The Experiences of Children with a Mental Health Disorder: A PhotoVoice Approach to Understanding What Matters

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December, 2015

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master's of Science (Rehabilitation Sciences)

Acknowledgements

This thesis would not have been possible without the support of many wonderful people in my life. First and foremost, I would like to thank my husband for his endless support throughout this entire process. Thank you for understanding how important this was for me to do and for always making sure that I took some time for myself and for us. The days of “I can’t this weekend, I have a paper due” are almost over!

To my parents, in-laws and siblings – thank you for all your help. Whether it was proof-reading, sorting through and stapling pages together, bringing over a cooked meal or simply letting me vent my frustrations, I appreciate every kind gesture over the last four years.

I also have an endless amount of gratitude for the staff of the day hospital program at the Center for Child Development and Mental Health. Thank you for your support, collaboration and flexibility that allowed me to attend courses and carry out this research project during program hours without affecting the quality of the work that we do. It is such a privilege to be part of this team of dedicated professionals. And to Dr. Guzder, thank you for your enthusiasm and for believing in the potential of this project. This project truly would not have been possible without the wonderful children and their families who agreed to participate in this research study. Thank you for your hard work, for sharing your life experiences with me and for letting me learn so much from you.

Finally, I would like to thank the members of my supervisory committee who allowed me to bring my ideas to fruition and provided me with the resources to do so. Dr. Steven Jordan, thank you for your expertise and guidance during study design.
Heather, and your word sickle of course, you have this natural ability to take something that looks so complicated and shape it into small, manageable steps. Your influence is a large part of the reason why this thesis is anywhere near completion. Melissa, there are no words to express how thankful I am for your seemingly endless time and dedication to me and to this project. Thank you for making me feel like your number one priority, even when I knew you had a million other things going on. Thank you also for listening to me ramble on about my many ideas and somehow hearing something that made sense, and then asking me enough questions to get me to see it for myself. Your feedback throughout this process has been invaluable and I have learned so much from you.

Statement of Authorship

The candidate is the primary author of all manuscripts and claims full responsibility for the content and style included in this thesis.

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The following images were included by the participants for their lifebooks. Please note that these images can be found at the end of Chapter Four, prior to the Tables and References sections.

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Abstract

Mental health disorders in childhood are highly prevalent throughout North America and can result in drastic impairments in a child's social, emotional and academic functioning. Recent initiatives for the delivery of mental health care services across Canada and the United States of America include a model of recovery-oriented care, whereby clients become active participants in making health care decisions and become experts in the management of their difficulties. As children are becoming increasingly recognized as competent reporters about their health needs, this collaborative process between professionals and clients when making health care decisions has now extended to include children.

As such, the development of self-reporting measures allowing children to express their needs is growing. A scoping review of the literature identified thirty-three self-report measures used with children among a range of disciplines. However, among these child-focused assessment tools used in rehabilitation, most are created using adult-defined constructs and consist of questionnaire format which can limit the scope of the dialogue between client and professional. While these tools allow children to be part of the rehabilitation process, the information obtained does not necessarily reflect what matters to children. Furthermore, many clinicians continue to rely on the reports of parents or other proxy reports rather than the child's perspective directly. This is particularly true for children with mental illness whose views are often ignored. Therefore, more research is needed on clinical approaches that directly address the unique experiences of children with mental illness.

Qualitative methods have been used to explore the lived experiences of children. The methods employed in this particular study consisted of a narrative-phenomenological approach to a focused ethnography in order to examine the experiences of four children with a mental health disorder before, during and after nine PhotoVoice sessions. The purpose of this study was to examine what the PhotoVoice process can add to self-report measures for children with mental health disorders.

The PhotoVoice approach and the ethnographic methods employed in this study allowed us to capture the experiences of children with a mental health disorder, and specifically to understand what mattered in those experiences. The results of this study

highlight how the PhotoVoice process could provide a medium through which the children articulated what mattered about particular activities. The PhotoVoice activity also demonstrated the potential to empower the children as active participants and resulted in child-driven content, in line with the principles of recovery-oriented services. In addition, the ethnographic methods employed, i.e. interviews and participant observations, allowed for observation beyond performance of an activity to include meaning and the real-world context of the child's experiences. Thus, the PhotoVoice activity offered several advantages as a potential activity-based intervention. This is particularly important for occupational therapists who promote the client's engagement in activities that are meaningful, purposeful and goal-directed, while supporting child-driven recovery initiatives.

Sommaire

Les troubles de santé mentale de l'enfance sont très répandus en Amérique du Nord et peuvent entraîner des dépréciations sévères dans le fonctionnement social, affectif et scolaire de l'enfant. Les initiatives récentes pour la prestation de services de soins de santé mentale au Canada et aux États-Unis amènent un modèle axé sur le rétablissement ou « Recovery », par lequel les clients deviennent des participants actifs dans la prise de décisions de soins de santé et des experts dans la gestion de leurs difficultés. Comme les enfants sont reconnus de plus en plus compétents au sujet de leurs besoins de santé, cette collaboration entre professionnels et clients est maintenant étendue pour inclure les enfants.

À cet effet, le développement de mesures d'auto-évaluation permettant aux enfants d'exprimer leurs besoins augmente. Une revue de la littérature a identifié trente-trois mesures d’auto-évaluations utilisées avec des enfants parmi plusieurs disciplines. Cependant, la plupart des outils d'évaluation sont créés en utilisant des concepts définis par les adultes et consistent en forme de questionnaire qui peut limiter la portée du dialogue entre le client et professionnel. Bien que ces outils permettent aux enfants de faire partie du processus de réadaptation, les informations recueillies ne reflètent pas nécessairement ce qui compte pour les enfants. De plus, de nombreux cliniciens continuent de compter sur les rapports des parents ou d'autres rapports de proxy plutôt que la perspective de l'enfant directement. Cela est particulièrement le cas pour les enfants souffrant de troubles de santé mentale, dont les vues sont souvent négligées. Par conséquent, plus de recherche est nécessaire sur les approches cliniques qui répondent directement aux expériences uniques des enfants atteints de troubles de santé mentale.

Les méthodes de recherche qualitatives sont souvent utilisées pour étudier les expériences vécues par les enfants. Les méthodes empruntées dans cette étude consistent d’une approche narrative - phénoménologique à une ethnographie qui vise d'examiner les expériences de quatre enfants avec un trouble de santé mentale avant, pendant et après neuf séances de PhotoVoice. L’objectif de cette étude était d'observer ce que le processus de PhotoVoice peut accroître aux mesures d'auto-évaluation pour les enfants souffrant de troubles de santé mentale.

L'approche de PhotoVoice et les méthodes ethnographiques utilisées dans cette étude nous ont permis de saisir les expériences vécues des enfants avec un trouble de santé mentale, et en particulier à les comprendre ce qui leur comptait. Les résultats obtenus mettent en évidence la manière dont le processus de PhotoVoice fournit un moyen par lequel les enfants expriment ce qui comptait par rapport à leurs activités et expériences particulières. L'activité de PhotoVoice démontre également le potentiel d'habiliter les enfants en tant que participants actifs, en ligne avec les principes des services axés sur le rétablissement, et résultant en données emmenées par l'enfant. De plus, les méthodes ethnographiques, c'est-à-dire les entrevues et les observations des participants, ont permis l'observation au-delà de la performance d'une activité pour inclure la signification et le contexte réel des expériences de l'enfant. Donc, le processus de PhotoVoice offert plusieurs avantages comme une intervention axée sur l'activité. Ceci est particulièrement important pour les ergothérapeutes qui favorisent l'engagement du client à des activités significatives, ciblées et orientées vers un but, tout en soutenant les initiatives de l'enfant.

Statement of Originality

The manuscripts presented in Chapter 2 and 5 represent original contributions to the field of rehabilitation science for occupational therapy and pediatric mental health disorders.

Chapter 2, the first manuscript, presents the results of a scoping review of the literature, done to identify existing self-report measures used with children across a range of disciplines and the extent to which these measures elicited the children's perspective of what matters to them.

Chapter 5, the second manuscript, presents how PhotoVoice was used as a therapeutic modality during a participatory group activity to understand what mattered in the experiences of four children with severe behavioural problems referred to a day hospital program. This manuscript also presents how ethnographic methods were used to evaluate the effectiveness of the PhotoVoice process as a self-report assessment.

Preface & Contribution of Authors

This thesis represents the culmination of several years of ongoing discussions and evolving ideas. For the last eight years I have had the pleasure of working with young children and their families. However,

> *"Children who think, feel, or act in ways that do not conform with the dominant social views of normal child development or mental health are viewed as different, experiencing their social identities and lives as deviant and marginalized, and their treatment within society as regulated and controlled"* (James & Jenks, 1996 as cited in Liegghio, Nelson & Evans, 2010, p.85).

The children that I work with are labelled with a variety of mental health disorders and are often described using terms such as difficult to manage, disruptive or violent, to name a few. Yet, my experience in working with these children has brought me away from any label, and has allowed me to truly get to know these children who continually inspire me every day.

More specifically, my work as an occupational therapist has allowed me to appreciate each child as a unique individual, with their own personal interests, values and experiences. However, the methods I had at my disposal for uncovering these interests, values and experiences were lacking. I would often ask myself if I was asking the right questions. Then, after filling out questionnaires with them, for example about their interests and activities, I was left wondering whether there were other parts of their lives that the questionnaires just didn't address, and what those parts could be.

I began to reflect on whether my practice could be considered client-centered, particularly since I felt that part of their story was missing. Was I helping the children to attain goals they found meaningful and relevant? Of course the answer to this question was also complicated by the fact that children were typically referred for occupational therapy support due to parental or professional concerns, and ultimately influenced the selection of treatment goals.

I started to think about the different ways used to access the perspectives of children directly, and then, more specifically, how to understand what children found meaningful. Certainly interviews and drawings came to mind. Then, after having taken a course in qualitative research methods, I discovered many interesting alternatives which I was able to combine for the research project that I executed while working towards the completion of this degree.

Contribution of Authors

All authors contributed extensively to the manuscripts included in this thesis. The candidate was primarily responsible for executing the scoping review presented in the first manuscript, and for recruitment and data collection procedures presented in the second manuscript. Dr. Melissa Park and Dr. Heather C. Lambert assisted with study design and data analysis.

Both manuscripts were written primarily by the candidate. Dr. Melissa Park and Dr. Heather C. Lambert provided extensive feedback and revisions to both the content and style of the final manuscripts.

References

Liegghio, M., Nelson,G. & Evans, S.D. (2010). Partnering with children diagnosed with mental health issues: Contributions of a sociology of childhood perspective to participatory action research. *American Journal of Community Psychology,* 46: 84-99.

Thesis Format

In accordance with the McGill Graduate and Postdoctoral Studies regulations and guidelines for thesis preparation, this document is comprised of a manuscript-based thesis. This thesis includes two manuscripts which have been submitted for publication.

Chapter 1 provides a general introduction of the prevalence, impact and treatment of mental health disorders in childhood. This chapter also introduces the recovery model as an emergent approach to the delivery of mental health care services.

Chapter 2 introduces the first manuscript, which provides the results of a scoping review of the literature, done to identify existing self-report measures used with children across a range of disciplines and the extent to which these measures elicited the children's perspective of what matters to them. This manuscript has been submitted for publication in the journal entitled *Occupational Therapy in Mental Health*.

Chapter 3 provides a comprehensive review of the methodology employed in this research project to access what matters to children with a mental health disorder. This includes a description of the setting, the participants, data collection methods and data analysis procedures.

Chapter 4 presents the results of the thematic and narrative analysis of the data collected related to the experiences that matter to children with a mental health disorder.

Chapter 5 presents the second manuscript included in this thesis, with specific focus on how PhotoVoice was used as a therapeutic modality during a participatory group activity to understand what mattered in the experiences of four children with severe behavioural problems referred to a day hospital program. This manuscript also presents how ethnographic methods were used to evaluate the effectiveness of the PhotoVoice process as a self-report assessment. This manuscript has been submitted for publication to the *Scandinavian Journal of Occupational Therapy*.

Chapter 6 includes a discussion of the clinical implications resulting from this project and the future implications of PhotoVoice for children with a mental health disorder.

Finally, all of the references used for the manuscripts and for additional supporting material have been consolidated and are included at the end of this thesis.

Chapter I. Introduction

Mental Health Disorders in Children

It is estimated that one in three-to-four children meet criteria for a mental health disorder according to the Diagnostic and Statistical Manual of Mental Disorders (Merikangas, Nakamura & Kessler, 2009). Disorders include "attention deficit hyperactivity disorder, oppositional defiant or conduct disorders, depression or mood disorders, anxiety disorders, and schizophrenic or psychotic disorders" (Forness, Kim & Walker, 2012, p.3). About one in ten children experience a "mental health problem that has a drastic impact on a child's ability to function socially, academically, and emotionally" (Merikangas et al., 2009, p.18). These mental health disorders cause significant disruption within various environmental domains of a child's life, including the family home and the school community, and result in impairments in the child's social, emotional and academic functioning (Clark & Jerrott, 2012). Long-term outcomes include "school failure, greater dropout rates, and unsuccessful transition to the work force" (Ryan, Pierce & Mooney, 2008 as cited in Farley, Torres, Wailehua, & Cook, 2012, p.42).

The difficulties experienced by children with a mental health disorder also become apparent when creating and maintaining interpersonal relationships (Heward, 2006; Farley et al., 2012). Children with a mental health disorder reported lack of empathy for others, poor participation in leisure and extra-curricular activities, and poor quantity and quality of friendships (Schonert-Reichl, 1993 as cited in Heward, 2006, p.228). These social factors place these children at risk for depression, poor self-image, future delinquency, substance abuse, and criminal charges (Grizenko, Papineau & Sayegh, 1993; Pardini & Fite, 2010). Yet, approximately only half of these children who experience mental health difficulties will receive treatment and, often, these children are those that are experiencing more severe difficulties (Merikangas et al., 2009). This is a serious problem as "[t]he majority of young people who require specialized mental heath care do not receive it" (Kutcher & McLuckie, 2010, p.10).

Recovery: An Emergent Model of Mental Health Care

Over the years, there have been notable paradigmatic shifts in the care and services rendered for people with mental health illnesses stemming from the deinstitutionalization initiative of the 1970s, with increased provision of services in community settings (Young & Ensing, 1999). Concurrently, there was a movement towards evidence-based practice with implementation of clinical interventions that have been scientifically proven effective (Frese, Stanley, Kress & Vogel-Scibilia, 2001). In the United States of America, mental health services of the early 1990s begin to focus on the concept of recovery (Anthony, 1993). Recovery is seen as therapeutic approach for people with mental illness and is described as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles” (Anthony, 1993, p.527). The underlying belief is that those with “severe mental health problems can be sustained in their local communities within their naturally evolved support network” (Kaplan & Racussen, 2013, p.246).

Persons with mental illness become active participants in taking responsibility and becoming experts in the management of their difficulties (Frese et al., 2001; Jacobson & Greenley, 2001; Kaplan & Racussen, 2013). While most of the literature surrounding the use of the recovery model in mental health centres around the adult population, the National Alliance for Mental Illness advocates that all clients with mental illness and their families can benefit and be empowered from learning to manage their own illness (Wittiwer, 2006). For an adolescent population, Kaplan and Racussen’s (2013) novel implementation of the recovery model resulted in shorter lengths of admission, increased client and family satisfaction, stronger therapeutic alliance and inspired resilience. Additionally, Christens and Peterson (2012) underline that empowerment, self-efficacy and supportive environments, central tenants of the recovery model, are important influences in youth and adolescent development and well-being.

With their recent mental health strategy published in 2012, the Mental Health Commission of Canada stated that the recovery model allows for active involvement of people with mental illness in decision making and provides them with the opportunity to live meaningful and purposeful lives and *can be applied to all ages* [emphasis added] (Mental Health Commission of Canada, 2012). The Evergreen Framework, another recent Canadian initiative developed by the Mental Health Commission of Canada, involved the collaboration and active participation of young people with mental illness and their families as well as mental health professionals across the country in an effort to improve the “mental health of and mental health care for children and youth across Canada” (Kutcher & McLuckie, 2010, p.10). The resulting values and strategic directions included in the framework aim to ensure that mental health services address the *values and needs identified by children with mental health issues* [emphasis added] and their families (Kutcher & McLuckie, 2010).

The Gap Between Recovery and Assessment in Mental Health Care for Children

Emergent recovery-oriented practices foreground the important influence of subjective life experiences on health and development (Kutcher & McLuckie, 2010). Typical assessment practices integrate information from multiple sources and using multiple methods, including reports from parents and any other caregivers as well as direct observation of the child (Carter Briggs-Gowan, & Ornstein Davis , 2004). This often results in an objectivist approach by which a diagnosis is made and through which mental health services are received, often taking precedence over the child's subjective experiences (Liegghio, Nelson & Evans, 2010). Specifically, adults act as the controlling social agents and "children with mental health issues often have little say over what type of help they get and limited influence over treatment decisions" (Ibid., p.88). However, as identified by Kutcher and McLuckie (2010) "youth frequently stressed the need to be active partners and decision makers related to their health and mental health" (p.29). Furthermore, despite recent policy and the strategic plan described above for recovery-oriented care in Canada to empower clients, *including youth* [emphasis added], in the management of their own care, there continues to be a lack of research on what matters to children and on clinical approaches that can more directly capture their experiences first hand (Mental Health Commission of Canada, 2012).

Aims and Objectives

The primary objective of this study was to understand what is meaningful or important in a child's life, from the perspective of a child with a mental health disorder. More specifically, this study examined how the PhotoVoice process, as a modality for self-report, could be used to access the experiences of children with a mental health disorder and to understand what mattered in those experiences. The knowledge gained could be used to enhance child-focused and child-driven interventions in clinical practice.

How Can We Access the Child's Perspective?

In order to truly understand their unique experiences, "it is important that children have the opportunity to describe their own subjective experience" (Cremeens et al., 2006, p.751). In order for children to be included in the therapeutic process, clinicians need a way to access the child's perspective on what matters or what is meaningful in his/her life. The use of self-report allows children to express their subjective concerns and needs. As such, a review of the literature was done in order to identify what self-report measures were currently available across a range of disciplines to access the unique experiences of children directly from their perspective.

In the following chapter, I present the manuscript completed in collaboration with Dr. Heather C. Lambert and Dr. Melissa Park, and submitted for publication in *Occupational Therapy in Mental Health* on September 29, 2015. In line with the clinical context of the research study that was employed, we begin with an overview of the impact of mental health disorders in childhood. However the main purpose of this manuscript is to present the results of this scoping review, which provided an important foundation and starting point for the research study described in this thesis that aimed to access the experiences of children with a mental health disorder.

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Chapter II. Capturing the child's perspective: A review of self-report measures used with children

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Article submitted for publication in *Occupational Therapy in Mental Health.*

Abstract

The collaborative process between professionals and clients when making health care decisions has now extended to include children. However, among child-focused assessment tools used in rehabilitation, most rely on the reports of parents or professionals involved while few elicit the child's perspective directly. Nevertheless, the development of self-reporting measures allowing children to express their concerns is growing. A review of the literature identified thirty-three self-report measures used with children among a range of disciplines. While these tools allow children to be part of the rehabilitation process, the information obtained does not capture what matters to children. This is particularly true for children with mental illness whose views are often ignored. Therefore, more research is needed on clinical approaches that directly address the unique experiences of children with mental illness.

Introduction

A substantial number of North American children experience a mental health disorder, with an estimated prevalence of 23.4% among Canadian children and 22.2% among American children (Mental Health Commission of Canada, 2013; Merikangas et al., 2010). However, only those experiencing severe difficulties, or about half of these children, will receive treatment (Merikangas, Nakamura & Kessler, 2009). Yet, all mental health disorders regardless of severity cause significant disruption within various domains of a child's life and result in impairments in social, emotional and academic functioning (Clark & Jerrott, 2012). Left untreated, mental health disorders in childhood can have effects lasting into adulthood, with serious impacts on health care costs (Mental Health Commission of Canada, 2013).

Recent initiatives in mental health service delivery across North America include models of recovery. These models indicate that all clients, including youth, be empowered and actively participate in the management of their own care (Cook et al., 2008; Hoy, 2012; Mental Health Commission of Canada, 2012; Wittiwer, 2006). Research indicates that collaborative decision making and goal setting with the client are more meaningful and relevant and, thus, more likely to be realized (Missiuna et al, 2001; Perry et al., 2008; ten Brummelaar et al., 2014). However, to date, this process of client involvement has been limited to adult populations, as traditional evidence-based models afford children limited influence over health care decisions (Liegghio, Nelson & Evans, 2010).

Within adult physical and occupational therapy practice, clinicians routinely encourage the active involvement of clients in identifying their difficulties and selecting their treatment goals (Kramer, 2011). In pediatric practice, Palisano (2014) describes a gradual evolution from goals set solely by clinicians to goals developed in collaboration with families. Yet, the subjective life experiences of children that impact on their health and development are often ignored or deemed irrelevant (Liegghio, Nelson & Evans, 2010). Instead, clinicians often rely on proxy-reports provided by the parents and professionals working with these children, resulting in treatment goals that primarily reflect the concerns of the adults and not those of the child (Arnould et al, 2004; Browne & Bourke-Taylor, 2014; Rajmil et al., 2006).

Children are increasingly being viewed as competent reporters of their health needs (Cremeens et al., 2006). Many researchers and clinicians advocate for their inclusion in health care decisions and exploring child-centered and age-appropriate methods that allow children to express their needs and concerns (Cremeens et al., 2006; Dell Clark, 2011; Missiuna et al, 2001; Polatajko et al., 2001; ten Velden et al., 2013). Furthermore, understanding what is at stake or 'what matters' to a particular child within a particular narrative context is essential for engaging the child and facilitating treatment sessions which address both the clinical problem as well as the experience of disability, itself (Mattingly & Lawlor, 2001; Mattingly, 2000; Park, 2008; 2012).

The shift towards the inclusion of children in their own health care parallels the development of self-report measures that allow children to express their concerns and collaborate with the clinician in establishing goals for treatment (Cermak & Bissell, 2014; Keller & Kielhofner, 2005; Missiuna et al., 2006; Ricon et al., 2013). The purpose of this paper is two-fold: (1) review existing self-report assessment measures used with children; and (2) identify the extent to which these measures elicit children's perspectives and access what matters to them.

