**

The goal of the audiotaped interviews is to allow researchers to review the interview to improve data analysis. We also plan, with your consent, to use the transcription of these recordings for other purposes such as teaching and research during scientific conferences.

### **Risks associated to the research project**

Risks associated to your participation to this research project are minimal and should be no greater than those experienced in your everyday life. For some people, discussing sensitive topics might cause them to become emotionally upset or anxious. If this happens to you, we will take all measures necessary to support you, such as pause or stop the discussion, or talk about what's bothering you. You can also talk to a healthcare worker at the Day Hospital with whom you feel comfortable.

The student researcher will gladly answer any questions or address any concerns you may have at any time during the study.

### **Disadvantages associated with the research project**

Possible disadvantages to your participation to the study include anxiety, stress, or frustration related to the topics that could be discussed.

### **Advantages**

You will not get any personal benefit from your participation in this research project. However, the study results may assist in the advancement of knowledge in this field.

### **Voluntary participation and possibility to withdraw**

Your participation in this research project is voluntary. You are therefore free to refuse to participate. You can also withdraw from the project at any moment, without giving any reason, by informing the researcher in charge of the project or the student researcher.

Your decision not to participate in the study or to withdraw from it will not have any impact on the quality of care and services to which you and your child are entitled or your relationship with the researcher in charge of the project, the student researcher and the caregivers.

The researcher in charge of the research project, the research ethics committee, or the granting agency could put an end to your participation, without your consent, if new findings or information indicate that your participation is no longer in your interest or for administrative reasons that would force ending the project.

If you withdraw or are withdrawn from the project, the information that was already collected in the course of the project will be destroyed and not used by the research team.

Any new findings obtained during the course of the research project that may have an impact on your decision to continue to participate in the project would be transmitted immediately to you orally and by writing.

### **Confidentiality**

During your participation in this project, the project researcher and his team will collect and record the information concerning you in a study file. Only the data required to meet the project scientific goals would be collected.

All the information collected during the research project will remain strictly confidential to the extent prescribed by law. In order to protect your identity and the confidentiality of this information, only a code number will identify you. The key to the code linking your name to your study file will be kept by the project student researcher. Only the written transcripts of the audio recordings will be kept. The audio recordings will be destroyed immediately following transcription, by deleting the audio file and any potential copies. All information and data will be stored in a locked cabinet in a locked office accessible

only to the project researcher and his team. All the computerized information will be kept on a password-protected computer in password-protected files, which will be accessible only to the project researcher and his team.

The project researcher would use this data for research purposes, in order to achieve the project scientific goals, described in the information/consent form. This data would be kept by the researcher in charge of the project for 7 years following publication of the results, and will then be destroyed in conformity with the rules in effect. Coded data might be used for possible future research studies with your consent. However, no identifiable information would be used in future research.

The data could be published in scientific specialized magazines or shared by other individuals during scientific meetings; however, it would not be possible to identify you.

For surveillance and control purposes, your study file could be examined by a person mandated by the Research Ethics Board, if necessary. All these individuals agree with the privacy policy.

You have the right to consult your study file in order to verify the information gathered and to correct them, if necessary, as long as the project researcher or the institution holds this information.

### **Funding of the research project**

The researcher in charge of the project received funding from a Granting Agency, the Social Sciences and Humanities Research Council of Canada for the successful completion of the research project. The student researcher received funding from a Granting Agency, the Fonds de recherche du Québec - Santé, and from the Richard and Edith Strauss Foundation, for the conduct of this project as part of her doctoral studies.

### **Rights of the research participant**

By accepting to participate in this project, you are not waiving any of your legal rights nor discharging the researchers or the institution of their civil and professional responsibility.

### **Compensation**

You will receive a small lump sum (10\$) in compensation for costs incurred and for constraints.

