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**Parents of Children with Complex Trauma: Occupations Viewed Through
Photovoice**

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A doctoral project submitted in partial fulfillment of the requirements for

The Doctor of Occupational Therapy,

St. Catherine University, St. Paul, Minnesota

December 15, 2017

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Chapter 1 Introduction

This qualitative study represents a project idea that shifted focus during the three-year doctoral program. The original idea was to develop an intervention model in response to an identified need within a clinical setting. Specifically, within a clinic that specialized in services for people with sensory processing disorders, a trend was observed that suggested a more traditional sensory processing approach was no longer as effective as it had been in the past. Further investigation into potential factors revealed that the children who did not demonstrate expected improvements presented some common factors. Many of the children were adopted, some from orphanages and some from foster homes. Many, if not most children were identified with trauma histories. Jane Koomar, a well-known expert in sensory integration, and Dan Hughes, a renowned expert in the field of trauma and attachment disorders, developed a conceptual model incorporating sensory integration-based occupational therapy, mental health, and the family. My project in the Evidence Based Practice class addressed the evidence for this approach, in preparation for an anticipated feasibility study.

Clinic circumstances necessitated a change, however, and in the Occupation, Participation, and Justice class I interviewed one parent and conducted a focus group of three parents whose children had complex trauma. Parents described feelings of isolation and marginalization, they experienced diminished social circles, and services were difficult to find, even though their families had financial resources to access them. It was clear that the families were affected, not just the children, and in fact parents identified their wish for improved quality of family life. Further literature review suggested that these feelings and experiences were similar to those of parents with children who had

mental health difficulties and disabilities in general. Missing from the literature, however, was a broad discussion of the occupations of parents whose children had complex trauma, from their own perspectives. This doctoral project therefore focused on the occupations of parents whose children had complex trauma.

While all the course work in the doctoral program helped provide building blocks for this doctoral project, three classes were especially helpful in this regard. The Educational Methods and Practices class furthered my interest in critical theory, extending into theories of learning, especially constructivism. Each person's perspective is unique, informed by past experiences, and as such, study of parent occupations as individuals was compelling to me. The Evolution of Ideas class subsequently provided the framework for my study of occupation. Wilcock and Townsend's (2014) conceptualization of occupation as doing, being, becoming, and belonging became the framework for this study.

Input from the first Occupation, Participation, and Justice class study, paired with the relatively sparse literature on the topic of occupations of parents whose children have complex trauma, suggested the need and benefit of further study in this area. Specific aims of the current doctoral study are to explore the occupations of this group of parents, and to provide an empowerment opportunity for the parents as they understand and advocate for desired changes in their lives. Results of this current study will hopefully contribute to knowledge and literature in the field of occupational science, and in turn will help inform occupational therapy practice and further research.

Reference

Wilcock, A. A. & Townsend, E. A. (2014). Occupational justice. In H. S. Willard & B. A. Schell (Eds.), *Willard & Spackman's occupational therapy* (pp. 541-552). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Chapter 2 Literature Review

Complex Trauma and its Effects

Within the field of trauma theory and intervention, complex trauma is increasingly recognized as a specific developmental presentation of trauma with far reaching effects for the child, family, and community (Greeson et al, 2011; D’Andrea, Ford, Stolbach, Spinazzola, & van der Kolk, 2012; National Child Traumatic Stress Network, n.d.[a]; van der Kolk, 2005). As distinct from other types of trauma, complex trauma results from early, ongoing or repeated traumatic events, such as abuse or neglect, separation from parents or caregivers, or other traumas of a relational nature (Greeson et al, 2011; D’Andrea et al., 2012; NCTSN, n.d.[a]; van der Kolk, 2005). As a result of their traumatic experiences these children encounter: difficulty forming healthy relationships, negative effects on physical and neurological development (Andersen et al., 2008; NCTSN, n.d.[b]; Perry, 2009; Teicher, Anderson, Ohashi, & Polcari, 2014), problems in learning and self-esteem, and later chance of physical and mental health problems and risk behaviors (Felliti et al.,1998; Mate, 2012).

Numerous studies address effects of children’s complex trauma on parents and caregivers in terms of secondary or vicarious traumas, and how the parents cope with trauma-related stressors (Duchovic, Gerkenmeyer, & Wu, 2009; Kiser, Nurse, Lucksted, & Collins, 2008; Banyard, Englund, & Rozelle, 2001). Also described are factors such as lost work time and financial losses resulting from lost work and child care demands (Busch & Barry, 2007).

Parenting children with post-traumatic stress is also described in the literature. One systematic review of 14 studies examined the relationship between parenting and

children's post-traumatic stress symptoms. The authors described positive parenting behaviors, such as warmth and support, and negative behaviors, like criticism or hostility, that impact children's post-traumatic stress symptoms (Williamson et al., 2017). The authors also suggested a provisional relationship between parent behaviors and child PTSD symptoms, as well as the benefit of addressing parenting behaviors within the children's trauma treatment. Burgeoning research in the field of trauma includes parenting children adopted from institutions, a population of children often identified with complex trauma. Curry-Lourence (2010) interviewed adoptive parents and analyzed interviews of their "lived experiences," identifying themes including choosing, parent identities, vigilance about children's needs, and resources to meet their needs.