Methods

A scoping review of the literature, using the Arskey and O'Malley (2005) framework, identified children's self-report measures across a range of disciplines. In consultation with a librarian, we developed a list of search terms based on the research question and a database commonly used by clinicians. The primary author then executed a search of the Medline database, combining key terms such as child/, self-assessment/ or self-assess*.mp, and the Medline search string for finding instruments, measures, scales or tests [*((screen* or evaluat* or assess* or diagnos* or rating or rate or measur* or case finding) adj5 (index or test* or instrument* or inventor* or battery or batteries or tool* or scale* or checklist* or check list* or schedule*)).ti,ab.*]. The search was limited to English-language articles and yielded 326 abstracts. The primary author screened the abstracts to identify the articles that included an existing self-report measure used with children. Articles were excluded when no specific measure was identified, the study did not involve children, or when measures were duplicated. This screening resulted in 27 articles.

The primary author also employed a search of WorldCat records using the search term: child self-report instrument development. This was done to identify the extent to which the child's perspective was included during the development of self-report measures, as related to the second part of the research question. This search yielded 9079 peer-reviewed article titles. An additional 30 articles were selected for review.

Using the screening process identified above, the final 57 articles were then reviewed to obtain a total of 33 child self-report measures. The following characteristics were extracted for each self-report measure: population, discipline, format, content, level of child involvement, and presence or not of an observational component.

Results

Children's self-report measures are accessible across disciplines and suitable for a range of clinical populations between eight and fifteen years of age (see Table 2.1). Among the measures reviewed, disciplines included rehabilitation (11/33), psychology (10/33), psychiatry (7/33), education (6/33), health (3/33) and nutrition (2/33). While 16 measures could be used with any child regardless of diagnosis, other measures were geared towards specific disabilities, such as: mental health (9/33), chronic conditions (3/33), cerebral palsy (2/33), physical disability (1/33), spinal cord injury (1/33), experience of trauma (1/33), and organizational difficulties (1/33). Questionnaires were the most common self-report measures (29/33), followed by picture card sorts (2/33), checklist (1/33) and semi-structured interview (1/33). The majority of the measures elicited responses from the child alone (25/33), while others involved the child and family (5/33) or the child, family and therapist (3/33). The child's responses were most often prompted through the use of a scale (27/33) or multiple choice (3/33). Three of the scale measures included verbal responses, and only two included an observational component.

Items for children’s self-report measures can be generated through the use of expert advisors (Christie et al., 2011), redesigning an existing measure used with adults (Arnould et al., 2004; McDougall et al., 2013; Webster & Kennedy, 2007), or following an extensive literature review (Perry et al., 2008; Phillips & Power, 2007; Schonert-Reichl et al., 2013). Among the reviewed instruments, children were involved in generating items through pilot testing, and/or focus groups (King et al., 2004 as cited in Imms, 2008; Missiuna et al., 2006; ten Velden et al., 2013) as well as qualitative interviews (Pachter et al., 2010; Perry et al., 2008; Stewart et al., 2005).

[INSERT Table 2.1]

Discussion

This review identified thirty-three measures in which the child’s input was solicited. However, despite the growing evidence for and availability of self-report measures, proxy reports continue to dominate the assessment process. For example, in a review of child-focused assessment tools published in the American Journal of Occupational Therapy between 2009-2013, most tools relied on parental report (n=10) or professional report (n=22), while only eight tools elicited the child’s perspective in the form of self-report (Brown & Bourke-Taylor, 2014). However, thirty-three measures do exist across disciplines that can be used to access information directly from children, including eleven measures specific to rehabilitation. Furthermore, eight of the children self-report measures also included family or professional perspectives, which allow for a more comprehensive description of the child’s difficulties.

Of the self-report measures reviewed, five measures could be used with both the child and their parents and an additional three measures could be used with the child, parents and therapist. Research indicates that child and parent reports often differ, which underlines the imperative to include both child and parent perspectives during assessment (Kmett Danielson & Roecker Phelps, 2003; McDougall et al., 2013; Stewart et al., 2005). For example, Davis, Nicolas, Waters, Cook, Gibbs, Gosch, and Ravens-Sieberer (2007) found poor agreement related to social and emotional domains and only slightly better parent-child agreement on physical domains, which they attributed, at least in part, to differences in response strategies or in the interpretation of the item. However, Wolpert, Ford, Trustam, Law, Deighton, Flannery, and

Fugard (2012) highlighted that children with a mental illness may be less aware of their difficulties than adults with mental illness.

If children are less aware of how mental health disorders impact on their everyday life, then assessment practices must be able to effectively access a full range of their experiences and how they value those experiences. Of the thirty-three assessments reviewed, twelve engaged children's perspectives on performance and seventeen on symptomatology (see Table 2.1). In comparison, only four assessments considered how children valued different experiences, as done through constructs such as participation and enjoyment (King et al., 2004 as cited in Gates et al., 2012), satisfaction (Law et al., 1990 as cited in Gates et al., 2012; Ricon et al., 2013) and importance (Keller et al., 2005 as cited in Kramer, 2011). However, even these measures consist of adult-constructed domains and thus may not capture the full range of experiences that are important from the perspective of children.

Although the methods employed for instrument development and item generation impact upon the validity of the measure, items included in self-report measures for children are typically pre-determined and selected by adults. In the rare situations where children were involved during instrument development, a review of child self-report measures developed between 1980 and 2004 reported that only 47% underwent pilot testing, while child interviews or data from pilot tests informed item content in only 40% (Cremeens et al., 2006). Feedback provided by children has also been used to modify the content or format of self-report measures to strengthen the validity of the data generated – such as whether the question is understood by the child and/or whether the child's answer matches the researcher's intention when selecting a particular item (Christie et al., 2011; Missiuna et al., 2006; Schonert-Reichl et al., 2013). Of the thirty-three measures reviewed, only seven measures described involving children during instrument development (Arnould et al., 2004; King et al., 2004 as cited in Imms, 2008; Missiuna & Pollock, 2000; Perry et al., 2008; Ricon et al., 2013; ten Velden et al., 2013; Young et al., 2000).

Rehabilitation professionals need a way for their child clients to express what matters about a particular activity, to ensure that the goals set in collaboration with our child clients are relevant to what the child hopes for, values, and enjoys. According to Stewart et al. (2005), "One promising method for developing valid children's self-report measures is using qualitative data generated by children to define and index the content domain of interest" (p. 414). In a validation study of the Dutch translation of the Child Occupational Self-Assessment, authors employed cognitive interviewing with child participants, who identified that a key component of children's lives, the concept of play, was missing entirely from the self-report measure (ten Velden et al., 2013). Nevertheless, the extent to which the child's feedback is integrated is ultimately done at the discretion of the adult researchers. Thus, the final measure may not necessarily reflect what is truly meaningful to the child.

Conclusion

Children with mental illness want to be active participants when it comes to making health care decisions (Kutcher & McLuckie, 2010). In the reviewed articles, researchers agreed that obtaining information directly from our child clients is essential for the provision of quality care. Self-report measures allow children to voice their concerns and collaborate with the clinician in establishing goals for treatment. However, the information obtained does not reflect what matters to children, particularly for children with mental illness whose views are often ignored. Therefore, more research is needed on clinical approaches that directly capture and address the unique experiences of children with mental illness.

Table 2.1. Summary of characteristics of self-report measures used with children

Name of Tool	Author (Year)	Population	Discipline	Format	Content	Level of Child Involvement	Observation Component
Depression Self-Rating Scale	Birleson et al. (1981)	Mental health Ages 8 to 14	Psychiatry	Questionnaire	Depression and mood disturbance.	Likert Scale	No
Hospital Anxiety & Depression Scale	Zigmond & Snaith (1983)	Any All ages	Psychiatry	Questionnaire	Psychological health, depression and anxiety.	Likert scale.	No
Harter & Pike's Pictorial Scale of Perceived Competence **Harter's Self-Perception Profile for Children**	Harter & Pike (1984) Harter (1985)	Any Ages 4 to 7 Any Ages 8 to 14	Rehab Education	Questionnaire	Global self-worth: scholastic competence, social acceptance, athletic competence, physical appearance, and behavioural conduct. This tool measures youth personal adjustment, positive youth/school	Ordinal Scale	No

					connection, positive youth/peer connections		
Children's Depression Inventory	Kovacs (1985)	Mental health Ages 7 to 17	Psychiatry	Questionnaire	Depressive symptoms, mood and interpersonal relationships.	Likert Scale	No
Harkavy-Asnis Suicide Scale	Harkavy-Friedman & Asnis (1989)	Mental health Ages 10 to 18	Psychiatry	Questionnaire	Suicidal ideation and behaviour.	Likert scale	No
Canadian Occupational Performance Measure	Law et al. (1990)	Any	Rehab (OT)	Semi-structured interview with child and/or parents.	Performance and satisfaction in daily living activities.	Individual interview with likert scale for performance and satisfaction scores.	No
Youth Self-Report Form	Achenbach (1991)	Mental health Ages 11 to 18	Psychiatry	Questionnaire	Emotional problems, behavioural problems and social competency.	Likert Scale	No
Barrier Self-Efficacy	Marcus et al. (1992)	Any Ages 8 to 10	Psychology	Questionnaire	Overcoming barriers to exercise.	Likert Scale	No

Questionnaire (BSEQ)							
Behaviour Assessment System for Children (BASC)	Reynolds & Kamphaus (1992)	Mental health Ages 4 to 18	Psychology	Comprised of: 1-Structured Developmental History 2-Parent Rating Scale 3- Teacher Rating Scale 4- Self Report of Personality 5-Student Observation System	Parent and teacher reports assess problem and adaptive behaviours. Self-report looks at anxiety, attitude to teachers, social stress, self esteem and sensation seeking.	Self-report is in true/false format.	Observational component of problem and adaptive behaviours occurring in the classroom done by rater.
Spence Children's Anxiety Scale	Spence (1994)	Mental health Ages 8 to 15	Psychiatry	Questionnaire	Anxiety symptoms	Likert Scale Parent version also exists and can be used for younger children.	No
Child	Parcel et	Children	Education	Questionnaire	The child's ability to	Likert scale.	No

Dietary Self-Efficacy Scale (CDSE)	al. (1995)	with or without disabilities Ages 8 to 10	Public Health		select healthy food options.		
Trauma Symptom Checklist	Briere (1996)	Experiences of trauma. Ages 8 to 17	Psychiatry	Questionnaire	Scales include: anxiety, depression, posttraumatic stress, sexual concerns, dissociation and anger.	Likert scale	No.
Strength & Difficulties Questionnaire	Goodman (1997) *self-report version developed in 2003	Mental health Ages 3 to 16 (*self-report ages 11 to 16)	Psychology	Questionnaire	Behaviour: hyperactivity/inattention, emotional symptoms, conduct problems, peer relationships, and pro-social behaviour.	Likert Scale (ages 11 to 16) Otherwise completed by parent or professional.	No
Pediatric Quality of Life Inventory	Varni et al. (1999)	Chronic conditions (cancer, cerebral palsy)	Rehab	Questionnaire (parent report and self-report available)	Daily activities, school activities, movement and balance, pain and hurt, fatigue, and	Likert scale	No

		Ages 8 to 12			eating activities		
Quality of Life Questionnaire for Children	Bouman et al. (1999)	Chronic conditions Ages 8 to 12	Psychology	Questionnaire	Child's physical, psychological and social functioning.	Likert scale	No
Activity Scale for Kids	Young et al. (2000)	Physical disabilities Ages 5 to 15	Rehab	Questionnaire	Child's physical functioning within their environment. Includes performance (what child usually does) and capability (what child thinks they could do).	Ordinal Scale	No
Perceived Efficacy and Goal Setting	Missiuna & Pollock (2000)	Physical disabilities Ages 6 to 9	Rehab (OT)	Picture cards with statements of pre-determined activities	Performance related to gross and fine motor activities	Card selection and ordinal scale followed by therapist facilitated discussion with child re. context and child's	No

						individual performance of activity.	
Children's Automatic Thoughts Scale	Schniering & Rapee (2002)	Mental health Ages 7 to 16	Psychology	Questionnaire	Negative thoughts.	Nominal Scale	No
Piers-Harris Children's Self-Concept Scale	Western Psychological Services (2002)	Chronic conditions Ages 7 to 18	Educational Psychology	Questionnaire	Child's perception of behaviour, intellectual status, school status, physical appearance, anxiety, popularity, happiness, and satisfaction	Child provides Yes/No answers to descriptive statements.	No
Children's Self-Report Social Skills Scale	Kmett et al. (2003)	Any Ages 5 to 12	Psychology	Questionnaire	Social behaviour.	Likert Scale	No
School Physical Activity &	Hoelscher et al. (2003)	Any Ages 8 to 10	Education Nutrition	Questionnaire	Physical activity and eating behaviours	Multiple choice format.	No

Nutrition (SPAN)							
ABILHANDS-Kids	Arnould et al. (2004)	Cerebral palsy Ages 6 to 15	Rehab (PT)	Questionnaire	Performance of manual tasks.	Likert Scale	No
Children's Assessment of Participation & Enjoyment **Preferences for Activities of Children**	King et al. (2004)	Any Ages 6 to 21	Rehab (OT)	Questionnaire	CAPE: Five domains of participation related to pre-determined activities: diversity, intensity, 'with whom', 'where', and enjoyment PAC: Child's interest in an activity	Likert Scale	No
KIDSCREEN	European Commission (2004)	Any Ages 8 to 18	Public Health	Questionnaire	Health and well-being, including moods and emotions, self perception, autonomy, parent relations and home	Likert Scale Parent version also available.	No

					life, peers and social support, school life and financial resources		
Child Occupational Self-Assessment (COSA)	Keller et al. (2005)	Range of disabilities (developmental delay, mental health, neurological conditions) Ages 8 to 13	Rehab (OT)	Self-report questionnaire	Performance of pre-determined everyday activities.	Nominal Scale. Includes child's perception of self-competence and importance of the activity.	No
Child Needs Assessment Checklist	Webster & Kennedy (2007)	Spinal Cord Injury Ages 0 to 16	Rehab	Behaviour Checklist	Activities of daily living, skin management, bladder and bowel management, knowledge of spine and promoting healthy growth, mobility, wheelchair	Likert Scale Responses can be used to establish goals. Parent version available.	No

					and equipment, community and education, discharge coordination, and psychological issues.		
Regulation of Emotions Questionnaire	Phillips & Power (2007)	Mental health Ages 12 to 19	Psychology	Questionnaire	Strategies used to regulate or respond to emotions.	Likert scale	No
Physical Activity and Healthy Food Efficacy Scale for Children (PAHFE)	Perry et al. (2008)	Any Ages 8 to 10	Education Nutrition	Questionnaire	Personal goal-setting, decision making efficacy and challenges related to physical activity and healthy food choices.	Likert Scale	No
Children's Organizational Skills Scale	Abikoff & Gallagher (2009)	Organizational difficulties. Ages 8 to 13	Psychology	Questionnaire	Child's performance related to organization, time management and planning.	Likert Scale Parent and/or teacher version available.	Observation can be done, but not required.

Healthy Pathways Child-Report Scale	Bevans et al (2010)	Any Ages 6 to 21	Public Health	Questionnaire	Comfort, energy, resilience, risk avoidance, subjective well-being and achievement.	Likert scale	No
Self-Report Coping Measure	Causey & Dubow (2010)	Any Ages 5 to 12	Psychology	Questionnaire	Coping strategies with daily stressors, problem solving, social support, internalizing and externalizing behaviours.	Likert Scale	No
'Make My Day' Assessment for Young Children	Ricon et al. (2013)	Any Ages 4 to 7	Rehab (OT)	Includes a set of picture cards of pre-determined activities for children and a questionnaire for parents.	Performance, independence and satisfaction in daily activities.	Child provides Yes/No response for performance of an activity with likert scale responses for satisfaction and independence	No

(OT=Occupational Therapy; PT=Physical Therapy; Rehab=Rehabilitation).

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Chapter III. Qualitative Methods to Access What Matters

The scoping review presented in the previous chapter identified a number of self-report measures available for use with children. However, this review also identified several limitations, particularly the dominance of adult-defined constructs, the continued reliance on parent-reported and proxy-reported information, and the limited dialogue between the child and clinician that is afforded by the questionnaire format of current self-report measures. Yet, children are viewed as competent reporters about their health needs and should be included in the assessment process by having the opportunity to express their experiences and relay information about their health (Cremeens et al., 2006). As such, methods employed to gather such information from children should be done in a child-centred and age-appropriate way (Dell Clark, 2011).

As a result, qualitative methods were selected for this study in an effort to directly access the experiences and perspectives of children with mental illness. Qualitative methods have often been used in health research as a way to explore client needs and experiences of illness and recovery (Denzin & Lincoln, 2013) and can be particularly valuable when exploring the lived experiences of children (Drew, Duncan & Sawyer, 2010). The intention is to capture the child's subjective experiences of his/her world (Dell Clark, 2011).

Methods

For this mixed methods project, we conducted participatory research using PhotoVoice on what matters in the life experiences of children with mental illness. The participatory research approach involves a partnership between researchers and end users that guides the research process and produces knowledge that is co-created and relevant (Parry, Salsberg & Macauley, 2013). Ethnographic methods allow for documentation of particular experiences that occur in particular contexts and allow for ongoing observation over time (Spencer, Krefting & Mattingly, 1993). Thus, in parallel, we conducted a focused ethnography using a narrative-phenomenological framework to evaluate the participatory research process and whether the experiences that mattered to children were made visible through the PhotoVoice activity or lifebooks.

Participatory Research

"In participatory research, academic investigators work in full partnership with those who are affected by the issue or who ultimately will use the research results – clients, health professionals, organizations, policy makers and community members" (CIHR, 2013, p.7). Participatory research allows children to be active partners in the production of knowledge by involving them in decision making throughout the research process (Dell Clark, 2011; Liegghio, Nelson & Evans, 2010). Participatory research gives value to the direct experiences of the participants and shares principles consistent with client-centered practice (Clark, 2010 as cited in Carter & Ford, 2013). Having the participants involved allows for a higher degree of authenticity in the data that is created (Lal, Jarus & Suto, 2012; Liegghio, Nelson & Evans, 2010). As Letts states, "applying participatory methods can help researchers create knowledge that is more closely centered on the experiences of individuals with illness and disability (as cited in Lal, Jarus & Suto, 2012, p.181)

In particular, PhotoVoice is a participatory research approach where participants are provided with cameras and asked to photograph significant aspects or events of their lives (Foster-Fisherman et al., 2005). PhotoVoice was found to be well-suited to the purpose of this project. First, this approach is often used to highlight the experiences of vulnerable populations (Asaba et al., 2015). Second, child-centered researchers emphasize that methods used to understand a child's unique values and experiences must be age-appropriate and client-driven (Dell Clark, 2011). Through PhotoVoice, the child participants had full control in selecting and shaping the content included in their individual lifebooks. Finally, PhotoVoice allows for multiple means of self-expression, using both visual images and verbal descriptions, thus taking into consideration that, for a child, verbal reports alone may not be sufficient (Dell Clark, 2004; Jorgenson & Sullivan, 2010).

For the purpose of this project, children were asked to use photographs to create an individual life book describing all of the important things in their lives. The participants had full control over the selection and shaping of the content they wished to include in these books. Similar to other PhotoVoice projects, participants attended a series of group sessions where they shared the pages they had created with the other participants and decided whether to share their stories with a broader audience (Foster-Fisherman et al., 2005; Valenzuela et al., 2013; Fitzgerald, Bunde-Birouste & Webster, 2009). This process accessed, from the participants' perspectives, the areas and experiences that are meaningful in their lives. Specifically, we explored how PhotoVoice could be used as a self-report measure to understand what matters to children with a mental health disorder.

Ethnography Using a Narrative-Phenomenological Framework

An *ethnography* is a methodology used to describe other cultures or communities in order to explore the participant's understanding of their world (Greene & Hogan, 2006). Focused ethnography is an intensive and focused approach used to explore beliefs, practices and context (Knoblauch, 2005; McElroy et al., 2011), that is well-suited to address specific clinical questions (Spencer et al., 1993). In this case, the focused ethnography was used to explore what matters in the experiences of children with a mental health disorder and to evaluate whether what matters was made visible during the PhotoVoice process used in the participatory group sessions.

Ethnography using a narrative-phenomenological framework explores the participant's understanding of their world (Creswell, 2013; Davidsen, 2013) and provides a deeper understanding of the meaning behind the lived experience, where "what matters" often becomes visible (Kleinman, 2006; Mattingly, 2010). Stories are often constructed to make sense of our lived experience (Creswell, 2013; Davidsen, 2013). In a *phenomenological* framework, the researcher sets aside their own experiences in order to explore those of their participants (Creswell, 2013). More specifically, phenomenological researchers aim to understand how meaning is constructed around daily experiences (Bogdan & Bilken, 2010, Creswell, 2013). The aim of phenomenological qualitative research is to deal with experiences and meanings and "to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" (Giorgi & Giorgi, 2003 as cited in Davidson, 2013, p. 27). In combination, the narrative-phenomenological framework considers meaningful events as being both person-centered as well as situated within the larger clinical context (Mattingly, 2010).

In the context of this project, the use of interview and participant observations, both in the context of regular program activities and during the participatory group sessions, provided thorough documentation of the daily experiences of a child with a mental health disorder. Specifically, the various interactions – between the researcher and the participants – and observations recorded by the researcher provide a "thick description" of the participants, their experiences and the context in which these experiences are being lived (Geertz, 1973, p.6). This thorough documentation also allowed us to monitor the participatory group experience and facilitated comparison across the data collected to determine whether "what mattered" to the participants was made visible through the PhotoVoice process.

Context of the Study

This study took place at the Center for Child Development and Mental Health of the Jewish General Hospital located in the Greater Montreal Area. The program services primarily Anglophone, Allophone and Jewish communities of the Greater Montreal Area and surroundings. This is a center offering multidisciplinary interventions for elementary-school aged children and their families, with a child-centered and family-focused philosophy of treatment. The members of the multidisciplinary team include a psychiatrist, a psychologist, a social worker, a psychiatric nurse, an occupational therapist, special education teachers, and child care workers. Each child and family unit is assigned to a case manager (child care worker or nurse) and to a family worker (any member of the treating team).

