

BEYOND PLAY: MEANINGFUL OCCUPATIONS OF CHILDREN WITH
INTELLECTUAL DISABILITIES IN ETHIOPIA

A thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy.

by

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Certification of Approval

I certify that I have read *Beyond Play: Meaningful Occupations of Children With Intellectual Disabilities Ethiopia* by Janet Katrina B. Branch, Blake H. Lord and Sidavann Monica Kem, and in my opinion this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Dedication

To Adanech Mekonnen for allowing us to use the Center for Mentally Challenged Children (CMCC) to collect our data.

To the children at the CMCC. Thank you for having enthusiasm to participate in this thesis.

Acknowledgement

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We would also like to thank Adanech Mekonnen for allowing us to use the CMCC to collect our data. Lastly, to the children at the CMCC who participated in our study, you have inspired us, and we hope you enjoyed the participation in this study. Thank you for sharing the little pieces of your life with us on the photographs that you took and for having the enthusiasm to participate in this thesis. We would also like to thank Stanbridge University for this opportunity to contribute to the field of occupational therapy.

Lastly, we would like to thank all our friends and family members who donated to this research and helped edit and revise, provide ideas, and support us through the entirety of this process. Without them, it was not possible.

Sincerely,

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Abstract

Objective: The purpose of this thesis is to gain insight into the perspectives of children, ages ten to sixteen with intellectual disabilities in Addis Ababa, Ethiopia regarding the meaning of their daily occupations to increase participation, knowledge, and expand the literature. There is minimal published research on children with disabilities in developing countries regarding their occupations. Research by Kinebanian and Stomph (1992) shows that occupational therapy comes from Western values through personal independence, engaging in activities, and doing things for oneself. Therefore, it is important for occupational therapy practitioners and students to understand various cultural norms and occupations of vulnerable, marginalized populations to provide the best practice available when working across cultures.

Method: Using an exploratory method design, participants were recruited from the Center for Mentally Challenged Children (CMCC) in Addis, Ethiopia. Participants took photos of meaningful occupations in their home, school, and community over a two-week period. Investigators interviewed participants regarding the meaning of the occupations they photographed. Participants discussed eleven photographs; three each from home, school, and community and two free choice photos. Investigators used the coding software Dedoose to analyze themes and patterns based on participant's interviews using operational definitions from the *Occupational Therapy Practice Framework: Domain and Process (Framework-III)*.

Results: Results were based on one participant's response; Bubu, a ten-year-old boy. Several themes arose during analysis: autonomy, a new occupation, and participation in activities. Bubu expressed every area of occupation according to the *Framework-III*

except for work and frequently expressed autonomy by stating: "I need it." Overall, Bubu's most frequently photographed occupation was leisure participation in which photography became a new occupation.

Conclusion: Exploratory methods using photography and the Participatory Occupational Justice Framework allowed a child with an intellectual disability in a vulnerable, marginalized community to feel empowered, develop new skills, and engaged to share his experiences. Photography allowed Bubu to use problem-solving skills, abstract thinking, fine motor skills, increased participation, and socialization among family, peers, teachers, and investigators. Therefore, through participatory action research using a photographic method and interview, investigators attained insight into meaningful occupations of the participant's life in environments such as life at home, school, and in the community.

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Beyond Play: Meaningful Occupations of Children with Intellectual Disabilities in Ethiopia

Occupational therapists (OTs) who practice in developing nations aim to understand the meaning of children's occupations to provide appropriate, client-centered care. "Occupational therapy is the art and science of helping people do the day-to-day activities that are relevant and meaningful to their health and well-being through engagement in valued occupations" (Schell et al., 2014, p. 50). Occupations are "the everyday activities that people do as individuals, in families, and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to, and are expected to do" (World Federation of Occupational Therapy [WFOT], 2016, para 2). Occupational therapy (OT) plays a significant role in ensuring that all individuals, including individuals experiencing disabling conditions, can engage in daily routines and participate in their favorite activities and involves a broad range of people, ages, backgrounds, cultures, and occupations (Lao, Jarus, & Suto, 2012).

Research by Kinebanian and Stomph (1992) shows that OT comes from Western values through personal independence, engaging in activities, and doing things for oneself. Kinébanian and Stomph interviewed OTs from different countries with a Western background and concluded that while students were being taught to consider the client's history, they were not being taught how to treat clients with various ethnic backgrounds. Therefore, OTs must understand the culture norms of various groups and what is meaningful to them in order to work with clients (Bourke-Taylor & Hudson, 2005; Iwama, 2003).

In some developing nations, work is expected of children and valued by parents

(Abebe, 2007). Children gain responsibility at early ages to help with income or take care of their siblings while their parents work (Abebe, 2007). Estimates show that approximately 168 million children in the world are involved in child labor (UNICEF, 2015a). In Ethiopia, about 22% of children between the ages of five and fourteen are working, 54% are attending school, and 17% work and attend school (USDL, 2014). Although a large percentage of children participate in the workforce, there are very few published studies from the perspective of children on this topic (Lygnegård et al., 2013).

Furthermore, little is known about which occupations hold meaning to children with disabilities in developing nations (Anderson & Berger, 2016). Several studies show that children with intellectual disabilities mostly participate in daily routine activities for personal hygiene at home and quiet leisure (Anderson & Berger, 2016; Arvidsson et al., 2014; Harding et al., 2009). According to the African Child Policy Forum (ACPF, 2011) there is little understanding and knowledge about disabilities in Ethiopia. This policy states that only a few children who are disabled have an education and many adults who are disabled are unemployed. The policy also states that there is little understanding of the social model of disability which views disability as part of everyday life and centers around barriers in society that discriminate against and limit opportunities for those who are experiencing disabling conditions (ACPF, 2011; Sopczyk & Viggiani, 2011). Discrimination against children with disabilities often leads to decreased access to essential services such as education, work, and lack of recognition from society (UNICEF, 2015b). Therefore, this study aimed to add to the sparse body of literature describing the experiences of children with intellectual disabilities from their perspective in a developing country.

Statement of the Problem

The purpose of this thesis is to gain insight into the perspectives of children with intellectual disabilities in Addis Ababa, Ethiopia, regarding the meaning of their daily occupations. The primary investigator established and operates a fieldwork program for international OT students at the Center for Mentally Challenged Children (CMCC), a privately funded school serving approximately 360 students from birth to twenty-one years old in Addis Ababa. She collaborates with school administrators to develop service learning projects providing learning opportunities for fieldwork students and OT services to the students, their families, and the staff at the CMCC. Because students age ten to sixteen participate in prevocational training classes which prepare them for vocational classes at the center, investigators were interested to learn which occupations students in this age range find meaningful in order to inform future fieldwork projects and consultations related to vocational training program development at the center.

There are many organizations that contribute to OT practice. First, the American Occupational Therapy Foundation's (AOTF) Research Agenda promotes production of basic research related to the experience of individuals with intellectual disabilities (AOTF, 2011). The WFOT is another organization that encourages OTs to engage in global research and evidence-based practice (WFOT, 2016). American Occupational Therapy Association (AOTA) promotes client-centered care including “a client’s occupational history and experiences, patterns of daily living, interests, values, and needs” (AOTA, 2014, p. s3). The AOTA Centennial Vision promotes evidence-based practice “with a globally connected and diverse workforce meeting society's occupational needs” (AOTA, 2006); however a thorough search on PubMed, Google Scholar, and

Ebsco using MeSH terms children, developing country, occupations, occupational therapy, intellectual disability and other closely related terms yielded no current literature published in English describing the experiences of children in developing countries with intellectual disabilities.

Therefore, in order to increase client-centeredness and evidence-based OT services at the CMCC in alignment with AOTA and WFOT values and to contribute toward basic research in alignment with AOTF goals, investigators collected data through photographs and interviews at the CMCC. The goal was to identify and describe occupations of students with intellectual disabilities and the meaning they find in those occupations. According to Tijm, Cornielje, and Edusei (2011), an effective way to research this information is through the use of photographic qualitative research. Photographic qualitative research involves using photographs taken by participants and stories told related to each picture observed (Tijm et al., 2011). Similar to research done by Johnson (2011), the community would speak through their photos guiding the investigators to answer the question, “What is important to them?”

Ignoring culture can cause ethical, therapeutic, or procedural problems in OT practice (Castro et al., 2014). Castro et al. (2014) found that culture may be invisible expressions such as “knowledge, beliefs, attitudes, morals, norms, and customs” (p. 408) which underline visible manifestations such as traditions, celebrations, and crafts. Occupational therapists should be competent in cultural beliefs and traditions because culture can interpret different meanings. Thus, the investigators partnered with an Ethiopian sociologist to assist in interpreting the culturally specific data to increase competency.

Literature Review

Occupational Therapy in Ethiopia

Previous research conducted by Hammarlund (2015) assessed the need for OT at a school for children with autism in Addis Ababa. Also, Béguin (2013) provided an overview of OT in Africa. Both Hammarlund and Béguin unveiled that there are no licensed OTs or OT programs in Ethiopia. Hammarlund showed that OTs could assist with communication, behavior, stress management, as well as play and leisure. Béguin interviewed several OTs from different countries in Africa to document their views on success, challenges, and issues of OT there. Of the people interviewed, most said that there is a lack of knowledge, understanding, and education of OT in Africa.

The WFOT has helped establish the Occupational Therapy Africa Regional Group (OTARG) in hopes to further promote OT, set requirements for OT programs to meet minimum WFOT standards, support the development of OT training centers, and encourage African countries to join WFOT (Hammarlund, 2015; OTARG, 2016). The OTARG started in 1996 with nine African countries. By 2015, the number had grown to seventeen African countries including Ethiopia (OTARG, 2015). As of 2013, eighteen educational institutions in ten African countries granted Bachelor or Diploma degrees in OT with eight of the educational institutions located in South Africa (Béguin, 2013).

Occupations of Children in Ethiopia

Some studies regarding meaningful occupations of children focused on children from Western countries (Njelesanil et al., 2010); however, Njelesanil et al. (2010) found that non-disabled children in Mbarara, Uganda have three types of occupations: play, work, and nothing in particular. In Mbarara, children would play and engage with their

peers to occupy themselves or do nothing, just “hanging out” while waiting for their parents or watching the other kids. Children also worked at markets or on the streets selling goods and doing household chores (Njelesanil et al., 2010). Studies of children in developing countries showed that children found ways to play using a variety of materials and equipment in their environment (Bartie et al., 2016; Berinstein & Magalhaes, 2009); however, Berinstein and Magalhaes (2009) found that Mayan children’s activities revolved around adult work rather than play.

Also, Bazyk, Stalnaker, Llerena, Ekelman, and Bazyk (2003) observed that children at young ages learn to take responsibilities in household work or take care of their younger siblings. The researcher’s observation showed that children took on more responsibilities at a young age and play was not a priority. Codependence and community were prevalent because children played together nearby and often played while taking care of their younger siblings (Bazyk et al., 2003). Instead of being encouraged to foster social, physical, and cognitive development in the communities mentioned, play focused on waking up the body and occupying free time (Bartie et al., 2016; Bazyk et al., 2003; & Berinstein & Magalhaes, 2009).

Working in Ethiopia

In Ethiopia, children are expected to perform various work tasks based on their gender (Abebe, 2007; Boyden, 2009). Abebe (2007) found that young girls’ roles are driven towards domestic chores such as preparing and cooking food, sweeping floors, washing dishes and clothes, or looking after siblings whereas boys tend to work in public spaces. Age also influences income received. (Abebe, 2007; Poluha, 2004). The role of seniority exhibits to adults that they have authority over children and that children do not

have their own rights (Abebe, 2007; Poluha, 2004). Children are paid less and are also aware of it. According to Boyden (2009), the role of working complements the tasks of adults as they highlight a sense of active duty and importance because they can contribute to their household.

Abebe (2007) also shows that in Gedeo, Ethiopia, parents considered their children's household chores as a responsibility in contributing to the families' well-being. In Gedeo, children are expected to contribute to the family while going to school to get an education. Children are expected to work around the agricultural seasons instead of the educational system. The study found that school dropout rates were high when it was peak season for agriculture; however, not only were the children working during peak seasons, but were also working all year round either planting seeds or selling products (Abebe, 2007). According to Poluha (2004), at early ages children are taught to work to a point where consider work as a part of their everyday lives and responsibilities rather than work; however, Boyden (2009) found that household hardships underlined potential sources of protection, resilience and skills development. The phases of childhood go through an accelerated process of developmental change as children living in a developing country adapt to their social and physical environments (Boyden, 2009). During the start of their teenage years, girls and boys can play a significant role in preventing and alleviating impacts of household adversity and share responsibilities for household maintenance with the adults (Boyden, 2009).

Children at young ages also sacrifice their health for the health of their parents (Boyden, 2009). In Boyden's study, a participant with epilepsy dealt with his chronically ill father for a long time. The participant believed that his epilepsy got in the way of work

time and that he had to do better to help out his father. Boyden's research indicated that children were more concerned about their parents' and grandparents' health because they knew it could disrupt the household functioning and advance their passage into adulthood before they were ready to do so. Although stepping up to these responsibilities may have seemed contrary, it gave children some experience of responsibility at an early age. The child practiced taking care of their siblings, provided income for their family, and promoted well-being, self-efficacy, and social skills (Boyden, 2009). In these cases, children saw work as a protective factor as it may have enhanced resilience (Boyden, 2009).