### **Identification of contact persons**

If you have questions concerning the research project or if you feel you have a problem related to your participation in the research project, you can communicate with the researcher in charge of the project, Franco Carnevale (nurse) at the following number: xxx-xxxx. You can also contact the student researcher, Marjorie Montreuil (nurse) at the following number: xxx-xxxx.

For any question concerning your rights as a research participant participating in this research project or if you have comments or wish to file a complaint, you can communicate with the Service Quality Commissioner at the following number: xxx-xxxx.

### **Control of the ethical aspects of the research project**

The Research Ethics Board approved this research project and guarantees the follow-up. In addition, it will first approve any review and amendment made to the information/consent form and to the study protocol.

### **The research participant's consent**

I took notice of the information/consent form. I acknowledge that the research project was explained to me, that my questions were answered and that I was given sufficient time to make a decision.

I agree to participate in this research project according to the conditions stated above. A dated and signed copy of the present information/consent form was given to me.

---

Name and signature of the research participant

Date

### **Use of audiotaped interviews**

Do you accept to be audiotaped during interviews?

YES ☐ NO ☐

---

Signature of the research participant

Do you accept that the transcription of these recordings could be used for teaching and research purposes, and during scientific conferences?

YES ☐ NO ☐

---

Signature of the research participant

### **Future use of data**

Do you accept that coded data be used for possible future research projects, subject to the approval of the research project by the Research Ethics Board?

YES ☐ NO ☐

---

Signature of the research participant

### **Signature of the person who obtained the consent if different from the researcher in charge of the research project**

I have explained to the research participant the terms of the present information/consent form and I answered all his questions.

---

Name and signature of the person who obtains the consent

Date

### **Signature and commitment of the researcher in charge of the project**

I hereby certify that we have explained to the research participant the terms of the present

information/consent form, that we have answered the questions that the participant had in that respect and that we have clearly indicated that he remains free to withdraw from the study, without suffering any prejudice

I commit myself, as well as the research team, to respect what was agreed upon in the information/consent form and to give a signed copy of this form to the research participant.

---

Name and signature of the researcher in charge of the research project      Date

**Participant Information/Consent Form – Adult Participation  
Healthcare Worker: Interview as Key Informant**

**Title of the research project:** Crisis management in a child mental health setting: Solutions from a participatory hermeneutic ethnographic study

**Researcher in charge of the research project**

Franco Carnevale, RN, PhD  
Professor, McGill University  
Director of Nursing Research, Douglas Institute

**Student researcher**

Marjorie Montreuil, RN, MSc(a)  
Doctoral Student, McGill University

**Funding**

Fonds de Recherche du Québec – Santé  
Richard and Edith Strauss Fellowship in Nursing  
Social Sciences and Humanities Research Council of Canada

**Preamble**

We are soliciting your participation in a research project. However, before accepting to participate in this project and signing the information/consent form, take the time to read, understand and carefully examine the following information.

This form may contain words that you do not understand. We are inviting you to ask any question that you may deem useful to the researcher in charge of the research project or the student researcher, and ask them to explain to you any word or information that is unclear.

**Nature and objectives of the research project**

This project is about how challenging situations are managed with children receiving services from the Day Hospital program for children aged 6-12. The purpose of this project is to gain a better understanding of the practices, structures, and rules that are in place in child mental health. We are also interested in people's experiences related to these services, including the perspective of children, parents, and healthcare workers. We are aiming for the recruitment of a maximum of 4 healthcare workers to participate to the interviews.

**Procedures of the research project**

We are going to collect data through interviews with children, family members and healthcare workers. The student researcher will meet with you to discuss your experience as a healthcare worker at the Pediatric Day Hospital. The interview will take place at the Pediatric Day Hospital, at a time that is convenient to you and the student researcher, during your working hours. There could be only one interview, or more than one if you agree. Each interview will last a maximum of one hour and will be recorded. If you disagree to the audio recording, the student researcher will write notes to remember what is discussed and the interview will not be recorded. The student researcher will ask questions related to your experience working at the Pediatric Day Hospital, as well as the rules, structures and practices that are in place.