There are a total of fifty-six children admitted to the day hospital programs at any given time. Children are referred to this program by parents in conjunction with community professionals expressing concern regarding the child's severe behavioural difficulties that are interfering with their ability to participate in their daily life activities both at home and at school, often despite usual services offered in the community, i.e. additional resources in the classroom, support for parents through the CLSC. Referrals are received from the Greater Montreal Area and its surroundings. Prior to an admission, the child and family undergo a psychiatric evaluation involving a series of individual and family interviews, a medication review and exploration of a preliminary diagnosis. The length of admission to this out-patient program varies by case and typically ranges between three and twelve months.

Children admitted to the program are divided into groups of seven students based on age and assigned to a special education teacher. In the classrooms, each child works individually on their respective academic tasks. The children are predominantly male and range from five to twelve years of age. They are diverse in terms of ethnic background, socioeconomic status, and family composition (i.e. intact family unit, divorced or separated family, single-parent family, adopted family, etc.). Referrals to this program are received from the bilingual public education sector (i.e. English Montreal School Board, Lester B. Pearson School Board, Riverside School Board, and Sir Wilfred Laurier School Board) or from semi-private Jewish day schools. These children generally have average cognitive potential, however many are identified as having learning difficulties and are on modified curriculum tracks. As children are admitted to the program due to severe emotional and behavioural difficulties, their primary diagnoses vary tremendously and can include disruptive behaviour disorders, anxiety disorders, depression, autism spectrum disorders, attention deficit disorders, learning disabilities, language and other developmental delays, attachment issues and other neurological conditions. When necessary, children may be prescribed medication by the treating psychiatrist, such as a stimulant medication or a mood stabilizing medication.

Children generally attend the program four days per week from 8:30 am to 2:30 pm. On Wednesdays, children attend school in their regular community settings. Prior to discharge in some cases, children will attend a transitional class, where they spend 3 days per week at the hospital program and 2 days per week at their community schools.

The day program follows a cognitive-behavioural approach using a token economy system. Children rate their behaviour on a scale of ten points for each period of the day (i.e. time spend on the bus, classroom, recess, lunch). Any time a problem occurs, points are deducted from their total score. The number of points deducted depends on the severity of the issue, with any form of aggression automatically resulting in loss of all points (i.e. they receive 0 out of 10) for that period of the day. At the end of each month, these points are tallied and an overall percentage is calculated. The child's overall percentage is then compared to the target percentage for that month. If achieved, the child is deemed to have "passed" the month, earning additional privileges (jobs and responsibilities) and rewards (games accessed at recess) on the unit.

Throughout each school day, various therapeutic and skill-building activity groups are integrated into the child's routine. These activities are offered on an individual or group basis and can include occupational therapy, art therapy, peer group activities, social skills training, individual support and family therapy. Children are taught to work through and process their problems (i.e. social or peer interaction, academic issue with work or with the teacher, problem from home with a sibling or parents, etc.) either individually with a staff member or within a group context with staff and peers. This reflective work is done verbally or written as a reflection sheet and allows for the child to understand the problem from different perspectives, to identify the role they played, and to process how such a problem could be dealt with differently in the future.

Parental involvement is mandatory and consists of weekly family meetings with the entire family unit and daily contact with the child's teacher and case manager. Behavioural strategies are recommended by the treating team to be implemented at home and at the child's community school. Daily communication between professionals at the hospital program, at the school and the parents is maintained throughout the child's admission through a designated communication book in which behaviours can be recorded and communicated to all members involved in the child's care. Communication books are read daily by members of the treating team.

Recruitment

Recruitment for the participant sample was limited to the latency day hospital program of the Jewish General Hospital, an out-patient program serving children between the ages of eight and twelve identified as having significant behavioural and/or emotional difficulties. Recruitment for this study took place in September 2014. An electronic list was compiled with the names of the children enrolled in the latency day hospital program who met the criteria for inclusion. This list was provided by the program coordinator and was organized by classroom assignment, i.e. children from class A followed by class B, followed by class C, followed by class D.

Of the twenty-eight potential candidates, six children were excluded from the study in line with the exclusion criteria stated in the protocol. Reasons for exclusion included a low cognitive intelligence profile (2/6) and when discharge from the program was anticipated prior to the completion of the study (4/6). This resulted in a list of twenty-two children eligible for participation. Each child on the electronic list was assigned a number, from one through twenty-two. A random sampling strategy using a random number table, generated on September 12, 2014 through Stat Trek (www.stattrek.com), was then used to select the four participants that would be invited to participate in the study. Once selected, a letter inviting the child to participate in the study was sent home to the child's parents in a sealed envelope. Parents were asked to return their contact information in order for the researcher to contact them by phone to explain the study in more detail. Following the telephone contact, the researcher met the parents were met in person at the Center for Child Development and Mental Health in order to review the consent forms with the parents and child and to obtain consent/assent.

In order to access a range of experiences of children with mental health disorders, different characteristics were sought among the sample participants using quota sampling. Quota sampling allows the researcher some flexibility in the sample composition while ensuring that key characteristics are represented within the participant sample (Robinson, 2014). As such, the following quotas were set by the researcher prior to recruitment: male (n ≥ 1); female (n ≥ 1); diagnosis of attention deficit disorder (n ≥ 1); diagnosis other than attention deficit disorder (n ≥ 1); living with both biological parents (n ≥ 1); living without both biological parents (n ≥ 1). Thus, for each participant that was selected using a random number table strategy, as consent/assent was obtained, the extent to which the quotas were being filled was also being monitored closely. Sampling continued until consent/assent had been obtained for four participants. A summary of the anticipated and final quota counts are summarized in Table 3.1.

[INSERT TABLE 3.1]

The final participant sample consisted of two boys and two girls, aged between 9 and 10 years old (see Table 3.2). A chart review by the candidate determined that all of the participants were identified as having significant behavioural and/or emotional difficulties, including diagnoses of attention deficit disorder, oppositional defiant disorder, conduct disorder, anxiety disorder, and/or learning delays. The sample represented a variety of living arrangements of children with their families.

[INSERT TABLE 3.2]

Procedures

The participatory groups and the ethnography occurred in parallel; however different data collection procedures were used respective to each approach. These procedures will be described in more detail below. The following table presents the chronological order in which data was collected throughout the research study (Table 3.3).

[INSERT TABLE 3.3]

Participatory Research

The four participants were engaged in nine group sessions lasting between 60 and 90 minutes. The increase to 90 minutes was made at the request of group members who wanted more time to work on their individual pages. All group sessions were audio-recorded and transcribed verbatim by the candidate.

First session. In the first group session, the participants were introduced to each other as well as to the purpose of the group. This was followed by a collaborative discussion to review any rules that would promote the group members' successful participation (i.e. respect for others, respect for equipment being used). Then, the children were asked to reflect on the important areas of their lives that they would want to include in their life books, and determined what mattered to them by drawing on their own personal experiences. As the participants offered their suggestions, the primary author recorded their ideas on a large Bristol board. The participants were then asked to group their ideas and select five main themes.

Collaboratively, the participants, as co-researchers, identified six main themes, which then structured the content of the subsequent group sessions. These themes included: 1- Family, friends and pets; 2- What I like to do for fun; 3- School; 4- Home; 5- Places I've been and 6- My favourite place. While most of the ideas were brought forth directly by the participants, the primary author suggested additional themes based on the stories the children told. For example, when the participants suggested different amusement parks and outings they had experienced, Gummy Bear proceeded to present a story of a fun activity she had done with a friend from her summer camp. The primary author then asked whether friends should be on the list, and all of the participants agreed.

Finally, the primary author reviewed a handout of strategies and tips for appropriate camera use with the participants. This included a discussion on photograph restrictions, as due to ethical reasons the participants could not photograph other people for their projects.

Sessions two through eight. Each week participants were given forty-five minutes to work individually on their life books, adding photographs or text to their pages based on the theme of the day. These pages were unique representations of each participant's individual experiences relative to the themes they had chosen as a group. Thus, the participants chose both what important areas to include as well as how they would represent those areas in their life books. Each participant then presented their work to the group and was asked to select one photograph to explore in more detail. Then, the candidate and other members were invited to ask questions in order to further explore that child's experiences and understand what they valued about those experiences. This exploration was stimulated by the candidate using the following questions: 1-Describe your picture. 2- What's happening in this picture? 3- Why did you take this picture? 4- What does this picture tell us about your life?

Session nine. In the final group, each participant was provided with a printed draft of their life book to approve and/or edit as necessary. This was followed by a group discussion where the primary author obtained the participant's feedback regarding the group experience. This session was also used to explore and finalize the participant's dissemination plan.

Dissemination Plan. The participants discussed whether to share the content of their life books, and with whom. Various options were discussed including: not to present their book, holding separate in-class presentations, preparing a cumulative presentation for all of the students and staff on the unit, and preparing a cumulative presentation for students, staff and parents on the night of an upcoming family event. One participant chose not to present her work, preferring to show it to her family at home. The other three participants opted for separate in-class presentations that they arranged with their teacher once they received the final printed product.

Ethnography

We combined four methods of data collection in order to access the participants' experiences across a range of clinical contexts.

Data Collection. Four types of data collection were used as described below:

Interview. A forty-five minute semi-structured interview consisting of ten questions was conducted prior to the participatory group sessions with each participant who had assented. The candidate selected these questions based on her seven years of clinical experience as an occupational therapist working with children with a mental health disorder and their families. However, unlike a clinical interview used to understand the child's performance across their daily occupations, this interview aimed to explore the child's perceptions of various experiences in his/her life. Items were selected based on common reasons for referral to the day hospital program (i.e. family life, school life, social relationships with peers) and the daily experiences of the participants from the standpoint of an occupational therapist (i.e. the experience of attending an out-patient hospital program, their activities and interests). The interviews were audio-recorded, transcribed verbatim and de-identified.

Participant Observations. Field notes of the participants' activities in the classroom, recess, lunch, and group therapy activities were taken during two time points during the course of the three month study: once in the two-week period prior to the series of group sessions, and once in the two-week period following the end of the group sessions.

Communication book. The communication book is a notebook in which daily events are recorded for each child in the program by their parents and the professionals of the treating team. The primary author photocopied and de-identified excerpts from the participant's communication book at two time points during the course of the three month study: once in the two-week period prior to the series of group sessions, and once in the two-week period following the end of the group sessions. Within each time period, passages were selected that exemplified both positive and negative experiences in the child's home environment. These passages were sent home in a sealed envelope for the parent/guardian to approve in order to be used as part of the study.

Reflection worksheet. As part of the treatment program, children complete written reflection worksheets when a problem arises in their daily life. The primary author photocopied and de-identified any reflection sheets completed by the participants during the three month study. Two of the participants who had difficulty producing written work met with a member of the treating team to process reflections verbally, which were then recorded as field notes by the primary author.

Data Analysis. Following the completion of the participatory groups, the authors employed a hermeneutic analysis. This analytical process involves the interpretation of text to facilitate understanding of the phenomenon being explored (Kinsella, 2006). This process consisted of an iterative analysis between the initial interviews, field notes of participant observations, photographs, images and group session transcripts and literature on existing assessment practices.

Thematic Analysis. The primary author used the participants' themes to review the transcripts of the individual interviews and of the group sessions and highlighted moments where the children shared information about their lives while generating a list of the activities, people and places included in the participants' life books. These highlighted moments were then shared with the second author during weekly supervisory meetings.

Narrative Analysis. Next, the candidate re-read the interview transcripts looking specifically for any stories shared by the children. As per Mattingly and Lawlor (2000), a story consists of a moment when: a) events were temporally situated; b) dialogue was evoked; c) descriptions became specific and vivid. A triangulation of investigators was employed to establish trustworthiness of the data (Krefting, 1991). Thus, the candidate and supervisor read one transcript together to reach consensus on what constituted a story. The candidate then re-read all interview transcripts for stories and noted when a child repeated an idea or repeatedly spoke about the same subject, as this also provided an indication of the importance of these topical areas to the children. These stories and ideas were then shared with the supervisor during mentoring meetings.

Following this, the data obtained from the individual interview transcripts alone was used to create individual profiles of each of the participants using the participant's own words when possible, to develop a working hypothesis of what mattered among the child's unique experiences. This process allowed for critical reflection on the meaning behind the stories shared in order to further understand the experiences of the participants.

Finally, the candidate reviewed the content of the individual life books and the group session transcripts in order to identify any new ideas that emerged. Key ideas or events were recorded over time while simultaneously recording where the event occurred and the quality of the event. This level of analysis has been referred to as a phenomenological hermeneutic analysis, whereby interpretation of the text is used both for understanding as well as to uncover meaning (Lindseth & Norberg, 2004). Thus the researcher identifies key ideas and reflects on why these ideas are meaningful or important to each of the participants.

Within-case comparisons were made between what the participants identified during the interviews, the primary author's participant observations during classroom, lunch, recess and group therapy activity experiences while attending the day hospital program, and whether or not what mattered was visible in the content included in the participants' life books. Data collected from the children's reflection journals and communication books were used to support or reject any working hypotheses arising from the data. This comparison across data collection methods was done to highlight any similarities and differences in the uncovered themes. Specifically, we evaluated what the PhotoVoice process, using the life book as a modality, could offer to the traditional self-report assessments used in occupational therapy.

Finally, a between-case analysis was employed in order to highlight any similarities and differences across the participants' experiences and their representation of what matters with respect to those experiences. This allowed us to evaluate whether similar experiences were shared across the participants or whether the aspects that mattered related to these experiences varied across the participants.

Limitations

Research using qualitative approaches identifies the need for a minimum of three participants (Creswell, 2013). In this project, the sample was limited to four participants in an effort to maintain feasibility of the project and in accordance to hospital policy requiring a maximum ratio of four children per one staff member in any therapeutic context for safety and security reasons. Despite a relatively small sample size, the qualitative nature of the project allowed for robust and rich data collection with multiple and extensive entries for each participant (Creswell, 2013). The results of this study are not generalizable to the entire population of children with a mental health disorder, as not all children with a mental health disorder will have the same experiences and attribute meaning to those experiences in the same way. However, with rigorous documentation throughout the process of this research study, findings can be transferable to future projects and to clinical practice (Krefting, 1991).

In addition, due to ethical restrictions, the children were unable to photograph people for their lifebook projects. Although alternatives were offered, such as drawing or obtaining an image from the internet, this may have limited the content obtained regarding the important people in the children’s lives.

Table 3.1. Summary of Quota Categories

	Gender		Diagnosis		Biological Parents	
	Male	Female	ADHD	No ADHD	With both	Without
Anticipated	n ≥ 1	n ≥ 1	n ≥ 1	n ≥ 1	n ≥ 1	n ≥ 1
Final	n = 2	n = 2	n = 3	n = 1	n = 2	n = 2

Table 3.2. Summary of characteristics for the participant sample.

Participant (pseudonym)	**Nathaniel**	**Mitchel**	**Gummy Bear**	**Strawberry Shortcake**
Classroom	D	A	B	A
Age	10	9	10	9
Gender	Male	Male	Female	Female
Diagnosis (according to chart review)	Conduct Disorder Attachment Disorder	Anxiety Disorder Attention Deficit Disorder	Attention Deficit Disorder with Hyperactivity Oppositional Defiant Disorder	Attention Deficit Disorder Oppositional Defiant Disorder
Family Unit	Lives with his maternal grandparents and has separate visits with his biological parents	Lives with both biological parents	Lives with biological mother and spends alternate weekends with her biological father and stepmother	Lives with both biological parents
Presenting Problems upon Admission	Explosive temper Defiance with authority Refusal to do school work	Poor emotional regulation Excessive outbursts or tantrums Refusal to do school work Uneven development	Attention difficulty Multiple school changes Significant academic delays Refusal to accept help Defiance with authority	Attention difficulty Poor social skills – no friends, being bullied
Time in Program (at Recruitment)	7 months	1 month	1 month	1 month

Table 3.3. Timeline of data collection procedures.

September	October	November	December
Recruitment			
	Interviews		
	[1]Particip.Obs.		
	Participatory Groups		
			Particip.Obs.

([1]Particip. Obs. = Participant Observations completed during lunch, recess, classroom and group activities; Communication book entries collected; Reflection sheets collected)

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Chapter IV. Contribution of PhotoVoice to Self-Report Measures

The scoping review, presented in Chapter 2, confirmed my own clinical impressions of the fact that while self-report measures do exist for children, they do not necessarily access what matters to them. Similarly, an initial review of the data using a thematic analysis provided ample information about the group members, it did not yield what mattered about the people, places and activities in the children's lives. This chapter begins with the results and limitations of the thematic analysis. Then, specific illustrations are provided, relative to each participant, of how the PhotoVoice process accessed the meaning behind the experiences of children with a mental health disorder. This is followed by a comprehensive overview of participant Mitchel's experiences as collected across all methods over time, as this case provided a rich example of what was gained by using the PhotoVoice process. Mitchel's case was particularly interesting as notable inconsistencies were identified in the experiences he shared and/or that could be observed over time across the data collection methods. As such, Mitchel's case has also been selected to illustrate the findings presented in the second manuscript of this thesis, included at the end of this chapter.

Identifying Activities, People, Places

The six themes identified by the participants included: (1) Family, friends and pets; (2) What I like to do for fun; (3) School; (4) Home; (5) My favourite place; and (6) Places I've Been. How each child chose to represent each of the themes in their lifebook was relative to their own individual experiences. The thematic analysis of the content of the participants' lifebooks identified the important activities, people and places in the children's lives, summarized in Table 4.1. However, while the children could provide ample information about their lives, this did not yield what mattered to them.

[INSERT TABLE 4.1]

In contrast, the within-case comparisons across the various methods of data collection employed in this study, and especially the PhotoVoice process, provided a more comprehensive understanding of the children's experiences. One of the unique attributes afforded by this Photovoice group process was that since the content was child-driven, the lifebooks also provided a naturalistic ongoing assessment of their experiences. Specifically, they described the particular activities that they enjoy doing and the particular people with whom the activity was done.

Identifying What Matters about Activities, People, Places

Rather than generating a list, we begin to appreciate what is at stake in the activities, people and places in the children's lives and how the same activity, person or place can be experienced differently by each child with the descriptions the participants included of events as they emerged. This can be seen in the following case illustrations, in which each participant provides a unique representation of their family and of what matters in this experience. Even though each illustration is "about" family; for each there are different meanings that come forth with their accounts.

What matters: Mitchel's happy family

[INSERT FIGURE 4.1 AND 4.2]

The above images represent the initial (Figure 4.1) and final (Figure 4.2) images selected by Mitchel to represent his family for his lifebook. In his initial presentation to the group participants, Mitchel uses the picture on the left to depict his family. When asked if the girl in the picture is his sister, Mitchel replied "No I do not have a sister. I had to get it off the internet and there were no ones of only childs [sic]". Nathaniel suggests a search strategy to help Mitchel find a "mom, son and dad image of cartoon". Instead, Mitchel insists that this is the picture that he wants and enlists the help of the primary author to remove that section for his final image (on the right). One might say that the selection of this image represents an underlying feeling that his family is incomplete. However, Mitchel did not seem to be bothered by being an only child.

On the other hand, we know from his interview that he describes his family as "happy" and "nice". When asked if there was anything he would change about his family, he notes that there is "only one thing":

Mitchel: Sometimes when I go to sleep, my parents get in arguments. And sometimes I might be finishing up a book because I- "Ah it's time to go to sleep", I put a little bookmark in, I put it aside, then I get on my pillow to try and get cozy, the next thing I know they're yelling all the way downstairs. And the problem is, sometimes when they get mad, they say ****.

VG: Oh, so they say bad words to each other?

Mitchel: Sometimes- they always forgive each other. But I find when they're yelling bad words and getting mad at each other, I find it's hard to sleep.

VG: Yeah, I can imagine.

Mitchel: And also sometimes I get a little bit nervous. Just like- Sometimes I kind of feel like I should go down there and do something but by the time- even with all them yelling and screaming, even then I kind of fall asleep.

The lifebooks highlighted the process that the participants employed in selecting the images that would best represent the important areas of their lives. This aspect was missed using verbal reports alone. Furthermore, the use of photographs and visual images allowed the authors to see specific people, places and details in the child's environment. This excerpt identifies how getting to sleep can be difficult for Mitchel. However, the image he selects for his lifebook allows us to understand that what matters to him with respect to his family is for everyone to get along and be happy together. Therefore it should come as no surprise that the picture he selects is one where family members are holding hands and smiling together.

What matters: Gummy Bear's family relationships

In their descriptions of their families and pets for their lifebooks and in the group discussions that ensued each week, the participants clearly described a sense of belonging and ownership. When created the page on family for her lifebook, Gummy Bear made sure to include an image representing each member of her family, including her parents, stepmother, siblings, aunts, uncles and grandparents. She selects the following image (Figure 4.3) to represent her sisters and makes sure to add the "s" as she has more than one.

[INSERT FIGURE 4.3]

When explaining her selection of the above image to the rest of the group. Gummy Bear clearly articulates the relationships between her half-siblings and step-siblings using the following text in her lifebook:

> *My sisters I love them. My baby sister her name is [name], my other sister is called [name], and my other sister is called [name]. They're all cute. [Name] and [name] are not related to [name] and in fact we do not have the same dad. But all my sisters are related to me.*

Gummy Bear was clearly able to articulate that while her half-sisters were not related to her stepsister, all of her sisters are related to her. This relationship also extended to the participants' pets, as distinctions were clearly made for example between those that belonged to them versus those that belonged to their grandparents.

Similarly, in her lifebook Gummy Bear describes several experiences of the loss of people in her life, for example in how her parents separated, how her aunt and uncle recently broke up, how her grandfather has Alzheimer's disease, and how her other grandfather was put in a coma following a surgical procedure. In rehabilitation the term 'support network' is used to describe people in your life that can be relied on to help you in a time of need. For a child, this is often the family members and particularly those who, in the child's eyes, are available and getting along. Gummy Bear was able to clearly formulate and describe each of these relationships in the text she included as part of her lifebook page on family.

What matters: Strawberry Shortcake's family and cultural connections

Strawberry Shortcake is a young girl of Jewish descent who follows a kosher diet. From her chart review, we learn that she also has additional dietary restrictions due to allergies and food intolerances – a trait she shares with her mother. Strawberry Shortcake was the only participant to include images of specific food items in her lifebook, such as:

[INSERT FIGURE 4.4]

[INSERT FIGURE 4.5]

The following excerpt was written to explain her selection of the olive tree image (Figure 4.4). On the day this was written, Strawberry Shortcake was eating olives as part of her lunch.