Linking the parents' lived experiences with their children's needs, numerous intervention models address parent roles in building relationships with their children and in managing their children's behavior. (Becker-Weidman & Hughes, 2008; Cornell & Hamrin, 2008; Hughes, D., 2004; Rushton et al., 2010; Lieberman et al, 2005). While these models emphasize the attachment and relational aspects of parenting children with complex trauma, they do not specifically explore the parents' occupations in this context. Similarly, the effects of complex trauma on children's occupations are discussed in some studies (e.g. Kjorstad et al., 2005), although the effects of complex trauma on their parents' engagement in occupations is not addressed.

Occupation

Occupation is described throughout occupational therapy and occupational science literature in varied terms and with varying emphases (American Occupational Therapy Association, 2014). Several authors have suggested that occupation necessarily

extends beyond doing, or goal-directed activity. It also involves the meaning people derive and how they feel as they engage in chosen occupations (Hammell, 2004; Hasselkus, 2011; Wilcock, 1998). Wilcock (1998) outlined doing, being, and becoming as concepts inherent in occupation, while Rebeiro, Day, Semeniuk, O'Brien, and Wilson identified the themes of being, belonging, and becoming as elements of occupation in their study of an occupation-based mental health program (2001). Hammell (2004) suggested descriptions for doing, being, belonging, and becoming. She goes further, however, in stating that occupational therapy is well positioned to help our clients experience greater meaning and satisfaction, although we do not routinely consider these aspects of occupation.

Wilcock and Townsend (2014) offered a description of occupation that is used in this study, one that encompasses the elements of doing, being, becoming, and belonging as they relate to the life experiences of parents whose children have complex trauma.

Occupation is used to mean all the things people want, need, or have to do, whether of physical, mental, social, sexual, political, or spiritual nature and is inclusive of sleep and rest. It refers to all aspects of actual human doing, being, becoming, and belonging. The practical, everyday medium of self-expression or of making or experiencing meaning, occupation is the activist element of human existence whether occupations are contemplative, reflective, and meditative or action based (p. 542)

Barriers to participation in occupations of choice must also be considered as they pertain to parenting children with complex trauma, a mental health difficulty often burdened with stigma and marginalization (Dempster, Winders Davis, Faye Jones,

Keating, & Wildman, 2015; Gale, 2006; Mukolo, Heflinger, & Wallston, 2010; Pescosolido et al., 2008; Rebeiro, 2001). Limited occupational freedom and well-being are additional societal barriers described by Hammell & Iwama (2012). Constraints imposed by isolation and limited opportunities often in turn limit participation in meaningful occupations, suggesting that what is meaningful may not be possible (Galvaan, 2012; Hammell and Iwama, 2012).

Occupation and Parenting

Parenting is specifically described as an occupation in several studies examining the experiences of mothers. Mothering is characterized as a learned occupation, one that is embedded in social contexts in the lives of mothers/caregivers (Llewellyn & McConnell, 2005). Francis-Connolly (2005) also views the occupation of motherhood within a social context, describing it as a social construct that extends throughout the life span. Additionally, when parenting children with intellectual, physical, or sensory disabilities, mothers often, out of necessity, engage in activism as a “mothering occupation” in their advocacy for their children and even for others (Llewelyn, Thompson, & Whybrow, 2005).

Fingerhut has developed a tool for assessment of parental occupational participation within her conceptualization of family-centered occupational therapy intervention (2005, 2009). In discussing occupational therapy interventions for children with cognitive and physical special needs, she writes of the need for occupational therapists to consider each parent’s unique occupational context and to provide family-centered interventions.

Photovoice

Photovoice, the method utilized in this study, is a visual research method often used in qualitative and action studies. Photovoice is grounded in critical education theory, feminist theory, and documentary photography (Strack, Magill, & McDonagh, 2004; Wang & Burris, 1997). As described by Wang & Burris (1997), photovoice builds on Freire's conceptualization of the visual image as a means of facilitating identification and discussion of community needs and the social and political influences that affect them.

Giroux (1979) described Freire's notion of visual representation in the context of action:

What is at stake in Freire's notion of liberation is that people be able to generate their own meanings and frame of reference, to be able to develop their self-determining powers through their ability to perform a critical reading of reality so that they can act on that reality (p. 261)

The process of taking photographs to illustrate one's lived experience thus becomes a potential means of empowerment and effecting change.

Occupation and Photovoice

As a methodology of action and empowerment, photovoice is utilized in studies representing a wide range of fields, including public health, education, nursing, social work, disability or illness, and more recently in occupational therapy (Lal, Jarus, & Suto, 2012). Photovoice has been used to explore community needs assessment (Strack, Magill & McDonagh, 2004; Wang & Redwood-Jones, 2001) and the nature of participation, stigma, and recovery in mental health (Mizock, Russinova, & Shani, 2014; Russinova, Mizock, & Bloch, 2017).

Photovoice is used increasingly in occupational therapy research, as a participatory tool, to explore participation, occupation, occupational choice, and occupational justice. The process of taking pictures within the photovoice methodology allows for creativity and self-expression different from interviews or surveys, for example. Andonian (2010) utilized photovoice to study community participation access for persons with mental illness, specifically how they belong and are connected to their communities. Photovoice has also been used to examine issues of occupational choice, occupational justice, and empowerment as they relate to socio-economic and political contexts for adolescents (Gallagher, Pettigrew, & Muldoon, 2015; Galvaan, 2012). Gallagher et al. (2015) described how occupational choice, though often considered to be internally determined and a right, depended on external context, such as opportunity, social expectations and youth perceptions of their potential occupational choices. Galvaan (2012) suggested that in addition to availability of resources, occupational choice also depended on internal factors such as skills.