Education in Ethiopia

Boyden's (2009) study showed that Ethiopian children tend to express pride in their work contributions and also appreciated educational opportunities. In recent years, an expansion in access to education and school attendance became a feature of modernity and well-being for many children (Boyden, 2009); however, many children follow a half-day shift system to combine education and work responsibilities. Although there has been an increase in primary school enrollment, Ethiopia still has one of the lowest enrollment rates and one of the highest illiteracy rates in the developing world (Woldehanna, Mekonnen, & Jones, 2009). Children's enrollment in school has been found to be associated with the number of household members, birth order, ownership of livestock, economic shocks, distance to school, and child labor (Alvi & Dendir, 2011; Woldehanna et al., 2009). Alvi and Dendir's (2011) study indicated that parents want older children to attend school first, then the younger siblings may attend. The study also showed gender differences and the impact on an individual's ability to attend school based on their

number of siblings. Families prioritized sending boys to school because of the cultural gender difference and saw education for girls as a secondary priority to domestic household chores (Abebe, 2007).

Woldehanna et al. (2009) also found that the deciding factor of whether or not to send children to school depended on cost benefits for the household. When children go to school indirect costs such as loss from unpaid farm labor and household chores affect the family (Woldehanna et al., 2009). Findings show that girls who did not attend school worked 14-16 hours a day engaged in housework, while boys engaged in farm work (Woldehanna et al., 2009). Direct costs due to education include higher quality clothing, book rentals, and school fees (Woldehanna et al., 2009). In this study, parents valued education and considered net benefits of either losing income now while their children went to school or earning income in the future with higher education (Woldehanna et al., 2009).

Disability in Ethiopia

The average population of people with disabilities in Ethiopia has never been truly known and prevalence increases with age (ACPF, 2011; Geda et al., 2016; Tamrat et al., 2001). Two studies have shown that the most prevalent type of disability was lower locomotor disability followed by visual impairment; however, a recent study shows that hearing impairment is the most prevalent disability (Fitaw & Boersma, 2006; Geda et al., 2016; Tamrat et al., 2001). The leading causes of disability include trauma, illness, infections, lathyrism, neurolathyrism, poverty, and war, and often included more men than women (ACPF, 2011; Fitaw & Boersma, 2006; Geda et al., 2016; Tamrat et al., 2001).

The moral model of disability, which views disability as a sin, is still prevalent in Ethiopia (ACPF, 2011; Sopczyk & Viggiani, 2011). Children with disabilities are often “hidden” due to shame or rejection from family and peers (ACPF, 2011). Children are also often seen as a burden on the family in belief that disability is the consequence of a curse or wrongdoing committed by the family (ACPF, 2011). Due to this, children are hidden at home, exploited by peers, and denied their rights to education, participation, employment, and independence (ACPF, 2011).

In Ethiopia, children with disabilities have limited access to services and assistive devices and are neglected from accommodations, education, work, and family support (ACPF, 2011; CMCC, 2016). Children miss school because there are not enough special need teachers or they do not have access to proper materials such as Braille for those with visual impairments or hearing aids for those with hearing impairment (ACPF, 2011). The majority of people with disabilities have problems with self-care such as toileting, bathing, and dressing (ACPF, 2011; Fitaw & Boersma, 2006). The Ministry of Education (2006) reports that only 1% of children in Ethiopia with special needs have access to primary education and that most remain at home where education officers are not aware of their situation. These children experience further barriers to participation due to a range of socio-economic problems, a lack of facilities, and absence of teacher education (Ministry of Education, 2006).

According to the ACPF (2011) the most common household chores for children in Ethiopia are cleaning the house, washing clothes, cooking, and fetching water; however, chores for children with disabilities vary by disability type and children with intellectual disabilities are less likely to perform chores in these areas except for cleaning the house

(ACPF, 2011). If a child had an intellectual disability, they were more likely to fetch water, cook, and collect firewood. Most children found joy in doing chores because it resulted in positive emotions and family inclusion (ACPF, 2011).

Dynamics change when a child has a disability compared to a child who is typical (Boddy et al., 2015). A study conducted on the playfulness between young children with disabilities and children who are typically developing showed that children with disabilities demonstrated less play (Okimoto et al., 2000). In comparison, Boddy et al. (2015) found that children with intellectual disabilities show insufficient physical activity which impacts their overall physical health. There are fewer opportunities for children with disabilities to interact with peers or caregivers, which can affect their development (Boddy et al., 2015).

The Research Site: Center for Mentally Challenged Children

The CMCC is privately funded through donations from the Ethiopian and Swedish Evangelical Churches and a sliding fee scale for students (CMCC, 2016). It is the oldest center in Ethiopia to serve children with intellectual disabilities. The CMCC serves children with a broad range of both intellectual and physical disabilities through early intervention and home care programming. In contrast, their preschool, primary school, and vocational training programs serve children with mild intellectual and physical difficulties (CMCC, 2016). The CMCC utilizes the Montessori teaching method which includes self-directed and hands-on teaching methods, multisensory activities, and self-care activities learning in the classroom environment (American Montessori Society, 2016). Preschool aged children focus on learning activities of daily living (ADLs) and adolescents focus on prevocational training (CMCC, 2016). Also, teachers participate in

continuing education one Friday of every month (M. Toporek, personal communication, July 20, 2016). Staff members train families to improve motor skills of the child through the early intervention program (CMCC, 2016). The CMCC has not employed an occupational therapist since 2015; however, the primary investigator is available for consultation on an annual basis (M. Toporek, personal communication, August 11, 2016).

Photographic Methods

Wang and Burris developed the use of photography, or Photovoice, to engage women in a Chinese village to participate and photograph their everyday lives relating to work and health (Wang, 1999). Wang (1999) provides concepts for collecting photographic qualitative data to apply to the participatory approach. The first concept is that images teach. Using visual images can influence the thoughts of the community and show what is happening around them. The second concept states that pictures can influence policy. By showing pictures of how a community perceives itself, the images can influence policymakers and broaden that community's society. The third concept is directed towards how images are processed. According to Wang (1999), taking the photographs is negligible; how the individual defines the pictures and discusses the meaning behind the image is most important. The fourth concept states that there needs to be an audience for the community. Without an audience, there is no reason to capture photographs and data. Lastly, photographic qualitative research has an important characteristic that focuses on community action (Wang, 1999). A photographic approach may provide opportunities for children with intellectual disabilities to increase their well-being and self-esteem around the community (Povee et al., 2014).

Additionally, the amount of information delivered from a single photograph is so immense that it can instill the most complex emotions, which can lead to enlightenment of a situation (Keat et al., 2009). Keat et al. (2009) described that through the use of images from disposable cameras, teachers were able to gain perspective to identify strategies that either helped or hindered their immigrant preschool students' educational progressions. If results from classroom study can enlighten educators, then individuals with disabilities will be able to communicate their message by using Photovoice methods to those who implement and change policies to improve their quality of life (Keat et al., 2009; Tijm et al., 2011).

By using photographic methods in vulnerable populations such as children with intellectual disabilities in a developing country, OTs will be able to expand on the literature and knowledge to understand the experiences through the perspectives of individuals from this population (Lao et al., 2012). Photographic qualitative data establishes an understanding of a population's problems, provides support using photographic evidence for policy change, and enables individuals to show their perspective on the lives they live (Johnson 2011, Povee et al., 2014). Johnson's (2011) study indicates that an effective way to portray an individual is by looking through the eyes of that particular individual. Also, the participatory approach presents various challenges when using photographs. Researchers have to share control during the research process and prepare for unexpected outcomes (Povee et al., 2014). Researchers should understand that they need to forfeit control so that people with intellectual disabilities can feel empowered and develop new experiences and skills (Povee et al., 2014).

Furthermore, the use of photography from the perspectives of persons with disabilities allowed participants in a developing African nation an opportunity to provide evidence of the societal barriers they experience and requiring civil justice that may influence policy change (Tijm et al. 2011). Similar to Tijm et al. (2011), another study found that working with people with intellectual disabilities presented various opportunities and challenges (Povee et al., 2014). Researchers found that by using this approach, individuals with intellectual disabilities were able to develop new skills and self-esteem, feel empowered, and engage in the research to represent their experiences (Jurkowski & Paul-Ward, 2007; Povee et al., 2014; Wang et al., 2000).

Journaling Methods

Journaling methods involve the researchers writing about their experiences, values, and beliefs throughout the research process (Ortlipp, 2008). Ortlipp's (2008) paper expresses that reflective journaling is useful to show how an individual's personal ideas, values, and experiences can be made visible to the researcher and the reader. By journaling, researchers can avoid "producing, reproducing and circulating" (p. 704) ideas throughout the research process in an orderly manner (Ortlipp, 2008). Journaling also provides the researchers the ability to critically think about the research and make informed decisions about what is and is not important (Lamb, 2013). Reflection can assist researchers to examine and analyze the methods rather than the data or outcome of the research (Lamb, 2013). Finally, journaling adds to the validity and authenticity of the data collected (Lamb, 2013).

Although journaling methods allow researchers to show their thoughts, there are limited resources and guidelines for novice researchers, such as students, on how to keep

and use reflective journals during the research process (Ortlipp, 2008). Using journaling and self-criticism can also change how the individual approaches the research process and therefore the interpretation of data might be skewed (Ortlipp, 2008). Journaling also requires time and thought, which needs to happen after a particular situation to reflect on current ideas that the researcher develops (Lamb, 2013).

Interview Methods

Interviews are among the most used method for qualitative research (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006; Qu & Dumay, 2011). Interview techniques work to gain insight into the experiences from the participant involved in the research process (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006). Interview methods also depend on the type of investigation conducted. For instance, researchers may use interviews to test a hypothesis while others may use interviews to gain an understanding of the theory (DiCicco-Bloom & Crabtree, 2006). Interviews gather information and leave the interpretation up to the researcher (DiCicco-Bloom & Crabtree, 2006).

Interviews are broken down into two categories, structured and semi-structured. Structured interviews are mainly used for quantitative research while semi-structured interviews are used for qualitative research (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006).

Semi-structured interviews involve open-ended questions along with additional questions that emerge with the dialogue (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006; Qu & Dumay, 2011). Using semi-structured interviews on a one-to-one basis allows for the interviewee to express his or herself in a more personal manner unlike group interviews (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006). It is also important

for the researcher to develop a rapport with the participant to gain a deeper insight when addressing the questions in the interview (DiCicco-Bloom & Crabtree, 2006).

Interviews also have various methods of recording for documentation such as audio recording, video recording, and note taking. Using these approaches require the consent of the interviewee (Opdenakker, 2006). One disadvantage of audio or video recording is the background noise, weak batteries or placement of the recorder (Opdenakker, 2006). These factors can make the analysis of the interview difficult later in the research process (DiCicco-Bloom & Crabtree, 2006). Another disadvantage of recording is transcribing the data, which can take time and may be inaccurate or misinterpreted (DiCicco-Bloom & Crabtree, 2006).

Overall, interviews are sufficient to gain an understanding of the experiences and values of the participants involved in the research (Alsaawi, 2014). Interviews also gather meaningful information through stories that share their personal experiences (Alsaawi, 2014). Interviews that are face-to-face allow the researcher to attend to social cues which can relate to interpreting the data (Opdenakker, 2006). Finally, interviews are more flexible than any other qualitative method (Alsaawi, 2014). On the other hand, interviews take time because “the researcher needs to go through a long process, starting from establishing access to making contact with participants, conducting the interview followed by transcribing the data and making use of it” (Alsaawi, 2014, p. 154). Researchers may also misinterpret what the participant states, which may influence the outcome of the study (Alsaawi, 2014).

Chi Square Testing

The quantitative methods of this research include chi-square testing. The chi-

square test is a non-parametric test that uses nominal data such as gender and occupation (McHugh, 2013). According to McHugh (2013), the requirements for proper use of a chi-square test include the measurements being nominal or ordinal, the sample size of groups being unequal, and the original data being measurable at an interval or ratio level (McHugh, 2013). An advantage of the chi-square test is that it allows calculating for expected values as an output. Without the expected values, researchers simply conclude that the independent variables are significantly different or not independent (McHugh, 2013). Another advantage is that the test provides substantial information about the data. It also allows researchers to test hypotheses using qualitative data (McHugh, 2013). Lastly, when using the chi-square test, results are most reliable when samples are randomly selected and adequately large (McHugh, 2013); however, in this research, the last advantage would be a disadvantage due to participants not being selected randomly and using a small sample size of fifteen. Another disadvantage of using the chi-square testing is if researchers use the test in violation with the assumptions in which the outcomes may not be reliable (McHugh, 2013).

Statement of Purpose, Hypothesis and Research Questions

The purpose of this exploratory methods design was to identify and describe the perspectives of Ethiopian adolescents with intellectual disabilities regarding their daily occupations and the meaning they ascribe to those occupations. In Ethiopia, children make up nearly half of the population; however, studies which have focused on children are rarely researched from the children's perspective of their everyday lives (Tekola et al., 2008). Children are not usually in control and do not always have a say in the activities that they do (Berinstein & Magalhaes, 2009); however, an emphasis on

children's participation reflects that children are knowledgeable about their lives and are capable of participating in qualitative research (Abebe, 2009).