**Use of audiotaped interviews**

The goal of the audiotaped interviews is to allow researchers to review the interview to improve data analysis. We also plan, with your consent, to use the transcription of these recordings for other purposes such as teaching and research during scientific conferences.

### **Risks associated to the research project**

Risks associated to your participation to this research project are minimal and should be no greater than those experienced in your everyday life. For some people, discussing sensitive topics might cause them to become emotionally upset or anxious. If this happens to you, we will take all measures necessary to support you, such as pause or stop the discussion, or talk about what's bothering you. You can also talk to a manager or colleague at the Day Hospital with whom you feel comfortable.

The student researcher will gladly answer any questions or address any concerns you may have at any time during the study.

### **Disadvantages associated with the research project**

Possible disadvantages to your participation to the study include anxiety, stress, or frustration related to the topics that could be discussed.

### **Advantages**

You will not get any personal benefit from your participation in this research project. However, the study results may assist in the advancement of knowledge in this field. The discussions with the student researcher may help you reflect about the rules and practices used at the Day Hospital.

### **Voluntary participation and possibility to withdraw**

Your participation in this research project is voluntary. You are therefore free to refuse to participate. You can also withdraw from the project at any moment, without giving any reason, by informing the researcher in charge of the project or the student researcher.

Your decision not to participate in the study or to withdraw from it will not have any impact on your work or your relationship with the researcher in charge of the project, the student researcher, and your manager.

The researcher in charge of the research project, the research ethics committee or the granting agency could put an end to your participation, without your consent, if new findings or information indicate that your participation is no longer in your interest or for administrative reasons that would force ending the project.

If you withdraw or are withdrawn from the project, the information that was already collected in the course of the project will be destroyed and not used by the research team.

Any new findings obtained during the course of the research project that may have an impact on your decision to continue to participate in the project would be transmitted immediately to you orally and by writing.

### **Confidentiality**

During your participation in this project, the project researcher and his team will collect and record the information concerning you in a study file. Only the data required to meet the project scientific goals would be collected.

All the information collected during the research project will remain strictly confidential to the extent prescribed by law. In order to protect your identity and the confidentiality of this information, only a code number will identify you. The key to the code linking your name to your study file will be kept by the project student researcher. Only the written transcripts of the audio recordings will be kept. The audio recordings will be destroyed immediately following transcription, by deleting the audio file and any potential copies. All information and data will be stored in a locked cabinet in a locked office accessible only to the project researcher and his team. All the computerized information will be kept on a password-

protected computer in password-protected files, which will be accessible only to the project researcher and his team.

The project researcher would use this data for research purposes, in order to achieve the project scientific goals, described in the information/consent form. This data would be kept by the researcher in charge of the project for 7 years following publication of the results, and will then be destroyed in conformity with the rules in effect. Coded data might be used for possible future research studies, with your consent. However, no identifiable information would be used in future research.

The data could be published in scientific specialized magazines or shared by other individuals during scientific meetings; however, it would not be possible to identify you.

For surveillance and control purposes, your study file could be examined by a person mandated by the Research Ethics Board, if necessary. All these individuals agree with the privacy policy.

You have the right to consult your study file in order to verify the information gathered and to correct them, if necessary, as long as the project researcher or the institution holds this information.

### **Funding of the research project**

The researcher in charge of the project received funding from a Granting Agency, the Social Sciences and Humanities Research Council of Canada for the successful completion of the research project. The student researcher received funding from a Granting Agency, the Fonds de recherche du Québec - Santé, and from the Richard and Edith Strauss Foundation, for the conduct of this project as part of her doctoral studies.

### **Rights of the research participant**

By accepting to participate in this project, you are not waiving any of your legal rights nor discharging the researchers or the institution of their civil and professional responsibility.

### **Compensation**

No compensation will be provided for your participation to this study.