Photovoice has been utilized in studies of mental health, occupational choice, occupational justice, participation and belonging in communities, and empowerment within communities. To date, the lived experience of parents whose children have histories of complex trauma has not been explored through this method. The range of creative and individual expression possible in photovoice allows parents to convey their experiences, from their perspectives and in their own voices.

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Chapter 3 Approach

Introduction

This qualitative study explored the occupations of parents whose children have experienced complex trauma. Photovoice, a participatory action research method (Wang & Burris, 1997; Food Action Research Centre, 2013), was used to elicit participant reflections of doing, being, becoming, and belonging, as elements of occupation (Wilcock & Townsend, 2014). Within the time constraints of this study, the researcher established the research question and the photomission, or assignment, related to parent occupations. Through discussion, participants developed general definitions of doing, being, becoming, and belonging, which served as guidelines for the photos taken within each category. In addition, participants reviewed and provided feedback for the researcher's initial analysis, subsequently suggesting potential actions following the study.

Participants

A convenience sample of six parents was recruited from an outpatient mental health clinic in western Massachusetts. Mental health clinicians assisted in recruitment by identifying parents of children with complex trauma, the only inclusion criterion. The clinicians described the study to parents who met the criterion; the exclusion criterion was that participants must be non-offending parents if the trauma involved the family. Upon parent indication of interest and with permission to contact them, the researcher contacted the parents, who then signed consent forms to participate if they wished to continue. From a pool of nine potential participants, six began and completed the study. Parents were all mothers, and they included birth parents, adoptive parents, a grandparent

with guardianship of her child, and foster parents. The participants' children ranged in age from seven to thirteen years. Some children lived at home and one was currently in residential placement, although several participants related that their children had at some time been placed in residential programs or out-of-district educational programs.

Group Meetings

Participants attended two group meetings for this study, each lasting between 90 minutes and two hours. Three meetings were originally planned, however the schedule was condensed into two meetings to accommodate the needs of group members. Group meetings were audio-recorded and transcribed for accuracy.

First session.

The first group session included group introductions, description of the project, and discussion of participant experiences related to the study. The background of the project was outlined and participants were instructed in the photovoice methodology, including its participatory nature, procedures, and ethics of consent and picture taking (Wang & Redwood-Jones, 2001). Instruction in camera operation was provided, and the group established definitions and general guidelines for photo taking in each of the categories: doing, being, becoming, and belonging (see Table 1). Issues related to time, reflected in how parents were not currently able to engage in activities and tasks that were possible and enjoyable in the past. They discussed limitations in their current roles and duties, and they described what they wished and hoped for in the future.

Table 1
Parent developed definitions of elements of occupation

Doing	Being	Becoming	Belonging
Tasks, chores, routines	Identity and aspiration	Reclaiming previous lives and identities	Communities: family, church, school, therapy
Activities	Who they were, who they are, who they wish to be	Growth	Acceptance
Pastimes currently impossible/ previously enjoyed	Who they would be if they did not have a child with complex trauma	Finding meaning in new roles	Being with people who “get it” and give meaning to life
Roles		Empowerment	

Second session.

Five of the six participants attended the second session; the sixth participant was absent due to her children’s illness. However, she sent her photos and written narratives, along with comments and responses to study questions, via e-mail. The remaining participants provided photos and written descriptions of their photos at the beginning of the second session.

The written descriptions included captions, phrases, and/or brief narratives. During this second session each participant presented her pictures and comments, explaining the symbolism of photos and providing context for their inclusion, in addition to the captions they had written. Group members frequently interjected comments and questions, making connections with their own experiences. Of note was their reflection on how their participation in the study had already impacted their lives.

Potential next steps were discussed, with suggestions for the researcher to present the results to various groups, including the clinical therapists at the clinic, agencies that train potential foster or adoptive families, professionals who work with children and families, and schools. Participants were invited to provide feedback on the results of the study once data was analyzed and sent to them, to insure completeness and accuracy. Some comments on the study process were submitted to the researcher after the final group session and these comments were included as additional narrative for analysis.

Data Analysis

Framework analysis and critical reflection served as the basis for initial analysis of results. Participant feedback was an integral component of the final analysis. The Pell Institute (2010) outlined several steps in qualitative data analysis, which this study followed: immediate recording of data, ongoing analysis, consolidation of data, and identification of themes (p. 2-3).

Framework analysis.

A modified version of framework analysis (FA) was used to structure the analysis. The steps in framework analysis include: 1. familiarization with the data, 2. identifying a working thematic framework, 3. coding/indexing the data, 4. charting data into a matrix, and 5. analyzing the data (Brian, Cook, Taylor, Freeman, Mundy, & Killaspy, 2016; Gale, Heath, Cameron, Rashid & Redwood, 2013; Ward, Furber, Tierney, & Swallow, 2013). The FA model was modified for the purposes of this study, with points of similarity and modification described below.

Familiarization with data.

Immersion in and familiarization with the data were consistent between this study and framework analysis procedure. Immersion in the data was accomplished through transcription of group meetings, which were reviewed multiple times, as were written narratives accompanying the photographs. Key ideas related to the thematic framework (below) were noted and comments relevant to later analysis were made in margins of the transcripts.