> *I love Olives. Olives are healthy for some people like me because I like olives. Even though olives aren't healthy for some people, I would say I take lots of pictures of olive trees.*

She chooses to describe the olives as *healthy* for some but not others. In light of her own dietary restrictions, a clinician could then explore what being healthy means to Strawberry Shortcake, as well as her own experiences related to food and her health, and particularly in the context of her family life. In another excerpt related to food associated with the image above (Figure 4.5), Strawberry Shortcake writes:

> *Cookies are my favorite thing in the whole wide world. Even my mom and my grandmother's cookies. Finally, cookies are cooked.*
> *My mom calls me a smart cookie :)*

In this excerpt, Strawberry Shortcake's description goes beyond the activity of cooking or eating and allows us to access the meaning behind what the food represents. In this example, the word cookie is used to represent two different meanings - a delicious treat made by a particular person in her family (i.e. mother and grandmother) and also represents a term of endearment from her mother. With Strawberry Shortcake's excerpts we can appreciate the connection she makes between family, food and well-being.

What matters: Nathaniel's good and bad family moments

Nathaniel chose to add a story to his life book about going bowling at his friend's birthday party over the weekend. However as he writes this page of his life book, his story transforms to reveal the events that followed and the dynamics within his family.

> *This weekend Nov. 24 2014 I went bowling at my friend's birthday and I beat him over three times because he really sucks at bowling, but he's gotten better at it since last year. My brother came over to my house for the day, then my dad came over with my sister. My brother and my sister had a lot of fun playing together and me and my dad played skate three together. It was a lot of fun. I kicked his butt at hockey. Then I went to my mom's house, and she has a big stomach because she's pregnant, and we ate the world's most delicious supper ever - jumbo shrimp and scallops which I helped cook of course. It was delicious and nutritious.*

From the moments Nathaniel chooses to highlight about his weekend, several important areas are uncovered that can be further explored, such as: his experience playing with friends, time spent with his family, seeing his father and playing a game with him, an upcoming new sibling, and being a helper at dinnertime. Common to all these areas is the sense of enjoyment in the activities that he is able to do well, for example at having gotten a better bowling score, how he "kicked his [dad's] butt" and of being able to help cook a delicious meal.

Meanwhile from his individual interview, we learn that spending time with his family is not always so positive. In fact, Nathaniel describes the difficulties he had when he lived with his mother ("I didn't behave, I kicked stuff and everything") and how he currently lives with his maternal grandparents who are "nice". He describes his family as being "funny. Most of them aren't mean. Well actually all of them have a good sense of humour and they're all nice".

However, he notes that his father's family can be "a lot different" from his mother's side of the family … "In sort of a bad way sometimes. But in a good way sometimes." In this case, we can see that the videogame may be an activity that Nathaniel reports enjoying, but the story from his life book indicates that what really mattered to him from this event was the time spent with his family.

What Matters Made Visible

The above illustrations from all four participants demonstrate how through PhotoVoice, the participants could express what they valued about specific experiences and the specific people with whom they shared those experiences, what Lawlor (2003) drew forth in her description of children as a socially occupied being, “doing something, with someone else, that matters” (p.432). In addition, the interviews and participant observations conducted as part of the ethnographic methods could be used to support and further enhance what matters in the experiences of the participants as uncovered through the PhotoVoice activity. On the other hand, the comparison between the lifebook content and the data derived from the interviews and participant observations could also be used to highlight inconsistencies in the experiences that mattered to the participants, as was the case for Mitchel. Specifically, the lifebook process highlighted the absence of one of the child-selected themes, i.e. friends, and signalled the need for more detailed reflection regarding whether an area of Mitchel’s life that he valued was missing from his life.

What follows here are the comparisons made of the data that was collected from or about Mitchel across the various sources. The key ideas that emerged through Mitchel’s individual interview, lifebook content, participatory group session transcripts, and participant observations are summarized in Table 4.2 allowing for a comparison of the data that emerged across the different methods.

[INSERT TABLE 4.2]

Upon review of Mitchel’s interview transcript, the following key ideas were identified as being important: his family, cat, and friends; the things he likes to do (play and world technology); and school. One area in which he spoke at length about during his individual interview was his experiences with friends, either at his school, at the hospital program or in his neighbourhood.

When the participants generated their ideas of what to include in their life books, Mitchel emphasized sports, electronics (video games and computers), and pets. All of these ideas were included in the final life book that Mitchel created.

Although the idea of friendship was a recurrent theme during his individual interview, his friends were not part of the content of Mitchel’s lifebook. Yet, a comparison of the participant observations taken at recess time at the day hospital program made in the weeks before and after the participatory group sessions highlight a positive change in Mitchel's engagement with his peers.

Upon more detailed review of the PhotoVoice group transcripts, a similar change in his interactions and relationships with the other group members, as identified from the participant observations described above. This evolution is presented in the chronological order in which they were observed (see Table 4.3). In the first group session, Mitchel's questions and comments were at times ignored by his peers. However, each week he continued to ask questions and show genuine interest in what the other children shared. In the fifth group session, Mitchel reveals an experience of his school that is common to all of the participants, and becomes a spokesperson for the group. This session becomes a pivotal point where Mitchel becomes visible to the other members of the group. Following this session, there is a noticeable shift in the way his peers respond to him, where the same question that was previously ignored now stimulated a conversation between peers.

[INSERT TABLE 4.3]

These findings are discussed in more detail in the manuscript that follows. This manuscript presents the participatory research project conducted with four children attending a day hospital program for children with mental illness, described in Chapter 3. Mitchel was selected as an exemplary case to highlight the findings included in this manuscript, as his lifebook allowed what matters to become visible and also alerted us as to how what matters became visibly absent. This manuscript was completed in collaboration with Dr. Heather C. Lambert and Dr. Melissa Park and was submitted for publication to the *Scandinavian Journal of Occupational Therapy* on June 1, 2015.

Figure 4.1(left) and 4.2(right). The before and after transformation of Mitchel’s family image.

Figure 4.3 – Image selected by Gummy Bear to represent her sisters for her lifebook.

Figure 4.4 – Strawberry Shortcake’s image of olive trees.

Figure 4.5 – Strawberry Shortcake’s image of cookies.

Table 4.1 - Lifebooks: Summary of the activities, people and places included.

Activities	Sports: *Soccer; Karate; Hockey; Swimming; Sledding; Snowboarding* Physical Activities: *Scooter; Ziplining, Going to the Park, Going for a Walk* Electronics: *Video Games; Minecraft; Xbox; Computer; iPad; Television* Sedentary Activities: *Reading; Coloring* Daily Living Activities: *Eating; Cooking; Going Shopping*
People	Family: *Cousins; Siblings; Parents; Grandparents; Aunts and Uncles* Friends Pets: *Dogs, Cats* Teachers Principals
Places	Home: *Bedroom; Living Room; Backyard; Neighbourhood; Grandparent's Home* School Hospital/Program Other Places They Had Been: *Vacation; Farm; Community Park; Water Slides; Amusement Park; Ziplining Trails; Camp*

Table 4.2. A summary of what matters to Mitchel as identified through different methods

Life Book Themes	**Interview**	**Life Book Content and Discussion**	**Participant Observations**	**What Matters**
Family	• His family is nice, happy. • He does activities with his father but doesn't have a lot of time with his mother. • His parents argue when he goes to bed and this makes it hard for him to sleep.	• *Session 2*: He is an only child. Mom loves bananas. Dad loves music. 	• Mitchel was upset when his grandmother's pet died and as a result began to cry at his community school, as per a report in his communication book.	• People getting along, being happy. • Spending time with those who matter.
Pets	• Asks if he can put his cat in his life book. • Helped him to make a new friend on the bus, as they like to talk about their cats together.	• *Session 3*: He considers his cat to be part of the family and "the thing [he] love[s] the most"  • *Session 9*: Asks whether he can share his life book with his cat.	• *Session 8*, Mitchel mentions that his cat tries to teach him things.	• Doing things with those who matter.
Friends	• Coming to the program	• No friends are in his life	• In *session 7*, Mitchel	• Being with the

	makes him miss the friends he has at his community school. - He is friends with almost everyone in his grade. - On the day that he is at his community school many of his friends have signed up for a lunchtime activity and do not come out to play. - He has friends in his neighbourhood that he plays with. - He *barely has any friends here* at the program.	book	mentions that his best friend has a pet rat. - Mitchel was observed during recess and lunch periods at the hospital program. At time 1, he was observed to be more isolated and generally playing in parallel to his peers. However, at time 2 he initiated conversations with peers and made plans to play together at recess time. - In a communication book entry, Mitchel's father describes how he "lost it" and had a "meltdown" at a weekend camping trip because the "chemistry	people who matter. - Working towards obtaining what matters to him, i.e. doing something that you enjoy with others that you enjoy being with.

			with his 2 friends who were there was a bit off" but later goes on to say that he was a "social butterfly in meeting new kids during events".	
What I Like To Do For Fun	• He loves to nerf gun fight with his friends. • He hates football because the game led to an injury and also to 'world war 3' in his neighbourhood. • He likes to play video games. • He attends a cubs group but almost got kicked out by another kid who threw a dodgeball extremely hard at him and upset him. • He makes stop motion films.	• *Session 2*: He likes to play at the park, ride his scooter and play hockey.   • *Session 6*: His favourite thing to do is nerf gun fight. • *Session 7*: He wants new video games and a new toy	• *Session 4*: Mitchel used to go to Karate. • Mitchel and Nathaniel frequently discuss video games together (*session 2, 4, 6, 7, 8*). • Mitchel attempts to make plans with Nathaniel to play video games together online (*session 4, 6*). • Mitchel and Nathaniel play a game together in session 8 while waiting for others to finish their	• Doing things that make you happy; that are fun. • Working towards obtaining what matters to him, i.e. doing something that you enjoy with others that you enjoy being with.

		car for Christmas. • *Session 1*: He likes to be on the computer but is not a fast typer.	work.	
School	• He describes his elementary school as his “favourite place to be for school” and a place where he can be with his friends. • Having mean substitute teachers makes him stressed. • Reading and writing are difficult for him. • Used to get in trouble at recess when he first started the hospital program for things he was usually allowed to do at his community school.	• *Session 5:* He likes most of the activities there but also describes school as a “bad place for a kid” because of the “doom of home work”. 	• During recruitment, parents express concerns over Mitchel’s diagnosis of dyslexia and whether it will impact his participation in the group. • Mitchel begins to cry when a volunteer asks him to read out loud in the classroom. • During a group activity with his peers Mitchel notes that he liked it when the rules are the same as his outside school.	• Being able to handle stress and frustration when things are difficult or different.

			• During the life book groups, Mitchel frequently asks for help when spelling words (*session 2, 3, 5, 6 –to the group, 8*).	
Home	• Bedtime can be an issue and he sometimes has a temper tantrum because he's not tired yet and his parents want him to go to bed.	• *Session 5:* "My favorite place is home but I do not like home I love home" 	• Communication book entries are largely focused on his behaviour and attitude related to completing his homework. As per the notes his attitude is great and he works hard despite his academic difficulties.	• Spending time with those who matter. • Being able to handle stress and frustration when things are difficult or different.
My Favourite Place	• Was not discussed.	• *Session 5*: "My favorite place is home but I do not like home I love home" • "My 2nd favorite place is church"	In *session 1*, Mitchel makes a connection with another boy about going to church when Nathaniel reports	• Making a friend – sharing common interests.

		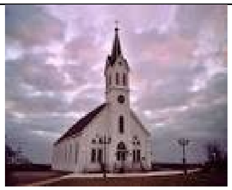	that he used to attend church.	
Places I've Been	• Cubs • Neighbourhood • Day hospital program	• *Session 5*: School, home, and church.	• When discussing different places they've been Mitchel adds the farm. He also notes in this conversation that he used to go to zig zag zoo and hates the amusement park LaRonde.	• Doing things that you enjoy.

Table 4.3. The evolution in Mitchel's relationships during participatory group sessions.

	Session Number								
Observation	1	2	3	4	5	6	7	8	9[*]
Finding common interests	🟫	🟫		🟫		🟫			⬛
Asking questions to peers		🟧	🟧	🟧	🟧	🟧	🟧		⬛
Directs questions to primary author		🟫	🟫		🟫				⬛
Offers advice to peers/ Offers to help peers			🟫	🟫				🟫	⬛
Receives questions from peers			🟫	🟫	🟫		🟫		⬛
Being assertive			🟫			🟫	🟫		⬛
Engages in conversation with a peer (>3 turns each)			🟫	🟫	🟫	🟫	🟫	🟫	⬛
Initiates conversation with a peer						🟫	🟫	🟫	⬛
Making a joke					🟧			🟧	⬛
Directs questions to his peers						🟧	🟧	🟧	⬛
Making plans with a peer						🟧		🟧	⬛
Being included by a peer						🟧	🟧	🟧	⬛

[*] *Session nine has been excluded from this analysis as this session was highly structured, used to obtain the participants' feedback on the participatory groups and did not allow for these behaviours to be observed.*

References

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Chapter V. Being visible: PhotoVoice as assessment for children in a school-based psychiatric setting

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Article submitted for publication in the *Scandinavian Journal of Occupational Therapy*.

Abstract

Background: Practice guidelines on recovery accentuate the need to understand what matters to children with a mental health disorders from their perspective. Yet, current self-report measures may neither assess what children hope for nor lead to child-driven interventions.

Aim: This study examines what PhotoVoice can add to self-report measures for children with mental health disorders.

Materials and Methods: We used a narrative-phenomenological approach to a focused ethnography (interviews, participant observations) in order to examine the experiences before, during and after 9 PhotoVoice sessions of 4 children referred for severe behavioural problems to a day hospital program.

Results: PhotoVoice engaged children in articulating what mattered in their everyday lives, facilitated changes that generalized outside of the PhotoVoice group sessions, and revealed an additional category not found in current self-report measures, such as “mattering to others."

Conclusion: PhotoVoice foregrounded children’s perspectives, rather than clinical or parent perspective on function, essential for client-driven, recovery-oriented services.

Significance: PhotoVoice provides a participatory, activity-based method for identifying and facilitating child-driven interventions

Introduction

Pediatric occupational therapy practice places prime importance on measures and interventions that promote children’s successful participation within their natural environments and emphasize the child’s preferences and family’s priorities (Case-Smith, 2013; Case-Smith & Arbesman, 2008). The now international emphasis on empowerment and hope in recovery models represents a shift from client-centered to client-driven care (Wittiwer, 2006; World Health Organization, 2013). In this approach, clients of all ages become experts in the management of their difficulties (Frese et al., 2001; Jacobson & Greenley, 2001) with increasing attention towards youth and families (Mental Health Commission of Canada, 2012). Johnston and Case-Smith (2009) agree that self-management can be applied to all clinical populations and problems. Thus, understanding what matters from the perspectives of pediatric clients is not only essential to establishing meaningful goals and selecting relevant intervention plans, but also a key aspect of emerging practice guidelines on recovery.

The challenge for clinicians is how to best access the experiences of children. In order to truly capture the child's perspective, self-report must be age-appropriate and child-driven (Dell Clark, 2011). Yet, clinicians often rely on their clinical experiences and research evidence to select goals and interventions for children (Case-Smith & Arbesman, 2008). In addition, self-report measures for children continue to be plagued by a number of issues (Greco et al., 2015). First, many professionals use proxy-reports rather than asking children directly (Brown & Bourke-Taylor, 2014). Second, self-report measures consist of adult-defined domains and may not reflect children's needs and values. Finally, the common format of questionnaires predetermine, and often limit, the scope of the dialogue between the child and clinician, which Kielhofner (2008) affirms is essential to "generating a deeper understanding of the client's circumstances and determining directions and strategies for therapy" (as cited in ten Velden et al., 2013, p.56).

Many researchers and clinicians advocate for including pediatric clients in health care decisions and obtaining their perspective on their health needs (Cremeens, 2006; Dell Clark, 2011; ten Velden et al., 2013). Participatory research involves stakeholders as active partners in the production of knowledge and decision-making (Dell Clark, 2011; Liegghio, Nelson & Evans, 2010). Consistent with the principles of client-centered practice (Clark, 2010 as cited in Carter & Ford, 2013), participatory approaches place value on creating "knowledge that is more closely centered on the experiences of individuals" (Letts, 2003 as cited in Lal, Jarus & Suto, 2012, p.181). In addition, child-centered researchers support visual methods as an effective way to explore the child's world, respecting that a child's method of communicating meaning may not be accessible through verbal reports alone (Dell Clark, 2004; Jorgenson & Sullivan, 2010). Thus, the aim of this study was to explore how PhotoVoice, a participatory approach used to empower and highlight the unique experiences of vulnerable groups (Asaba et al., 2014), facilitated understanding of what matters to children with a mental health disorder in order to enhance child-driven interventions.

Materials and Methods

We conducted a PhotoVoice project, a participatory research approach where participants use cameras to photograph significant aspects or events of their lives (Asaba et al., 2014; Foster-Fisherman et al., 2005), with the aim to understand the experiences that mattered to children with severe emotional and behavioural difficulties. In parallel, we conducted a focused ethnography using a narrative-phenomenological framework to evaluate the PhotoVoice process.

Setting

This study took place at a hospital program at a psychiatric treatment center providing psychosocial, emotional, behavioural and academic interventions for elementary school-aged children whose behavioural difficulties interfere with their participation at their community schools and homes. The children attend the program 4 days per week, between 3 to 10 months. Ethical approval was obtained from the Research Ethics Committee of this institution.

Participants

Children between the ages of 8 to 12 who had average cognitive potential, determined by a chart review of neuropsychological test scores, were eligible for inclusion. A random number table generated the order in which letters of invitation were sent to the child's parents. Interested parents were provided more details and parental consent and child assent obtained. The final sample consisted of two boys and two girls, aged nine and ten years old, with diagnoses of attention deficit disorder, oppositional defiant disorder, conduct disorder, anxiety disorder, and/or learning delays who had behavioural challenges, such as refusal to complete school work and/or social difficulties with peers.

PhotoVoice sessions

Participants used photographs to create individual life books over nine group sessions, lasting from 60 to 90 minutes (Table 5.1).

[INSERT TABLE 5.1]

Data collection and analysis (sessions 1-8). The children selected their pseudonyms and chose the following themes for their life books in collaboration with the primary author: (a) family, friends and pets; (b) what I like to do for fun; (c) school; (d) home; (e) places I've been; and (f) my favourite place. At the end of each session, the children presented the page they had worked on, and the other group members and primary author asked questions to further explore that child's experiences and understand what they valued about them. Group sessions were audio-recorded, transcribed verbatim and de-identified.

Dissemination plan (session 9). Similar to other PhotoVoice projects (Fitzgerald et al., 2009; Valenzuela et al., 2013), the children decided whether and with whom to share the content of their life books, including: (a) to not present their book; (b) separate in-class presentations; (c) a cumulative presentation for all of the students and staff; and/or (d) an exhibit at a family event. One participant preferred to show her book to her family at home. The other three participants opted for in-class presentations that they arranged with their teacher.

Ethnography

Ethnographic methods provide a thick description of the participant and their experiences in a local context (Creswell, 2013; Geertz, 1973). In this project, we used a narrative-phenomenological conceptual framework (Mattingly, 2010) to focus data collection and analysis on the lived experience of mental disorders (Davidson et al., 2007) with a particular focus on what really matters in those experiences (Kleinman, 2006).

Data collection. The primary author conducted a 45 minute semi-structured interview prior to the PhotoVoice sessions. Unlike a clinical interview, the focus was on the child's perspective of various experiences in his/her life. The interviews were audio-recorded, transcribed verbatim and de-identified. In addition, field notes of participant observations during classroom, recess, and/or lunch were taken once in the two-week period prior to the series of group sessions, and once in the two-week period following the end of the group sessions.

Data analysis. The authors employed a hermeneutic analysis, which involves the interpretation of text to facilitate understanding of the phenomenon being explored (Kinsella, 2006). This consisted of an iterative analysis between the initial interviews, field notes of participant observations, images in the life books, group session, and literature on existing assessment practices using the following steps:

First, the primary author reviewed the individual interview and group session transcripts looking specifically for any stories defined by: (a) temporally situated events; (b) evoked dialogue; and/or (c) specific and vivid descriptions (Mattingly & Lawlor, 2000). The primary and last author read one transcript together to reach consensus on what constituted a story, using triangulation to establish trustworthiness of the data (Krefting, 1991). Second, the primary author re-read all transcripts, noting when a child repeated an idea as another indicator when topical areas mattered. This generated individual profiles and a working hypothesis of what mattered to each child using his/her own words, which allowed for critical reflection on the meaning behind their stories. Third, the primary author reviewed the life books and group session transcripts for stories or significant events to identify any new ideas and refine working hypotheses on what mattered to each child. Finally, within-case comparisons were made between the analysis of the initial interviews, group session, and participant observations to examine if what had been identified as what mattered to the children was visible in their life book content and how this was related to changes in actions over time and in different contexts (i.e. classroom, recess). Specifically, we evaluated the PhotoVoice process, using life books as a modality, relative to existing self-report assessments.

Results

The children's life books provided rich details of their everyday experiences. PhotoVoice sessions added value to current self-report measures available by foregrounding the children's changing perspectives of what mattered over time, as opposed to a one-time clinical assessment or parental perspective on functional status or diagnosis. Further, group interactions also identified a new category for future self-report measures. Drawing from the ethnographic data, Mitchel's experiences provide a particularly powerful illustration of these added values.

Refocusing the self-report: From function to experience

According to his chart, Mitchel has severe learning difficulties, with presenting problems listed as "anxiety, attention difficulties, poor emotional regulation, excessive outbursts or tantrums, refusal to do school work and uneven development." During recruitment, Mitchel's father referred to his diagnosis of dyslexia to express concern that the group would be too challenging.

Initial interview and participant observation: "It ended up like pieces". The interview took place in a small, quiet office at the hospital program. I showed Mitchel my list of questions but told him that since he was the expert today, he could talk about anything he wanted. After a few preliminary questions, I asked Mitchel to "tell me what it's like for you at school". Mitchel volunteered an event at his community school from the previous year that describes, in vivid details, how his challenges with writing impact on his experience of school.