Through the use of photography and interviews about the photographs, investigators gained insight into the meaningful occupations of the participants' lives categorized into three aspects: life at home, life at school, and life in the community. Studying the lives of children with disabilities in Ethiopia can help further the knowledge and understanding on how health care professionals such as OTs can best serve this population in a client-centered manner. Therefore, to increase client-centeredness and evidence-based OT services at CMCC in alignment with AOTA and WFOT values and AOTF research goals, investigators collected data in person through photographs and interviews at CMCC to identify and describe occupations of students with intellectual disabilities and the meaning they find in those occupations.

Theoretical Framework

Because investigators worked with a vulnerable and marginalized population and aimed to collaborate to learn about their opinions, investigators drew from the Participatory Occupational Justice Framework (POJF) developed by Ann Wilcock and Elizabeth Townsend (Townsend & Wilcock 2004) to frame the methodology. The framework describes a concept in which all populations have the opportunities and resources to engage in meaningful occupations to their full potential and aspires to an occupationally just world by empowering populations who routinely experience social exclusion, such as those with disabilities (Nilsson & Townsend, 2010; Townsend & Wilcock, 2004).

Occupational justice is defined as a justice of difference to identify occupational

rights regardless of capability, age, gender, and social class (Nilsson & Townsend, 2010; Townsend & Wilcock, 2004). Occupational injustice involves social exclusion through occupational alienation, imbalance, deprivation, and marginalization (Townsend & Wilcock, 2004). Social exclusion prevents individuals with disabilities from participating and experiencing meaningful occupations in diverse contexts, such as care facilities (Nilsson & Townsend, 2010; Wilcock & Townsend, 2014). Additionally, social exclusion limits individuals so that some have lesser burdens while others have greater burdens in their everyday lives (Nilsson & Townsend, 2010; Wilcock & Townsend, 2014). It can also prevent individuals from experiencing independence due to a lack of choice in meaningful occupations (Nilsson & Townsend, 2010; Wilcock & Townsend, 2014). Occupational injustice exists for individuals with disabilities and persists in communities, hospitals, education, employment, and those who use assistive technologies (Townsend & Marval, 2013). Individuals who live in poverty or who are homeless often experience occupational injustice in cultural changes or occupational transitions as well (Townsend & Marval, 2013); however, occupational justice can be achieved by implementing laws and policies through the social model of disability by engaging individuals with disabilities equally in education, employment, and health care (AlHeresh et al., 2013).

It is an occupational therapist's responsibility in a professional, ethical, moral, and financial capacity to enable individuals when possible (Nilsson & Townsend, 2010; Whiteford & Townsend, 2011; Wilcock & Townsend, 2014). Through an enabling approach, "practitioners employ participatory, empowerment-oriented methods for working in partnership with people and organizations" (Whiteford & Townsend, 2011, p. 68). Occupational therapy frameworks utilize an enabling approach as a facet of client-

centered practice (Townsend & Wilcock, 2004; Whiteford & Townsend, 2011); however, if enablement is not addressed, practitioners assume they know what is best without communication with those involved (Whiteford & Townsend, 2011). They may implement policies and laws for populations without learning what works best in their cultural context (Whiteford & Townsend, 2011). Therefore, with adequate enablement, populations, neighborhoods, and individuals can collaborate to empower an occupationally just world (Whiteford & Townsend, 2011).

The POJF is intended for practitioners to recognize that enabling occupational justice may start with individuals (Whiteford & Townsend, 2011). Therefore, justice can be understood through student projects in education or fieldwork settings (Townsend & Wilcock, 2004). Students are encouraged to learn “to critically appraise the power relations that control clients’ and occupational therapists’ opportunities” (Townsend & Wilcock, 2004, p. 84). According to the POJF by Whiteford and Townsend (2011), there are six skills required for enablement: raise the consciousness of occupational injustice, engage collaboratively, mediate and agree on a plan, strategize resource funding, support the plan, and inspire advocacy.

Occupational therapists have the knowledge and skills to encourage individuals who experience occupational injustice to participate in meaningful occupations (Wilcock & Townsend, 2014). Occupational therapists also have a role in educating others to recognize and raise issues of occupational limitations and barriers and to work with populations, communities, and societies to enhance participation in occupation for all individuals (Wilcock & Townsend, 2014). By having different approaches to various cultures and populations, an occupational therapist can accomplish and reach an

occupationally just society (Wilcock & Townsend, 2014).

The POJF provides an appropriate foundation for this research because it offers a framework for collaboration with marginalized populations, a definition of occupational injustice. As the use of photography is an empowering force for both children and people with disabilities (Lao et al., 2012) and face-to-face interviewing provides an opportunity for the interviewee to narrate their experiences (Opdenakker, 2006), the POJF promotes empowerment of those who experience social exclusion and provides an appropriate framework for these research techniques.

Methodology

The design for this thesis is exploratory methods and based on the ideas of researchers using Photovoice, a participatory action methodology (Tijm et al., 2011; Wang, 1999). Contrary to the artistic and professional ideals of Photovoice projects (Photovoice Manual, 2004), the investigators use of digital cameras is a means for recording aspects from the children's lives to promote dialogue and community reflection. The use of photography as a means for collecting qualitative data has become an efficient and useful tool in qualitative research (Walker & Early, 2010). This participatory action methodology encourages the participants to come together with the researchers to analyze and reflect on factors of their community that are important to them (Walker & Early, 2010). In earlier research conducted by Carnahan (2006) the use of the photographic research techniques uncovered new aspects in the lives of children with autism that led to accidental intervention techniques. The information gathered by these children, whose voices are not usually heard, gave teachers an opportunity to witness hidden patterns that impeded their learning process (Carnahan, 2006).

Photographs and subsequent interviews may uncover information about intervention strategies that hinder participation (Walker & Early, 2010). Thus, investigators posited that collaborating with participants to discuss the meaningful aspects of their daily lives may lead to client-centered interventions for OT.

Investigators also utilized journaling methods to visibly show their thoughts about their experiences and assist with analysis of methods and data (Lamb, 2013; Ortlipp, 2008) to uncover and reduce bias. Semi-structured interviews allowed the investigators to gain a deeper insight of the experiences through the view of the participants and allowed the investigators to pick up social cues that the participant expressed during the interview (Alsaawi, 2014; DiCicco-Bloom & Crabtree, 2006; Opdenakker, 2006).

Future investigators will use chi-square testing to determine if there is a significance between observed variables and the expected variables of two independent groups (McHugh, 2013; Stein et al., 2013). McHugh (2013) presents and describes how chi-square tests apply with a case study example. The formula for calculating chi-square is:

$$\sum x_{i-j}^2 = \frac{(O-E)^2}{E}$$

where O= observed (actual count of cases in each cell), E= expected value, X^2 = chi-square value, $\sum X^2$ = sum of all chi-square values, and $X_{i-j}^2 = i-j$ is the observed frequency to represent all the cells from the first cell, (i), to last cell (j). This analysis is a simple but powerful statistic to use when comparing nominal data that pertains to research studies (Stein, Rice, & Cutler, 2013).

Preparation: Fundraising and Collection of Cameras

The investigators created a fundraising website to purchase plane tickets,

accommodations, and supplies. The primary investigator bought the same digital camera to create an equal opportunity for the participants so that one child would not have an advantage over another. The cameras were mid-range in quality and were required to have a flash for dim light pictures at night and in low light situations due to lack of electricity in many locations and frequent blackouts. The cameras were powered by disposable battery so that they could be used without having to charge the battery in the case of a power outage.

Investigators chose to utilize digital cameras over disposable cameras for three reasons: to quickly download pictures to a computer, to avoid the cost and logistical difficulty of film processing in Addis Ababa, and to allow participants to take a larger number of photos. Disposable cameras would need to be developed and then scanned into a computer whereas digital cameras can be directly downloaded onto the computer. Also, only about twenty-five photos per camera can be taken on a disposable camera while greater than twenty-five photos can be taken on digital cameras depending on the amount of memory space.

Data Collection

The Participants

The participants were recruited from CMCC in Addis Ababa, Ethiopia. Inclusion criteria consisted of children who attend CMCC, have an intellectual disability, and whose ages range from ten to sixteen years old. The participants had to be able to answer who, what, when, where, why and how questions to elaborate on their photos. Participants also had to communicate verbally or through the use of an assistive device and be able to demonstrate appropriate use of simple digital camera after training. The

lead investigator selected this school due to previous connections. The administrator, Adanech Mekonnen, gave written permission to do research at the school prior to starting the research process.

Confidentiality: Consent and Assent Forms

To provide information and consent in the participant and guardian's native language, co-investigator Debay translated recruitment letters, information forms, consent forms, assent forms, and participant's bill of rights from English to Amharic; a translator licensed in Addis Ababa, Ethiopia retranslated these documents from Amharic to English to ensure an accurate translation. Because there was a high chance that all potential participants were illiterate, co-investigator Debay read the assent forms out loud to all potential participants to ensure their understanding. He paused after each section to allow the participants to verbally summarize their understanding of that section. He denoted a checkmark to indicate understanding or an x mark to indicate misunderstanding in the margin of the assent form next to each section. He gave an opportunity for the prospective participant to ask clarifying questions and answered those questions as necessary. He reread to the potential participants up to three times and rephrased for comprehension when he deemed necessary. If participants were unable to demonstrate understanding, they were excluded from the study. To further protect the minor children's right to informed assent, a witness familiar with the potential participant's function, such as a guardian, teacher, or administrator, was present in person and signed the assent form if they believed the participant understood them. The translator also signed a consent form protecting the confidentiality rights of the participants and the research. Furthermore, the researchers provided pictures of themselves as well as contact

information to assure support during the research process.

Uncontrollable safety concerns, such as giving the children something valuable, may put them at risk for theft and bodily harm (Tijm et al., 2011). Therefore, participant safety was addressed during the orientation and ethical implications regarding the privacy of others when taking photos were discussed (Tijm et al., 2011). This was explained in the risks section of the consent form and was emphasized throughout the entire process. The children were encouraged to use caution when in transportation and in busy settings with possession of the camera to decrease the chances of theft or harm.

The Process

The primary investigators collected data by training participants to take photographs of meaningful occupations and then discussing the subjects of the photographs and the meaning they attributed to the occupation over a span of twelve days at the Mekanisa campus of CMCC in Addis Ababa, Ethiopia.

Data collection included the participant's name, age, gender, and grade/class level at school, photos they took, and answers to open-ended questions in a face-to-face interview recorded on an iPhone 5S.

The primary investigator and co-investigator trained participants to use the cameras by taking practice photos in a conference room at CMCC. The training session ran approximately two hours and occurred during regularly scheduled school hours. The exact timing and room assignment of training were arranged with CMCC administrator, Adanech Mekonnen, prior to the start of data collection. Prior to training, cameras were adapted with black tape to prevent participants from using specific buttons or taking out the memory card (see Figure 1). During the training session, Co-Investigator Debay

translated training information from English to Amharic and participant questions/responses from Amharic to English. Investigators used repetition, small group instruction, individual instruction, and multisensory techniques to teach, and return demonstration to ensure understanding (Fitzgerald, 2011).

At the conclusion of the training session, investigators assigned numbered cameras to participants and instructed participants to take pictures of objects that were meaningful to them. Participants took photographs of meaningful occupations over the course of five days at school, in their homes, and in their communities. The participants gave the cameras back to investigators several times throughout the week, which allowed investigators to download the images and to check camera and battery function (see Appendix D).

Interviews

Investigators prepared nine photographs (according to availability) from each category (home, school, community) and an additional ten photographs with different subjects to discuss in the interview. Of those ten photographs, participants chose two photos for discussion in the interviews. The ten photos were divided into two groups of five photos each and participants chose one picture from each grouping to discuss (see figure 10).

Interviews consisted of participants, investigators, a translator, and a parent or guardian if necessary. Investigators asked open-ended questions such as, “Why did you take this picture?” or “Why is this photo important to you?” to prompt dialogue during the interviews (see Appendix F). Investigators audio recorded interviews and later translated and dictated the data. Simultaneous translation took place, allowing the

investigators to ask follow-up questions to the participants.

Transcription was done afterward for coding and analysis using a MacBook Pro and Microsoft Word software. After transcription of the audio file, investigators checked for accuracy and uploaded to the coding software, Dedoose.

Data Analysis

Exploratory methods were used to describe the data. Stein, Rice, and Cutler (2013) identified six key principles of qualitative data analysis: concurrent collection and analysis, systematic processing, coding, use of a coding tool, data organization, and data synthesis. To increase rigor and transparency of analysis, investigators incorporated several widely accepted methods of increasing transparency and rigor including a multidisciplinary team, triangulation of data, an audit trail, and journaling (Curry, Nembhard, & Bradley, 2009; Ortlipp, 2008).

Investigators utilized open coding methods based on grounded theory on data obtained from interviews and photographs. Investigators coded data individually and compared to achieve triangulation of data. Investigators discussed any differences until a mutual understanding was reached and documented discussions in writing to create an audit trail. Investigators also utilized the Occupational Therapy Practice Framework (Framework-III; AOTA, 2014) based on the descriptions and categories to code the interview (see Table 3). Investigators chose the coding software Dedoose due to its affordability and collaborative features. The investigators live in different time zones and continents; therefore, web-based accessibility features were important for collaborative data analysis. Dedoose had the ability to import transcripts, audio files, photographs, and allowed investigators to tag excerpts related to the research questions, label with themes,

and organize into trees (Dedoose, 2015).