Identifying a working thematic framework.

Identification of a thematic framework represents a modification to the FA procedure. FA suggests that the initial thematic framework emerges from the data (Brian et al., 2015; Gale et al., 2013; Ward et al., 2013). In this study, however, the elements of occupation: doing, being, becoming, and belonging (Wilcock & Townsend, 2014), served as the thematic framework. As a group, participants further defined these elements according to their conceptualization of each element and to help them represent each element through their photographs (See Table 1). The researcher's immersion in the data was informed from the outset by the same thematic framework, and initial coding therefore involved identification of words, phrases, and concepts related to each of the elements doing, being, becoming, and belonging.

Categorizing/indexing the data.

From the coded words and phrases, categories and themes were developed in accordance with FA procedures. Development of categories and themes were completed with the assumption that written and discussion narratives were two distinct sets of data. Comparison of the categories and themes between the two data sets indicated that the data were substantively the same. Therefore the data were combined into one data set and

considered as one set for the remainder of the project. Themes were established based on the combined data and were sent to participants for their review and feedback for accuracy and completeness.

Charting data into a matrix.

This step is also consistent with FA procedures. Once categories were refined into concise themes, a matrix was designed, identifying key themes in each of the four elements of occupation. In order to preserve the stories of individual participants, sample quotations from each were also charted (See Table 2). Elements of occupation, with developed themes in each, were included in the header row, with individual participants listed along the left column.

Analyzing the data.

Data analysis was also consistent with FA procedures. The researcher compared themes and sub themes, considered associations among them, and suggested possible explanations for identified relationships among the data. In addition, analysis identified issues for further study.

Reflexivity.

To minimize the possibility of researcher bias, critical reflection was included as an intentional process in the study. The researcher's role within the study was considered, so that she was not viewed as an expert, connoting authority, but rather as a facilitator and a participant. Corbin, Dwyer, and Buckle (2009) discussed the researcher's role in qualitative studies, suggesting that the researcher is not required to be either in the group or outside of it, and that the relationship may be more complex and flexible. The researcher may occupy "the space between" as she/he plays a role in data collection and analysis. The concept of the space between was particularly apt in the context of this

study, as the researcher was both inside the group process and outside at various times, functioning as a facilitator, a researcher, and a practitioner. Bryce (2012) similarly described her role in a qualitative photovoice study in this way as she moved among roles of researcher, participant, and practitioner in occupational therapy mental health groups.

In addition to careful consideration of roles, each communication and interaction was considered with the intention to provide requested or required guidance, without influencing responses or biasing results. The crafting of the photomission was worded to elicit each participant's life experiences while avoiding the researcher's expectations or influence. The researcher's roles, interactions, and even choice in wording were carefully considered to minimize these influences. Acknowledging that each parent's experiences and history were unique, narratives were considered from alternate viewpoints several times during data analysis to insure that parents' voices were heard without preconception or misinterpretation, as suggested by Evans-Agnew and Rosemberg (2016).

Parent Feedback on Outcomes

Parent feedback was solicited following data analysis, to ensure accuracy and completeness of findings. The outcomes were shared with participants, specifically themes and how they were developed, photos illustrating parent perspectives, and quotes from group discussions. This additional parent perspective helped to insure that their voices are heard in their own words and as they intend, with minimal risk of researcher bias.

Actions

In keeping with participatory research (Huot & Laliberte Rudman, 2015), results of this study determined potential future actions, in both the near and far term.

Participants suggested possible uses of the data, which at this time center around the researcher disseminating the results of the study.

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Chapter 4 Outcomes

Definitions

Parents struggled to arrive at the definitions of doing, being, becoming, and belonging referenced in previous chapters. Without exception, they reported their difficulty considering their own experiences, rather than those of their children as they conceptualized aspects of occupation. Group discussions routinely cycled through descriptions of family life, returning to both parent and children experiences. This process resulted in a consensus that the definitions discussed among the parents, and then summarized by the researcher, were accurate reflections of the participants' opinions.

Data Analysis

Written narratives of the photos and transcripts of the group meetings were first coded separately. Initial analysis indicated that the two data sets were substantively similar, reflecting many of the same concepts, grouped into the same or quite similar categories, as described below. The data were therefore combined and thereafter considered as one data set. Developed themes and examples of parent responses in each of the framework categories doing, being, becoming, and belonging are presented in Table 2.