### **Identification of contact persons**

If you have questions concerning the research project or if you feel you have a problem related to your participation in the research project, you can communicate with the researcher in charge of the project, Franco Carnevale (nurse) at the following number: xxx-xxxx. You can also contact the student researcher, Marjorie Montreuil (nurse) at the following number: xxx-xxxx.

For any question concerning your rights as a research participant participating in this research project or if you have comments or wish to file a complaint, you can communicate with the Service Quality Commissioner at the following number: xxx-xxxx.

### **Control of the ethical aspects of the research project**

The Research Ethics Board approved this research project and guarantees the follow-up. In addition, it will first approve any review and amendment made to the information/consent form and to the study protocol.

### **The research participant's consent**

I took notice of the information/consent form. I acknowledge that the research project was explained to

me, that my questions were answered and that I was given sufficient time to make a decision.

I agree to participate in this research project according to the conditions stated above. A dated and signed copy of the present information/consent form was given to me.

---

Name and signature of the research participant

Date

### **Use of audiotaped interviews**

Do you accept to be audiotaped during interviews?

YES ☐

NO ☐

---

Signature of the research participant

Do you accept that the transcription of these recordings could be used for teaching and research purposes, and during scientific conferences?

YES ☐

NO ☐

---

Signature of the research participant

### **Future use of data**

Do you accept that coded data be used for possible future research projects, subject to the approval of the research project by the Research Ethics Board?

YES ☐

NO ☐

---

Signature of the research participant

### **Signature of the person who obtained the consent if different from the researcher in charge of the research project**

I have explained to the research participant the terms of the present information/consent form and I answered all his questions.

---

Name and signature of the person who obtains the consent

Date

### **Signature and commitment of the researcher in charge of the project**

I hereby certify that we have explained to the research participant the terms of the present information/consent form, that we have answered the questions that the participant had in that respect and that we have clearly indicated that he remains free to withdraw from the study, without suffering any prejudice.

I commit myself, as well as the research team, to respect what was agreed upon in the information/consent form and to give a signed copy of this form to the research participant.

---

Name and signature of the researcher in charge of the research project      Date

## Appendix F

### Example of Letter Sent to Parents for Recruitment

#### **Research Project**

Dear parent,

In follow up to our phone discussion regarding the research project on [name of unit], here is the consent form to authorize your child's participation to the project. Please take the time to read the form and let me know if you have any questions or concerns. You can send the signed form back through your child's agenda.

For any questions, don't hesitate to contact me.

Sincerely,

Marjorie Montreuil  
[Phone number and email address]

## Appendix G

### Interview Guides

#### Interview Guide: Child

Please note that even though the questions are numbered, the questions could be addressed in an order different than the one presented here, to allow the participants to freely share their experience.

N.B.: With children, no questions will specifically address the use of control measures to prevent the recall of potentially distressing situations. It is only in the event that a child initiates a discussion related to the use of control measures that this discussion will be pursued. Particular attention will be given to the child's verbal and non-verbal expressions that he/she wants to stop the interview, which will be respected.

#### 1. Introduction:

- Invite child to address student researcher on a first name basis
- Icebreaker: For example, ask child to tell a little about themselves (e.g. name, age, number of siblings)
- Mention there is no right or wrong answer; it is an open discussion
- Mention that their comments will remain strictly confidential
- Specify that the interviews will be audio-recorded if they agree, in order for the student researcher to remember what is being said
- Specify that the child can withdraw at any time
- Mention that by accepting to participate in this project, the child is not waiving any of his or her legal rights nor discharging the researchers or the institution of their civil and professional responsibility.
- “So, [first name of participant], we are trying to understand how children like you think and feel about the Day Hospital. How is it at the Day Hospital?”

#### 2. Norms, structures, practices:

- How is it on the unit?
  - What happens at the beginning of the day?
  - What are the activities that you do during the day [morning, lunchtime, afternoon]?
    - What do you think of these activities?
    - What do you prefer?
    - What do you dislike?
  - Who is present on the unit?
    - What does each person do?
- What are the rules on the unit?
  - What do you think of these rules?
  - How do they make you feel?
  - Who decided what the rules are?
- What happens when there is a disagreement?

