Examining The Lived Experiences Of Families Who Have Adopted Children And Received Occupational Therapy Services

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EXAMINING THE LIVED EXPERIENCES OF FAMILIES WHO HAVE ADOPTED CHILDREN AND RECEIVED OCCUPATIONAL THERAPY SERVICES

By

David F. Simpson

Thesis Approved:

[Signatures]

Chair, Advisory Committee

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EXAMINING THE LIVED EXPERIENCES OF FAMILIES WHO HAVE ADOPTED CHILDREN AND RECEIVED OCCUPATIONAL THERAPY SERVICES

By

David F. Simpson

Master of Science
Eastern Kentucky University
Richmond, Kentucky
2016

Submitted to the Faculty of the Graduate School of Eastern Kentucky University in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE August, 2016
DEDICATION

This thesis is dedicated to my wife
Heather Simpson
for her unwavering support.
ACKNOWLEDGMENTS

I would like to thank my thesis chair professor, Dr. Julie Baltisberger, for her guidance and patience. I would also like to thank the other committee members, Dr. MaryEllen Thompson and Dr. Leslie Hardman, for their support and assistance over the past year. I would like to express my thanks to my wife, Heather, for her understanding and patience during those times when there was no light at the end of the tunnel. She encouraged me and made me stick with it.
Abstract

**Purpose:** This qualitative descriptive study focused on the experiences of families who have adopted children from different countries and placed them in occupational therapy services.

**Method:** Three different sets of parents were interviewed to gather data on the adoption process and on their experiences with receiving services from an OT. Each interview was conducted either with one or both parents present. Only one interview was conducted with each family.

**Discussion:** While families often have quality experiences working with an OT and observe improvements in their children, some families do not receive quality services. This is due to lack of communication with the OT and the inability of the parents to give input on activities completed in therapy. Implementing family-centered and client-centered therapy increases the effectiveness of OT skills and improves client and caregiver satisfaction.

*Keywords:* lived experiences, adoption, occupational therapy, family impact
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CHAPTER 1

Introduction & Literature Review

Background & Need

This thesis seeks to explore the lived experiences of families who have adopted children internationally and have required Occupational Therapy (OT) services for their children once they return to the United States. Several studies have explored the experiences of families who participate in international adoption but few explore specific aspects of the adoption and how the children may benefit from OT services. This study will focus on both the quality and poor experiences from the perspective of the adoptive parents.

Grand question: What is the lived experience of a family with a child who has been adopted and required OT services?

Sub Questions: How does the family member describe his or her interactions with the occupational therapist?

How have occupational therapy services influenced the family’s daily life?

What is the quality of care experienced by the family?

How does the duration of treatment influence the family’s daily life?

Introduction

For many families in the U.S., starting a family can be difficult, so they often choose to proceed through the process of adoption. Adoption is the statutory process by which a new parental tie with an adoptive parent is established, after a child’s ties to his or her biological parents have been permanently severed (Seaton, 2008). These ties are severed for different reasons, but it ultimately leaves the child without a family and a
place to call home. In the end, adoption creates a parent for a child who needs one and a parent provides protection for children who otherwise have none (Reitz, 2013).

**History of Adoptions**

The United States is now known as the largest "importer" of foreign-born children, having brought in nearly a quarter of a million children for adoption in just over a decade. The "sender" nations have generally shifted with the political, social, and economic winds of the time, as negative conditions abroad made more children available for adoption (Gossett, 2013). Families in the U.S. often choose to take the journey of intercountry adoption, or adopting a child from another country. In fact, the U.S. is the largest receiver of intercountry adoptees with 9,319 in 2011 (High, 2014). In past decades, international adoption has become a global phenomenon involving cross-border movement of vulnerable children, mainly from poor, underdeveloped countries to wealthier countries (Misca, 2014).

Domestic or international, the placement of a child with a family who wants to and can care for that child, is the best thing we can do for a child who otherwise will not have a family (Reitz, 2013). Often children sit in orphanages or children’s homes and wait there for an extended period of time. International adoption is critical and can play an important role to children’s rights to early, permanent and nurturing parents (Bartholet, 2011). Having a permanent family with nurturing parents will improve and sustain the child’s development and ensure that they are properly cared for.

One goal of Healthy People 2020 is to reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles to 0 persons 21 and under (Johnson & Kastner, 2005). This would encompass children in
orphanges and children’s homes and would encourage them to decrease in size and not become a permanent location for the children. Special needs children often fall into this category because they are overlooked and not deemed meaningful or important. According to Seaton (2008), a “special needs” child is one who has a physical or mental handicap. Due to the vast number of special needs children in the adoption care network, the number of families who are willing to adopt them are inadequate (Seaton, 2008).

The Adoption Process

The adoption process can be long and tenuous and families adopt for a variety of different reasons. There are three types of adoption processes that families can choose, which are adoptions through foster care, private domestic adoption, or international adoption. The most common reason couples adopt is due to infertility (Karim & Welti, 2010). While it is sometimes easier and quicker to adopt through foster care or private domestic, international adoptions have grown in number and continue to be on the rise.