Table 2
Developed themes of occupation, with parent responses

	Doing <i>Restricted choices Responsibilities for others</i>	Being <i>Self/loss of self Fear/strength Isolation</i>	Becoming <i>Reclaiming self Transformation Empowerment</i>	Belonging <i>Supportive Communities/loss of relationships Life meaning</i>
Parent 1	“That’s a big part of my life. OK, is it going to matter if his clothes are wrinkled? Probably not. Is it going to matter if I make something he will eat? That’s more likely going to matter.”	“Tattered and torn, but still proudly standing. That’s how I feel.”	“I have no idea what I’m becoming. I’m like a train on a track. I can’t get off, so I’m just following the rails to see where I end up.”	“In the woods and mountains is where I feel most myself, most at peace.”
Parent 2	“I’m still constantly having to choose between the two... (children)”	“What you would want to be if you didn’t have a child with mental illness”	“I chose a picture of a poster on my wall. Why that poster? Well, I aspire to be Wonder Woman not only because she's hot (lol), but because she's fierce, strong, and that is what I am becoming inside - strong - strong to finally stand up for myself and see my worth.”	“I don’t belong anywhere, so I’m just a target, an easy one at that, for judgment.”
Parent 3	“I realized we've been parenting little kids at the park since 1989 - first as a birth parent and now as older foster parents. Apparently, you are what you do.”	“It’s healthy to inhibit the isolation.”	“At the top of the hill the fog and mist obscure the road ahead but the sun still patiently waits behind the clouds. Thinking of my child in the middle of a mental health crisis waiting for an inpatient bed. Hard to remember the sun is still there.”	“That’s one of the commonalities of this group we belong to...we get it. The running theme is you’re not alone. It’s like this whole universe of other moms that are doing exactly what you’re doing, experiencing exactly what you’re experiencing.”
Parent 4	“So much time spent doing for the kids, it’s easy to forget about doing for me... I don’t know what that says about me, but I had to pay for it and put it (class) on the calendar.”	“I see and feel a sense of spirituality in the photo and that's a part of me that has taken a less prominent place in the last few years. I miss the ritual and community that comes with it.”	“Trying to regain ... pieces of myself that have taken very much a back burner.”	“I’m not alone in this attempt at parenting kids from trauma.”
Parent 5	“I just feel like I’m just doing... cleaning up from everyone else. That’s the way I feel all the time.”	“Being... the space in between, because you know, how can you address who they are and... how I can be for them (daughters) when they are just more opposite than you can ever imagine?”	“‘I used to be happy, right?’ I ask my husband. ‘I used to be carefree and a lot of fun, right? Because I can’t quite remember it.’”	“Oh, this is belonging (picture), and then I look at (daughter) and I’m like, ‘Does she feel like she belongs?’”
Parent 6	I never knew how difficult, really, it was going to be. I had never dealt with kids with trauma...”	“I have felt isolated almost from the beginning and have allowed myself to continue being isolated. The energy it takes to educate friends and family in order to allow them in is just too exhausting.”	“(I am) becoming more aware of what to expect from him, but at the same time separating myself from him, feeling stronger.”	“Belonging to myself, doing things that I find pleasure (in) – making soap.”

Doing.

Within the framework concept doing, written narrative captions for photos included responsibilities, roles, caretaking/doing for others and self, and restricted choices. In particular, participants described the never-ending routine of doing for others, as represented and Figures 1 and 2. One parent commented that what she had to do impacted what she felt she was, illustrating how the elements of occupation intersected one another in her life experience:

It's kind of who you want to be, who you're like...I want to do all these things, but I can't because I've got all this that stops me from doing all these things.

That's part of being, too, what you would want to be if you didn't have a child with mental illness.

Medications, driving to appointments, and unceasing vigilance about the needs of their children comprised many of the duties and responsibilities articulated by the parents.

Discussion narrative categories were quite similar: roles, responsibilities, activities, and limited choices/setting priorities. Restricted choices as parents "did for others" threaded through both narratives, as did responsibilities for others, often at the expense of doing for themselves. As a result, themes of *restricted choices* and *responsibilities for others* were identified as overall themes.



Figure 1. “Doing: driving...”



Figure 2. “Doing: meds...”

Being.

Being categories included the concepts of place (Hasselkus, 2011), isolation and judgment, spirituality, self (and loss of self), stress, fear, and strength/resilience. Isolation was a frequently expressed state of being for parents. One parent compelling described her sense of isolation:

I saw this (one large and one small flower) in a friend’s garden, and I just thought, “That is me, and that is my child.” And we are – so isolated. I just feel very, very isolated from community, from family.

The duality in concepts was represented throughout parent responses and was thus retained in the final developed themes self/loss of self, and fear/strength. Fear, of agencies and of their children’s difficulties in social contexts, was an important feature of parents’ experience, as illustrated in comments such as,

“I’m just terrified. I mean, I’ve been filed on,” and “They’re (public agencies) scary. They’re scary when you have kids with trauma. They’re scary.”

Parents often perceived a lack of understanding on the part of professionals as they described mixed interactions and relationships with the professionals. They described being hopeful as they sought help and in many cases found support and assistance. At other times, however, they felt that they had to teach professionals about the reality of

their lives with their children, including the impossibility of complying with advice they were given. An example of living with a child's difficulties is illustrated in Figure 3. As the child in this photo plays in a body sock, his parents commented that they at times feel that they were in a body sock, navigating their world without benefit of seeing it.

Parents were grateful and happy with supports professionals provided to schools on behalf of their children, such as education about adoption issues, while also being frustrated that sometimes the professionals did not even know how to spell their child's name. Both the strength and the fear represented in these parent responses were included in the concept of self. Also included in self is the idea of place, as described by Hasselkus (2011). In this conceptualization place includes the memories we have of places and our personal experiences there (see Figure 4). The concept of time is also represented in many parent comments, as they relate past, present, and future components of being. Parents related spiritual connections to mountains, nature in general, and retreats in describing how they sought peaceful experiences. Time, place and spirituality are considered as components of self, and isolation encompasses judgment of others. Therefore, overall *being* themes were: *self/loss of self*, *fear/strength*, and *isolation*.



Figure 3. Becoming: “Our child from difficult beginnings exploring with a Body Sock. Some days it feels like we are the ones wearing the body sock!”