- Tell me about a specific situation

3. Moral experiences:

- What does it mean to you to be fair? To be good?
- Describe a situation in which you felt what happened was fair or unfair [or good or bad]. The situation can be related to you or to others around you.
  - Who was involved?
  - How did you feel?
  - What do you think of this situation?
  - What did you do?
  - What did others do?
  - What happened after that?
  - What does this situation mean to you? To others?
  - What could have been done differently?
- Is there another situation you would like to share with me?

### Interview Guide: Family Member

Please note that even though the questions are numbered, the questions could be addressed in an order different than the one presented here, to allow the participants to freely share their experience.

#### 1. Introduction:

- Mention that their comments will remain strictly confidential.
- Specify that the interviews will be audio-recorded if they agree, in order 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 relationship with the child receiving care at the Day Hospital.
- How long has [name of the child] been receiving mental health care? At the Day Hospital?
- We would like you to tell us your thoughts on the program that is in place at the Day Hospital, and also to hear about your experience with these services.

#### 2. Norms, structures, practices:

- What do you think of the program that is offered at the Day Hospital?
- Are you present during the activities or meetings that are taking place?
  - [If yes] What do you think of these activities or meetings?
- Have you been informed of the rules that are in place?
  - What do you think of these rules?
- Are family members involved in care decisions?
  - [If yes] How are you involved?
  - [If not] Would you like to be involved? [If yes] how?
- What do you think of the use of control measures (e.g. seclusion room or holding) at the Day Hospital?
- [If the person interviewed is the parent or legal guardian] Regarding the use of control measures, do you have to consent to their use with your child?
  - How is this decision made?
- Have control measures been used with your child?
  - [If yes] Please tell me about a situation when control measures were used.
  - [If not] Have you witnessed a situation in which control measures were used? [If yes] please describe.
    - [Follow up with probes on moral experience below, to explore the moral experience related to the use of control measures]
    - From your perspective, what other practices could be used?

#### 3. Moral experiences:

- Please describe what it means to you to be just? To be good? To be right?

- Describe a situation in which you felt what happened to your child at the Day Hospital was just or unjust [or good or bad, right or wrong].
  - Who was involved?
  - How did you feel?
  - What do you think of this situation?
  - What did you do?
  - What did others do?
  - What happened after that?
  - What does this situation mean to you? To others?
  - What could have been done differently?
- Is there another situation you would like to share?

## Interview Guide: Healthcare Worker

Please note that even though the questions are numbered, the questions could be addressed in an order different than the one presented here, to allow the participants to freely share their experience.

### 1. Introduction:

- Mention that their comments will remain strictly confidential.
- Specify that the interviews will be audio-recorded if they agree, in order 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 current position and past work experience.
- We would like you to tell us your thoughts about the program that is in place at the Day Hospital, and also to hear about your experience working in this setting.

### 2. Norms, structures, practices:

- Please describe the program in place at the Day Hospital.
  - What philosophy guides the program?
  - What are some of the practices and norms/rules in place [implicit and explicit]?
  - How is the program structured?
  - Who is present on the unit? What are the different roles?
- What are the rules on the unit?
  - Who decides what the rules are?
  - What do you think of these rules?
  - [If the person is enforcing the rules] How does it make you feel to apply these rules?
- Tell me about a typical day on the unit.
  - What happens at the beginning of the day?
  - What are the activities during the day [morning, lunchtime, afternoon]?
    - What do you think of these activities?
    - How is the schedule established?
    - Who decides what the schedule will be?
- How are disputes/disagreements handled with children on the unit?
  - Tell me about a specific situation
  - What do you think about the way disputes/disagreements are handled?
  - How does this make you feel?
- Have you used control measures with children at the Day Hospital?
  - [If yes] Please tell me about a situation when you used control measures.
  - [If not] Have you witnessed a situation in which control measures were used? If yes, please describe.
    - [Follow up with probes on moral experience below, to explore the moral experience related to the use of control measures]