The first step of the international adoption process is identifying with an adoption agency, deciding if special needs adoption is an option, and getting connected with an orphanage overseas. Choosing the country is also important because that will determine the qualifications and specific adoption policies of each country. While international adoptions are increasing in popularity, placements are difficult because children cannot live with the parents prior to coming to the U.S. (Hegar & Watson, 2013). When the parents are able to go overseas, they are either able to take the child home immediately or must stay in the country for an extended period of time. This is detrimental to the child and the family because they are unable to form a bond prior to coming to their new home together and must start connecting in a new environment, which is unfamiliar to the child.
This process puts them immediately into a new situation and forces the families to adapt and learn the effects the child faces from being isolated in an orphanage or children’s home.

Persisting effects of early deprivation on social-emotional, activity level, and behavioral organization is evident once the child comes home to the U.S. (Kadlec & Cermak, 2002). They are often deprived because they are placed in an environment overseas where there are too many children and not enough workers or volunteers to give them attention or love. Typically longer institutionalizations produce greater lasting negative effects on the child (Kadlec & Cermak, 2002). The deprivations do not necessarily increase but prolonged deprivation is the main contributing factor. Maternal and environmental deprivations result in delays in physical, emotional, social, and intellectual development (Cermak & Groza, 1998). Maternal deprivations exist because the children do not have a maternal figure in their life for some time. They experience environmental deprivations due to being secluded and isolated in an orphanage or children’s home for a significant portion of their life.

**Adoption Experiences**

Special-needs adoptions are recognized as challenging to adoptive parents and families (McGlone, Santos, Kazama, Fong, & Mueller, 2002). Adoption is often harder than the families expect because they are given little to no information prior to the adoption being finalized (McDonald, Propp, & Murphy, 2001). This is due to the adoption agency or adoption center having little information on the child. International adoptions also present more risk factors than adoptions through foster care or private domestic organizations (Hegar & Watson, 2013). It is risky working with international
organizations—other countries always have the right to deny the adoption finalization once the family is in the country. However, those children who can be adopted internationally can and do thrive in their adoptive countries (Misca, 2014).

Adoption is a complicated and emotional process that affects the entire family (Ku, 2005). There is a long list of paperwork to complete and it is a long waiting game, which can end up taking its toll on all members of the family. Families who are successful describe the process as including high levels of social supports and low psychological distress (Welsh, Viana, Petrill, & Mathias, 2008). Permanency in a “forever home” is essential for the adoption process (Barthollet, 2011). Ensuring that the child will be in their adoptive home permanently gives the child security and hope for a positive future. This security also helps the child fit into the already established family dynamic and they help contribute positively to the family’s life (McDonald, Propp, & Murphy, 2001).

There are also various experiences and program supports that are essential in order for adoptive families to be successful. Health care experiences occur almost immediately upon the family’s arrival back into the U.S. and can either support or hinder the child’s well-being. Parents stress that there are unique health care needs of international adoptive families and it is important to have the support of health care providers (Smit, 2010). Working with institutionalized children who have been adopted is a different experience for health care professionals working with them and they must be educated on how to properly manage their care. Health care providers who work with such families may include doctors, therapists, and social workers, and all of them must be familiar with the internationally adopted population. Educational programs for
transracial families are also important to consider (Ku, 2005). Children who are adopted from Asia, Africa, or the Middle East often have noticeable skin differences from their adoptive parents, which may pose issues for them as they get older. Their parents must be able to adequately describe their cultural differences and prepare them for questions they may receive from their peers. Lastly, children who are adopted may have attachment difficulties and may have attachment disruptions. The most effective treatment for this is Child Parent Relationship Therapy (Carnes-Holt & Bratton, 2014). This helps the child cope with their attachment difficulties and learn to self-regulate so they do not act out and cause disruptions. Overall, these program supports can help the adoptive child and the family cope with their life as a new family unit.

Conclusion

Adoption can be an overwhelming but satisfying experience both for the child and for the adoptive family. Children who are adopted often experience environmental disruptions such as shifts in language, culture, lifestyle, diet, and educational regimen (Hegar & Watson, 2013). The most useful resource these families have at their disposal are health care providers. Health care providers must be aware of the unique experiences afforded to adoptive families (Smit, 2010). They have to be aware of their situation and well-versed in working with institutionalized children in order to be successful. There is a lack of evidence-based practice for interventions best suited to the needs of children post-international adoption (Misca, 2014), so this was the direction taken for this study.
CHAPTER 2

Journal Manuscript

Introduction

International adoption is a growing area of interest for families in the U.S. who are seeking to grow their family through the adoption process. Each family has experiences that are specific to their family, and the impact of adoption is different for each of them. The experiences of each family are important to describe and interpret in order to build a foundation on the knowledge base already in place of international adoption experiences.

Methods

A qualitative research framework was used for this study in order to understand the experiences of families who have adopted and placed their children in occupational therapy services. The approach used for this study was qualitative description, which is describing a phenomenon in detail and recording the different aspects of the phenomenon. This study was designed to identify the experiences of families in the context of international adoption (Sandelowski, 2000).