Future investigators will analyze quantitative data to look for associations between participant responses and various subsets of participant demographics. By using Dedoose, future investigators will perform chi-square tests to measure the association between pairs of descriptors/categories such as age or gender and presence of specific themes. The purpose of chi-square tests is to measure differences between observed and expected frequencies of two independent groups (Stein et al., 2013). Results of $<.05$ indicate that there is an association between the categories with a 95% confidence interval.

Results

The results presented are based on one ten-year-old male participant's response (Bubu). Descriptive statistics including frequency tables, bar graphs, and pie charts illustrate results. Cameras were adapted to prevent the child from changing the setting or taking out the battery and memory card (see figure 1).

Figure 1. Adapted camera





Figure 1. Example of adapted camera using black tape.

Choosing of Photographs

Bubu took multiple photographs of the same thing. Therefore, photos were chosen based on clarity and content of the picture. An example is given in Figure 2 to show the difference between two similar photographs. Additionally, two pictures are illustrated to present what photographs were thrown out of the selection. Out of the 142 photos that Bubu took, 79 (56%) were usable, 22 (15%) were thrown out or discarded, and 41(29%) were practice photos (see Table 1 and Figure 3). The results display that out of the 142 photos taken Bubu understood the concept of the project in which he could take photographs of occupations that are meaningful to him.

Of the 79 usable photos, 31 (39%) are school photos, 16 (20%) are home, and 32 (41%) are the community (see Table 2 and Figure 4). All the photos were evaluated by environmental context. School photos were evaluated by being in the school or premises of the school, home photos were in the home or premises of the home, and community photos were everything else. For example, Bubu took pictures on the bus to school, and since this is not on the premises of the school or home, it was considered in the community.

Table 1

Total number of photos taken

| Type of Photo | Total Photos Taken |
|---------------|--------------------|
| Practice | 41 |
| Thrown out | 22 |
| Usable | 79 |
| Total | 142 |

Note. Practice pictures were taken during training at the school.

Table 2

Number of Photos in Environmental Context

| Environmental Context of Photo | Total Photos Taken |
|--------------------------------|--------------------|
| School | 31 |
| Home | 16 |
| Community | 32 |
| Total | 79 |

Note. Total does not include practice or thrown out photos.

Figure 2. Photographs taken by Bubu.



Figure 3. Top: Left photo, Bubu school #3. Right photo, thrown out. Middle: Left, Bubu home #3. Right, thrown out. Bottom: Right and Left are thrown out photos.

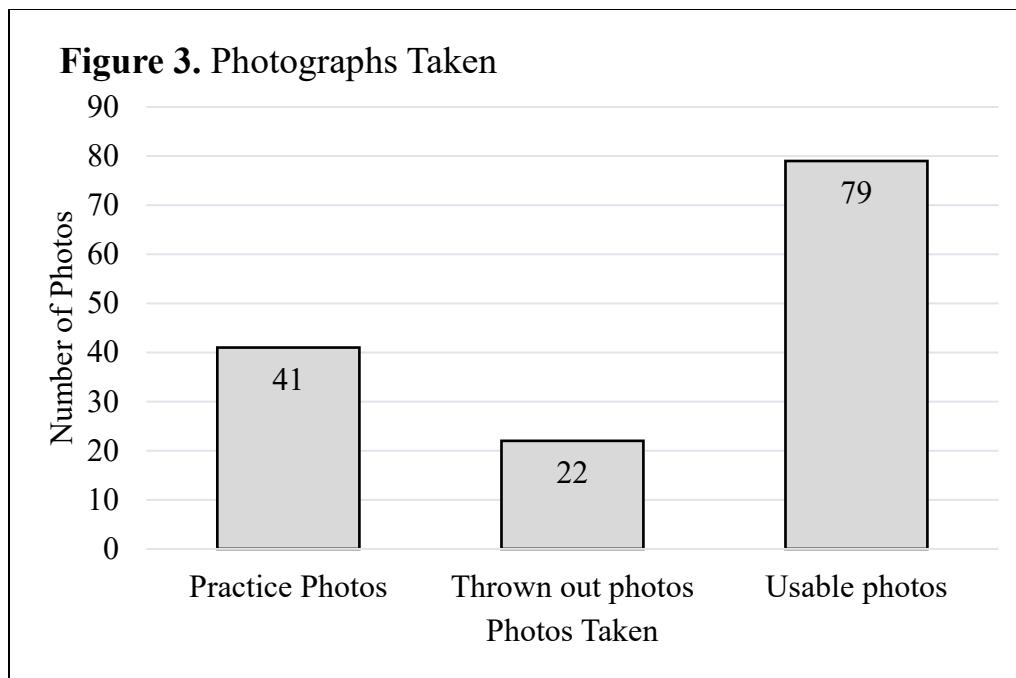


Figure 2. Total photos taken over one-week period.

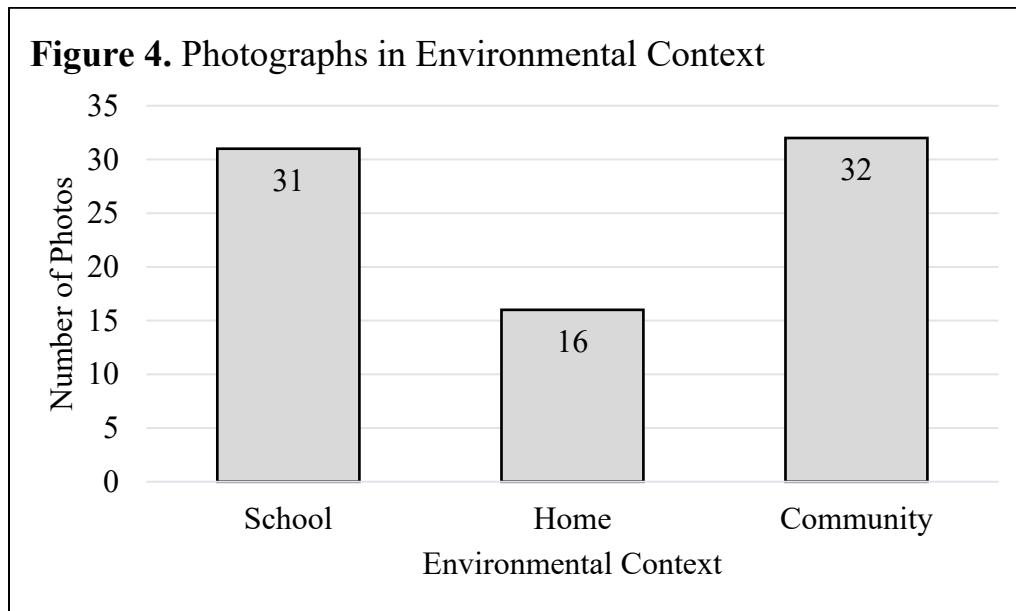


Figure 4. Total photos taken in each environmental context

Coding

Operational definitions from Framework-III were used to describe the content in the interview. Based on the content, a total of 62 phrases were coded. Of the 62 phrases, 4 (6.5%) were used for ADLs, 3 (4.8%) for instrumental activities of daily living

(IADLs), 6 (9.7%) for education, 4 (6.5%) for play, 10 (16.1%) for leisure, 6 (9.7%) for social participation, 3 (4.8%) for routines, and 26 (41.9%) for value or freedom of speech (see Table 4 and Figure 5). Descriptions of categories were used to code the content of the transcribed interview except for value. Value is based on the phrase “I need it” as stated by Bubu. In Amharic, this translates to a personal expression of needing it in the soul (A. Debay, personal communication, January 04, 2017). The term “freedom of speech” was used since it is a term used under the category value.

The most common occupation that Bubu related to was leisure participation. Leisure participation was based on watching television (TV) with his family or the fact that he loved taking photographs. The second common occupations were education and social participation. Bubu explained pictures for education that involved numbers, although they were letters, and stated he liked learning. Bubu also mentioned books, which were coded as education because he said he could read them. Social participation involved his family members and friends in all three environmental contexts (see Figure 7). Third are ADLs and play. Bubu described ADLs that included washing hands and eating or drinking. The occupation of play involved playing with puzzles, goods, or with a ball. Lastly, IADLs involved home management and establishment which were described when watering the flowers and turning on the light switch. Religious and spiritual activity were outlined in a photo of the Ethiopian flag which involved singing the national anthem in school. Routines included watering the flowers, playing with friends, and spending time with family.

Additionally, in each environmental context, phrases were analyzed. A total of 41 (66.1%) phrases relate to the school, 14 (22.6%) relate to home, and 7 (11.3%) relate to

the community. Occupations that related to each of the environmental contexts are IADLs and social participation whereas education only related to school. Leisure participation and ADLs only related to school and home setting. Lastly, play related to school and the community settings. For routines, settings included school and home. Finally, for value, the majority of phrases relate to school while home and community settings were equal. A summary of the total phrases in each category is shown in Table 5 and Figure 8. Additionally, phrases in each environmental context are shown in Figure 9.

A total of 10 free choice photos were displayed in sets of five for Bubu to pick one. How the photos were presented and actual pictures Bubu picked from free choice photos are shown in figures 10 and 11, respectively.

Table 3
Descriptions/Operational Definitions

| Domain | Category | Subcategory | Description/Operational Definitions |
|------------|----------------------------------|--|---|
| Occupation | Activities of Daily Living (ADL) | Feeding Personal hygiene and grooming | Setting up, arranging, and bringing food [or fluid] from the plate or cup to the mouth; sometimes called self-feeding. Obtaining and using supplies; removing body hair (eg, using razor, tweezers, lotion); applying and removing cosmetics; washing, drying, combing, styling, brushing, and trimming hair; caring for nails (hands and feet); caring for skin, ears, eyes, and nose; applying deodorant; cleaning mouth; brushing and flossing teeth; and removing, cleaning, and reinserting dental orthotics and prosthetics. |

| | | |
|--|---|--|
| Instrumental Activities of Daily Living (IADL) | Home establishment and management | Obtaining and maintaining personal and household possessions and environment (e.g., home, yard, garden, appliances, vehicles), including maintaining and repairing personal possessions (e.g., clothing, household items) and knowing how to seek help or whom to contact. |
| | Religious and spiritual activities and expression | Participating in religion, “an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent” (Moreira-Almeida & Koenig, 2006, p 844), and engaging in activities that allow a sense of connectedness to something larger than oneself or that are especially meaningful, such as taking time out to play with a child, engaging in activities in nature, and helping others in need (Spencer, Davidson, & White, 1997). |
| Education | | Activities needed for learning and participating in the educational environment. |
| Play | Play participation | Participating in play; maintaining a balance of play with other occupations; and obtaining, using, and maintaining toys, equipment, and supplies appropriately. |
| Leisure | Leisure participation | Planning and participating in appropriate leisure activities; maintaining a balance of leisure activities with other occupations; and obtaining, using, and maintaining equipment and supplies as appropriate. |

| | | | |
|---------------|-------------------------|----------------------|---|
| | Social Participation | Family | Engaging in activities that result in “successful interaction in specific required and/or desired familial roles” (Mosey, 1996, p 340) |
| | | Peer, Friend | Engaging in activities at different levels of interaction and intimacy, including engaging in desired sexual activity |
| Client Factor | Value | Freedom of Speech | Acquired beliefs and commitments, derived from culture, about what is good, right, and important to do (Kielhofner, 2008) |
| Performance | Routine Pattern | | Patterns of behavior that are observable, regular, and repetitive and that provide structure for daily life. They can be satisfying, promoting, or damaging. Routines require momentary time commitment and are embedded in cultural and ecological contexts (Fiese, 2007; Segal, 2004) |

Note. ADL= Activities of Daily Living; IADL= Instrumental Activities of Daily Living;
Descriptions were taken from the *Occupational Therapy Practice Framework: Doman and Process III*

Table 4.

Number of codes based on category

| Code | Total Coded |
|---|-------------|
| Activity of Daily Living (ADL) | 4 |
| Personal Hygiene | 1 |
| Feeding | 3 |
| Instrumental Activities of Daily Living (IADL) | 4 |
| Home establishment and management | 3 |
| Religious and spiritual activities and expression | 1 |
| Education | 6 |
| Play | 4 |
| Play Participation | 4 |
| Leisure | 10 |
| Leisure Participation | 10 |
| Social Participation | 6 |
| Family | 3 |
| Peer, Friend | 3 |
| Routines | 3 |
| Value | 26 |
| Freedom of Speech | 26 |
| Total | 62 |

Note. Code totals are in boldface.

Table 5.

Phrases related to each environmental context

| Type of Photo | ADL | IADL | Education | Play | Leisure | Social Participation | Routine | Value | Total |
|---------------|----------|----------|-----------|------|---------|----------------------|---------|-------|----------|
| School | 1 | 1 | 6 | 3 | 7 | 1 | 2 | 20 | 41 |
| Home | 3 | 1 | 0 | 0 | 3 | 3 | 1 | 3 | 14 |
| Community | 0 | 1 | 0 | 1 | 0 | 2 | 0 | 3 | 7 |
| Free Choice | 2 | 1 | | | | | | | 2 |
| #1 - Home | | | | | | | | | |
| Free Choice | | | | | | | | | 1 |
| #6 - Class | | | | | | | | | |
| Total | 4 | 3 | 6 | 4 | 10 | 6 | 3 | 26 | 62 |

Note. Free choice photos are added to the total count and are boldface.