> *Once I had this test and at the time I was really stressed about all of this. And also I hated reading and writing at the time-- I still hate the writing part but I now like*

> *the reading part--but I got so mad I put one hand on it, and took my eraser [makes a rough erasing motion] and then by accident it ended up like pieces...*

Despite saying he now likes "the reading part," my participant observations of Mitchel in his classroom at the hospital program a few days later suggested otherwise.

> *Mitchel, sitting at his desk with a red face, has tears pouring down his cheeks. His head is down and he is staring at a book on his desk. A classroom volunteer is leaning over his desk, her head close to his, talking to him in a hushed tone. I gather that she had asked Mitchel to read out loud. The more questions she asks about why he is crying, the more upset he gets. The classroom teacher intervenes and asks Mitchel to leave the classroom until he stops crying.*

Although the chart review, conversation with his father, and my observation highlight Mitchel's functional challenges and their impact on his participation at school, a month later, one of his life book pages provides a more nuanced, detailed and experiential "kid's eye view" on school.

PhotoVoice session # 5: "A horror movie". Next to a cartoon of a school house with groups of smiling children exploding from each window, which Mitchel found on the internet, the text reads: "School is [sic] bad place for a kid. The doom of home work!" He had chosen to place the red school house on a solid red background. The ensuing discussion among the participants marked a key moment, providing not only a window onto Mitchel's particular experience of school, but also of the other group members' experiences of school.

Mitchel begins emphatically, "I hate school!" "Me too," chimes in Strawberry Shortcake. "Well," Mitchel capitulates, "I like school, like the activities, like art, science, all that. I just hate school in general, like, all the work and homework."

VG: What's happening in this picture?

Mitchel: It's showing a ton of kids trying to escape from school.

VG: Trying to escape, I see. And what does this picture tell us about your life?

Mitchel: I just explained that.

Gummy Bear: That he hates school.

VG: That he hates school, ok.

Mitchel: Besides all the activities, like science.

VG: Besides the activities, so really it's just the work?

Mitchel: Yeah.

Gummy Bear: Yeah!

I ask Gummy Bear, “You agree?” and she, Strawberry Shortcake and Mitchel look at me and respond “Yes!” in unison.

Mitchel: Can’t you tell that from the angry face I put on it?

An angry expression, also in red, is just barely discernible super-imposed over the red school house on the red background. “Oh!” I say, “You put an angry face on it?” Nathaniel has not responded, so I turn to him and ask:

VG: Are you part of this ‘school work sucks’ group?

Nathaniel: Yeah I would agree with this, trust me.

VG: You agree?

Nathaniel: Yeah.

VG: Anyone else have any questions for Mitchel?”

Gummy Bear: Ok Mitchel, why did you-

Strawberry Shortcake: Yes!

Mitchel: Yes Strawberry Shortcake?

Strawberry Shortcake: Mitchel, why don’t you like school?

[Mitchel looks at her, opening his mouth to respond, when~]

Gummy Bear: Because he doesn’t.

Strawberry Shortcake: Oh.

VG [to Mitchel]: Because? What were you going to say?

Mitchel: Because I do not like the work.

Gummy Bear: Mitchel, why did you put red on the school?

VG: Oh that’s a good question. Gummy Bear has a question for you.

Gummy Bear: Why did you put red on the school?

Gummy Bear’s question, which is finally heard on her third try, elicits a rich depiction of the intensity of Mitchel’s school experience.

> *You mean the background? It was because~, I put red on the background of the school section~, is because I was making it, you know, in those horror movies they make it in black and white or red to try and represent ‘DOOM’? That’s pretty much what I did. I did it from the horror movies.*

Instead of a safe space to learn, “school as a horror movie” invokes an image of a place where only escape is possible; a view that is validated by his peers. In this sense, the participants’ co-construction through their questions and validation through their affirmations of school as a scene of horror recognizes Mitchel as a spokesperson for a shared school experience.

What matters most: Becoming visible

In the initial session, all the participants identified friends as a theme for their life books. Yet friends were noticeably absent in Mitchel’s life book, despite being a recurrent topic during his interview. For example, he missed his friends in his community school, adding that everyone in his grade was his friend before segueing into a story about his neighbourhood friends.

Initial interview: “World War III”. When asked what he enjoyed doing, Mitchel responded, “to go outside with a nerf gun and play. But there’s a problem right now. Right now we can’t really do that, can I tell you why?” “Why?” I ask.

> *It’s World War III. (VG: Really, between who?) Between [adversary], versus me, [ally] and [ally]. Because of the football, um, we started getting mad at each other and I just-, and [adversary] just told me “Come on Mitchel, we need to do something” and I was like “whatever”.*

For Mitchel, the conflict which occurred while playing football is nothing less than the devastation of a world war. Although his remark, “for a long time I didn’t really have anyone to play with,” indicates that he had made friends at the day hospital program since he started several weeks earlier, participant observations during recess later that same day indicate that Mitchel’s play with others is fairly limited.

Participant Observations of Indoor Recess: “Can I show you?” Mitchel enters a room to join three boys playing with Lego who are already in the process of building and modifying different types of aircrafts with machine guns.

> *Mitchel says “Hi guys!” No one responds. He builds a structure on his own and then flies it around the room. Stopping in front of a classmate sitting at the next table, he asks, “Can I show you what I made?” The boy nods, and Mitchel points out the different types of guns and shields. The boy does not ask any questions or comment. Mitchel flies his plane around the room until recess is over.*

Although he engages another classmate, the conversation remains one-sided and the other boys take no notice. From a clinical perspective, showing another person what he created rather than playing with another person (e.g. parallel versus cooperative play) might indicate social skills as a focus of intervention. Yet, a pivotal change in Mitchel's social interaction occurs during the PhotoVoice sessions, which had been entirely initiated by Mitchel himself.

PhotoVoice sessions 4-6: "And I could add you". At the beginning, Mitchel's questions and comments were often ignored by his peers. Every week, he persevered in asking questions and showing genuine interest in what the others shared. However, there was a qualitative change in his relationship with Nathaniel, between sessions four and six after he had become the impromptu spokesperson for his peers about school as horror movie in session five.

Session 4: The participants are working on their favourite place. When it's Nathaniel's turn to present his page, Mitchel is first to sit by him, asking, "Do you want to be friends on x-box?" Nathaniel focuses on his computer, "I don't have x-box live." Mitchel looks down, then, "Oh. Well if you ever do get it?" Nathaniel is having trouble opening the picture he wants to present, "This one is broken." Mitchel offers "I can fix it!" "No," says Nathaniel.

Session 5: During the fifth session, Nathaniel and the others' confirmation of Mitchel's experience of school is a pivotal point in which he becomes visible to his peers.

Session 6: Nathaniel and Mitchel, sitting side by side, are looking through pictures on their computers. Mitchel scrolls through different animals. Nathaniel stops on a picture of his room. Mitchel, looking over, exclaims, "Wait! Who has an X-box 360 connect?" "Me!" Nathaniel replies. Mitchel points to Nathaniel's picture and continues "I can see it. Do you have x-box live on it?" Nathaniel looks at Mitchel and states "No. Sadly. I might get it for Christmas though." Mitchel asks "Hey, wait, what's your gamer tag?" When Nathaniel gives him his tag, "Deadman," like a key, a door is opened up for a qualitative shift in their interaction.

Mitchel: If you get x-box live, and you get me your gamer tag on a piece of paper, would you like to know what we can do?

Nathaniel: Play together, I know.

Mitchel: Actually we need x-box gold to play together but we can message each other. Like you know the way you talk on x-box?

Nathaniel: We can always go on the same thing- do you have a microphone? Cause we can always just mute all the other people. Do you have Minecraft? (*Mitchel*: Yeah) I can always just mute all the other people, and I could add you if you have your microphone and we could talk.

If Mitchel initiated this interaction, it is Nathaniel who suggests two times that they can "always mute all the other people," granting them an exclusive type of relationship. After this session, Mitchel began to direct his questions to the group rather than to me. The subsequent changes in his self-assertion, flexibility, and in the increasing amount of jokes he made in the group also translated to outside of the group several months later.

Participant observation. "Yeah, let's do it!" After the participatory group sessions had ended, I observe Mitchel at recess as he enters the room with another boy from his class.

> *They are chatting about a videogame they both play. Mitchel asks the other boy if he wants to play a videogame and the boy replies, "Yeah, let's do it!" They join two other children already playing on the Nintendo game cube platform. The conversation between the players as they declare war against each other is full of exuberant and playful, "I'm coming for you!" and "I'm gonna get you!" followed by mutual laughter when one or the other falls off the platform.*

Contrary to the football incident resulting in World War III described in his initial interview that disrupted his play with friends, this "war" is full of inclusive, "I'm gonna get you," and "I'm coming for you." Compared to the recess observation prior to the PhotoVoice sessions, Mitchel has moved from "Can I show you something," to "Yeah let's do it," and from entering a room alone to entering-with another. As a self-report measure, the PhotoVoice process over time allowed me to follow the changing nature of Mitchel's social relationships while highlighting a critical area of focus for assessments in general: What matters most may be mattering, itself; that is, being visible to others.

Discussion

Qualitative research is well-suited to occupational therapists who are "dedicated to understanding the complexities of the human experience as a foundation to practice" (Case-Smith & Powell, 2008, p.484). PhotoVoice provided a medium through which the children articulated what mattered about particular activities. Re-appropriating PhotoVoice as a stand alone, or supplement to existing, self-report measures has implications for both client-centered and occupation-based assessment.

Implications for client-centered assessment

The themes chosen by the participants (e.g. family, friends and pets; what I like to do for fun; school; home; my favourite place; and places I've been) were similar to the content of the

Children's Assessment of Participation and Enjoyment (CAPE), a questionnaire where children indicate whether or not they engage in a particular activity, how often, with whom, where, and their level of enjoyment of the activity (Imms, 2008). While tools such as the CAPE allow children to quantify how often they engage in a certain activity, there is no indication as to the particularities about what the children value or don't about certain activities. For example, Mitchel's choice and creative alteration of the school house (red background, super-imposed angry face) also allowed him to express negative experiences with activities he must do frequently everyday, such as reading writing, which constrain his participation. Although the intensity of these experiences could be assessed through the initial interview and observations, the life book process allowed a more nuanced understanding (e.g. he enjoys some activities such as science, but dislikes paper/pencil homework). Further, in contrast to his self-report of the importance of friends in his initial interview, the lack of images associated to friends in his life book accentuated that something that he enjoys doing is missing from his daily experiences.

Hammell (2015) argues for the importance of critical perspectives to reflect on asymmetrical power relations in order to support client-centered practice. Examining power relations between adults and children is particularly important when trying to understand what is meaningful to children from their perspective (Dell Clark, 2011). The life book process raises questions on functional assessments that foreground clinical perspectives, which may not actually be useful for generating client- and family-centered goals. For example, Mitchel's performance in class, parent report and chart review would foreground assessing and working on skills needed for reading or writing prior to a life "book" group. Yet, Mitchel's life book image of school not only shifted the focus from his functional challenges to his experience of school, but also critiqued the popularized image of "school as a happy place."

Implications for occupation-based assessments

As indicated by our philosophy, "Our role consists in giving *opportunities* rather than prescriptions. There must be opportunities to work, opportunities to do and to plan and create, and to learn to use material" (Meyer, 1922, p.7). The PhotoVoice sessions provided an opportunity to engage in the creative and problem-solving process as they helped each other with the technology while reflecting on what mattered in their own experiences. Not only did they begin to rely on each other over time, but also the images stimulated collective discussions in which the children often guided the adult researchers on the meaning of experiences (Kondo &

Sjöberg, 2012). For example, the children guide the researcher towards what to focus on in the session of “school as a horror story,” such as when Mitchel asks, “Can’t you tell that from the angry face I put on it?” or the girls who ask, “Why don’t you like school?” or “Why did you put red on it?” that ultimately, also empowers Mitchel. As Hultqvist, Eklund & Leufstadius (2015) note, empowerment and satisfaction with care in adult psychiatric day centers is related to engagement in meaningful activities or occupational engagement.

Fisher (2014) notes the value of occupation-based and occupation-focused evaluations to articulating our central values to others. One of the unique attributes afforded by this life book as an activity-based process was the child-driven content of the PhotoVoice sessions. This content provided material for a naturalistic or ecologically valid ongoing assessment of their experiences at school in addition to learning about their experiences in their community and home. Through PhotoVoice, the participants could express what they valued about specific experiences and the specific people with whom they shared those experiences, what Lawlor (2003) drew forth in her description of children as a socially occupied being, “doing something, with someone else, that matters” (p.432). Furthermore, Mitchel’s shift in his interactions with his peers after session five in which he became visible as the spokesperson for his peers, does not just highlight the potential of PhotoVoice to illuminate new child-generated categories for self-report measures, such as the importance of being visible or mattering to others. The lifebook activity in which this change occurs, also makes visible the potency of occupational engagement as both the ends and means (Gray, 1998) that lies at the heart of our practice.

Conclusion

The children-created life books provided a window for adults (e.g. teachers, researchers, parents) to access their experiences and explore the meaning and value of those experiences from their perspectives. The ethnographic methods supported the meanings attributed to the images in the life books as a self-report measure of what matters, while also showing how what happened in the PhotoVoice sessions translated outside of the group in the children’s recess and classroom experiences. This is particularly important for occupational therapists to also express the value of engagement in meaningful activities in the assessment process, while supporting child-driven recovery initiatives. In essence, when the children were given the opportunity to act, they gave us the opportunity to learn.

Table 5.1. Overview of session content.

Session	Content
1	Introduce group members and group purpose Collaborative review of rules Review camera use – Tips and Information Sheet Brainstorming and selection of main themes (participants)
2-7	Computer set-up and picture upload Each child works on theme of the day (30 – 45 minutes) Presentation of page, group discussion stimulated by: 1-Describe your picture. 2-What's happening in this picture? 3- Why did you take this picture? 4- What does this picture tell us about your life? (20 minutes) Selection of theme for next session
8	Computer set-up and picture upload Adding additional content and making revisions (30 – 45 minutes) Presentation of page, opportunity to ask questions (20 minutes) Initial discussion re. dissemination plan
9	Group members provide feedback regarding the group process/experience stimulated by pre-determined questions Group members shown a printed draft of their life books to approve Finalize dissemination plan

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Chapter VI: Summary and Conclusion

Clinical Implications

In the practice of occupational therapy, the involvement of all clients as collaborators and active participants in the therapeutic process is central to the profession (Canadian Association of Occupational Therapists, 2007; Kramer, 2011). This client-clinician collaboration results in the selection of treatment goals that are meaningful and relevant to the client (Missiuna et al, 2001; Perry et al., 2008; ten Brummelaar et al., 2014). Occupational therapy practice also values the unique experiences that are specific to each client (Canadian Association of Occupational Therapists, 2007). However, as Liegghio and colleagues (2010) state, the dominant approach to mental health care has been “based on objectified forms of knowledge” (p. 86) and the subjective experiences of children with a mental health disorder are often ignored. Thus, an enduring challenge for clinicians working with children with a mental health disorder is to determine how best to access the unique experiences, values and needs of these children in order to promote child-focused interventions and support their engagement in treatment.

PhotoVoice as a self-report measure

Following the view of children as competent reporters of their health needs (Creemens et al., 2006), there has been an increased focus, within occupational therapy practice, on developing self-report measures that allow children to express their concerns and collaborate with the clinician in establishing goals for treatment (Cermak & Bissell, 2014; Missiuna et al., 2006; Keller & Kielhofner, 2005; Ricon et al., 2013). However, a scoping review of self-report measures for children identified how, despite their availability, many professionals continue to rely on parent report and adult-defined constructs in current self-report measures, which may not reflect a child’s needs or values (Greco et al., 2015).

The PhotoVoice approach and the ethnographic methods employed in this study allowed us to capture the experiences of children with a mental health disorder, and specifically to understand what mattered in those experiences. Spencer, Krefting and Mattingly (1993) drew a parallel between the participant observations done from an ethnographic perspective and the clinical observations used as part of the traditional assessment process. While both can be used to gather information regarding the client’s functioning, the participant observations used in ethnography go beyond the client’s performance to also include meaning and the client’s real world context (Spencer et al., 1993). In the case of Mitchel, the comparison of the participant observations made in the weeks before and after the participatory group sessions, identified a positive change in Mitchel's engagement with his peers during recess and lunch times. Thus, while the life book process accessed experiences from Mitchel's perspective, in this case the combination of life book and ethnography methods (interview and participant observations) provided a more complete representation of his experiences. In fact, we can gather from his individual interview that friendships do matter to Mitchel and while they may not be included in his life book just yet, we can observe how over time he is able to develop friendships with the other members of the participatory group and thus obtaining what matters to him.

PhotoVoice as an occupation-based intervention

Several studies demonstrate that intensive psychiatric day treatment programs offering multiple or multimodal interventions are effective in treating children with a mental health disorder (Clark & Jerrott, 2012; Grizenko, 1997; Grizenko, Papineau & Sayegh, 1993, Kotsopulos et al., 1996; Reeves & Anthony, 2009). Traditional psychiatric and psychological interventions can include cognitive-behavioural techniques, behavioural strategies, parent support and psychopharmacological treatment (Clark & Jerrott, 2012) and have been shown to reduce difficult behaviours, strengthen parenting skills, improve family functioning, alleviate family stress, foster more appropriate social skills and peer relationships, facilitate participation in community activities, and, in some cases, improve the child's academic performance (Clark & Jerrott, 2012; Grizenko, 1997; Grizenko, Papineau & Sayegh, 1993; Kotsopulos et al., 1996; Reeves & Anthony, 2009).

Occupational therapy services are often one of the many interventions offered in these day treatment programs. Within occupational therapy practice, activity or occupation provides the foundational basis for intervention – particularly when the activity or occupation provides the client with a sense of enjoyment, accomplishment and renewal (Fisher, 2014). In a position statement on occupational therapy and mental health care, the Canadian Association of Occupational Therapy (2008) recognizes the relationship between mental health and participation in meaningful occupations and the unique ability of the occupational therapist to promote the client's engagement in activities that are meaningful, purposeful and goal-directed (Gray, 1998; Krupa & Clark, 2004).

As a compliment to traditional services, the PhotoVoice activity employed in this study offered several advantages as a potential activity-based intervention. The PhotoVoice process was found to be a particularly engaging method of understanding what was meaningful in the lives of the child participants. The participants described the group as fun and calming. The participants were excited about the use of cameras for their projects and actively took photographs prior to each group session. During the group sessions, participants were eager to show their photographs to each other and complimented themselves on the work they had done. For example, Nathaniel proclaimed the photograph of his cat to be the "best picture" he had ever taken. Over the course of the sessions, each participant was able to create something that was unique, all about themselves and their lives, and that they could share with others. They were also able to express genuine interest in the experiences of the other participants, and through their questions to each other the authors were able to capture a deeper understanding of these experiences.

The PhotoVoice activity also demonstrated the potential to empower the children as active participants and resulted in child-driven content, in line with the principles of recovery-oriented services described earlier in this thesis. Over the course of the participatory group sessions, the candidate became an active observer rather than the group leader, as the participants began to rely on each other for support (i.e. spelling suggestions, ensuring all participants were ready for presentation part of the session). Between group sessions, the participants would often seek out the candidate to ask about the project and confirm the date and time of the next session. The participants were also independent in taking photographs between group sessions and ensuring that all materials (i.e. camera and photographs) were brought to the group sessions each week. Thus, what began as a partnership allowed the children to gradually take the lead themselves.

The PhotoVoice method was easily applicable to the day hospital program context and was well-received by the participants. This project also accessed seemingly hidden potential in the participants, who attended each session in good spirits regardless of their emotional and behavioural challenges and who worked tirelessly each week to produce written text despite their academic challenges. This project also highlighted how children, who otherwise have been identified as having social challenges, were able to be courteous, kind and friendly to each other in a context where their views were respected, validated and visible.

The PhotoVoice process used in this study was time-consuming, and may not be applicable to all clinical contexts, particularly in situations where group interventions are not feasible. However, this process can be applied to individual contexts and further exploration to this effect would be beneficial. Nevertheless, there are multiple benefits to providing PhotoVoice opportunities in a group context. The series of group sessions also allowed for ongoing assessment of the children's experiences, providing a window into the child's view of what matters and how this changes over time. Additionally, the participant observations allowed us to follow how the PhotoVoice process also shaped the participants actions across different contexts.

Implications for Future Research

Self-report measures used with children often consist of structured questionnaires that have been designed by adult researchers. However, the typical assessment process may not fully appreciate what matters to our clients. What this project highlights is how much we can learn from our child clients, provided that we are listening to what they need us to know. The PhotoVoice process broadens the scope of these traditional assessment methods by capturing the meaningful areas of a child's life, directly from their perspective. Doing so speaks directly to the recent guidelines for recovery-oriented care, as this child-driven process would allow for child-centered interventions to be based on what matters to them.

Additionally, this process underscored the need to also examine if and how a child feels that they 'matter to others' — this emerged as a central concern for the participants. Within the context of this project, we observed how a child "became visible" to his peers, that is to say that his feelings and thoughts were both acknowledged and validated by his peers, and the positive impact this had on his social relationships.

As such, future research might explore the child-clinician relationship and whether the child feels that their feelings and thoughts matter to the clinician and how this relates to client-centered care. Thus, through our unique understanding of the impact of engagement in meaningful occupation on recovery, occupational therapists are well-suited to become key leaders in the application of these recovery-oriented principles.

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Appendices

Appendix A. General Letter Informing All Parents of Research Project

Dear Parents,

This letter is to inform you of a research project being conducted with some of the children attending the day hospital program in which your child is currently admitted.

For the next three months, a researcher will be observing and recording the daily events on the unit for the children participating in the study. These observations will take place in the classroom, at recess time and during group times. Details of these events will be recorded in order for the researcher to understand these events from the perspectives of the children. **Observations will only be made and recorded for children whose parents and who themselves have agreed to participate in the research study**. For this to be the case, your permission would have been obtained through a detailed information and consent form and you would have met with the researcher in person to discuss the research project.

If you have not met with the researcher or provided consent for your child to participate in this project, please be assured that no information related to your child will be recorded for this project. This project is approved by the research ethics committee and will protect the privacy of all children admitted to the day hospital program.