Sample

Three families, with parents aged 20-60, were recruited as participants for this study. Inclusion criteria were (1) legal guardians of at least one child who has been adopted domestically or internationally, (2) parents of children with special needs, (3) child has received or is currently receiving occupational therapy services. Exclusion criteria were (1) participants do not speak English as their first language or (2) have
hearing or cognitive deficits. Gender, ethnicity, and health status were not relevant to this study.

Sample Selection

Participants were identified either through a flyer that was posted around EKU and/or posted in local churches or by snowball sampling to identify adoptive families who may be familiar with one another. A telephone script or verbal recruitment script was given to a potential participant if interested. Once the participants were recruited, the Principal Investigator (PI) identified if they followed the inclusion criteria and did not follow the exclusion criteria. Written consent was obtained through the use of an informed consent form approved by the Institutional Review Board (IRB) at Eastern Kentucky University.

Data Collection

The IRB approved the study before any data was collected. Semi-structured interviews were conducted with each of the participants. Either one or both parents were present at the time of the interview. The interviews were conducted either over the phone or in person. Up to three separate interviews were administered so more depth is available and a member check can be completed. Each of the interviews were audiotaped for the purpose of transcription later in the research process. The interviews lasted between 30 minutes to one hour.

Data Analysis

Once each the interviews were complete, they were transcribed verbatim using Hyper Transcribe software. Each interview was transcribed individually and once it was complete, the researcher re-read each transcription before the data was analyzed. Data
was analyzed using Hyper Research software. Each of the transcriptions was coded to find important phrases and key terms and then the codes were collapsed to find major themes across all three interviews. During the process of data analysis, peer debriefing was completed when the researcher discussed the findings with the faculty advisor for the project. Overall, this software for data coding was selected because it was easy to use and understand and compiled all of the data in one program, making it convenient to use for research purposes.

**Results**

The results of the data provided information that allowed the researcher to describe experiences of each of the participants with the adoption process and the therapy process. The following results were divided into categories based on the country the participants adopted from and each category describes the family’s experiences before adoption, during adoption, and after adoption. Furthermore, five major themes developed from the data collection and included (1) paper pregnancy, (2) living situations, (3) barriers to OT, (4) interactions with practitioners, and (5) impact of adoption on the family.

**Participant Characteristics**

**Russia**

The first interview was with a mother whose family had adopted a child from Russia. The child that was adopted from Russia was 19 months old at the time of the adoption and is diagnosed with Down syndrome. Before the adoption process began, his parents were part of a Down syndrome list serv and became connected with various organizations, one of which was an adoption agency. They found an agency in California
and once they decided to continue in the adoption process, they received a picture and immediately knew the boy was their son.

During the adoption process, the parents had to travel to multiple airports in Russia and make a very long drive through the country in order to reach the orphanage. Along the way, they had to exchange money with men with machine guns, which was a very humbling experience for both parents. The mother stated that it was the most intimidating experience of her life but she was willing to do anything in order to reach her son. The orphanage their son was in was very full, containing almost 600 children.

In the interview, the mother stated that he was the first child adopted from that particular orphanage in Russia. Before they left the country, they were asked to do a T.V. interview with a local news station as the adoption was very popular and noticeable in the country. The news anchor was confused as to why they would want a child in this condition, but the parents reassured her that he was meaningful and important to them and they were going to take him back home to the U.S.

After they returned home, the son had to have double digit surgery. He was born with two thumbs on one of his hands and he had to have it removed in order to have functional abilities of his hand. The recovery process took some time but once he was healed, they were referred to a private practice for occupational therapy. The skills that the therapist worked on with him were handwriting, different grasps, and bilateral coordination. Unfortunately, this family had more bad experiences than good with the overall therapy process.
China

The second interview involved a family who had adopted from China. They adopted two girls from China when they were six and seven years old and both are diagnosed with cerebral palsy. Before the adoption process, the family had previously adopted domestically, so they were familiar with adoption and wanted to try to adopt internationally the second time. The paperwork process for them to adopt the girls was described as a long and tedious process.

During the adoption process, the family was in China for approximately two weeks before they were able to bring the girls home. The orphanage they were in was structured like a large complex with a nursing home on one side, an orphanage on the other side, and a medical complex in the center. The girls both received physical therapy services in the medical complex from therapists who came in from different countries but neither of them had OT services when in China.

Once they brought them home, they started OT after receiving a recommendation from a pediatrician, but their insurance ran out, so they were dropped from the OT list. The skills they worked on in therapy were cutting, writing, and completing puzzles. The mom stressed that both girls crave sensory input because they were not held or received much attention when they were infants. Overall, the mom was not impressed with the OT services the girls have received.

Uganda

The final family involved in this study adopted two children from Uganda and the interview was completed with both parents present. The parents adopted a boy and a girl from Uganda when they were both three years old. The boy was diagnosed with seizure
disorders and the girl was diagnosed with neurofibromatosis. Before they were adopted, the parents received a referral after researching different adoption agencies and then they raised support. They researched the requirements for adoption both for Uganda and for the U.S. so they could ensure everything was in order and the process would go smoothly.

During the adoption process, they had to wait about five weeks after arriving in Uganda to receive a court date. The judge had to sign their adoption papers but the process was very slow and all the family could do was wait. The children’s home where they adopted from had about 50-60 children total. There was one “head momma” in charge and there were several other women under her who kept an eye on the children during the day. Once the judge eventually signed the papers, they made the long journey home.