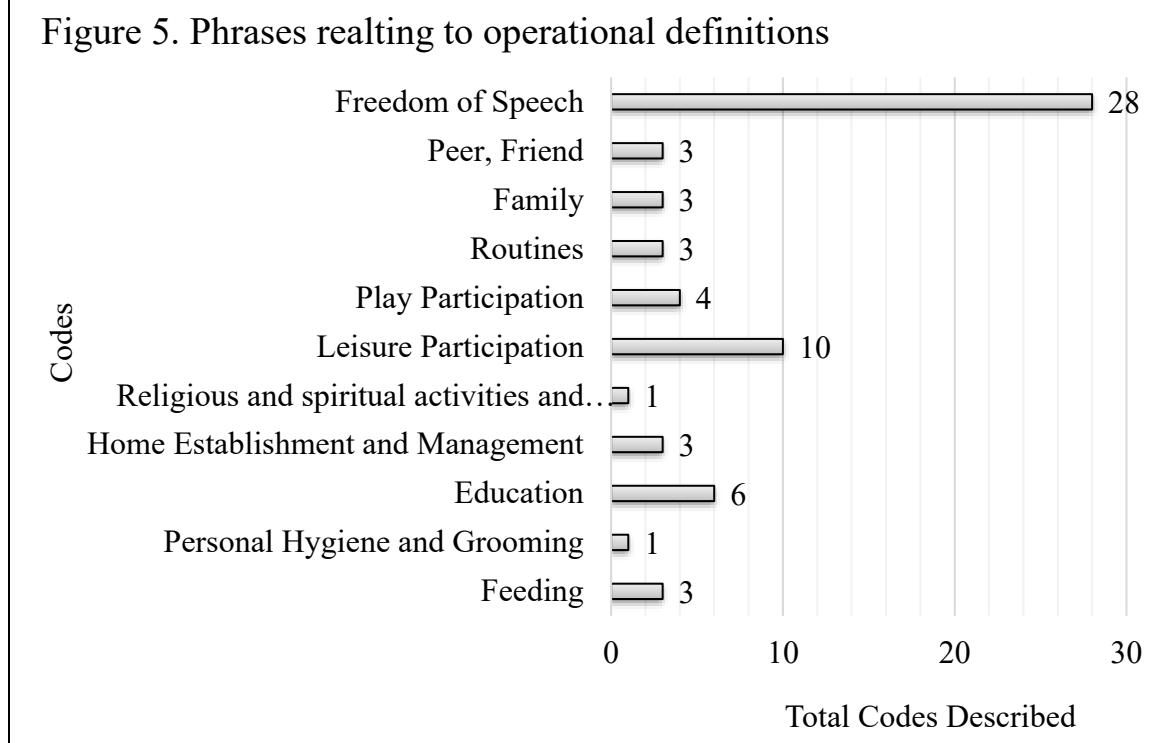


Figure 5. Total phrases analyzed based on definitions from Framework III.

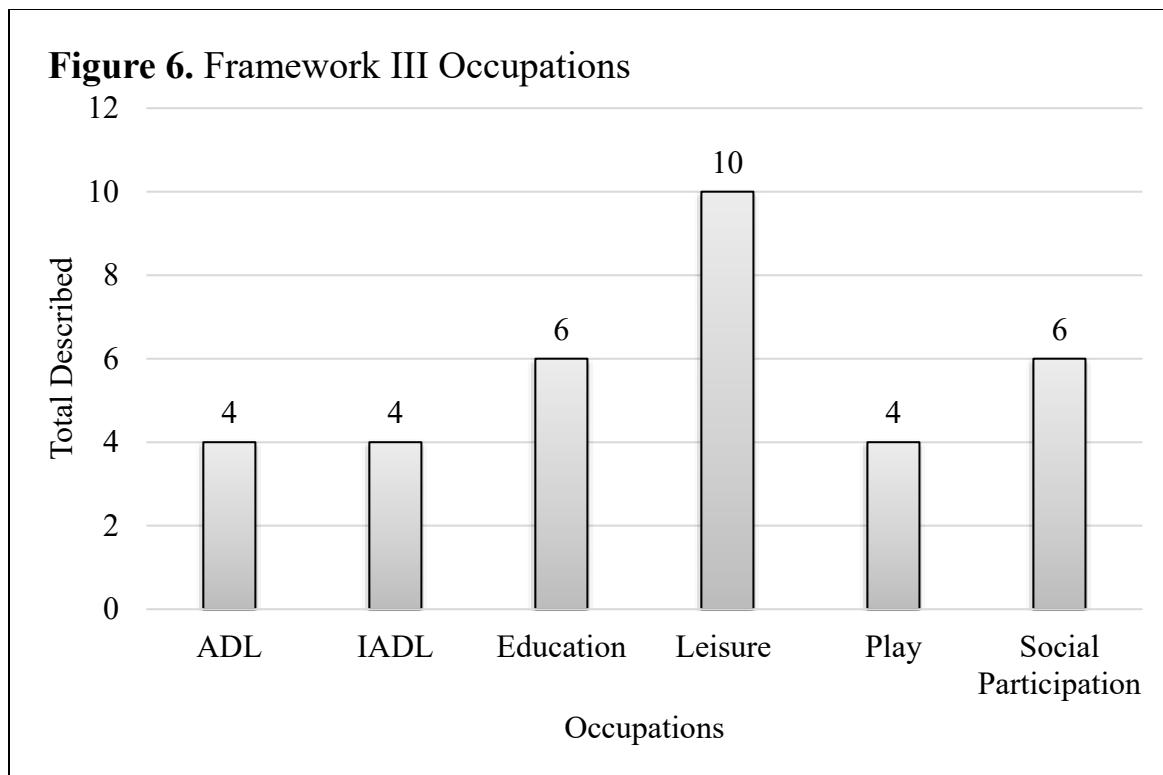


Figure 6. Illustration of occupations related to *Framework-III*

Figure 7. Social participation photos



Figure 7. Top Right to Left: Bubu community #1, community #3; Bottom right to left: home #2, home #3

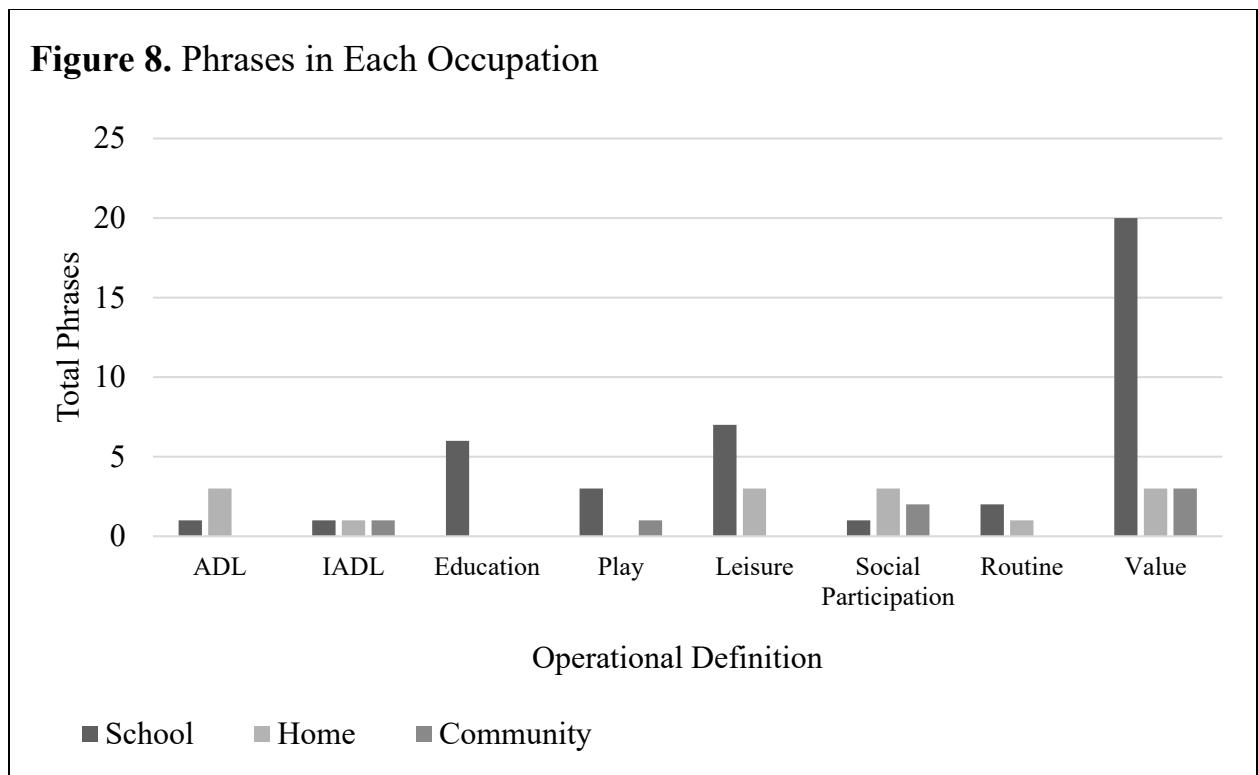


Figure 8. Detailed diagram of phrases in each occupation, routine, and value.

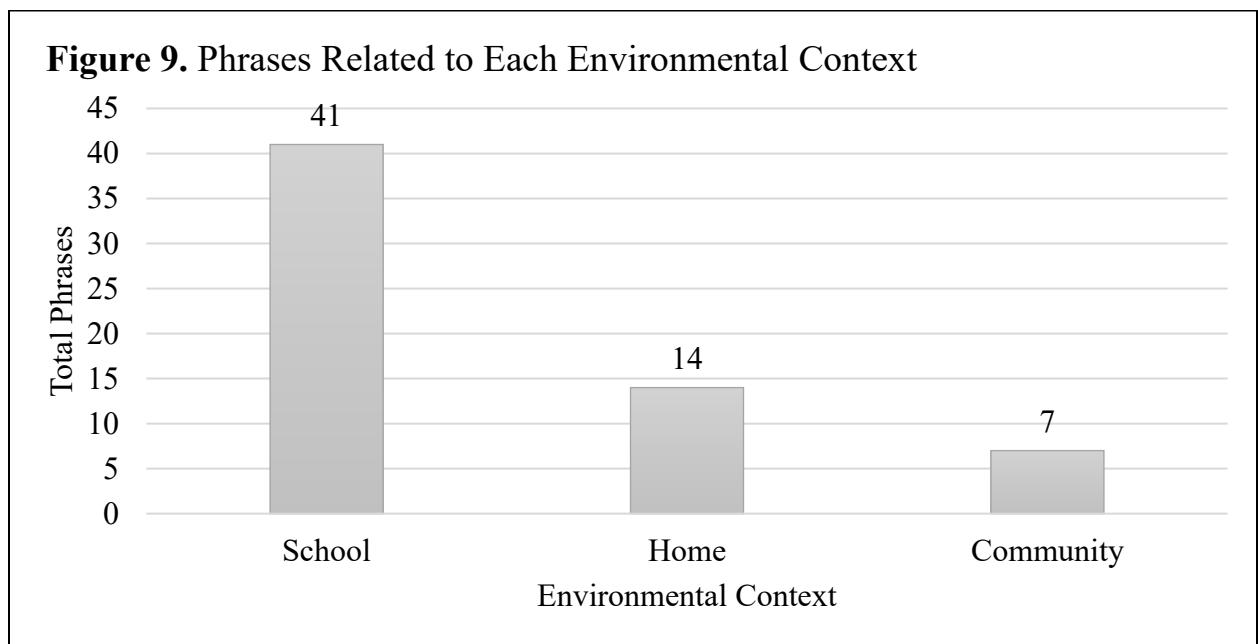


Figure 9. Diagram of phrases in each environmental context.

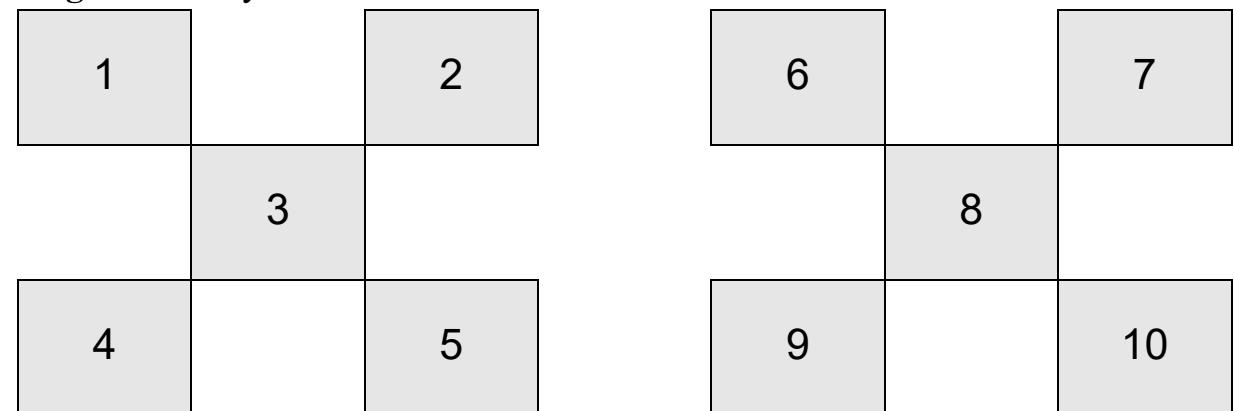
Figure 10. Layout of Free Choice Photos

Figure 10. Layout of free choice photos when presented to Bubu. Picture choices were presented with photos 1-5 first then 6-10 after the discussion of the photo previously picked.