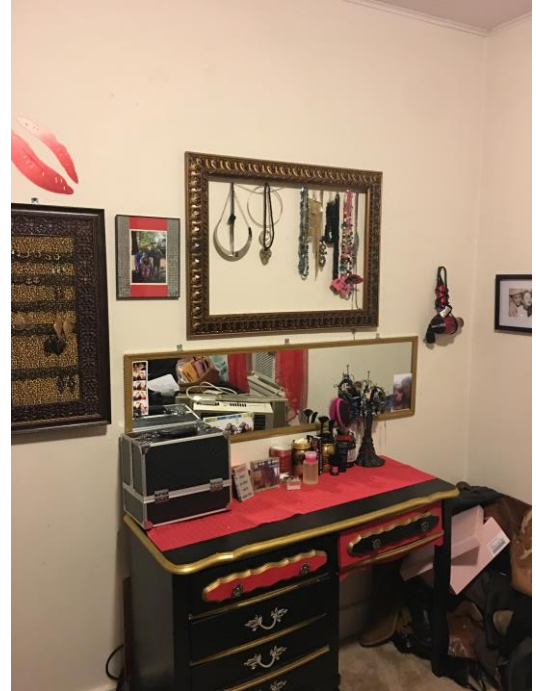


Figure 4. Becoming – “A glam area I made in my room. All of that is me – the old me, the new me, and the me I want to be.”

Becoming.

Categories within the becoming framework concept emphasized reclaiming the self, represented in Figure 5, as one parent described reclaiming her previous identity as a fun-loving person. Other categories included moving through transitions, transformation, and empowerment. Becoming oneself and the transformative quality of rediscovering one’s identity is depicted in Figure 6. The caption described the parent’s effort to connect with another person as part the process of becoming an individual. Uncertainty was also prominently mentioned in parent responses, such as this:

I struggled with becoming, because I had no idea where I’m going in life, no idea where I’m going, what I’m doing. I just live day by day...to be perfectly honest, just trying to think about me, who I am, what I’m doing, that was really hard for me, because I... have a really hard time separating that from everybody else in my life.

Uncertainty is considered to be an aspect of transition and more broadly, transformation. Thus, *reclaiming self*, *transformation*, and *empowerment* were determined as becoming themes.



Figure 5. “Becoming – who I was.”



Figure 6. “The chair represents myself and another person. I am once again working on becoming involved in my own life as an individual. I felt I was so lost... I almost wish I had a photo of a caterpillar or a chrysalis... TRANSFORMATION.”

Belonging.

Within the belonging theme parents identified communities, life changing understanding and collective wisdom, belonging to a greater universe, and belonging to oneself. An example of one parent’s photo of facebook groups she belongs to, is illustrated in Figure 7. She related that she benefited from the support, wisdom, and meaning available to her through her participation in these groups. Importantly, the loss of meaningful relationships and groups, as well as isolation arising from these losses, was also identified in parent responses, again representing the duality of the parent experience. As one parent stated,

...I’d like you to write a list of your ten favorite friends, ten favorite family members, and ten favorite hobbies. You know, cross half off each list, at least, and if you’re lucky, that’s what you’ll have left.

Because you're going to lose your family, you're going to lose your friends, and you're going to lose your hobbies, and you might even lose yourself.

Representative themes were therefore identified as *supportive communities/loss of relationships* and *life meaning*.

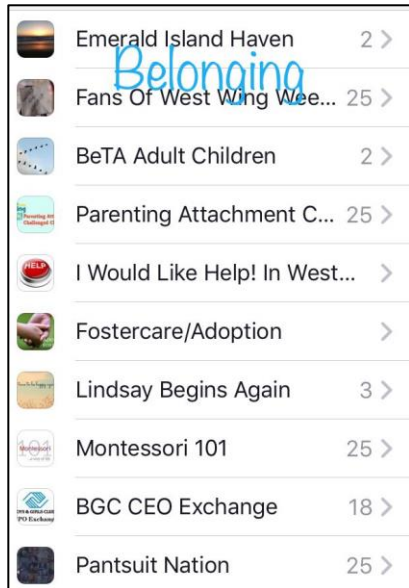


Figure 7. “I am not alone on this parenting adventure. There is a collective wisdom available to me

Parent Feedback

Two parents contacted the researcher after receiving and reviewing the study outcomes. Each felt that the results were presented accurately, though one parent disagreed with the characterization of complex trauma as a mental illness. She viewed her child’s difficulties as related to adjustment to her adoption and as such were remediable. Care was subsequently taken to refer to complex trauma or mental health difficulty, rather than mental illness. The second parent who provided feedback expressed growth

and empowerment even during the time of the study. She also alluded to the temporary nature of the children's difficulties, as illustrated in her comment below:

In my opinion the outcome of the study you're presenting was written and documented quite well. I think the photos chosen represented a good amount of feelings felt daily parenting our beautiful but temporally broken children. A heart felt thank you for thinking of and following through with the research you chose and presenting this topic. I do believe professionals need to hear this directly from parents who have in many cases chosen to parent these beautiful and deserving children.

Although only two parents provided feedback, their input is important to the overall accuracy and participatory nature of the study. As the participants all shared, their lives are extremely busy, to the point of being overwhelming. The fact that they took time to provide feedback suggested the value they placed in the process and the investment they felt in the findings.