After they returned to the U.S., they placed both children in speech therapy since they couldn’t speak English. Eventually they were referred for occupational therapy services. Their daughter only had OT services for one year but their son currently receives services. The skills that the OT worked on in therapy were motor planning, sequencing, and following directions. Both children were only placed in school OT services due to financial constraints of the parents.

Themes

After all of the interviews were completed, the researcher compiled the information that was provided into five major themes: paper pregnancy, living situations, barriers to occupational therapy practice, interactions with practitioners, and impact of adoption on family.
Paper Pregnancy

Paper pregnancy was the first theme because each family had to deal with a long paperwork process, which took about as long as an actual pregnancy. The first mother said “when you’re called and your paperwork is approved you go back for the second time.” Not only did the paperwork take a long time to complete, they had to make multiple trips to the country. The second mom said “after a very long paper pregnancy, which takes about as long as an actual pregnancy in China…” The steps to adopt a child from China proved to be a long and tedious process. Lastly, the third mom said “we searched the requirements in the states in order to bring home children. So paperwork, paperwork, and then waiting for the U.S. to okay it and then for Uganda to okay it.” Steps had to be taken in both countries and there were chances the approval process will be halted with any slight discrepancies in the paperwork.

Living Situations

The next main theme that arose from the data was the living situations of each of the children. The first mom stated that in Russia they had “an orphanage that has what they say are neurological disorders. In this particular orphanage, they said there was about 600.” With so many children in the orphanage, there was not a lot of room to move about and develop normally. The second mom stated that in China, there was a general type dorm setting within the orphanage, where one of her daughters was her entire life. The other daughter was in a foster home within the orphanage for some time. The third mom said “they lived in a children’s home that cared for I think about 50-60 children. Most of them were age 5 and under.”
Barriers to Occupational Therapy Practice

While there were many barriers to OT, the main barrier was insurance problems. The first mom said “Unfortunately for many people, insurance is a factor so we’ve had to go the private route and just pay out of pocket for different services.” The second mom said “we had a problem with our insurance running out and so we got dropped from the list.” The third mom said, “We got tested for speech therapy through the school system because our insurance doesn’t cover that, but you can get it for free through the school system...”

Interactions with Practitioners

Interactions with practitioners, specifically occupational therapists, was also a major theme. The first mom said “When they were little, there was a huge problem because it was all the early intervention and we were assigned to an OT that was horrible.” The second mom said “I wasn’t terribly impressed with our therapist. She mainly had them cutting and writing their name.” The third mom said “I mean it’s never been bad. It’s not been like, oh I don’t like you or you’re not doing your thing.”

Impact of Adoption on Family

The final theme was the impact adopting a child has had on the entire family. The first mom said “I thought I was gonna teach them everything and the short of it is they have taught me everything.” The second mom said “I found they love movement. They swing in their room and I try to reach out to them and just touch her frequently so she knows we’re here basically.” The third mom said “I think just like having to think about the fact that what comes naturally to my other kids does not come naturally to my adopted son and daughter.”
Discussion

The findings of this study provided an insightful understanding into the experiences of families who adopt children internationally and place them in OT services. The following discussion follows the establishment of the five major themes for this study.

Paper Pregnancy

Paperwork is an integral part of the adoption process and it is imperative that it is completed accurately and efficiently to ensure the adoption process runs smoothly. If there are any mistakes in the process, the adoption can be delayed for some time. Since it is a lengthy process anyway, it is important that everything is in order so there is no additional delay. McDonald, Propp, & Murphy (2001) stated that many adoptive parents are dissatisfied with the speed of adoption. It is up to the adoptive country and the U.S. to approve and sign off on the adoption of a child, so ensuring that the paperwork is done accurately will speed up the adoption and please both the parents and the child.

Living Situations

The living situations of children who are adopted usually consist of an orphanage or children’s home. The environment is not always ideal as some places are overflowed with children and there is not adequate space for them to navigate around their environment, which can impair them socially, emotionally, and developmentally. Cermak & Groza (1998) stated that orphanages often have inadequate developmental interaction and stimulation for the children in the environment. This causes children to develop issues with development as well as sensory issues that can negatively impact their lives if not addressed. It is the role of the occupational therapist to develop
interventions to correct these issues caused by their previous living situations so they can have a quality lifestyle.

**Barriers to Occupational Therapy Practice**

Based on the results of this study, the main barrier to OT is insurance problems. Hegar & Watson (2013) stated that parents have financial barriers to health care and difficulty locating and accessing specialized and culturally appropriate services. All of the families had problems with their insurances and pushed them in separate directions for therapy. The families received OT services from a private practice, outpatient clinic, and the school system. Each of these families were still able to receive services eventually, but had to maneuver around the barriers that appeared due to insurance problems.