Figure 11. Free choice photos chosen by Bubu

Figure 11. Right: Free choice #1. Left: Free choice #6.

Themes

When coding the transcription, three themes arose:

1. Autonomy: The investigator did not try to justify why a particular answer was said. The investigator allowed Bubu to have self-expression and if he did not respond to the question “Why?” the investigator moved onto the next question.
2. New Occupation: When interviewing Bubu, he twice mentioned that he likes to take photographs. Occupation is a theme because in doing this project, Bubu learned an activity that became meaningful to him that made him happy.
3. Participation in Activities: Of the phrases coded, 36 (58%) of items were coded under occupations and routines in which the participant said they liked doing. The remaining 26 (42%) phrases were based on values and the concept of freedom of speech in which Bubu stated: “I need it.”

Discussion

Investigators gained insight into the perspectives of children with intellectual disabilities in Addis Ababa, Ethiopia, regarding the meaning of their daily occupations. Unfortunately, student investigators decided not to participate in data collection in Ethiopia due to safety concerns. As a result, approximately half of the donated funds raised were given back to individuals who requested it and the other half was used by the primary and co-investigator. The primary investigator and co-investigator collected data as planned and utilized the POJF developed by Ann Wilcock and Elizabeth Townsend (Townsend & Wilcock 2004). Through an enabling approach, investigators collaborated with teachers, parents, and the participants empowering the participants, using the photographic method.

Results were based on one participant's response and show that the most meaningful occupation of ten-year-old Bubu is leisure participation. In addition, several themes appeared during analysis: autonomy, new occupation, and participation in activities. Studies have shown that children with disabilities have fewer opportunities to express freedom of speech (Anderson & Berger, 2016); this study, however, allowed participants to capture their perspectives. Although Bubu was not able to elaborate on certain questions such as "How?"; he was able to answer "Why?" by using the phrase "I need it" which represented the theme of autonomy or self-expression. Bubu took photographs because he wanted to and expressed his reason for doing so, which did not need to be justified further.

Because Bubu wanted to take these pictures, an activity of leisure participation, the theme of new occupation is related. Bubu expressed leisure participation in two of the three environmental contexts – school and home. Bubu's occupations of leisure participation included taking photographs and watching television. To determine the occupation of taking photographs, Bubu stated phrases such as "Because I like to take photos." The use of the POJF provided the primary investigator and co-investigator the ability to enable occupational justice for Bubu by allowing him to engage to his full potential, which presented him with a new occupation he finds meaningful.

According to WHO (2008), social participation has a positive impact on an individual's overall health and well-being. Though studies have shown it was common for children with disabilities to have limited social participation and integration in society (ACPF, 2011; Anderson & Berger, 2016), Bubu expressed social participation in all three environmental contexts (see Table 5). Social participation included interacting with peers

in the community and school and family members at home. Activities included playing football with peers and interacting with others at a birthday party. Furthermore, Law (2002) stated that there are several factors that may impact social participation such as the environment, family, and personal considerations. Occupational therapists can assist individuals with disabilities to increase social participation through group activities such learning to take photographs.

Bubu took approximately the same number of photos at school and in the community; however, his photographs showed a greater variety of occupations in the school as compared to the community setting. Bubu's expression of various occupations in school rather than in the community may be due to accessibility of resources. Occupations occurred in school may resemble the Montessori curriculum at CMCC which addresses daily occupations such as self-care, self-directed, and multi-sensory activities. Additionally, Bubu took fewer pictures of ADLs and IADLS, which could mean that he may not do all tasks independently or that they may not be as meaningful compared to leisure participation, social participation, and education. The majority of individuals with disabilities have difficulties with self-care such as toileting, bathing, and dressing (ACPF, 2011; Fitaw & Boersma, 2006); however, Bubu works on these activities to increase performance at CMCC. If OTs were on site, Bubu, along with other children at CMCC, may benefit from their services and achieve independence to a higher degree. Bubu's photos did not show any potential barriers he had in his daily routines and was able to capture all areas of occupation related to the Framework-III except work.

Building relationships with the community is an important step to success and improvement. The Occupational Therapy Africa Regional Group (OTARG) established

by WFOT can recommend OTs to CMCC and establish rapport with the parents or guardians and teachers to educate the community about OT and its benefits for children with disabilities. Through OT services, children such as Bubu can improve participation in occupations and gain new occupations such as a photographer. The occupation of the photographer is important in Ethiopian culture and photographers are frequently invited to important events such as weddings and celebrations (A. Debay, personal communication, January 04, 2017). Bubu was proud to take photos and may be more likely to take photos in places where he is comfortable exploring his interests, such as his home, and showing his skills to his family members.

The purpose of this exploratory methods design was to identify and describe the perspectives of Ethiopian adolescents with intellectual disabilities regarding their daily occupations and the meaning they ascribe to those occupations. The exploratory method approach made it suitable to use cameras to capture their daily routine and interviews to elaborate on their experiences. Investigators hoped to gain insight into the meaningful occupations of the participant's lives as categorized into three environmental contexts: life at home, life at school, and life in the community. Povee et al. (2014) found that cameras offered an opportunity for participants with intellectual disabilities to learn new skills, make decisions, and have control over their photo choices. The results of this thesis concur with Povee et al. (2014) based on the themes observed and occupations Bubu expressed. The investigators experienced that this was an acceptable design for the aim of this thesis as investigators were able to gather information regarding various daily occupations of participants.

Ethical and Legal Considerations

There are many aspects to take into consideration when research is performed with a vulnerable population, such as children with disabilities in a developing country. First, investigators have different cultural backgrounds which may reflect on the interpretation of the data. Although investigators have a translator/co-investigator as a team member to reduce bias, investigators use reflective journals throughout the study to “examine personal assumptions and clarify individual belief systems and subjectivities” (Ortlipp, 2008, p. 695). According to Ortlipp (2008), researchers were able to create transparency of data and process the unconscious into consciousness, open for observation and discussion by using a reflective journal. Journaling personal thoughts allowed investigators to be aware of biases that could have affected the study and understand their role as an interviewer and interpreter. Self-reflection also allowed investigators to change approaches if needed and discard methods that did not work for the study.

Second, as with any given study, participants needed to agree to be a part of the study and were given the opportunity to leave the study or leave questions unanswered if they felt uncomfortable. Prior to the data collection process, parents were given consent forms to check yes or no in order for their child to participate (see Appendix C). Co-investigator Debay provided help by reading the consent forms and also made sure that the participants assented to their parent’s consent. To maintain confidentiality, each participant was given a pseudonym for coding, publication and/or presentation of data. Investigators know the pseudonyms for the participants but those outside the study will not. A black bar was put across the eyes, brow, and upper part of the nose of every face

used in documentation to reduce the possibility of unwanted identification without removing all vivid details of the photo.

Third, data was saved on an encrypted and password protected computer/hard drive and accessed only by investigators. Therefore, each investigator also signed a confidentiality agreement and will destroy all records after one year following the completion of this thesis and all follow-up research projects based on this data. Destruction of all records will be accomplished by deleting the project from the coding software, securely deleting data from all personal computers, and shredding consent and assent forms (see Appendix B).

Lastly, to reduce the risk of potential theft, bodily harm, and loss of financial purchases, participants were provided with cameras of little monetary value. Investigators encouraged participants to use caution during transport and in busy settings while in possession of the camera. Also, during the camera training session (see Appendix E), investigators informed participants that they would not have to pay for a lost or damaged camera and that they should not risk bodily harm to save the camera from theft or damage (see Appendix C). Overall, the condition of the equipment was well taken care of with the exception that some cameras were damaged and investigators had to make judgment calls to not use the tampered or altered data.

Limitations

The generalizability of this study may be limited to Ethiopian culture and children with mild to moderate intellectual disabilities who attend school. Investigators only gathered data from children with intellectual disabilities who attend the Mekanisa campus at the CMCC in Addis Ababa, Ethiopia. Thus, the results may be difficult to generalize

with a similar population from other developing countries due to different cultural backgrounds.

Culture and environment may have caused limitations impacting the research results. The investigators and participants are from different cultural backgrounds which resulted in the translation of the participant's answers from Amharic to English. The time it took to translate may have affected attention span, the flow of conversation, and overall interview. Student investigators were also unable to be physically present for the interviews, possibly affecting what types of codes represented the photographs and the interviewee's response. Although they were able to listen to the interview, student investigators may have gained a better understanding of the phrases by observing body language and facial expression during the interview. Also, the conference room may not have been best suited for the discussion because Bubu was easily distracted when he heard outside noises. In Bubu's interview, it was noticeable when outside noises disrupted the flow of the interview. This interfered with the investigators asking questions and Bubu's answers.

Data collection factors such as culture, environment, family, and teachers may also cause limitations in the study. Limitations of how the participant took the photos, chose the photos, and how the investigators presented the photos and questions may have affected outcomes. The physical presentation of the photos may have also influenced choices. Photos were displayed similar to five dots on a dice (see Figure 10), but Bubu chose one and six possibly because they were first in the sequences. Another limitation was how interview questions were phrased. Based on Bubu's answers from the interview, he had trouble answering, "How do you feel?" The translation of feel from English to

Amharic could be interpreted as “listen” or “hear” (A. Debay, personal communication, January 18, 2017). The question would then be interpreted as “How do you hear?” from the picture, which may explain why Bubu did not respond or needed clarification. Investigators refrained from giving multiple choice suggestions to prevent leading participant answers. Lastly, authority figures such as teachers or parents may have restricted the times and activities the participant was allowed to take photos. Photo selection bias may have occurred when investigators were selecting photos for the interview because of their opinions of what they wanted to hear from the participants.

Another limitation included the inability to take pictures in the dark. Investigators did not teach the participant how to use the flash on the camera because the steps for turning the flash on and off were complicated as it involved pushing the switch twice, reading symbols, and waiting for the flash to be ready each time. The participant was told to turn on the light when possible if he wanted to take pictures in the dark. With limited electricity and frequent blackouts, the participant may have been unable to take pictures in dark environments as often as he wanted to, which may have provided fewer opportunities to photograph other occupations.

Implications to Occupational Therapy

The information collected can positively affect OT practice through education and understanding. Occupational therapy practitioners can benefit from information brought by research to improve participation in individuals such as children with intellectual disabilities in a developing country. Therefore, understanding perspectives of an individual’s daily occupations can enhance participation through various implications.

First, photography and interviews may be an effective tool for OTs to increase occupational justice through empowerment of children with intellectual disabilities in developing nations. Photography provides an effective way to portray individuals by looking through the eyes of the individual and gain insight into their daily lives. The amount of information gathered from a single photo may help express the importance of meaningful activities in ways that cannot be verbally expressed. Also, the interviews can allow investigators to gather personal experiences, values, and beliefs of the participant involved. By using both photography and interviews, OTs can attend to social cues related to the photographic data and expand the literature and knowledge to understand experiences of the individual through their perspective (Lao et al., 2012).

Second, participatory action research (PAR) may introduce new meaningful leisure or vocational occupations to children with intellectual disabilities in developing nations. The use of PAR may improve quality of life, health and empower individuals to take action over their life (Baum et al., 2006). Individuals can participate in new occupations and expand their horizon of what they are capable of doing. Also, PAR may increase participation for those who experience social exclusion or alienation and allow them to be part of something important.

Third, photography and interviews may be an effective and engaging method for OTs to increase cultural competency and knowledge of the meaningful occupations of children with intellectual disabilities in developing nations. Western culture norms are different from those in developing countries; children's main occupation in the Western culture is play, whereas in developing nations, such as Ethiopia, a child's main occupation may be leisure participation. Visual images can provide details of the

community and show what children find meaningful. Occupational therapists can gain insight to identify strategies that either help or hinder the activities the children find meaningful at school, home, and in the community.

Fourth, results of this study may further assist OTs and staff at the CMCC to incorporate meaningful occupations in interventions. Routines may get repetitive, and students may lack motivation to participate in activities. From the results of the photographs, individuals at the CMCC will be able to show which activities they enjoy doing and which they struggle with. As communication may be difficult, using photographs as another source could provide further information about the student. If OTs and staff at the CMCC incorporate meaningful occupations to the individual, interventions may increase participation and skills required.

Lastly, photography as an intervention incorporates fine motor and social interaction skills. The buttons on a camera allow individuals to practice fine motor skills such as finger isolation and dexterity. Photography also allows children to increase socialization by sharing and communicating with others about the photographs they have taken to show off their creativity. Interventions may also incorporate abstract thinking and problem-solving skills which are practiced when looking at the world through a lens. Utilizing problem-solving skills such as turning on a light or opening a window to capture an image is practice for higher cognitive thinking. Details come to life using photography as an intervention, and the skills learned allow individuals to show their perspective of the world and what it means to them to the therapist, teachers, family, and peers.

Conclusion

The purpose of this research is to understand the meaningful occupations among children ages ten to sixteen with intellectual disabilities in Addis Ababa, Ethiopia. There is little research on this demographic even though children with or without disabilities make up nearly half of the population in Ethiopia (Tekola et al., 2008). Moreover, the average population of people with disabilities in Ethiopia is inexact as children with disabilities are often “hidden” due to shame or rejection from family and peers (ACPF, 2011). Boddy et al. (2015) stated that few opportunities are provided for children with disabilities to interact with peers and caregivers, which can impede their development, thus providing the importance for this research.