If you have any questions or concerns about the project, please feel free to contact the principal researcher directly using the contact information provided below.

Sincerely,

Vanessa Greco, erg., M.Sc. candidate
Occupational Therapist for the Center for Child Development and Mental Health
Principal Researcher
(514) 340-8222 ext 5624
vanessa.greco@mail.mcgill.ca

Appendix B. Letter to Parents Requesting Permission to Contact

Dear Parents,

Your child has been selected to participate in a research study during their admission to the day hospital program of the Jewish General Hospital. The purpose of this letter is to ask for your permission to be contacted by telephone by the researcher in order to discuss the project in more detail and to answer any questions you may have.

What is this study about?

This study seeks to capture the perspectives of children enrolled in this institution on what is meaningful to them in their lives.

What will my child be asked to do?

To address this question, your child would be involved in nine weekly group sessions in which he/she will *design and create individual books about his/her life* reflecting the areas that he/she identifies as being meaningful.

Throughout this study, the researcher will create a thorough description of your child and their experienced by:

- Performing *narrative interviews* with your child
- Conducting *participant observations* to document different daily experiences of your child while on the unit (i.e. "life on the unit")
- Capturing multiple perspectives of situations by reviewing your child's *communication book* and their *personal reflections* (i.e. "life at home").

The decision to participate in this research study is voluntary. Your child does not have to participate in this project if you or your child does not want to. The decision to be involved in this project does not affect the care you and your child will receive.

Sincerely,

____

Vanessa Greco, erg., M.Sc. candidate
Principal Researcher
(514) 340-8222 ext 5624
vanessa.greco@mail.mcgill.ca

Please complete and return the bottom portion of this letter to allow the researcher to contact you.

I, ______________________________, agree to be contacted by the researcher to discuss this project in more detail at: (______) _______ - __________.

Appendix C. Individual Interview questions

-Tell me about why you came to this program.

    -How did you find out you would be coming to this program?

-Tell me about the kinds of problems you were having that made you come to this program.

    -How did you know you had a problem?

-Tell me about what it was like when you first started this program.

    -How do you remember feeling about starting in this program?

    -How do you feel now about being in this program?

-Tell me about what it's like for you at school.

    -Has being at school changed since you've been in this program? How?

    -What do you like about your school?

    -What do you wish you could change about your school?

-Tell me about what it's like to be in your family.

    -Has your family changed since you've been in this program? How?

    -What do you like about your family?

    -What do you wish you could change about your family?

-Tell me about your friends.

    -What do you like about your friends?

    -What do you not like about your friends?

-What do you like about your life?

    -What kinds of things are you good at?

    -What kinds of things do you like to do?

-What would you change about your life?

    -What has changed in your life since being in this program?

What do you think other people think about you?

-What else would you like to tell me about yourself?

Appendix D. PhotoVoice Group Sessions

Script for Session 1

“I want to welcome the four of you today to this new group. We’ve already met separately before today and I asked each of you some questions about school, your family, and your friends. We’ve also talked about what research is and what this project is about – so that I can learn about what it’s like to be you. For the next part of the project, we will be meeting altogether and you will be working on a new project where each of you will design and create a book about your life so far. In most of the groups you attend in this program, the leader is usually an adult and that adult is usually the one telling you what to do. In this group, we’re going to work a little bit differently. Since you are the experts on what it’s like to be you, you will be the ones guiding me in how this project should work. Before we leave today, we’re going to talk about all the different topics to explore and to include in your books. While these big themes may be the same for everyone to start off, what you choose to include in your own books will be personal, specific to you and your life.

We are going to meet like this each week. Each group you will work on one page of your lifebook according to the themes that you select as a group. For each page you will work on a picture and a written description of how that theme relates to you and your life.

Just like all of the groups we do in this program, the most important rule is that anything you choose to discuss is confidential or private. That means that if it is said in the group, it stays in the group, and you must not share what another person from the group has said outside of the group. Could you think of any reasons why we keep things private? [Allow time for discussion].

We also need to decide today, how you would like to create your lifebooks. One thing we need to decide is whether you want to use paper scrapbooks, or make a digital book using the computers. I also want you to think about what kind of materials you would want to use. For example, you could draw the pictures for your book; you could cut out pictures from magazines or print pictures from the internet and glue them into your book. Another option you have is to borrow a digital camera and to take pictures of things you want to put in your book.

If you do choose to use the digital cameras, privacy becomes important again. Taking a picture of another person is a private thing, especially when you plan on showing the picture to a group of people they may not know and the person may not want other people to see the picture. For this project, you will only be allowed to take pictures of objects, things and places, but not of any people. If you would like to include people in your lifebook you may do so by using the other materials I mentioned. I have a document that I would like to go over together that gives you tips on how to take good pictures and also talks about how to make sure you respect the privacy of others when taking pictures. [Allow time for review] Can you think of any other private situations that you should not be taking a picture of? [Allow time for discussion].

Do you have any questions about anything I've said so far?"

Discussion of main themes to include in the life book – trigger questions

1. What does the term life book mean to you?
2. What does "a good life" mean to you?
3. What makes something important?
4. What would you include in a book about your life?
5. What would you not want to include in this book?
6. What are some of the problems that can happen in life?
7. How do you see your life book being organized?

Discussion of lifebook pages – trigger questions

Each week participants presented a page they worked on to the group. Participants were asked a series of trigger questions to explore the meaning behind the page they have created. Participants will also have the opportunity to ask each other questions about the pages they have presented to the group. The trigger questions in the PHOTO method described by Hergenrather, Rhodes and Bardhoshi (2009) correspond closely to the purpose of the study and the language used is suited to the children's developmental level. These questions include:

(1) Describe your picture.
(2) What is happening in your picture?
(3) Why did you take a picture of this?
(4) What does this picture tell us about your life?

(Hergenrather et al., 2009)

Appendix E. Additional PhotoVoice Information Available for Parents and Participants

In this project, we will take pictures of our lives and talk about them with others. But, you must keep certain guidelines in mind:

Stay safe! Make sure you are "safe" when you take the picture. For example:

- Stand on a solid surface.
- Look before you step into or cross a street.
- Be aware of things around you, like traffic.

Tips for taking good photographs

- Try different angles
- Try different points of view
- Keep the sun to your back, or to the side
- Is your subject in the center of the photo?
- Does your subject fill the photo?

Tips for avoiding common mistakes

- Keep your finger away from the lens
- Don't cover the flash
- Stand about three to eight feet away from your subject
- To prevent blurry pictures, hold your elbows close to your sides, and hold your breath when you press the shutter (button).

Photograph Guidelines

For this project you may take pictures of:

- Objects and things
- Places or buildings without people in them

Respect the lives and safety of others. When you take photos for your project, make sure that other people are not in the picture.

When permission is not necessary. In a public place like a park, you can take someone's photo without permission, especially if they are far away, if you cannot see their face and they can't be recognized in the picture.

Take pictures that mean something to you or of things that are important in your life. Think of the themes that the group agreed upon and what that theme means for you.

(Adapted from Doing your own PhotoVoice Project: A Guide by Laura Lorenz, PhD & Barbara Webster: http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)

Appendix F. Consent and Assent Forms

Jewish General Hospital	4335 Ch. Cote Ste Catherine
Department of Child Psychiatry	Montreal, Quebec
Vanessa Greco, erg.	H3T 1E4

Consent to Participate in a Research Study - Parent

This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.

PRINCIPAL INVESTIGATOR

Vanessa Greco, erg., M.Sc. candidate
School of Physical and Occupational Therapy, Faculty of Medicine, McGill University

Collaborators

Dr. Melissa Park, PhD OT/L, Assistant Professor
Dr. Heather Lambert, PhD, erg., OT(C), Faculty Lecturer
School of Physical and Occupational Therapy, Faculty of Medicine, McGill University

INTRODUCTION

Your child is invited to be a research participant in a research project that is designed to explore the experiences of children with a mental health disorder that are enrolled in the day hospital program at the Center for Child Development and Mental Health of the Jewish General Hospital. You have the right to be informed about the purpose and procedures that are to be used in this research project, and of the potential risks and benefits. Before you agree to have your child take part in this study, it is important that you read the information in this consent form. Your child will receive a separate consent form to inform them of the purpose of this study. You should ask as many questions as you need to in order to understand what you and your child will be asked to do. Your child does not have to take part in this study if either you or your child does not want to.

PURPOSE OF STUDY

The purpose of this study is to learn more about the everyday experiences that children with a mental health disorder identify as being meaningful. Children's experiences play an important part in their health and development. Children are viewed as competent reporters about their health needs and should be included in the assessment process by having the opportunity to express their experiences and relay information about their health. Yet, there is a lack of research on what matters to children and on clinical approaches that can more directly capture and address the unique experiences of children with mental illness. Information gained by exploring the experiences of these children can help to ensure that services being delivered are suited to their needs.

Recent initiatives in Canada indicate that children should play more of an active role in making decisions that affect the care that they receive. Through this study, children will be empowered to be involved in and have control over decisions made within the group sessions involved in this project that are described in the procedures section of this form.

PROCEDURES

1. After agreeing to this study, your child will be invited to meet with the researcher in order to explain the research project and to answer their questions. Your child's assent will be obtained in order to participate in the research project. Your child will be informed that they do not have to participate in the research project if they do not want to.

2. If you and your child agree to participate in the project, a "thick description" of your child and their experiences will be created by the researcher. This is a rich and detailed account or story describing your child's experiences and the environment in which these experiences are being lived. This information will also provide background information to support what your child includes in their life books (described below). This means that the researcher would be involved in many of your child's activities during their time in the day hospital program.

    a. Your child will be invited to participate in one 60 minute **individual interview** with the researcher. This interview will take place at the hospital during regular program hours. In this interview, your child will be asked about his/her experiences within their family, at their schools, at the program, and with friends. These interviews will be recorded and transcribed (reviewed and written out as a text) by the researcher. Any identifiable information (names of people or places) will be removed and your child will choose a pseudonym that the researcher will use to identify them for the purpose of the research study.

b. **Participant observations** will be done with your child at the Center for Child Development and Mental Health. This would mean that the researcher would join your child in the classroom, at recess, at lunch and during group times while in the program to observe and document your child's interactions and experiences with the people around them as they are happening. The researcher would keep a written record of their observations in order to add to the "thick description" of your child and their experiences. Finally, participant observations will include discussions about your child during weekly team meetings. These discussions will be used as examples of the ways in which clinical cases are reviewed and new information is discussed with all members of the multidisciplinary team.

c. Additionally, in order to get a perspective on the situations where the researcher cannot observe directly, information regarding your child's behavior and reactions to various situations at home and at school will be obtained from your child's **communication book** that you and the professionals from the day hospital program complete on a regular basis. With your permission, these entries will be photocopied by the researcher and used to add details about your child's experiences in different environments. This would be recorded twice for your child, once in the week before the group sessions start, and once in the week after the group sessions are over. The researcher will re-contact you to obtain your permission before photocopying the contents of the communication book.

d. As part of the day hospital program, your child may be asked by their primary worker to complete a **reflection sheet** when they have a problem they need to reflect upon. In this sheet your child is often asked to identify the problem, to identify the role they played and to process how such a problem could be dealt with differently in the future. The researcher will collect the **reflection sheets** completed by your child over the course of this study as it allows the researcher to understand these experiences from the child's perspective. For this to happen, the researcher will photocopy the reflection sheet and send it home for you to read, initial and return to the researcher in a sealed envelope if you agree to allow the researcher to use the content of the reflection sheet.

3. Your child would be invited to participate in nine 60-minute weekly **group sessions**. These sessions would also take place at the hospital during regular program hours. Over the course of these sessions, each child will create a lifebook about important experiences in their lives. Your child will be given a camera to use for the purpose of this project and will be taught how to use the camera appropriately, including ethical considerations surrounding the kinds of situations or things that would be appropriate to photograph. You would be asked to supervise the photographs taken by your child to ensure that they adhere to the guidelines set by the researcher. For example, your child will only be allowed to take pictures of objects, things or places and not of people. If your child wishes to include pictures of people in their books, they may be created by your child using alternative materials provided by the researcher (i.e. paper and crayons for drawing; magazines; images from the internet). Your child will be responsible for taking the pictures and for bringing them to the group session for group discussion. Your child will also be responsible for selecting and organizing what to include in the book about their lives. Any photographs taken by your child will be filtered by the researcher to ensure that they adhere to the guidelines and scope of the project. You will be informed in the event that your child takes a picture that does not adhere to the guidelines of the project.

4. Following the group sessions, the lifebooks that your child would create would be on display in the program to share with other children, parents and professionals. The content of the lifebooks can also be used by the researcher for educational purposes, presenting the project and its results to other professionals (for example at a conference or in a research article). The researcher will provide a second consent in which you and your child can decide whether the photographs and lifebooks that your child has created can be displayed and/or used for academic purposes. You and your child have the right to remove any content from this lifebook that you, or your child, do not want to be made public. Any content, including photographs, that is not used in the final product will be destroyed by the researcher.

POTENTIAL RISKS/DISCOMFORT

There are some possible discomforts and inconveniences associated with participating in this study. You may have some discomfort in having photographs taken within your home. Your permission will be sought in the event that such photographs would be made public.

ANTICIPATED BENEFITS

You and your child will not receive any direct benefits from your participation in this study. However, information learned from this study may lead to better treatment in the future for children with a mental health disorder and their families.

VOLUNTARY PARTICIPATION/WITHDRAWAL

You and your child's participation in this study is VOLUNTARY. You or your child may choose to participate now and decide to stop your participation at any time. You may choose NOT to participate in this study without fear of negative consequences. Your decision to participate or not in this study will not affect the care you and your child will receive. If you withdraw (or are withdrawn) from this study, any information collected up to the point of withdrawal for the purpose of this research may still be used in order to protect the scientific integrity of the study.

NEW INFORMATION LEARNED

If new information is learned that could affect your choice to continue in the research, you will be told about this information and given an opportunity to decide if you want to continue your participation in the research. We may also learn information about you or your child that was not known before, if this happens we will contact you directly to discuss information learned and may invite you to share this information with your primary worker and/or family worker for further discussion.

CONFIDENTIALITY

While you take part in this research study, the researcher will collect and store personal identifiable information about you and your child in a file for the purpose of the research study. Only information necessary for the research study will be collected. During the study, the interview transcriptions, researcher notes, photocopies of communication book entries and reflection sheets, and the contents of your child's lifebooks will be stored in a locked file cabinet at the Center for Child Development and Mental Health, Jewish General Hospital, 4335 ch. Cote Ste Catherine, room 130, Montreal QC H3T 1E4. Once the study is completed your child will keep all original content used in the creation of their lifebooks. A copy will be kept for the researcher's file. This information will be kept for ten (10) years according to the institution's policy regarding data collected for the purpose of research. After this time, all information will be destroyed by the researcher.

Every effort will be made to keep information about you and your child confidential. No information about you, or provided by you during the research, will be disclosed to others without your written permission, except if necessary to protect you or your child's rights or welfare. Should the child participant disclose information about themselves, either verbally or through a picture they have taken, where the researcher would be concerned about their safety (i.e. they express the thought or intention to harm themselves, pets or others; they describe situations of abuse or neglect; picture portrays an insecure environment) the researcher will be obliged to report this information to the proper authorities (i.e. Youth Protection services, Society for the Prevention of Cruelty to Animals). In the event that this should happen, the researcher will meet with the child and their case worker from the treating team immediately following the group session. Additionally, you will also be informed by the researcher and the case worker through a phone call or face-to-face meeting.

In an effort to maintain confidentiality and respect for the content discussed and created during the group sessions, all children participants will be asked not to disclose any personal information shared by other members outside of the group sessions. While all children will be asked to agree to a group contract to this effect, please not that this is not a legally binding contract.

To protect your child's identity, your child's name and identifying information will be replaced with a pseudonym chosen by your child. The link between the pseudonym and his/her identity will be held by the researcher in charge of the study. No information that discloses your child's identity will be allowed to leave the institution. The researcher will only send information about your child to the collaborators using the pseudonyms. This information does not include your child's name or address. The collaborators will use the information collected about your child only to reach the study goals as they are explained in this Information and Consent Form. The study information could be printed/published in medical journals or shared with other people at scientific or educational meetings, but your child's identity will not be revealed.

For the purpose of monitoring this research, your research study file as well as your medical records identifying you could be checked by a person authorized by the Research Ethics Committee of the Jewish General Hospital. This person is obliged to respect your privacy.

You have the right to look at your study file in order to check the information gathered about you and your child and to correct it, if necessary, as long as the study researcher or the institution keeps this information. However, you may only have access to certain information once the study has ended so that the quality of the research study is protected.

COSTS AND COMPENSATION

Your child will not be paid for his/her participation in this study. At the end of the project your child will be treated to a special lunch by the researcher. There will be no costs to you for your child's participation in this study. All materials required for the purpose of this project will be supplied by the researcher. Also, please note that you and your child <u>will NOT be responsible</u> for any loss or damage to materials provided by the researcher, including the digital camera.

CONTACT INFORMATION OR QUESTIONS:

If you have any questions about the study or if you feel you have a problem related to taking part in the study, you can communicate with the researcher in charge of the study, <u>Vanessa Greco,</u> at <u>(514)340-8222 ext. 5624.</u>

For any questions concerning your rights as a person taking part in this study or if you have comments or wish to file a complaint you can communicate with the Jewish General Hospital's Local Commissioner of Complaints & Quality of Services, Rosemary Steinberg, at (514) 340-8222 ext. 5833.

STATEMENT OF CONSENT TO PARTICIPATE IN RESEARCH PROJECT

This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.

Parental Consent

I, _________________________, agree to have my child, _______________________, participate in the study described above. I have read the above information and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. My child's participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my child's medical care now or later. I do not give up any of my legal rights by signing this consent form.

Parent Signature:______________________________________Date:_____________________
Name of Participant: ____

Consent form administered and explained in person by:
Signature:____Date:______________________
Name of Investigator: ____

CONSENT FOR THE COLLECTION OF INFORMATION FROM THE COMMUNICATION BOOK

I, ______________________________, in my title as _____________________________ authorize Vanessa Greco, principal researcher, to collect information from the communication book of ____________________________________ between the dates of ______________________________ and ____________________________ to be used for the purpose of a research project that I have consented to be involved in.

Signed: _____________________________________
Date: _____________________________________

Witness: ____________________________________
Date: _____________________________________

CONSENT FOR THE DISPLAY OF LIFEBOOK CONTENT

My child has been taking photographs of different things that he/she experiences in his/her life and has created a lifebook. With this form I give — or refuse — permission for my child's photos and stories to be used in a public display. I have the right to remove any content from my child's lifebook that I do not want to be made public.

- ☐ Yes, I am willing to have my child's photographs and stories about their life experiences used in public displays.
- ☐ No, I do not want my child's photographs and stories used in public displays.

I also need to give — or refuse — permission for my child's name to be listed as the photographer.

- ☐ I want my child's PSEUDONYM listed as the photographer.
- ☐ I DO NOT want my child's name listed at all.

Please list any concerns or comments:

____

____

____

____

____

I have discussed this with my child.

____

Name

____

Signature

____

Date

(Adapted from Doing your own PhotoVoice Project: A Guide by Laura Lorenz, PhD & Barbara Webster: http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)

Hôpital général juif
Division de pédopsychiatrie
Vanessa Greco, erg.

4335 Ch. Côte Ste Catherine
Montréal, Québec
H3T 1E4

Consentement de Participation à une Étude de Recherche - Parent

TITRE: Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.

CHERCHEUR PRINCIPALE: Vanessa Greco, érgothérapeute
École de physiothérapie et d'ergothérapie, Faculté de médecine, Université de McGill
Collaborateurs
Dr. Melissa Park, PhD OT/L, Professeure adjointe
Dr. Heather Lambert, PhD, erg., OT(C), Professeure agrégée
École de physiothérapie et d'ergothérapie, Faculté de médecine, Université de McGill

INTRODUCTION

Votre enfant est invité à être un participant dans un projet de recherche qui vise à explorer les expériences des enfants avec un trouble de santé mentale qui sont inscrits dans le programme de l'hôpital de jour au Centre de développement de l'enfant et la santé mentale de l'Hôpital général juif. Vous avez le droit d'être informé sur les objectifs et les procédures qui font partis de ce projet de recherche, et des risques et avantages potentiels. Avant de consentir pour que votre enfant participe à cette étude, il est important que vous lisiez bien les informations dans ce formulaire de consentement. Votre enfant recevra un formulaire de consentement distinct pour les informer de l'objet de cette étude. Vous devriez poser autant de questions que vous devez afin de comprendre ce que sera demandé de vous et votre enfant. Votre enfant n'est pas obligé de prendre part à cette étude si vous ou votre enfant ne veut pas.

OBJECTIFS DE L'ÉTUDE

L'objectif principal de cette étude est de prendre conscience et mieux comprendre les expériences quotidiennes que les enfants atteints d'un trouble de santé mentale s'identifient comme étant significative. Les expériences des enfants jouent un rôle important dans leur santé et leur développement. De plus en plus, les enfants sont considérés comme informants competents sur leurs besoins de santé et devraient avoir la possibilité d'exprimer leurs expériences et transmettre l'information au sujet de leur santé. Pourtant, il ya un manque de recherche sur ce qui compte pour les enfants et sur les approches cliniques qui peuvent plus directement capturer et traiter les expériences uniques des enfants atteints de maladie mentale. Les informations obtenues en explorant les expériences de ces enfants peuvent aider à assurer que les services livrés sont adaptés à leurs besoins.

Des initiatives récentes au Canada indiquent que les enfants devraient jouer un rôle plus actif dans la prise des décisions qui affectent les soins qu'ils reçoivent. Grâce à cette étude, les enfants seront habilités à participer et avoir le contrôle sur les décisions prises dans le cadre des séances de groupe impliqués dans ce projet qui sont décrits dans la section des procédures de ce formulaire.

PROCÉDURES

1. Lors de votre accord, votre enfant sera invité à rencontrer le chercheur afin d'expliquer le projet de recherche et à répondre à leurs questions. L'assentiment de votre enfant sera obtenu pour participer au projet de recherche. Votre enfant sera informé qu'ils n'ont pas à participer au projet de recherche s'ils ne veulent pas.