**Interactions with Practitioners**

It is important that families who have adopted children internationally are able to connect with practitioners who can modify their child’s environment and set them up for success. The first practitioner that the families will most likely interact with is a pediatrician. Johnson & Kastner (2005) state that a pediatrician should be familiar with the principles of permanency planning. They can be educated on how to handle these clients and know how to give them the medical care they need. They can also refer the parents to other services like occupational therapy. Two of the families had negative therapy experiences while the other family had a mediocre experience. The family who adopted from Russia said their therapist was very “by the book” and would not listen to the desires and interests of the family. She even covered up the play equipment in the therapy gym with sheets so the child would not see it and be distracted. The mother who
adopted form China also had a poor experience with a therapist who would not take her suggestions into consideration. She mainly had them cutting and writing their name, which are both skills the mother already works on at home with the girls. The parents who adopted from Uganda said they have never had an exceptional experience with a therapist and no experiences that have caused any alarm.

**Impact of Adoption on the Family**

All of the families stated that their lives have been positively affected by the adoption process. Although it was a long journey, they all stated that they would not change anything for the world. They are all very grateful that they chose to go the route of adoption. Each child that was adopted became an addition to the families and made them more complete than they ever thought was possible. This is important information for families who may consider adoption in the future because it shines a light on the positive effects of adoption and encourages families that there may be bumps in the road, but with the proper resources and support, anything is possible.

**Limitations**

There were several limitations to this study. One limitation was the quality and type of interviews that were completed. First, the parents were only interviewed once. It may be beneficial to interview them more than once across an extended period of time to gather data on the long term effects of occupational therapy services for the adopted children. Second, only one of the interviews was conducted with both parents. It would have been helpful to have both parents present for both interviews so different perspectives and experiences can be shared. Third, the siblings and other family members were not included in the interview process. Often siblings can be the best
therapists and including their thoughts and opinions concerning the adoption process could have helped this study become more family-centered. Another limitation for this study was the goals of the parents were not obtained. This would have provided useful information into the history of the families and help gauge if the families feel their children have made progress. One other limitation to this study was the children were not interviewed or observed. This would be helpful to gain direct observational evidence on the status and progress the children make during therapy.

**Future Research**

Given the findings, there are some recommendations for future research that could assist other adoptive parents complete the process more fluidly. These include education of occupational therapists encouraging family-centered practice, and interacting with children on their level. OTs should be educated more about working with institutionalized children so they can better serve them during therapy and future research needs to be done about the skills OTs must possess in order to do so. Family-centered practice is also important so the therapist can learn to take the parents’ suggestions into consideration and future research could study the effectiveness of family-centered practice for therapists working with the parents of institutionalized children. Lastly, interacting with children on their level is important so they are more engaged and willing to participate in therapy. Future research needs to be conducted on proper practices for working with the pediatric population and how to interact on their level instead of going by the book and following strict guidelines.
References


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Appendix A:
IRB Approval
Institutional Review Board
Application for Expedited/Full Review

1. Title of Project:
Examining the Lived Experiences of Families Who Have Adopted Children and Received Occupational Therapy Services

2. Principal Investigator/Faculty Advisor:
Principal Investigator Name: David Simpson
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Faculty Advisor (required if PI is an EKU student): Dr. Julie Baitsberger, PhD, OTR/L

3. Other Investigators: Identify all other investigators assisting in the study. Attach additional pages if needed.
Name: ______ Authorized to obtain consent? ☐YES ☐NO
Responsibility in Project: ______
Name: ______ Authorized to obtain consent? ☐YES ☐NO
Responsibility in Project: ______
Name: ______ Authorized to obtain consent? ☐YES ☐NO
Responsibility in Project: ______

4. Study Period of Performance: upon IRB approval through 12/12/2015
Note that research may not begin until IRB approval has been granted.

5. Funding Support: Is the research study funded by an external or internal grant or contract?
☐NO ☐YES
Funding Agency: ______
Copy of funding application narrative attached? ☐YES (required if study is funded)

6. Risk Category:
☒Not greater than minimal risk. Minimal risk means, “The probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical, dental, or psychological examination of healthy persons.”
☐Greater than minimal risk, but of direct benefit to individual participants
☐Greater than minimal risk, no direct benefit to individual participants, but likely to yield generalizable knowledge about the subject’s disorder or condition
☐Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of participants

7. Type of Review: ☒Full Review (skip item #8 below) ☒Expedited Review (complete item #8 below)

8. Expedited Review Categories: If the proposed study represents not greater than minimal risk, and all activities fall within one or more of the categories below, the study is eligible for expedited review. Please check all applicable categories of research activities below.

1) ☐ Clinical studies of drugs and medical devices only when condition (a) or (b) is met.
   (a) ☐ Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.)
   (b) ☐ Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

2) ☐ Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:
(a) From healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or
(b) From other adults and children considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

3) ☐ Prospective collection of biological specimens for research purposes by noninvasive means. Examples: (a) Hair and nail clippings in a nondisfiguring manner; (b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction; (c) permanent teeth if routine patient care indicates a need for extraction; (d) excreta and external secretions (including sweat); (e) uncannulated saliva collected either in an unstimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue; (f) placenta removed at delivery; (g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor; (h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques; (i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings; (j) sputum collected after saline mist nebulization.