The exploratory method of using photography, interviews, and journaling produced a significant amount of data. The analysis of this thesis was based on one participant’s response, Bubu, a ten-year-old boy, and was analyzed for themes and patterns. Main themes uncovered included autonomy, new occupation, and participation in occupations. Bubu’s most meaningful occupation was leisure participation and overall gained a new occupation while participating in the data collection. Although most of Bubu’s occupations occurred in school, he was proud and excited about photos he had taken in his home and in the community. Bubu expressed every area of occupation according to the *Framework-III* except for work and frequently expressed autonomy by stating: “I need it.” The phrase “I need it,” does not mean he needs it to survive; rather, there is a deeper value that connects the details of the photo to Bubu’s soul. The information Bubu provided about the pictures could not have been observed through western-biased eyes or tested for in predetermined categorical surveying. Without the

collaboration with the Ethiopian translator/sociologist, meaning behind certain statements would have been overlooked if not for the cultural inclusion and knowledge.

By using this method with a vulnerable population, OTs can amplify their voices in alignment with the principles of the POJF to empower populations who routinely experience social exclusion, such as those with disabilities (Nilsson & Townsend, 2010; Townsend & Wilcock, 2004). Studies have also found that people with intellectual disabilities using the photographic method developed new skills, improved self-esteem, felt empowered to make their own decisions, and engaged in research to share their experiences (Jurkowski et al., 2007; Povee et al., 2014; Wang, et al., 2000). This research concurs with prior studies that have found positive outcomes using the photographic method because Bubu was able to develop a new skill, felt empowered in his community, and gained a new occupation.

Occupational therapists can achieve client-centeredness based on evidence-based practice to achieve occupational justice in vulnerable, marginalized populations (AOTA, 2014; AOTF, 2011; Nilsson & Townsend, 2010; Townsend & Wilcock, 2004). Through a photographic method and subsequent interview about the photographs, investigators gained insight into meaningful occupations of the participant's life in aspects such as life at home, school, and in the community. With the lack of published research, more research is needed to further investigate these topics of occupations, values, and meaning in the lives of children in developing countries.

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Appendix A

Permission Email

Gmail - from Melissa

8/25/16, 12:36 AM



MA T <mkeropot@gmail.com>

from Melissa

3 messages

MA T <mkeropot@gmail.com>
To: adanech mekonnen <adanechmek@yahoo.com>

Wed, Jun 15, 2016 at 8:16 PM

Hi Adanech!

Denanish?

I miss Ethiopia!

I have another group of 3 students from Stanbridge University in California I mentioned to you before I left. We are looking to do some research at CMCC which would benefit the children for 1-2 weeks sometime around October-December.

The research would be giving the children cameras to take photos of things important to them during the school day then interviewing them about the photos. They may explain, for example, "I took this photo of washing the dishes because I am very proud that I learned to wash dishes to help my mother" or "I took this photo of my friend because he is my best friend and I am happy to have the chance to meet him at school."

We hope to also have the kids photograph their lives at home and around the community (maybe this year or maybe another year) so we can compare their experiences between school, home, and community. We think the research may help you show how good the school is (and maybe help you get more funding) and also how important school attendance is for kids with intellectual disabilities. We would hope you could use the research to get more funding from the government or private foundations.

The photographs would NOT be published without consent of the families (or maybe not at all). The most important part is the child telling us WHY they took the photo so we can learn what is important to them.

We would of course want to stay in the guest house if it is available and would of course share the paper with the center when it is completed.

Is this something which would be possible?

I look forward to hearing from you!

Thanks so much!

--

Melissa Toporek OTD, OTR/L, BCP



Gmail - from Melissa

8/25/16, 12:36 AM

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adanech mekonnen <adanechmek@yahoo.com>
Reply-To: adanech mekonnen <adanechmek@yahoo.com>
To: MA T <mkeropot@gmail.com>

Thu, Jun 16, 2016 at 2:25 PM

Dear Melissa,
How are doing? here we are fine. we missed you and the students. Melissa I believe you, since the work of the student is helpful you can come any time. for the guest house inform me the duration I will reserve for you all what we have.

I wish you all the best!!

Adanech Mekonnen

On Thursday, June 16, 2016 3:16 AM, MA T <mkeropot@gmail.com> wrote:

Hi Adanech!

Denanish?

I miss Ethiopia!

I have another group of 3 students from Stanbridge University in California I mentioned to you before I left. We are looking to do some research at CMCC which would benefit the children for 1-2 weeks sometime around October-December.

The research would be giving the children cameras to take photos of things important to them during the school day then interviewing them about the photos. They may explain, for example, "I took this photo of washing the dishes because I am very proud that I learned to wash dishes to help my mother" or "I took this photo of my friend because he is my best friend and I am happy to have the chance to meet him at school."

We hope to also have the kids photograph their lives at home and around the community (maybe this year or maybe another year) so we can compare their experiences between school,

Gmail - from Melissa

8/25/16, 12:36 AM

home, and community. We think the research may help you show how good the school is (and maybe help you get more funding) and also how important school attendance is for kids with intellectual disabilities. We would hope you could use the research to get more funding from the government or private foundations.

The photographs would NOT be published without consent of the families (or maybe not at all). The most important part is the child telling us WHY they took the photo so we can learn what is important to them.

We would of course want to stay in the guest house if it is available and would of course share the paper with the center when it is completed.

Is this something which would be possible?

I look forward to hearing from you!

Thanks so much!

--
Melissa Toporek OTD, OTR/L, BCP



Confidentiality Notice

The documents accompanying this transmission contain confidential patient information belonging to the sender that is legally privileged and is intended to remain confidential. This information is intended only for the use of the individual or the entity named above. The authorized recipient of this information is prohibited from disclosing this information to any other unauthorized party and is required to maintain privacy/security of the information or to destroy the information after its stated need has been fulfilled, unless otherwise required by law.

If you are not the intended recipient you are hereby notified that any disclosure, copying, distribution, or action taken with respect to the contents of this information is strictly prohibited by federal and state laws. If you have received this communication in error, we apologize for the inconvenience. We would appreciate you notifying us immediately by phone and either destroying the document or returning the original document to us by the US Postal Service at the above address.

MA T <mkeropot@gmail.com>
To: adanech mekonnen <adanechmek@yahoo.com>

Thu, Jun 16, 2016 at 3:17 PM

Wow! Ameseganshalo!!!

Gmail - from Melissa

8/25/16, 12:36 AM

On Thu, Jun 16, 2016 at 2:25 PM, adanech mekonnen <adanechmek@yahoo.com> wrote:

Dear Melissa,

How are doing? here we are fine. we missed you and the students. Melissa I believe you, since the work of the student is helpful you can come any time. for the guest house inform me the duration I will reserve for you all what we have.

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Adanech Mekonnen

On Thursday, June 16, 2016 3:16 AM, MAT <mkeropot@gmail.com> wrote:

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We hope to also have the kids photograph their lives at home and around the community (maybe this year or maybe another year) so we can compare their experiences between school, home, and community. We think the research may help you show how good the school is (and maybe help you get more funding) and also how important school attendance is for kids with intellectual disabilities. We would hope you could use the research to get more funding from the government or private foundations.

The photographs would NOT be published without consent of the families (or maybe not at all). The most important part is the child telling us WHY they took the photo so we can learn what is important to them.

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Thanks so much!

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Melissa Toporek OTD, OTR/L, BCP



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If you are not the intended recipient you are hereby notified that any disclosure, copying, distribution, or action taken with respect to the contents of this information is strictly prohibited by federal and state laws. If you have received this communication in error, we apologize for the inconvenience. We would appreciate you notifying us immediately by phone and either destroying the document or returning the original document to us by the US Postal Service at the above address.

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Melissa Toporek OTD, OTR/L, BCP



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Gmail - from Melissa

8/25/16, 12:36 AM

above address.

Appendix B**Confidentiality Agreement****CONFIDENTIALITY AGREEMENT****Title of Research Project:****Local Principal Investigator:**

As a member of this research team, I understand that I may have access to confidential information about study sites and participants. By signing this statement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study sites and participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.
- I understand that all information about study sites or participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information, unless specifically authorized to do so by approved protocol or by the local principal investigator acting in response to applicable law or court order, or public health or clinical need.
- I understand that I am not to read information about study sites or participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I agree to notify the local principal investigator immediately should I become aware of an actual breach of confidentiality or a situation which could potentially result in a breach, whether this be on my part or on the part of another person.

Signature

Date

Printed name

Signature of local principal investigator

Date

Printed name

Appendix C**Consent/Accent Forms**

Dear Volunteer,

Lead investigator Dr. Melissa Toporek, sociologist/translator Abebe Damtew Debay, and students Blake Lord, Janet Branch, Sidavann Monica Kem, from Stanbridge University in California, USA, want to know about activities you find meaningful. If you join us, you will take photos of activities in your school, home, and community which are important to you and we will talk about them together.

You may not want to answers some of the questions we ask you and that is OK. You do not have to answer any questions if you do not want to. You can stop at any time. Only we will know who you are because we are doing the research. You will miss some class or free time at school, and you'll spend some time at home and the community taking photos. If you do join us, at the end, you will get a photo album of all the photos we discuss, and you can keep it to remember this experience.

YOU DO NOT HAVE TO DO THIS IF YOU DO NOT WANT TO. Participating or not participating in the project will not affect your care, grades, or status at CMCC. If you join, you are also free to exit this study at any point, and nothing bad will happen.

We hope people will be happy to know what is important to you and it will help them plan good activities for you and other kids.

Thank you,

Dr. Melissa, Abebe, Blake, Janet, Monica



Dr. Melissa
mkeropot@gmail.com
0929289267



Abebe
abezdebay@gmail.com
0913266363



Blake bhlord13@gmail.com
Janet branchjanet@gmail.com
Monica smonicakem@gmail.com

GUARDIAN INFORMATION FORM**Why do we want your child to join?**

We want to know the activities your child thinks are important.

Who will join?

If your child is 10-16 years old, goes to CMCC, if you agree, and if your child agrees.

Does everyone have to join?

No. If your child wants to exit, they can, and nothing bad will happen.

Who will be at the interview?

Dr. Melissa, Abebe, Blake, Janet, Monica, and your child. If your child wants you or their teacher there, it is ok.

What will happen during the interview?

We will ask your child about the photos they took. They will say why they took the photo and why it is important. We will audio record the interviews so we can remember what they said. Abebe will translate because he understands Amharic and English.

What will happen to your answers and pictures?

Your child's answers and photos will be kept in a safe place. The answers will be analyzed and compared to look for common themes. Answers will be shared with Stanbridge University, CMCC, and used for other projects but their name will never be shared. The information from this research may help plan programs for your children and others like them around Ethiopia and other nations.

What are the risks?

The camera may get lost or stolen. Your child may feel uncomfortable talking to us.

Why is this project good?

Your child gets to show and tell us the things they think are important.

Will we be paid?

No

How will I know the results?

We will email results to Adanech Mekonnen at CMCC when they are ready. You can see them in her office by asking her. We may also tell about the results at professional meetings or publish in scientific journals. If you want a copy by email, please email Dr. Melissa at mkeropot@gmail.com .

GUARDIAN CONSENT FOR RESEARCH**Procedures:**

If I allow my child to join:

1. My child will borrow a camera to take photos of activities my child finds meaningful.
2. My child will talk about the photos to Dr. Melissa, Abebe, Blake, Janet, and Monica. They will say what the photo is, why they took it, and why it is important to them.
3. Cameras will be given back at the end.
4. My child will receive a photo book of some of the photos they took so they can remember the experience.

Risks/Discomforts

1. Your child may not want to answers some of the questions we ask, and that is OK. They do not have to answer any questions if they do not want to. They can stop at any time.
2. We will use the photos the take and record what they say, but no one else will know who they are. We will never tell anyone else their name or show photos of their faces.
3. Someone may try to steal the camera.

Benefits

There is no direct benefit to you or your child if you join us. Other people may learn what your children think is important and this may help to plan programs in the future.

Costs

Your child will miss about 3 hours of class time or free time at school so they can learn how to use the camera, practice, take pictures, and talk to us about the pictures. They will spend as much time as they choose at home and in their community taking pictures.

Payment

None

Questions

If you have a concern, please tell Dr. Melissa, Abebe, Blake, Janet, or Monica.

Consent

YOU DO NOT HAVE TO DO THIS IF YOU DO NOT WANT TO. Your child is free to exit this study at

any point, and nothing bad will happen.

My child can join.

Yes No

You can record my child's voice in the interview.

Yes No

My child can take photos, and you can use them.

Yes No

You can use the information my child gives during the interview.

Yes No

Printed name of child's Parent/Guardian: _____ Date: _____

Signature of child's Parent/Guardian: _____ Date: _____

Printed name of researcher: _____ Date: _____

Signature of researcher: _____ Date: _____

Signature/printed name of Witness: _____ Date: _____

PARTICIPANT INFORMATION FORM

Why we want you to join.

We want to know the activities you think are important.

Who will join?

If you are 10-16 years old, go to CMCC, if you agree, and if your guardian agrees.

Does everyone have to join?

No. If you want to exit, you can, and nothing bad will happen.

Who will be at the interview?