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Chapter 5 Discussion

Parent Experience

The aims of this photovoice study were to explore the occupations of parents whose children had complex trauma and to empower the parents to identify and/or take action toward changes in their lives. Throughout this study participants referenced the past, present, and future as they told their stories of parenting their children with complex trauma. In describing their experiences and the meaning they made of their occupations (Hammell, 2004; Hasselkus, 2011), within the framework concepts of doing, being, becoming, and belonging (Wilcock & Townsend, 2014), parents provided insight about their lives that will help occupational therapists and others better understand their experiences and provide relevant services.

Throughout the study each parent communicated her discomfort and extreme difficulty in thinking about her own experiences and needs, separately from those of her child. They described limited, at times extremely limited, choices in life tasks, their feelings about them, and their shifting roles with a “24/7” focus on others, as one parent put it. Their children’s difficulties related to complex trauma required constant vigilance, as the safety and well-being of not only their children, but of others, could be at risk. Parent participants worried about their children’s physical needs, as well as their behavior and their social interaction differences. Related to their children’s difficulties, parents recounted the profound critical judgments they encountered from others. Some comments were criticisms of the children’s behavior, while others conveyed disapproval of the parents’ contribution to the behaviors. In addition to isolation, parents also described the

loss of relationships, and even the loss of their previous identities. They felt that a very basic lack of understanding and acceptance formed the basis for the judgment, rejection, and isolation they experienced.

At the same time, parents related that while they were excluded from some experiences and groups, they often found acceptance and meaning in others. Through commonalities with other parents of children with complex trauma they found wisdom and understanding. They shared support and the comfort of interacting with others who understood and accepted them and their children. This duality of experience was apparent in many contexts. For example, in discussion of state agencies and professionals, one parent spoke positively about an adoption worker who consulted with school staff concerning the impact of adoption on children. However, parents also related a constant state of fear and apprehension of state agencies and professionals who might give unrealistic advice or file complaints against them for choices they made for their children. The parents clearly expressed the need for providers and professionals to better understand the needs and realities of life with children with complex trauma.

Duality of experience was also expressed in day-to-day family life. “Putting one foot in front of the other,” is how one parent characterized the challenge of just getting through each day, without the possibility of choice in activities. At the same time, each parent illustrated strength in her narratives of attempts to find a mindful, peaceful existence in the places they sought and the activities for which they tried to find time.

Present and future choices were expressed in the themes of reclaiming or rediscovering the self, transformation, and empowerment, as they were discussed within the framework concept *becoming*. Parents recounted activities they tried or considered, as

well as what they felt facilitated their growth. Nature and spirituality-based experiences, understanding and supportive communities, the knowledge that they were not alone, and their own resilience were influential factors parents identified in their narratives. The element of choice re-emerged in the narratives as they described factors like enjoyable activities, and choosing fellowship and wisdom in communities “who get it.”

The concept of *belonging* clearly threads through the conversation of becoming, as parents identified the transformative importance of belonging to groups of other parents who “get it,” and who have provided the support and wisdom that nurtures the parents’ strength and growth. Again representing the duality of experience, parents described profound isolation and judgment from other people, those who did not have the experience of parenting a child with needs associated with complex trauma.

The flow of themes among doing, being, becoming, and belonging is in keeping with Hammell’s (2004) description of the dimensions of meaning in occupation. Parents described their wishes for others to better understand their experiences, and for opportunities to engage in occupations that increased the quality of their lives. Importantly, they also described how this group study provided a welcome venue for their focus on their own meaningful occupations.

Parent Empowerment and Action

During group sessions parents offered each other suggestions for support groups, activities, and community programs that worked well for their families. They related their feeling that this study group provided a lens through which to view their children’s progress, as well as to recognize their own growth as parents and individuals. While parents expressed different degrees of similarity with others in the group, they

nevertheless described the sense that they were in a group that shared and understood their experience as the parent of a child with complex trauma.

At the conclusion of this study parents identified future actions. Their recommendations focused on dissemination of findings to care providers, public agencies, private agencies, and schools. Specifically, they were most interested that the researcher convey the findings to increase understanding and to better prepare prospective foster and adoptive parents for what they might encounter with their children. Implicit in their comments was also the hope that with better understanding of trauma and the family experience, more compassionate and appropriate care would be generally available.

Limitations of this Study

One limitation of this qualitative photovoice study is that it represents the occupations of a small number of parents. By its nature the study is not, nor is it intended to be predictive of other parents' experiences. As suggested by participants, studying larger and/or more diverse groups of parents is an area for further study. In addition to the small sample size, the parents were all mothers and all participated in mental health intervention through the same clinic. Further study of fathers whose children have complex trauma and of parents who are either receiving services through different agencies or who may not yet receive services is an avenue for further research.

Three group sessions were originally planned in this study, which would have allowed for research extensions, such as more time for participants to review of findings. Parent schedules necessitated consolidating three shorter sessions into two slightly longer sessions, however, which did limit the opportunity for parents to review and provide

feedback in the group. A greater degree of parent participation in both planning and review would be preferred in future studies.

Another limitation of this study was that one researcher completed initial data analysis, with feedback solicited from participants as to accuracy and completeness of findings. While the data were examined numerous times, and care was taken to consider them from numerous perspectives, it is possible that researcher bias played a role. A larger study with more than one qualified researcher and participant reviewers will help minimize this risk in future studies.

Finally, as participants commented, some, though not all of the experiences described by parents of children with complex trauma appear to be issues of parenting in general. Further study in the area of occupation, trauma and parenting may help define aspects of each.