2. Si vous et votre enfant acceptez de participer au projet, une «description dense» de votre enfant et leurs expériences sera créé par le chercheur. Il s'agit d'un compte ou d'une histoire riche et détaillé décrivant les expériences de votre enfant ainsi que l'environnement dans lequel ces expériences sont vécues. Ces informations fourniront également des informations pour renforcer ce que votre enfant inclut dans son livre de la vie (décrites ci-dessous). Cela signifie que le chercheur serait impliqué dans de nombreuses activités de votre enfant au cours de leur temps dans le programme de l'hôpital de jour.

    a. Votre enfant sera invité à participer à une **entrevue** individuelle de 60 minutes avec le chercheur. Ceci aura lieu à l'hôpital pendant les heures de programmes. Dans cette entrevue, votre enfant sera interrogé sur ses expériences au sein de leur famille, à leurs écoles, le programme, et avec des amis. Ces entrevues seront enregistrées et transcrites (revues et mis en forme de texte) par le chercheur. Toute information identifiable (noms de personnes ou de lieux) sera supprimée et votre enfant choisira un pseudonyme que le chercheur utilisera pour les identifier.

b. Des **observations des participants** se feront avec votre enfant au Centre de développement de l'enfant et de santé mentale. Cela signifierait que le chercheur se joindra à votre enfant dans la classe, à la récréation, au dîner et pendant les activités de groupe afin d'observer et de documenter les interactions et les expériences de votre enfant lors qu'ils se produisent. Le chercheur maintiendra une trace écrite de leurs observations afin d'ajouter à la «description dense» de votre enfant et leurs expériences. Les observations des participants incluera les discussions au sujet de votre enfant lors des réunions d'équipe hebdomadaires. Ces discussions seront utilisées comme des exemples de la façon dont les cas cliniques sont revus et que nouvelles informations sont discutées avec tous les membres de l'équipe multidisciplinaire.

c. Afin d'obtenir un point de vue sur les situations où le chercheur ne peut pas observer directement, les informations concernant le comportement et les réactions à diverses situations à la maison et à l'école de votre enfant sera obtenu à partir du **carnet de communication** de votre enfant que vous et les professionnels de l'hôpital de jour programme complet sur une base régulière. Avec votre permission, ces entrées seront photocopiés par le chercheur et utilisés pour ajouter des détails sur les expériences de votre enfant dans des environnements différents. Les photocopies seront faites deux fois pour votre enfant, une fois dans la semaine avant le début des séances de groupe, et une fois dans la semaine après les séances de groupe sont plus. Le chercheur vous avisera avant de photocopier le contenu du livre.

d. Dans le cadre du programme de l'hôpital de jour, votre enfant peut être demandé par leur intervenant à remplir une **fiche de réflexion** quand ils ont un problème. Dans cette feuille votre enfant est souvent invité à identifier le problème, d'identifier le rôle qu'ils ont joué et d'identifier comment un tel problème pourrait être traité différemment à l'avenir. Le chercheur rassemblera les feuilles de réflexion réalisées par votre enfant au cours de cette étude, car ceci permet au chercheur de comprendre ces expériences du point de vue de l'enfant. Pour ce faire, le chercheur photocopiera la feuille de réflexion et l'envoyera à la maison pour que vous puissiez le lire. Si vous êtes d'accord pour permettre aux chercheurs d'utiliser le contenu de la feuille, vous serez demandés de la parapher et la remettre au chercheur dans une enveloppe scellée.

3. Votre enfant sera invité à participer à neuf séances de groupe hebdomadaires de 60 minutes. Ces sessions auront lieu à l'hôpital pendant les heures de programmes. Au cours de ces séances, chaque enfant créera un **livre de vie** sur les expériences importantes dans leur vie. Pour ce faire, un appareil photo sera disponible à votre enfant. Votre enfant sera enseigné comment utiliser l'appareil photo de manière appropriée, y compris les considérations éthiques entourant les types de situations ou des choses qui seraient appropriés pour photographier. On vous demandera de superviser les photos prises par votre enfant afin de s'assurer qu'ils respectent les consignes établies par le chercheur. Par exemple, votre enfant pourrait prendre des photos d'objets, des choses ou des lieux mais ne pourra pas prendre des photos de personnes. Si votre enfant souhaite inclure des photos de personnes dans leurs livres, ils peuvent être créés de facon alternatif par votre enfant en utilisant des matériaux fournis par le chercheur (e.g. le dessiner avec papier et des crayons; trouver une image dans une revue our sur l'Internet). Votre enfant sera responsable de prendre leurs photos et de les amener à la session du groupe. Votre enfant sera également responsable de la sélection et l'organisation de ce qu'il aimera inclure dans le livre de leur vie. Les photographies prises par votre enfant seront filtrés par le chercheur afin de s'assurer qu'ils respectent les consignes et la portée du projet. Vous serez informé dans le cas où votre enfant prend une photo qui ne correspond pas aux consignes ou aux objectifs de l’étude.
4. À la suite des séances de groupe, les livres de vie que votre enfant créerait serait partagés dans le programme avec les autres enfants, les parents et les interventants. Le contenu des livres de vie peut également être utilisé par le chercheur à des fins éducatives, la présentation du projet et de ses résultats à d'autres professionnels (par exemple lors d'une conférence ou dans un article de recherche). Le chercheur fournira un deuxième consentement dans lequel vous et votre enfant pouvez décider si les photographes et livres de vie que votre enfant a créés peuvent être affichés et / ou utilisés à des fins académiques. Vous et votre enfant avez le droit de supprimer tout le contenu de ce livre de vie que vous, ou votre enfant, ne voulez pas être rendue publique. Tout contenu, y

compris les photographes, qui n'est pas utilisé dans le produit final sera détruit par le chercheur.

RISQUES POTENTIELS / INCONFORTS

Il ya des inconforts et inconvénients possibles associés à la participation à cette étude. Vous pouvez avoir un certain inconfort à avoir des photographs prises au sein de votre maison. Votre autorisation sera demandée dans le cas où ces photos seraient rendues publiques.

LES AVANTAGES PRÉVUS

Vous et votre enfant ne recevrez pas de bénéfices directs de votre participation à cette étude. Toutefois, les informations obtenues de cette étude peuvent mener à de meilleurs traitements à l'avenir pour les enfants atteints d'un trouble de santé mentale et leurs familles.

PARTICIPATION VOLONTAIRE / RETRAIT

La participation de vous et votre enfant dans cette étude est VOLONTAIRE. Vous ou votre enfant pouvez choisir de participer maintenant et décider d'arrêter votre participation à tout moment. Vous pouvez choisir de ne pas participer à cette étude sans crainte de conséquences négatives. Votre décision de participer ou non à cette étude n'affectera pas les soins que vous et votre enfant recevrez. Si vous retirez à partir de cette étude, toute information recueillie au point de retrait pour le but de cette recherche peut encore être utilisé afin de protéger l'intégrité de l’étude.

NOUVEAUX RENSEIGNEMENTS TIRÉS

Si de nouvelles informations sont apprises qui pourrait influencer votre choix de continuer dans la recherche, vous serez informé de cette information et donné l'occasion de décider si vous voulez continuer à participer à la recherche. Nous pouvons aussi apprendre des informations sur vous ou votre enfant qui n'était pas connu avant. Si cela arrive, nous vous contacterons directement pour discuter de l'information apprise et vous inviterez à partager cette information avec votre intervenant et / ou travailleur familial pour poursuivre la discussion.

CONFIDENTIALITÉ

Pendant que vous prenez part à cette étude de recherche, le chercheur recueillira des informations personnelles identifiables sur vous et votre enfant dans un fichier designé à l'étude de recherche. Seules les informations nécessaires à l'étude de recherche seront recueillies. Pendant l'étude, les transcriptions d'entrevues, notes de chercheurs, de photocopies des écritures du carnet de communication et des fiches de réflexion, et le contenu du livre de vie de votre enfant seront conservés dans un classeur verrouillé au Centre de développement de l'enfant et la santé mentale, l'Hôpital général juif, 4335 ch. Côte Ste Catherine, salle 130, Montréal QC H3T 1E4. Une fois l'étude terminée votre enfant gardera tout le contenu original utilisé dans la création de leur livre de vie. Une copie sera conservée pour le dossier du chercheur. Ces informations seront conservées pendant dix (10) ans conformément à la politique de l'établissement concernant les données collectées à des fins de recherche. Passé ce délai, toutes les informations seront détruites par le chercheur.

Tous les efforts seront faits pour conserver la confidentialité des informations recueillis sur vous et votre enfant. Aucune informations sur vous, ou que vous avez fournies lors de la recherche, seront divulgués à des tiers sans votre autorisation écrite, sauf si nécessaire pour protéger les droits ou le bien-être de vous ou votre enfant. Si l'enfant participant divulgue des informations sur eux-mêmes, que ce soit verbalement ou par une photo qu'ils ont pris, où le chercheur s'inquiéte de leur sécurité (c'est à dire qu'ils expriment la pensée ou l'intention de faire du mal contre eux-mêmes, les animaux ou autrui; ils décrivent des situations d'abus ou de négligence; ils produisent un image représentant un environnement non sécuritaire), le chercheur est obligé de communiquer ces informations aux autorités compétentes (e.g. les Services de protection de la jeunesse, de la Société pour la prévention de la cruauté envers les animaux). Dans le cas où cela se produit, le chercheur rencontrera l'enfant et son intervenant après la séance de groupe. Vous serez également informé par le chercheur et l'intervenant par un appel téléphonique ou une rencontre en personne.

Dans l'effort de maintenir la confidentialité et le respect des informations partagés et créés lors des séances de groupe, tous les enfants participants seront invités à ne pas divulguer aucune information personnelle partagée par d'autres membres en dehors des séances de groupe. À cet effet, les enfants seront invités à accepter un contrat de groupe. Veuillez noter que ce n'est pas un contrat juridiquement contraignant.

Pour protéger l'identité de votre enfant, le nom de votre enfant et toutes informations d'identification seront remplacés par un pseudonyme choisi par votre enfant. Le lien entre le pseudonyme et son identité sera tenue par le chercheur principal de l'étude. Aucune information qui divulgue l'identité de votre enfant ne quittera l'établissement. Le chercheur utilisera les pseudonymes leurs d'envoyer des informations sur votre enfant aux collaborateurs. Cette information ne comprend pas le nom ou l'adresse de votre enfant. Les collaborateurs utilisent les informations recueillies sur votre enfant que pour atteindre les objectifs de l'étude car ils sont expliqués dans ce formulaire de consentement. Les informations de l'étude pourrait être imprimé / publiés dans des revues médicales ou partagé avec d'autres personnes lors de réunions scientifiques ou pédagogiques, mais l'identité de votre enfant ne sera pas révélée.

Aux fins de la surveillance de cette recherche, votre dossier de recherche ainsi que vos dossiers médicaux peuvent être vérifiés par une personne autorisée par le comité d'éthique de l'Hôpital général juif. Cette personne est tenue de respecter votre confidentialité.

Vous avez le droit de consulter votre dossier d'étude afin de vérifier les informations recueillies sur vous et votre enfant et à le corriger, si nécessaire, pendant que le chercheur de l'étude et l'institution conserve ces informations. Cependant, l'accès à ces informations sera disponible une fois l'étude terminée, afin de maintenir la qualité de l'étude de recherche.

LES FRAIS ET INDEMNITÉS

Votre enfant ne sera pas payé pour sa participation à cette étude. À la fin du projet de votre enfant sera traité pour un dîner spécial par le chercheur. Il n'y aura aucun frais pour la participation de votre enfant dans cette étude. Tous les matériaux nécessaires aux fins de ce projet seront fournis par le chercheur. Aussi, s'il vous plaît noter que vous et votre enfant *ne sera PAS responsable* de toute perte ou les dommages au matériel fournis par le chercheur, y compris l'appareil photo numérique.

RENSEIGNEMENTS OU QUESTIONS

Si vous avez des questions au sujet de l'étude ou si vous sentez que vous avez un problème lié à participer à l'étude, vous pouvez communiquer avec le chercheur responsable de l'étude, Vanessa Greco, à (514)340-8222 poste. 5624.

Pour toute question concernant vos droits en tant que personne participant à cette étude ou si vous avez des commentaires ou souhaitez déposer une plainte, vous pouvez communiquer avec le commissaire local de plaintes et de la qualité des services de l'Hôpital général juif, Rosemary Steinberg, au (514) 340 -8222 poste. 5833.

DÉCLARATION DE CONSENTEMENT À PARTICIPER AU PROJET DE RECHERCHE

Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.

Consentement parental

Je, _________________________, suis d'accord que mon enfant, _______________________, participe à l'étude décrite ci-dessus. J'ai lu les informations ci-dessus et mes questions ont été répondues à ma satisfaction. Une copie de ce formulaire de consentement signé me sera donnée. La participation de mon enfant est volontaire et je peux lui retirer de l'étude à tout moment sans donner de raisons, sans que cela affecte les soins médicaux de mon enfant maintenant ou plus tard. Je ne perd pas mes droits légaux en signant ce formulaire

Signature du parent:____________________________________Date:_____________________

Nom du participant: ____

Formulaire de consentement administré et expliqué en personne par:

Signature:____Date:______________________

Nom du chercheur: ____

CONSENTEMENT POUR LA COLLECTE DE RENSEIGNEMENTS DU CARNET DE COMMUNICATION

Je, ______________________________, dans mon titre de _____________________________ authorise Vanessa Greco, chercheur principal, de receuillir les informations du carnet de communication de mon enfant ____________________________________ entre les dates du ______________________________ au ____________________________ pour être utilisé dans le but d'un projet de recherche que j'ai consenti à être impliqué.

Signature: _____________________________________

Date: _____________________________________

Témoin: ____________________________________

Date: _____________________________________

CONSENTEMENT DE L'AFFICHAGE DU CONTENU DU LIVRE DE VIE

Mon enfant a pris des photographs de différentes choses qu'il éprouve dans sa vie et a créé un livre de vie. Avec ce formulaire, je donne - ou refuse - l'autorisation pour que les photos et les histoires de mon enfant soivent utilisés dans un affichage public. J'ai le droit de supprimer tout contenu du livre de vie de mon enfant que je ne veux pas être rendue publique.

- ☐ Oui, je suis prêt à avoir les photos et les histoires de mon enfant au sujet de leurs expériences de vies utilisées dans les affichages publics.
- ☐ Non, je ne veux pas les photos et les récits de mon enfant utilisés dans les affichages publics.

J'ai aussi besoin de donner - ou refuser - l'autorisation pour que le nom de mon enfant soit identifié en tant que photographe.

- ☐ Je veux le PSEUDONYME de mon enfant inscrit en tant que photographe.
- ☐ Je NE VEUX PAS le nom de mon enfant inscrit.

S'il vous plaît inscrire vos préoccupations ou commentaires:

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- ☐ J'en ai discuté avec mon enfant.

____

Nom

____

Signature

____

Date

(Adapté de Doing your own PhotoVoice Project: A Guide by Laura Lorenz, PhD & Barbara Webster: http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)

Jewish General Hospital
Department of Child Psychiatry
Vanessa Greco, erg.

4335 Ch. Cote Ste Catherine
Montreal, Quebec
H3T 1E4

Assent to Participate in a Research Study - Child

TITLE: *This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.*
PRINCIPAL INVESTIGATOR: Vanessa Greco, occupational therapist

WHAT IS RESEARCH?

Research is a way to learn more about something. I want to learn more about what it's like to be a child who comes to this program. I would like you to be part of this project so you can help me learn what it's like to be you and can tell me about the things that are important in your life.
You should ask me any questions you have about this project. Your parents have a form to read so they can give their permission for you to join this project too.

WHAT WOULD HAPPEN IF YOU JOIN THIS PROJECT?

1. If you agree to join this project, we would spend time together to write a story about your life:
    a. I will meet with you in my office for **an interview** that will last about an hour to ask you some questions about your life, your family, your friends, this program and your school. The interview will happen on a day that you come to the program. I will have a recorder on during our interview so that I can re-listen to and write down everything we talked about.
    b. I will join you in the classroom, at recess, at lunch and during group times in the program to watch and write down the different things that happen to you during your day that will help me write your story. I will write things down in a book that I will keep in my office and that you can look at anytime if you want to.
    c. Your parents and your teacher write about your behavior everyday in your **communication book.** Sometimes I will make a photocopy of things written in this book to help me understand what your life is like at home.
    d. When you have a problem, sometimes your primary worker asks you to write a **reflection sheet**, where you have to write about the problem, what your part was

in the problem, and what you should do differently if the problem happens again. I will make a photocopy of these sheets so I can understand what you thought about what happened.

e. You will be part of a **group** with three other children where you will create your own book about your life. This group will happen nine times for one hour. In this book, you will write your own story about the important things in your life. You will also help me to decide how these books should look and what materials you would like to use. You will be allowed to use a camera to take pictures of things that you would like to put in your book. You cannot take any pictures of other people but if you want to put people in your book you could draw them or use a picture from a magazine or the internet. You decide what to put in your book.

WHAT WILL HAPPEN TO THE BOOK YOU MAKE?

You will get to keep the book that you make. I will make a photocopy of it for me to keep. You might want to show your book to other people, like your parents, the staff or the other kids at the program. We will decide as the group if we should present your books to other people. You can also choose not to share all or part of your book.

CAN ANYTHING BAD HAPPEN IF YOU JOIN THIS PROJECT?

Some of the questions might be hard to answer or make you uncomfortable. There are no right or wrong answers and you do not have to answer a question if you don’t want to.

HOW WILL THE RESEARCH HELP YOU?

This project will not help make your life better but I hope to learn something from you so that someday it can help other children like you.

DO YOU HAVE TO JOIN?

You get to decide if you want to be part of this project but you do not have to agree if you don’t want to. Nothing bad will happen if you decide not to participate in the project.

WHO WILL KNOW WHAT WE TALKED ABOUT?

I am not allowed to share any information about you unless I have your permission and permission from your parents. Any information about you is private. In order to protect your privacy, I will ask you to choose a different name that I can call you for the project. Only I will know which name you have chosen. Once the project is over I will want to talk about the project to help other people who work with children. Anyone else who reads about the project or your book will have no way of finding out your real name.

One important rule for the group is that anything we talk about is private. Everyone in the group must agree not to talk about things that other people have said in the group to other people.

The only time I can talk about something you told me using your real name is if I think you are in danger, if you talk about hurting yourself or someone else. If this happens I will need to tell your primary worker and your parents.

WHAT DO YOU GET FOR JOINING THIS PROJECT?

I will provide you with anything you need for this project. When the project is over, I will treat you to a special lunch.

DO YOU HAVE ANY QUESTIONS?

If you have any questions about the project, you can ask me anytime. My name is Vanessa Greco, and my office is room 130. You could even call me if you need to at: (514)340-8222 ext. 5624.

STATEMENT OF ASSENT

This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.

If you agree to be part of this project please check the box and write your name below.

- ☐ I want to join this project.
- ☐ I don't want to do this.

Remember: Don't talk about things that other people have said in the group to anyone!

Name:____Date:_____________________

Signature: ____

Form explained in person and questions answered by:

Signature:____Date:______________________

Name of Researcher: ____

SHARING THIS PROJECT WITH OTHER PEOPLE

I have created a book about my life.

I agree that Vanessa Greco (the researcher) can talk about and show my pictures and stories to other people who work with children like me.

- ☐ Yes, Vanessa can talk about my stories and my book.
- ☐ Yes, Vanessa can show parts of my book.
- ☐ No, I do not want my stories or my book shown to anyone.

I also need to give permission for my name to be listed.

- ☐ I want my PSEUDONYM listed.
- ☐ I DO NOT want my name listed at all.

Please list any concerns or comments:

____

____

____

____

____

- ☐ I have discussed this with my parents.

____

Name

____

Signature

____

Date

(Adapted from Doing your own PhotoVoice Project: A Guide by Laura Lorenz, PhD & Barbara Webster: http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)

Hôpital général juif
Division de pédopsychiatrie
Vanessa Greco, erg.

4335 Ch. Côte Ste Catherine
Montréal, Québec
H3T 1E4

Assentiment de Participation à une Étude de Recherche - Enfant

TITRE: *Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.*

CHERCHEUR PRINCIPALE: Vanessa Greco, érgothérapeute

QU'EST-CE QUE LA RECHERCHE?

La recherche est un moyen d'apprendre plus sur quelque chose. Je veux en savoir plus sur les expériences d'un enfant qui vient à ce programme. Je t'invite à faire partie de ce projet parce que tu peux m'aider à apprendre mieux de ta vie et peux me parler des choses qui sont importantes dans ta vie.

Je t'invite à me poser toutes les questions que tu as sur ce projet. Tes parents ont un document à lire afin qu'ils puissent aussi donner leur permission pour te joindre à ce projet.

CE QUE TU FERAS:

1. Si vous acceptez de participer à ce projet, nous allons écrire une histoire au sujet de votre vie:
    a. Je vais te rencontrer dans mon bureau pour **une entrevue** qui durera environ une heure pour te poser quelques questions sur ta vie, ta famille, tes amis, ce programme et ton école. L'entrevue aura lieu durant ta journée à l'hôpital. Je vais enregister l'entrevue avec un enregistreur pour me rappeler de tous que nous y allons parler ensemble.
    b. Pour m'aider à bien écrire ton histoire, je serais présente dans ta classe, à la recreation, à l`heure de dîner et pendant les activités de groupe. Je vais observer et écrire les différentes choses qui t'arrive pendant ta journée dans un cahier que je vais conserver dans mon bureau si tu veux le voire.
    c. Tes parents et tes enseignants écrivent au sujet de ton comportement dans ton **carnet de communication**. Parfois, je vais faire une photocopie de ce qui est écrit dans ce livre pour m'aider à comprendre ta vie à la maison.

d. Lorsque tu as un problème, parfois, ton intervenant te demande d'écrire une **feuille de réflexion**, où tu dois décrire le problème, ta partie dans le problème, et ce que tu feras différemment si le problème se reproduise. Je vais faire une photocopie de ces feuilles, donc je peux comprendre ce que tu pensais à ce qui s'est passé
e. Tu feras partie d'un groupe avec trois autres enfants où tu pourras créer ton propre livre sur ta vie. Ce groupe se réunira neuf fois pendant une heure. Dans ce livre, tu écriras ton propre histoire sur les choses importantes dans ta vie. Tu m'aideras aussi à décider comment ces livres devraient être conçus et quels matériaux que tu souhaiteras utiliser. Tu seras permis d'utiliser un appareil photo pour photographier les choses que tu souhaites inclure dans ton livre. Tu ne peux pas prendre des photos d'autres personnes pour ce projet. Si tu désire inclure des personages dans ton livre, tu pourras les déssiner ou trouver une image semblable sur l'internet. Tu décide quoi mettre dans ton livre.