Dr. Melissa, Abebe, Blake, Janet, Monica, and you. If you want your guardian or their teacher there, it is ok.

What will happen during the interview?

We will ask you about the photos you took. You will say why you took the photo and why it is important. We will record the interviews so we can remember what you said. Abebe will translate because he understands Amharic and English.

What will happen to your answers and pictures?

Your answers and photos will be kept in a safe place. The answers will be shared with your school and used for other projects. We will never tell anyone your name.

What are the risks?

The camera may get lost or stolen. You may feel uncomfortable talking to us.

Why is this project good?

You get to show and tell us things you think are important.

Will I be paid?

No

How will I know the results?

We will email results to Adanech Mekonnen at CMCC when they are ready. You can see them in her office by asking her. We may also tell about the results at professional

meetings or publish in scientific journals. If you want a copy by email, please email Dr. Melissa at mkeropot@gmail.com.

PARTICIPANT ASSENT FOR RESEARCH

Procedures:

If I join:

1. I will borrow a camera to take photos of activities think are important.
2. I will talk about the photos to Dr. Melissa, Abebe, Blake, Janet, and Monica. I will say what the photo is, why I took it, and why it is important to me.
3. I will give the camera back at the end.
4. I will get a photo book of some of the photos I took so I remember the experience.

Risks and/or Discomforts

1. I may not want to answers some of the questions, and that is OK. I do not have to answer any questions if I do not want to. I can stop at any time.
2. Researchers will use the photos and record what I say, but no one else will know who I am. Researchers will never tell anyone else your name.
3. Someone may try to steal the camera.

Benefits

There is no direct benefit to me. Other people may learn what I think is important, and this may help to plan programs in the future.

Costs

You will miss about 3 hours of class time or free time at school so you can learn how to use the camera, practice, take pictures, and talk to us about the pictures. You will spend as much time as you choose at home and in your community taking pictures.

Payment

None

Questions

If I have a worry, I can tell Dr. Melissa, Abebe, Blake, Janet, or Monica.

Consent

I DO NOT HAVE TO DO THIS IF I DO NOT WANT TO. I am free to exit this study at any point, and nothing bad will happen.

I agree to join.

Yes No

You can record my voice while we talk.

Yes No

You can use the photos I take with the camera.

Yes No

You can use the information I say when we talk.

Yes No

Printed name of child: _____ Date: _____

Signature of child: _____ Date: _____

Printed name of researcher: _____ Date: _____

Signature of the researcher: _____ Date: _____

RESEARCH PARTICIPANT'S BILL OF RIGHTS

STANBRIDGE UNIVERSITY RESEARCH SUBJECT/PARTICIPANT'S BILL OF RIGHTS

Every person who is asked to be in a research study has the following rights:

1. To be told what the study is about and what will be measured;
2. To be told what will happen in the study and whether any of the procedures, drugs or devices are different from what would be used in standard practice;
3. To be told about important risks, side effects, or discomforts of the things that will happen to her/him;
4. To be told if she/he can expect any benefit from participating and, if so, what the benefits might be;
5. To be told what other choices she/he has and how they may be better or worse than being in the study;
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study;
7. To be told what sort of medical treatment is available if any complications arise;
8. To refuse to participate at all before or after the study is started without any adverse effects. If such a decision is made, it will not affect his/her rights to receive the care or privileges expected if s/he were not in the study.
9. To receive a copy of the signed and dated consent form;
10. To be free of pressure when considering whether s/he wishes to agree to be in the study

Independent Contact: If you are in some way dissatisfied with this research and how it is conducted, you

may contact the Stanbridge University Vice President of Instruction, Dr. Everett Procter:

eprocter@stanbridge.edu or +1 9497949090

x 5217

Appendix D

Itinerary

| Itinerary | |
|--------------------------|---|
| Monday, Nov. 21, 2016 | Arrival - settle into lodging |
| Tuesday, Nov. 22, 2016 | <p>Meet with school administrators, check understanding of consent forms, meet participants, and go over training protocols and schedule within the team</p> <p>Investigators journal</p> <p>Investigators discuss topics to reduce bias as a group</p> |
| Wednesday, Nov. 23, 2016 | <p>Investigators will train participants on mechanics of how to use the digital camera and take photographs of meaningful occupations in their homes, the community, and school (see Appendix E).</p> <p>Investigators will assign numbered cameras to participants (see Appendix H) to begin photography in home, school, and community settings.</p> <p>Investigators journal</p> <p>Investigators discuss topics to reduce bias as a group</p> |
| Thursday, Nov. 24, 2016 | <p>Participants continue to take photographs in their home, school, and community.</p> <p>Investigators journal</p> <p>Investigators discuss topics to reduce bias as a group</p> |
| Friday, Nov. 25, 2016 | <p>Participants continue to take photographs in their home, school, and community.</p> <p>Investigators will collect cameras close to the end of the school day, download the photos to clear memory card, and return cameras to participants to take photos over the weekend</p> <p>Investigators sort photos</p> <p>Investigators journal</p> <p>Investigators discuss topics as a group to reduce bias</p> |
| Saturday, Nov. 26, 2016 | <p>Investigators sort photos</p> <p>Investigators journal</p> <p>Investigators discuss topics as a group to reduce bias</p> |
| Sunday Nov. 27, 2016 | <p>Investigators journal</p> <p>Investigators discuss topics as a group to reduce bias</p> |

| | |
|-----------------------------|--|
| Monday, Nov. 28, 2016 | Investigators collect cameras, download, and sort photos participants took over the weekend Investigators choose photographs to discuss during interviews for the following day Investigators journal Investigators discuss topics as a group to reduce bias |
| Tuesday, Nov. 29, 2016 | Interview 3-5 participants, begin transcription Investigators choose photographs to discuss during interviews for the following day Investigators journal Investigators discuss topics as a group to reduce bias |
| Wednesday, Nov. 30, 2016 | Interview 3-5 participants, begin transcription Investigators choose photographs to discuss during interviews for the following day Investigators journal Investigators discuss topics as a group to reduce bias |
| Thursday Dec. 1, 2016 | Interview 3-5 participants, begin transcription Investigators choose photographs to discuss during interviews for the following day (if necessary) Preparation for presentation of photo albums Investigators journal Investigators discuss topics as a group to reduce bias |
| Friday, Dec. 2, 2016 | Interview remaining participants, if any Present photo albums to participants/families/school Investigators journal Investigators discuss topics as a group to reduce bias |
| Saturday, Dec. 3, 2016 | Depart Addis Ababa |

Tentative Itinerary of Data Collection and Data Analysis

Appendix E

Training Protocol

For each of the following, indicate where the button is for the particular function before demonstrating that function (one at a time).

Note: Investigators will use multisensory techniques such as talking, pointing, hand over hand assistance, and modeling to teach the use of specific buttons on the camera

1. Teach how to turn on and turn off the camera
 - a. Show demonstration
 - b. Have child practice and show return demonstration
2. Teach how to point the camera and take a picture
 - a. Show demonstration
 - b. Have child practice and show return demonstration
3. Teach how to take a picture with flash
 - a. Show demonstration
 - b. Have child practice and show return demonstration
4. Have the child go through all these steps independently by asking the following:
 - a. “How do you turn the camera on and off?”
 - b. “How do you take a picture?”
 - c. “How do you take a picture with flash?”
5. Teach what a dead camera looks like and how to change the battery
 - a. Show demonstration
 - b. Have child practice with a dead camera and show return demonstration
6. Teach what full memory looks like and how to change memory card
(Use a memory card that is almost full)
 - a. Show demonstration
 - b. Have child take photos until full and show return demonstration

Symbols on camera to be aware of: (may be different depending on camera)



On/Off button - Button will be on the top of the camera



Make sure this symbol is set when taking a picture



If this symbol is set, change it to Auto, as shown above

At the end of the training, investigators will ask the participant if they have any questions on how to use camera and answer all questions

After training of camera and questions, be sure to:

Tell participants to take photos in their school, home, and community of occupations they find meaningful.

Give examples to ensure understanding and will give personal examples if

necessary such as, "I really like to cook so I might take photos of the stove, the food, or the kitchen."

Be sure to verbally remind participants of practical safety concerns to prevent potential theft and bodily harm when using and transporting in public spaces such as:

- keeping the camera in a closed bag during transportation
- having a guardian with them when out in the community
- not using the wrist strap so that if someone attempts to rob them, they will not be injured by the strap or pulling on their arm
- informing participants that they will not have to pay for a lost or damaged camera and that they should not risk bodily harm to save the camera from theft or damage.

Explain the timeline of camera use and procedures including

- giving the cameras back to investigators periodically to download photos
- returning cameras permanently at the end of the data collection period

To adapt the camera, if necessary (on individual basis)

- place tape over buttons which should not be pressed
- tape the battery compartment closed for safety
- place colored tape as a visual cue to press correct buttons

How to change batteries on camera

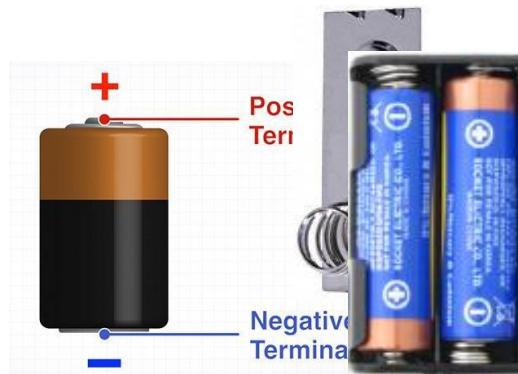
Change the batteries if you see a black screen during the day after turning the camera on.

Steps:

1. The battery cover will be at the bottom of the camera



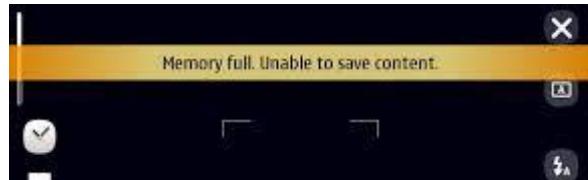
2. Slide the battery cover open and take out old batteries
3. Throw batteries away
4. Place new battery in the camera; the Negative end goes on the spring end and the Positive end without the spring. (Usually two batteries, each one going opposite direction)



5. Close the battery cover
6. Turn the camera on

How to change memory card

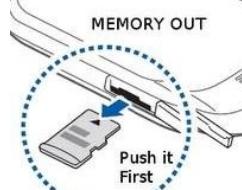
Memory card will be full if it says the photo cannot be saved as shown



1. The memory card slot will be at the bottom or side of the camera



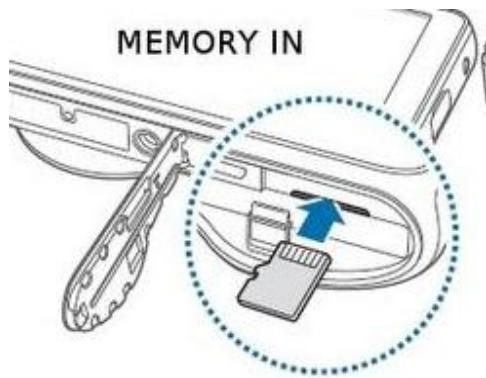
2. Press the memory card in and let go. The card will pop out.



3. Take out the full memory card

4. To Insert memory card

- a. Make sure each side is facing the correct direction to insert properly
- b. Insert in the correct orientation; otherwise, the camera will not recognize it.



5. Press until you hear a click and memory card is in place.

6. Close the cover

Appendix F**Interview Questions**

Primary open-ended interview Questions

- Why did you take this picture?
- What is this a picture of?
- Why is this picture your favorite?
- Why is this picture important to you?

Secondary interview questions.

- Can you tell me more about this picture?
- Why did you photograph this person?
- How does this picture make you feel?
- Who do you usually do this with?
- Where did you take this photo?
- When did you take this photo?
- What are they doing in this photo?

Clarification questions

- Did anyone tell you to take this picture?
- Did you take this picture?
- Did you want to take a picture but could not?
- Did anyone tell you not to take a picture?
- Who was with you when you took this picture?
- Who took this picture of you?

Appendix G

Operational Definitions

| Conceptual Variable: | Operational Definition |
|-----------------------------|--|
| Meaningful | Something that is significant and has purpose in someone's life |
| Multi-sensory | <p>Using all senses such as touch, sight and sound</p> <ul style="list-style-type: none"> ● example: using touch to press buttons on the camera, using sight to see where to focus the camera, and using sound to hear the sounds of the camera and follow the directions needed. |
| Occupation | <p>The act of being engaged in an activity that is central to a person's identity and sense of ability. An activity that has meaning and value to the person</p> <ul style="list-style-type: none"> ● examples: playing, cooking, cleaning, bathing, caregiving, being a student, working |
| Return Demonstration | An educational technique in which someone demonstrates what they have just been taught or demonstrated |

| Conceptual Variable: | Operational Definition |
|-----------------------------|--|
| Meaningful | Something that is important and makes someone happy. |
| Multi-Sensory | Using your eyes, ears, and fingers to use the camera. |
| Occupation | An interest, hobby, or job that makes you who you are. |

Appendix H**Camera assignment List**

| Camera Number | Participant Name |
|----------------------|-------------------------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |
| 5 | |
| 6 | |
| 7 | |
| 8 | |
| 9 | |
| 10 | |
| 11 | |
| 12 | |
| 13 | |
| 14 | |
| 15 | |