4) ☐ Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.) Examples: (a) Physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy; (b) weighing or testing sensory acuity; (c) magnetic resonance imaging; (d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography; (e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

5) ☐ Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)

6) ☐ Collection of data from voice, video, digital, or image recordings made for research purposes.

7) ☐ Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

8) ☐ Continuing review of research previously approved by the convened IRB as follows:
(a) ☐ Where (i) the research is permanently closed to the enrollment of new subjects; (ii) all subjects have completed all research-related interventions; and (iii) the research remains active only for long-term follow-up of subjects; or
(b) ☐ Where no subjects have been enrolled and no additional risks have been identified; or
(c) ☐ Where the remaining research activities are limited to data analysis.

9) ☐ Continuing review of research, not conducted under an investigational new drug application or investigational device exemption where categories two (2) through eight (8) do not apply but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.
9. Background:
   a. Provide an introduction and background information for the study and provide a discussion of past research findings leading to this study. Cite literature that forms the scientific basis for the research.

   The focus of my project will be on the lived experiences of families who have adopted children and placed them in occupational therapy services (OT). OT uses occupation, or everyday life activities, to improve the daily lives of individuals, and in this case these skilled services are applied to children who have been adopted. Areas of occupation that may be addressed in an intervention session with an adopted child may include activities of daily living, instrumental activities of daily living, play, and social participation. Some of these children may come from abusive or neglectful environments and may have limitations physically and socially, which is where OT services can step in and help modify the environment so it is more conducive to their needs.

   There have been many studies conducted on children who have been adopted but few focus on the lived experiences or the long-term effects of therapy on the child. Carnes-Holt and Bratton (2014) conducted a study that examined the effectiveness of child parent relationship therapy with 61 adopted families. While their study was effective, a limitation was it only revealed the immediate effects of the treatment and didn’t examine the child or family long term. Another study conducted was a preliminary investigation of the effectiveness of attachment therapy for adopted children with reactive attachment disorder. Wimmer, Vonk & Bordnick state that while their study was successful, the positive results highlight the need for further research in order to evaluate the long term outcomes of attachment therapy (2009). One other study examined the use of a family systems theory and theraplay to treat adoptive families. Weir, Lee, Canosa, Rodrigues, McWilliams, et. al. (2013) stated that their study did examine post-treatment data or do any follow-ups with the participants.

   Problem Statement: There is a lack of research on the role OT plays on the experiences of families who have adopted and my research will expand on this literature and try to fill in the gap.

   Purpose Statement: The purpose of this phenomenological study will be to describe the lived experiences of families who have adopted children and required OT services as a form of rehabilitation.


10. Research Objectives:
   a. List the research objectives.

   The research objectives include learning more about the adoption process, the specific therapy services that are provided for families who have adopted a child, and the lived experiences of families who have adopted and utilized therapy services.

   Grand question: What is the lived experience of a family with a child who has been adopted and required OT services?

   Sub questions: How does the family member describe his or her interactions with the occupational therapist? How have occupational therapy services influenced the family's daily life? What is the quality of care experienced by the family? How does the duration of treatment influence the family's daily life?
11. Subject Population:
   a. What criteria will be used to determine the inclusion of participants in the study?

   Participants must be the legal guardians of at least one child who has been adopted domestically or internationally, has special needs, and has received or is currently receiving occupational therapy services. The children must be currently utilizing OT services or have received services in the past 6 months that lasted at least 1 year.

   b. What criteria will be used to determine the exclusion of participants in the study?

   Participants who do not speak English well or have hearing or cognitive deficits may be excluded from the study as they may contribute data that cannot be properly analyzed.

   c. Anticipated Number of Participants (maximum): 3

   d. Age Range of Participants: 30-60

   e. Gender of Participants: □ Male □ Female or □ Gender not relevant to study

   f. Ethnicity of Participants: □ or □ Ethnicity not relevant to study

   g. Health Status of Participants: □ or □ Health status not relevant to study

   h. Which of the following categories of subject will be included in the study? Please check all that apply.

   1. □ Adult Volunteers
   2. □ College Students age 18 and older
   3. □ Minors (under age 18) – attach Form M
   4. □ Pregnant Women (other than by chance)
   5. □ Fetuses/Neonates
   6. □ Hospital Patients
   7. □ Patients at Inpatient Mental Health Facilities
   8. □ Decisionally-Impaired Individuals – attach Form I
   9. □ Institutionalized Decisionally-Impaired Individuals – attach Form I
   10. □ Prisoners – attach Form P
   11. □ Other – Please Describe:

12. Project Location:
   a. Where will the study take place?

   The study will take place either over the phone, over Skype, or in person at Eastern Kentucky University or at a location that is convenient to the participant.

   b. If the study will take place at a location other than EKU, attach a letter from an authorized representative of the organization granting permission to use facility for research purposes.

   □ EKU only □ Letter(s) attached

   c. Will any data be collected through organizations other than Eastern Kentucky University?

   □ No □ Yes, complete the following:

   * Will personnel of the organization be involved in the data collection process or have access to data after collection? □ No □ Yes - If yes, list personnel on page 1, include copies of CITI completion reports, and define role here: ______

13. Recruitment of Participants:
   a. How will prospective participants be identified for recruitment into the study?
Participants will be identified either through a flyer that is posted around EKU and/or posted in local churches. Snowball sampling may also be used since adoptive families often know each other.

b. Describe the recruitment procedures to be used with potential participants.