QUE FERONS-NOUS AVEC TON LIVRE?

Tu garderas le livre que tu crées. Je ferais une photocopie pour mes dossiers. À la fin du projet, tu pourras vouloir montrer ton livre à d'autres personnes, comme tes parents, tes intervenants ou les autres enfants du programme. Avec le groupe, nous allons décidés si nous devons présenter vos livres et comment le faire. Tu pourras également choisir de ne pas partager le tout ou une partie de ton livre.

EST-CE QUE CE PROJET VA ME FAIRE DU MAL?

Certaines de ces questions pourraient être difficiles à répondre ou peuvent te rendre inconfortable. Il n'y a pas de bonnes ou de mauvaises réponses et tu n'as pas à répondre à une question si tu ne veux pas.

EST-CE QUE CE PROJECT VA M'AIDER?

Ce projet ne va pas rendre ta vie meilleure, mais j'espère d'apprendre quelque chose de toi afin qu'un jour il peut aider d'autres enfants comme toi.

EST-CE OBLIGATOIRE?

Tu décide si tu veux faire partie de ce projet, mais tu n'es pas obligé de participer. Rien de mauvais ne se produira si vous décidez de ne pas participer au projet.

QUI SAURA DE QUOI NOUS AVONS PARLÉS?

Je ne suis pas autorisé à partager toute information te concernant à moins d'avoir ta permission et l'autorisation de tes parents. Les informations te concernant sont privées. Afin de protéger ta vie privée, je vais te demander de choisir un autre nom que je peux t'appeler pour le projet. Je serai le seule qui sait quel nom que tu as choisi. Une fois que le projet est terminé, je vais vouloir parler du projet pour aider d'autres personnes qui travaillent avec les enfants comme toi. Toute autre personne qui lit sur le projet n'aura aucun moyen de trouver ton vrai nom.

Une règle importante pour le groupe c'est que tout ce que nous parlons est privé. Les membres du groupe doivent accepter de ne pas partager nos discussions de groupe à d'autres personnes.

Le seul moment où je peux parler de quelque chose que tu m'as dit utilisant ton vrai nom est si je pense que tu es en danger, si tu parles de te faire mal, ou de faire mal à quelqu'un d'autre. Si cela se produit, je devrai informer ton intervenant et tes parents.

QU'EST-CE QUE JE REÇOIS POUR MA PARTICIPATION?

Je vais te fournir avec tout les matériaux tu as besoin pour ce projet. Lorsque le projet est terminé, je vais régaler au groupe un dîner spécial.

AS-TU DES QUESTIONS?

Si tu as des questions sur le projet, tu peux me les demander en tout temps. Je m'appelle Vanessa Greco, et tu peux me trouver dans le bureau 130. Tu peux aussi m'appeler au: (514)340-8222 poste. 5624.

DÉCLARATION D'ASSENTIMENT

Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.

Si tu veux de faire partie de ce projet s'il te plaît cochez la boîte et écrire ton nom ci-dessous.

- ☐ Je veux faire partie de ce projet.
- ☐ Je n'accepte pas.

Un petit rappel: On ne partage pas ce qui est discuté dans le groupe !

Nom:____Date:______________________

Signature: ____

Formulaire expliqué en personne et questions répondu par:

Signature:____Date:_______________________

Nom du chercheur: ____

PARTAGER CE PROJET AVEC D'AUTRES PERSONNES

J'ai crée un livre sur ma vie.

J'autorise que Vanessa Greco (le chercheur) peut parler de et montrer mes photos et histoires à d'autres personnes qui travaillent avec les enfants comme moi.

☐ Oui, Vanessa peut parler de mes histoires et montrer mon livre.
☐ Oui, Vanessa peut montrer des parties de mon livre.
☐ Non, je ne veux pas que mes histoires ou mon livre sont partagés.

Je dois aussi donner l'autorisation pour que mon nom soit inscrit.

☐ Je veux que mon PSEUDONYME soit inscrit.
☐ Je ne veux pas avoir mon nom inscrit.

S'il te plaît inscrire tes préoccupations ou tes commentaires

____

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____

☐ J'en ai discuté avec mes parents.

____

Nom

____

Signature

____

Date

(Adaptation de: Doing your own PhotoVoice Project: A Guide by Laura Lorenz, PhD & Barbara Webster: http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)

Jewish General Hospital
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Consent to Participate in a Research Study – JGH Staff

This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.

PRINCIPAL INVESTIGATOR

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Collaborators

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INTRODUCTION

This research project is designed to explore the experiences of children with a mental health disorder that are enrolled in the day hospital program at the Center for Child Development and Mental Health of the Jewish General Hospital. A child from this program that you interact with has been invited to be a research participant. You have the right to be informed about the purpose and procedures that are to be used in this research project, the potential risks and benefits, and how this will involve you as a professional working with the child participant. Before you agree to be involved in this study, it is important that you read the information in this consent form. You should ask as many questions as you need to in order to understand what will be asked of you. You do not have to agree to be involved in this study if you do not want to.

PURPOSE OF STUDY

The purpose of this study is to learn more about the everyday experiences that children with a mental health disorder identify as being meaningful. Children's experiences play an important part in their health and development. Children are viewed as competent reporters about their health needs and should be included in the assessment process by having the opportunity to express their experiences and relay information about their health. Yet, there is a lack of research on what matters to children and on clinical approaches that can more directly capture and address the unique experiences of children with mental illness. Information gained by exploring the experiences of these children can help to ensure that services being delivered are suited to their needs.

Recent initiatives in Canada indicate that children should play more of an active role in making decisions that affect the care that they receive. Through this study, children will be empowered to be involved in and have control over decisions made within the group sessions involved in this project that are described in the procedures section of this form.

PROCEDURES

Children who agree and whose parents agree to be involved in this project will be seen both individually and in group format for the researcher to develop an understanding of their experiences and create a detailed account of these experiences. This requires obtaining multiple perspectives of what these experiences are and for the researcher to be able to observe these experiences as they occur.

Your involvement in this project is sought in order to execute the following components of the project:

a. **Participant observations** will be done with the child. This would mean that the researcher would join the child in the classroom, at recess, at lunch and during group times while in the program to observe and document the child's interactions and experiences with the people around them as they are happening. The researcher would keep a written record of their observations in order to add to the "thick description" of the child and their experiences. Your permission is requested in order to allow the researcher access to observe the child within these different activities in the context of the unit. Finally, participant observations will include anecdotal reports related to the participants as presented by members of the multidisciplinary team during team meetings. The researcher will document discussions pertaining to the research participants as these provide rich examples of specific cultural practices of the institution, namely the way in which clinical cases are reviewed and new information is discussed with all members of the multidisciplinary team.

b. Additionally, in order to get a perspective on the situations where the researcher cannot observe directly, information regarding the child's behavior and reactions to various situations at home and at school will be obtained from the child's **communication book** that the parents and you, as professionals from the day hospital program, complete on a regular basis. With your permission, these entries will be photocopied by the researcher and used to add details about the child's experiences in different environments. This would be recorded twice for each child, once in the week before the group sessions start, and once in the week after the group sessions are over. The researcher will re-contact you to obtain your permission before photocopying the contents of the communication book.

POTENTIAL RISKS/DISCOMFORT

There are some possible discomforts and inconveniences associated with participating in this study. You may have some discomfort in having observations being made in your classroom or to have the contents of your communication book entries be used for the purpose of the project. The purpose is not to judge or to analyze your involvement with this child, but instead to describe their experiences and their reactions to different experiences in their lives.

ANTICIPATED BENEFITS

You will not receive any direct benefits from your participation in this study. However, information learned from this study may lead to better treatment in the future for children with a mental health disorder and their families.

VOLUNTARY PARTICIPATION/WITHDRAWAL

Your participation in this study is VOLUNTARY. You may choose to participate now and decide to stop your participation at any time. You may choose NOT to participate in this study without fear of negative consequences. Your decision to participate or not in this study will not affect the care you will provide to your student.

NEW INFORMATION LEARNED

If new information is learned that could affect your choice to continue in the research, you will be told about this information and given an opportunity to decide if you want to continue your participation in the research.

CONFIDENTIALITY

While you take part in this research study, the researcher will collect and store personal identifiable information (your name and job title) related to your involvement in the child's life in a file for the purpose of the research study. Only information necessary for the research study will be collected, which would consist of the photocopies of communication book entries and the researcher's notes of any observations made in your classroom or during a group activity that you are facilitating, and will be stored in a locked file cabinet at the Center for Child Development and Mental Health, Jewish General Hospital, 4335 ch. Cote Ste Catherine, room 130, Montreal QC H3T 1E4. This information will be kept for ten (10) years according to the institution's policy regarding data collected for the purpose of research. After this time, all information will be destroyed by the researcher.

Every effort will be made to keep information about you and the child confidential. No information about you, or provided by you during the research, will be disclosed to others without your written permission, except if necessary to protect you or the child's rights or welfare. To protect your identity, your identifying information (i.e. name) will be replaced with a pseudonym. The link between the pseudonym and your identity will be held by the researcher in charge of the study. No information that discloses your identity will be allowed to leave the institution. The researcher will only send information you have provided about the child to the collaborators using the pseudonyms. This information does not include your name or address. The collaborators will use the information collected about the child in your classroom only to reach the study goals as they are explained in this Information and Consent Form. The study information could be printed/published in medical journals or shared with other people at scientific or educational meetings, but your identity will not be revealed.

For the purpose of monitoring this research, the research study file could be checked by a person authorized by the Research Ethics Committee of the Jewish General Hospital. These people and groups are obliged to respect your privacy.

You have the right to look at the study file in order to check the information you have shared about the child in your classroom and to correct it, if necessary, as long as the study researcher or the institution keeps this information. However, you may only have access to certain information once the study has ended so that the quality of the research study is protected.

COSTS AND COMPENSATION

You will not be paid, nor is there a cost, for your involvement in this study.

CONTACT INFORMATION OR QUESTIONS

If you have any questions about the study or if you feel you have a problem related to taking part in the study, you can communicate with the researcher in charge of the study, Vanessa Greco, at (514)340-8222 ext. 5624.

For any questions concerning your rights as a person taking part in this study or if you have comments or wish to file a complaint you can communicate with the Jewish General Hospital's Local Commissioner of Complaints & Quality of Services, Rosemary Steinberg, at (514) 340-8222 ext. 5833.

STATEMENT OF CONSENT

This is my story: A qualitative research study exploring the experiences of school-aged children with mental health disorders admitted to a multimodal psychiatric hospital program.

Consent

I, __________________________, agree to participate in the study described above. I have read the above information and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my ability to provide quality care for my students. I do not give up any of my legal rights by signing this consent form.

Signature:____Date:______________________

Consent form administered and explained in person by:
Signature:____Date:_______________________
Name of Investigator: ____

CONSENT FOR THE COLLECTION OF INFORMATION FROM THE COMMUNICATION BOOK

I, _______________________________, in my title as ______________________________ authorize Vanessa Greco, principal researcher, to collect information from the communication book of _____________________________________ between the dates of _______________________________ and _____________________________ to be used for the purpose of a research project that I have consented to be involved in.

Signed: _______________________________________

Date: _______________________________________

Witness: ______________________________________

Date: _______________________________________

Hôpital général juif
Division de pédopsychiatrie
Vanessa Greco, erg.

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Montréal, Québec
H3T 1E4

Consentement de Participation à une Étude de Recherche - Intervenant

TITRE: *Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.*

CHERCHEUR PRINCIPALE: Vanessa Greco, érgothérapeute
École de physiothérapie et d'ergothérapie, Faculté de médecine, Université de McGill
Collaborateurs
Dr. Melissa Park, PhD OT/L, Professeure adjointe
Dr. Heather Lambert, PhD, erg., OT(C), Professeure agrégée
École de physiothérapie et d'ergothérapie, Faculté de médecine, Université de McGill

INTRODUCTION

Ce projet de recherche vise à explorer les expériences des enfants avec un trouble de santé mentale qui sont inscrits dans le programme de l'hôpital de jour au Centre de développement de l'enfant et la santé mentale de l'Hôpital général juif. Un enfant de ce programme avec qui vous travaillez a été invité à être un participant à la recherche. Vous avez le droit d'être informé sur les objectifs et les procédures qui seront utilisés dans ce projet de recherche, les risques et les avantages potentiels, et comment cela vous implique comme un intervenant avec l'enfant participant. Avant d'accepter de participer à cette étude, il est important que vous lisiez les informations contenues dans ce formulaire de consentement. Vous devriez poser autant de questions que vous devez afin de comprendre ce qui va être demandé de vous. Vous n'avez pas à accepter de participer à cette étude si vous ne voulez pas.

OBJECTIFS DE L'ÉTUDE

L'objectif principal de cette étude est de prendre conscience et mieux comprendre les expériences quotidiennes que les enfants atteints d'un trouble de santé mentale s'identifient comme étant significative. Les expériences des enfants jouent un rôle important dans leur santé et leur développement. De plus en plus, les enfants sont considérés comme informants competents sur leurs besoins de santé et devraient avoir la possibilité d'exprimer leurs expériences et transmettre l'information au sujet de leur santé. Pourtant, il ya un manque de recherche sur ce qui compte pour les enfants et sur les approches cliniques qui peuvent plus directement capturer et traiter les expériences uniques des enfants atteints de maladie mentale. Les informations obtenues en explorant les expériences de ces enfants peuvent aider à assurer que les services livrés sont adaptés à leurs besoins.

Des initiatives récentes au Canada indiquent que les enfants devraient jouer un rôle plus actif dans la prise des décisions qui affectent les soins qu'ils reçoivent. Grâce à cette étude, les enfants seront habilités à participer et avoir le contrôle sur les décisions prises dans le cadre des séances de groupe impliqués dans ce projet qui sont décrits dans la section des procédures de ce formulaire.

PROCÉDURES

Les enfants qui sont d'accord et dont les parents consentent d'être impliqués dans ce projet sera vu par le chercheur individuellement et en format de groupe pour comprendre plus de leurs expériences et pour créer un compte rendu détaillé de ces expériences. Cela nécessite l'obtention de multiples points de vue de ces expériences et que le chercheur puissent observer ces expériences comme ils se produisent.

Votre participation à ce projet est demandée afin d'exécuter les composants suivants du projet :

a. Des **observations des participants** se feront avec l'enfant. Cela signifierait que le chercheur rejoindra l'enfant dans la classe, à la récréation, au dîner et au cours des activités de groupe afin d'observer et de documenter les interactions et les expériences de l'enfant comme ils se produisent. Le chercheur maintienera une trace écrite de leurs observations afin d'ajouter à la «description dense» de l'enfant et leurs expériences. Votre autorisation est demandée afin de permettre l'accès au chercheur d'observer l'enfant au sein de ces différentes activités dans le cadre du programme. Les observations des participants incluront des rapports anecdotiques liées aux participants tel que présenté par les membres de l'équipe multidisciplinaire au cours des réunions de l'équipe. Le chercheur documentera les discussions concernant les participants à la recherche car ils offrent de riches exemples de pratiques culturelles spécifiques de l'institution, à savoir la façon dont les cas cliniques sont revus et de nouvelles informations sont discutés avec tous les membres de l'équipe multidisciplinaire.

b. Afin d'obtenir un point de vue sur les situations où le chercheur ne peut pas observer directement, les informations concernant le comportement et les réactions à diverses situations à la maison et à l'école de l'enfant sera obtenu à partir du **carnet de communication** de l'enfant que les parents et vous, en tant qu'intervenant, complètent sur une base régulière. Avec votre permission, ces entrées seront photocopiés par le chercheur et utilisés pour ajouter des détails sur les expériences de l'enfant dans des environnements différents. Les photocopies seront faites deux fois pour votre enfant, une fois dans la semaine avant le début des séances de groupe, et une fois dans la semaine après les séances de groupe sont plus. Le chercheur vous avisera avant de photocopier le contenu du livre.

RISQUES POTENTIELS / INCONFORTS

Il ya des inconforts et inconvénients possibles associés à la participation à cette étude. Vous pouvez avoir un certain inconfort en ayant des observations faites dans votre classe ou d'avoir le contenu de vos entrées dans le carnet de communication utilisés aux fins du projet. Le but n'est pas de juger ou d'analyser votre implication avec cet enfant, mais plutôt de décrire leurs expériences et leurs réactions à différentes expériences dans leur vie.

LES AVANTAGES PRÉVUS

Vous ne recevrez pas de bénéfices directs de votre participation à cette étude. Toutefois, les informations obtenues de cette étude peuvent mener à de meilleurs traitements à l'avenir pour les enfants atteints d'un trouble de santé mentale et leurs familles.

PARTICIPATION VOLONTAIRE / RETRAIT

Votre participation à cette étude est VOLONTAIRE. Vous pouvez choisir de participer maintenant et décider d'arrêter votre participation à tout moment. Vous pouvez choisir de ne pas participer à cette étude sans crainte de conséquences négatives. Votre décision de participer ou non à cette étude n'affectera pas les soins que vous fournirez à votre étudiant.

NOUVEAUX RENSEIGNEMENTS TIRÉS

Si de nouvelles informations sont apprises qui pourrait influencer votre choix de continuer dans la recherche, vous serez informé de cette information et donné l'occasion de décider si vous voulez continuer à participer à la recherche.

CONFIDENTIALITÉ

Pendant que vous prenez part à cette étude de recherche, le chercheur recueillira des informations personnelles identifiables (votre nom et titre de travail), liées à votre participation dans la vie de l'enfant, dans un fichier designé à l'étude de recherche. Seules les informations nécessaires à l'étude de recherche seront recueillies, qui consisterait aux photocopies du carnet de communication et les notes du chercheur concernant les observations faites dans votre classe ou lors d'une activité de groupe que vous animez. Ces informations seront conservés dans un classeur verrouillé au Centre de développement de l'enfant et la santé mentale, l'Hôpital général juif, 4335 ch. Côte Ste Catherine, salle 130, Montréal QC H3T 1E4. Ces informations seront conservées pendant dix (10) ans conformément à la politique de l'établissement concernant les données collectées à des fins de recherche. Passé ce délai, toutes les informations seront détruites par le chercheur.

Tous les efforts seront faits pour conserver les informations sur vous et l'enfant confidentielles. Aucune information sur vous, ou que vous avez fournies lors de la recherche, seront divulgués à des tiers sans votre autorisation écrite, sauf si nécessaire pour protéger vos droits ou votre bien-être ou ceux de l'enfant. Pour protéger votre identité, votre information d'identification (nom) sera remplacée par un pseudonyme. Le lien entre le pseudonyme et votre identité sera tenue par le chercheur principal de l'étude. Aucune information révélant votre identité ne sera autorisé à quitter l'établissement. Le chercheur envoyera des informations que vous avez fournies sur l'enfant aux collaborateurs en utilisant les pseudonymes. Cette information ne comprend pas votre nom ou votre adresse. Les collaborateurs utilisent les informations recueillies sur l'enfant dans votre classe seulement pour atteindre les objectifs de l'étude car ils sont expliqués dans ce formulaire de consentement. Les informations de l'étude pourrait être imprimé / publiés dans des revues médicales ou partagé avec d'autres personnes lors de réunions scientifiques ou pédagogiques, mais votre identité ne sera pas révélée.

Aux fins de la surveillance de cette recherche, votre dossier de recherche peut être vérifié par une personne autorisée par le comité d'éthique de l'Hôpital général juif. Cette personne est tenue de respecter votre confidentialité.

Vous avez le droit de consulter le dossier d'étude afin de vérifier les informations que vous avez partagé sur l'enfant en classe et de le corriger, si nécessaire, pendant que le chercheur de l'étude et l'institution conserve ces informations. Cependant, l’accès à ces informations sera disponible une fois l'étude terminée, afin de maintenir la qualité de l'étude de recherche.

LES FRAIS ET INDEMNITÉS

Vous ne serez pas payé, ni y a-t-il un coût, pour votre participation à cette étude.

RENSEIGNEMENTS OU QUESTIONS

Si vous avez des questions au sujet de l'étude ou si vous sentez que vous avez un problème lié à participer à l'étude, vous pouvez communiquer avec le chercheur responsable de l'étude, Vanessa Greco, à (514)340-8222 poste. 5624.

Pour toute question concernant vos droits en tant que personne participant à cette étude ou si vous avez des commentaires ou souhaitez déposer une plainte, vous pouvez communiquer avec le commissaire local de plaintes et de la qualité des services de l'Hôpital général juif, Rosemary Steinberg, au (514) 340 -8222 poste. 5833.

DÉCLARATION DE CONSENTEMENT À PARTICIPER AU PROJET DE RECHERCHE

Voila mon histoire: une étude qualitative visant les expériences des enfants d'âge scolaire ayant des troubles de santé mentale qui fréquentent un programme psychiatrique et multimodal de l'hopital de jour.

Consentement

Je, _________________________, accepte de participer à l'étude décrite ci-dessus. J'ai lu les informations ci-dessus et mes questions ont été répondues à ma satisfaction. Une copie de ce formulaire de consentement signé me sera donnée. Ma participation est volontaire et je peux retirer de l'étude à tout moment sans donner de raisons, sans que cela affecte ma capacité à fournir des soins de qualité pour mes élèves. Je ne perds pas mes droits légaux en signant ce formulaire.

Signature:_______________________________________Date:_____________________

Formulaire de consentement administré et expliqué en personne par:

Signature:____Date:______________________

Nom du chercheur: ____

CONSENTEMENT POUR LA COLLECTE DE RENSEIGNEMENTS DU CARNET DE COMMUNICATION

Je, ______________________________, dans mon titre de ______________________________ authorise Vanessa Greco, chercheur principal, de receuillir les informations du carnet de communication de mon enfant ____________________________________ entre les dates du ______________________________ au ____________________________ pour être utilisé dans le but d'un projet de recherche que j'ai consenti à être impliqué.

Signed: _____________________________________

Date: _____________________________________

Témoin: ____________________________________

Date: _____________________________________