- What other practices are used at the Day Hospital in case of a crisis situation?
    - What other practices could be used?
- 3. Moral experiences:
  - Please describe what it means to you to be just? To be good? To be right?
  - Describe a situation in which you felt what happened was just or unjust [or good or bad, right or wrong].
    - Who was involved?
    - How did you feel?
    - What do you think of this situation?
    - What did you do?
    - What did others do?
    - What happened after that?
    - What does this situation mean to you? To others?
    - What could have been done differently?
  - Is there another situation you would like to share?

## Appendix H

### Documentation Review Guide

The questions are related to the analysis of children's charts (e.g. professionals' notes) and other key institutional documents (e.g. policies, procedures, unit rules, code of conduct, and clinical tools). The identification of the specific documents will be done in collaboration with the members of the advisory committee and key informants.

#### **Guiding Questions for Chart Review and Review of Other Institutional Documents:**

1. What norms, structures, and practices are reported in the text?
  - How are the norms, structures, and practices described?
  - What is the meaning?
  - What is the deeper meaning?
2. How are crisis situations documented in the child's chart?
  - What are the similarities and differences with other notes?
  - When control measures are used, how is their use justified?
  - Who is involved? What is each person doing?
  - What happens before, during, and after a crisis situation?
    - What are the similarities and differences when control measures are used or not?
  - What practices are used?
3. What conceptions of right/wrong, good/bad, just/unjust are conveyed in the notes?
  - What are the underlying assumptions?
4. How is the child referred to?
  - Is the perspective of the child included in the notes?
    - Is this perspective similar or different when crisis situations are documented? When control measures are used?
  - Is the perspective of family members included in the notes?

## Appendix I

## Form and Flyer Sent to Parents for Advisory Committee Participation

November 11, 2015

**Parents' Committee**

Research Project

Dear parents,

We are inviting you to be part of an advisory committee for a research project. We are looking for 4 parents and children to help us improve the care offered at the Day Hospital.

Do you agree that I call you to give you more information on this project?

☐ Yes☐ No

Name\_\_\_\_\_

Phone number\_\_\_\_\_

Signature\_\_\_\_\_

Date\_\_\_\_\_

Thank you!

Marjorie Montreuil

Nurse

Doctoral student, McGill University

[phone number and email address]

## Project's Main Objective

Examine what is currently happening in the setting



Improve practices  
related to how  
difficult situations are  
addressed

Thank  
you!

If you have any questions or if  
you want to be part of the  
committee, please contact :

Marjorie Montreuil  
(Email address and phone number)

## Research Project

Crisis management in  
child mental health

Project conducted by :

Marjorie Montreuil  
Doctoral Nursing Student

Supervisor:

Franco Carnevale  
Professor McGill University  
Director of Nursing Research  
Douglas Institute

This project is receiving funding from:  
Fonds de recherche du Québec en santé  
Richard and Edith Strauss Foundation

Marjorie Montreuil is a doctoral trainee for the  
project conducted by Franco Carnevale  
VOICE: Views On Interdisciplinary Childhood

### Approach used : Participatory

The objective is to **collaborate** with key people from the setting during the research process.

This approach leads to the development of **practical** knowledge that can be applied concretely.



### Need to put in place an **Advisory Committee**

This committee will participate to the different steps of the research process.

The role of the committee members is to bring their **own perspective and experience**. This will help develop knowledge that is sensitive to the needs of the people in the setting.

#### **Committee Structure**

4 children  
4 parents  
4 healthcare workers

#### **Frequency of meetings:**

About once a month

#### **Length of meetings:**

Maximum 1 hour

N.B.: The details related to the functioning of the committee will be decided jointly with the members during the first meeting.