A telephone script or verbal recruitment script will be given when a potential participant is interested. Once the participants are recruited through the flyer or one of the scripts, the researcher will identify if they follow the inclusion criteria and do not follow the exclusion criteria. My contact information will be placed on the flyer so anyone that is interested may contact me and I can answer any questions they have.

c. Recruitment materials to be used: Check all that will be used and attach copies: □None □Advertisement, □Flyer, □Telephone Script, □Verbal Recruitment Script, □Cover Letter, □Other:

14. Ensuring Voluntary Participation
a. Who will be responsible for seeking the informed consent of participants?

The researcher will be responsible for seeking the informed consent of the participants.

b. What procedures will be followed to ensure that potential participants are informed about the study and made aware that their decision to participate is voluntary?

The potential participants will be informed about the study and made aware of their decision to participate in the study through informed consent. Informed consent will be reviewed at the beginning of the research process before any data or information is gathered.

c. How will consent be documented?

A written informed consent form will be printed and the participant will sign the document to ensure that they understand the study and are willing to participate.

d. What consent documents will be used in the study? (Attach copies of all). □Informed Consent Form, □Parent/Guardian Permission Form, □Child/Minor Assent Form, □Oral Script, □Other:

15. Research Procedures
a. Describe in detail the research procedures to be followed that pertain to the human participants. Be specific about what you will do and how you will do it. If applicable, differentiate between standard/routine procedures not conducted for research purposes from those that will be performed specifically for this study.

The researcher will conduct a semi-structured interview with the participant, which will be either one parent or both parents if they are both able to be present at the time of the interview. The interviews will be either over the phone or in person. Up to three interviews will be administered so more depth is available if needed and a member check can be completed. Each of the interviews will be audiotaped for the purpose of transcription later in the research process. The interviews will last between 1-2 hours.

The participant will be asked questions regarding their adoption and related questions to identify their experiences with the adoption process. Potential questions include: “Can you describe the adoption process? When did it occur and what did it look like?”, “What made you decide to pursue OT services for your child?”, “How long has your child been receiving OT services? How long do the sessions usually last?”, “What skills/activities does the OT do with your child?”, “How would you describe your interactions with the OT?”, “How have OT services influenced your family’s life?”

16. Potential Risks
a. Describe any potential risks—physical, psychological, social, legal, or other.
There may be some potential risks regarding the participant’s psychological health. Discussing the adoption may be difficult and cause bad memories to resurface if they had a bad experience.

b. What procedures will be followed to protect against or minimize any potential risks?

In order to minimize potential risks, the researcher will not push the participant to answer any questions they perceive to be difficult or probe further on questions that make the participant extremely emotional or overwhelmed.

c. How are risks reasonable in relation to the anticipated benefit to participants and in relation to the importance of the knowledge that may reasonably be expected to result?

The risks are reasonable because it is necessary to obtain this information for the study and it may benefit the participants psychologically if they are able to verbalize and talk through their experiences.

d. Will alternative choices be made available to participants who choose not to participate?

☐ No ☐ Yes, Describe: ___

17. Incentives and Research Related Costs

a. Will incentives be offered to participants? ☒ No ☐ Yes, complete the following items:
   1) What incentives will be offered?
   2) If monetary compensation will be offered, indicate how much the participants will be paid and describes the terms of payment. _____
   3) Describe the method of ensuring that the incentives will not compel individuals to agree to participate in the study. _____
   4) Describe how the incentives will be funded. _____

b. Will there be any costs to the subjects for participating? ☒ No ☐ Yes: Describe any costs that would be the responsibility of the subjects as a consequence of their participation in the research. _____

18. Research Materials, Records, and Confidentiality

a. What materials will be used for the research process? Include a description of both data collected through the study as well as other data accessed for the study.

The materials that will be used for the research process is a digital recorder, which will record the interviews that will be used for the study.

b. Who will have access to the data? If anyone outside the research team will have access to the data, provide a justification and include a disclaimer in consent documents.

Only the researcher and the faculty advisor will have access to the data.

c. Describe how and where research records will be stored. Note that all research-related records must be maintained for a period of three years from the study’s completion and are subject to audit. Following the completion of the study and throughout the records retention period, student research records must be maintained by the faculty advisor who signs the application.

The electronic recordings of the interview will be kept on a secure file on the computer and the paper transcriptions will be stored in a locked file cabinet.

d. How will data be destroyed at the end of the records retention period (i.e., shredding paper documents, deleting electronic files, physically destroying audio/video recordings)?

At the end of the records retention period the electronic files will be deleted and the paper documents will be shredded.

e. Describe procedures for maintaining the confidentiality of human subjects data.
The confidentiality of the human subjects will be maintained by giving them code names to which they will be referred so their actual identities will only be known to the researcher and the faculty advisor.