Conclusion

Parents of children with complex trauma describe a range of experiences related to the doing, being, becoming, and belonging aspects of occupation. Themes reflecting duality of experience illustrated their loss of past relationships and development of others within understanding and supportive communities. They described how their past identities were lost and then re-emerged or shifted as they parented children with complex trauma. They experienced overwhelming responsibility, limited choices in occupations, and fear, yet they found strength and experienced transformative relationships within understanding communities. Through this process parents related their own transformation and empowerment.

It is hoped that this and similar research will provide valuable information about the experiences of parents with children with complex trauma. This information will in turn generate more informed and responsive services and general understanding within communities and provider industries. Further potential benefits may include policy changes to support the needs of families and individuals who experience complex trauma. Photovoice presents a creative and flexible method with which to learn about, understand, and disseminate the experiences of parents, children, and families with complex trauma.

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Chapter 6 Reflection

Project Reflection

I begin this doctoral project reflection with a comment that has guided me throughout the process. As we discussed my project during the past three years, navigating a few unexpected twists and turns, Dr. Barrett expressed quite succinctly that a project for a master's degree deals with how we as occupational therapists affect our interventions with clients, and a project for a doctoral degree addresses how we think about those interventions, our clients, and their place in our communities and our society. While the paraphrasing may be a little off, I believe I have captured the essence of the thought.

My goal has been to contribute to the body of knowledge in OT, though my focus has shifted. While I originally anticipated accomplishing this goal through development of an intervention model, my project has evolved into an exploration of how parents of children with complex trauma experience their occupations. Now, perhaps even more than previously, it is my hope that this project will contribute to the body of knowledge of complex trauma, though the emphasis is now on trauma and occupation, rather than trauma and sensory integration theories.

My bachelor's and master's degrees actually predated the development of the Model of Human Occupation, so I have learned about this significant evolution in theory in the context of my practice, rather than in educational training. Interestingly, the "detour" my project has taken into the field of occupational science was unexpected, yet has helped guide the direction I hope my future work will take.

I find myself drawn to models of intervention that place parents and families at

their center, which is in keeping with AOTA's focus on family and community centered care. In the case of the population of families who deal with mental health problems in general, and complex trauma in particular, systemic change is clearly necessary. Families report feeling marginalized and isolated, which in turn limits occupational opportunities. Through my doctoral project I hope to contribute a perspective that helps increase knowledge and understanding of the parent and family experience, which may in turn contribute to changes in both financial and policy supports. It is my further hope to put a human and accessible face on the problem of discrimination against people with mental health problems, specifically complex trauma.

Process Reflection

Implementation of the project was actually quite fun. I labored over details, as I was the only researcher and this type of study was new to me, but at some point I realized that I was enjoying myself, too. Once the stress of recruitment was past it was easy to become immersed in the stories of the parent participants – and the sessions flew by. I took a very, very long time to complete the first session transcription, so I did have help for the second. Each time I read them I found something new in the transcripts – it truly was like turning it over and over and viewing the information from different angles.

Perhaps the most difficult part of the process for me was coding the data, then developing categories and themes. Since the study was designed as a qualitative exploration, rather than as a quantitative study, I tried to strike a balance between honoring the breadth of the parent responses while still summarizing themes. I was not trying to fit responses into theories or to “tidy them up.” I consciously tried to avoid thinking or saying, “most parents responded....” or trying to group responses into

categories that were so constraining that they lost the essence of the parent comments. At the same time, it was important to develop themes, rather than just listing responses in too broad a manner. In the end I believe I struck a balance by representing the duality of responses, with the concept of transformation knitting together being, becoming, and belonging.

Reflection on Reflexivity

Throughout the process of reviewing literature for my project I have come to appreciate the concept of reflexivity, both in theory and in practice. Reflection is a familiar process, though I may not previously have called it that, as in our clinical setting we base our work with clients on “the art of therapy.” Jean Ayres and our founder, Jane Koomar, described the art of therapy in our interactions with children who have sensory processing disorders. Use of self as a therapeutic agent is similar, but the art of therapy comes closer to how I view reflexivity. Considering our place and role in the therapeutic relationship requires us to consider the other person’s perspective in each interaction. People with sensory processing disorders, a population we see most often, see the world differently, both literally and figuratively. Understanding how easily we can be misinterpreted is the basis for our continual focus on clarity and openness to the experiences of others.

Similar to the experiences of people who have sensory processing problems are the experiences of people with mental health problems. I have reviewed previous course work on the theory of constructivism, which has provided a cornerstone for the implementation of this project. Considering the parents’ perspectives and life circumstances as formative to how they view therapists, systems, and their own situations

has informed every step. I have attempted to carefully consider my word choices in e-mails, letters, and texts to families; how I framed the project in a manner that respects parents' time constraints; how I considered my role within the project; and even how I consciously tried to refrain from comments a therapist might make. I worry that I may have missed the mark on occasion, but I am sure that my project was better for trying and for clearly defining reflexivity as a part of the process.

In sum, my project's aims have emphasized the theoretical base of occupational science, rather than program development or evaluation. Focusing on the parent perspective as it relates to occupation is a slightly different focus than has been studied in the context of families with children who have complex trauma. I am hopeful – and a bit excited – to think that this study may help shape further work, certainly my own, and maybe that of others as well.