19. **Application Components** (Check all items that are included):
A completed application package must include the following:

- Application Form
- CITI Training Completion Reports for all investigators, key personnel, and faculty advisors
- If applicable: Form M: Research Involving Minors/Children
- If applicable: Form P: Research Involving Prisoners
- If applicable: Form I: Research Involving Decisionally-Impaired Individuals
- If applicable: Form W: Research Involving Wards of the State
- If applicable: recruitment materials (i.e., advertisements, flyers, telephone scripts, verbal recruitment scripts, cover letters, etc.)
- If applicable: Consent form (required in most all cases), assent form (for subjects who are minors), and parent/guardian permission form (if subjects are minors)
- If applicable: Instrument(s) to be used for data collection (i.e., questionnaire, interview questions, or assessment scales)
- If applicable: grant/contract proposal narrative (required if study is funded)
- If applicable: letter(s) granting permission to use off-campus facility for research

20. **Principal Investigator Statement:**
I certify that this document fully discloses the involvement of human subjects in this research study and that human subjects will not be involved in any other way. I agree to follow the approved protocol in the conduct of this study and to abide by EKU Policy 4.4.12: Protecting Human Subjects in Research (http://www.policies.eku.edu/academic/human_subjects/4.4.12_protecting_human_subjects_in_research_tcr_1.11.pdf).

I agree:

A. to accept responsibility for the scientific and ethical conduct of this research study;
B. to obtain prior approval from the Institutional Review Board before implementing any changes to the research protocol or the study's documents, including those approved for recruitment, consent, and data collection;
C. to immediately report to the IRB any serious adverse reactions and/or unanticipated effects on subjects which may occur as a result of this study;
D. to maintain records related to this protocol for a period of three years following the project's completion;
E. to adhere to IRB reporting requirements, including annual continuing reviews and filing the final report.

David Simpson  
Name  
Signature  
Date  

21. **Department Chairperson's Approval:** (If the PI is also the Department Chair, the Dean or equivalent must sign.)
I have reviewed this application and attest to the scientific merit of this study and the competency of the investigator(s) to conduct the project.

Colleen Schnick  
Name  
Signature  
Date  

22. **Faculty Advisor's Approval:** (required if PI is an EKU student)
I have reviewed this application and attest to the scientific merit of this study and the competency of the investigator(s) to conduct the project. I understand that, as faculty advisor, I am responsible for guiding work on this project to ensure that the research protocol and EKU Policy 4.4.12: Protecting Human Subjects in Research (http://www.policies.eku.edu/academic/human_subjects/4.4.12_protecting_human_subjects_in_research_tcr_1.11.pdf) are followed. I understand that I am responsible for maintaining records related to this study for a period of three years from the study's completion. I understand that, as faculty advisor, I am responsible for ensuring that reports are filed with the IRB in a timely manner and agree to file reports on behalf of the student researcher if necessary.

Julie Baltisberger  
Name  
Signature  
Date  

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Appendix B:
Consent Form
Consent to Participate in a Research Study

The lived experiences of families involved in the adoption process who participate in OT services.

Why am I being asked to participate in this research?
You are being invited to take part in a research study about families who have both adopted a child and put them through OT services. You are being invited to participate in this research study because you have adopted a child and qualify for this study. If you take part in this study, you will be one of about two people to do so.

Who is doing the study?
The person in charge of this study is David Simpson at Eastern Kentucky University. He/She is being guided in this research by Dr. Julie Baltisberger, PhD, OTR/L.

What is the purpose of the study?
The purpose of this study will be to describe the experiences of families, or a group of individuals living together in a household, who utilize occupational therapy services for their children who have been adopted. By doing this study, we hope to learn how successful the OT services were for both the family and the child.

Where is the study going to take place and how long will it last?
The research procedures will be conducted at Eastern Kentucky University, over Skype, or at a location that is convenient for the participant. You will need to come to Eastern Kentucky University 1 time during the study. Each of those visits will take about 1-2 hours. The total amount of time you will be asked to volunteer for this study is no more than 120 minutes over the next 6 months.

What will I be asked to do?
You will be asked to sit for an interview with the researcher for about an hour or 2. You will be asked questions about the adoption and the therapy processes of which you participated in.

What are the possible risks and discomforts?
To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

If the research involves any procedures that could cause possible emotional or mental harm, include the following statement:
Although we have made every effort to minimize this, you may find some questions we ask you to be upsetting or stressful. If so, we can tell you about some people who may be able to help you with these feelings.

Will I benefit from taking part in this study?

You will not get any personal benefit from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don’t take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

This study is anonymous. That means that no one, not even members of the research team, will know that the information you give came from you.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly.

Can my taking part in the study end early?
If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

**What happens if I get hurt or sick during the study?**

If you believe you are hurt or if you get sick because of something that is done during the study, you should call David Simpson at 859-626-2321 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child’s care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer’s willingness to pay under these circumstances.

**What if I have questions?**

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, David Simpson at 859-626-2321. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

**What else do I need to know?**

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

_I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project._
Appendix C:
Data Collection Methods
Interview Protocol

1. Can you describe the adoption process? When did it occur and what did it look like?

2. What made you decide to pursue OT services for your child?

3. How long has your child been receiving OT services? How long do the sessions usually last?

4. What skills/activities does the OT do with your child?

5. How would you describe your interactions with the OT?

6. How have OT services influenced your family’s life?