LANGUAGE BARRIERS, CULTURAL DIFFERENCES, AND PARENTS'

EXPECTATIONS OF FAMILY-CENTERED CARE IN PEDIATRIC HOME HEALTH

THERAPY

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

SCHOOL OF PHYSICAL THERAPY

COLLEGE OF HEALTH SCIENCES

BY

COURTNEY QUINN-SCOTT, BS, DPT

DENTON, TEXAS

MAY 2021

DEDICATION

To my husband, Aaron, for your love, patience, and support throughout this journey. The last 10 years would have been impossible without your continued encouragement and sacrifice for our family and me. To my children, Weylin and Chyann, for your love, patience, and sacrifice over the years. To all my family and friends, for your encouraging words and prayers during this process. Last, but certainly not least, I have to thank God for His grace and incredible blessings that have given me the strength that led me to where I am today.

ACKNOWLEDGEMENTS

ABSTRACT

COURTNEY QUINN-SCOTT

LANGUAGE BARRIERS, CULTURAL DIFFERENCES, AND PARENTS'
EXPECTATIONS OF FAMILY-CENTERED CARE IN PEDIATRIC HOME HEALTH
THERAPY

MAY 2021

Background: While many definitions of family-centered care (FCC) exist, overall, the concept is to include families and patients in all aspects of the plan of care. To date, no studies have investigated how often FCC is utilized in the pediatric home health therapy setting. No studies have examined incorporation of FCC in this setting when cultural or language differences exist. The purposes of this study were to determine how many of the FCC concepts are being incorporated by therapists in the pediatric home health setting, to investigate the differences in incorporating FCC concepts among families with different cultures and different languages, and to explore parents' expectations of FCC within the home health pediatric setting.

Participants: A total of 76 parents/caregivers of children with special needs receiving physical, occupational and/or speech therapy from two pediatric home health agencies across Texas, USA completed data collection (16.9% return rate).

Methods: A quasi-mixed methods design was used. The Measure of Processes of Care-20 items set (MPOC-20) determined perceived FCC utilization. Participants completed the MPOC-20 to provide quantitative data on how often FCC concepts were incorporated and explore incorporation of FCC when language/cultural differences exist.

A 7-question open-ended survey was created and used to obtain qualitative data on parent expectations of incorporating FCC in this setting.

Results: MPOC-20 results showed FCC concepts were incorporated to "a great extent" or higher in this setting. Statistical analysis indicated no differences between English- and Spanish-speaking respondents, nor among cultures/ethnicities in regard to incorporating FCC concepts in home health pediatric therapies. Qualitative analysis revealed participants did not fully understand the FCC model. Nevertheless, parents expected a collaborative relationship with the therapists ensuring the child receives individualized and optimal care in order to make the best progress in his or her home health therapies.

Discussion and Conclusions: Findings from this study showed therapists incorporated FCC concepts in this setting regardless of language or cultural differences. Families expect to build relationships with therapists, receive information appropriate to preferred mode of interaction and level of involvement, and for therapists to be accepting of differences regardless of personal cultural or non-cultural beliefs.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Days of endless activities such as multiple hospital stays and numerous testing

sessions, specialist appointments and therapy sessions for a child's various diagnoses, on

top of being a caregiver for multiple children and/or a working parent seems to be the

typical life of a parent who has a child with special needs. One method healthcare

providers can use to help parents navigate their many responsibilities is family-centered

care (FCC). While many definitions of FCC exist, overall, the concept is to include

families and patients in all aspects of the plan of care. While there has been growth and

progression in the area of family-centered care over the years, implementation of FCC in

the pediatric home health setting is still limited (Kuo et al., 2012). In addition, family and

physician expectations regarding how best to assist families are often different (Kuo et

al., 2012). Cultural and language differences may also account for variations in such

expectations (Coker et al. 2010; Goode et al., 2009; Kuo et al., 2012).

There is currently a dearth of information on FCC being used in the home health

pediatric setting, especially with regard to therapy interventions. The majority of the

literature on patient and family-centered care analyzed by Gallo et al. (2016), was

conducted in the pediatric nursing field with 42 studies taking place in the inpatient

setting, mostly with Neonatal Intensive Care Unit (NICU) and Pediatric Intensive Care

Unit (PICU) populations, and 26 studies taking place in the outpatient setting (Gallo et

al., 2016). While there is some literature on FCC use in outpatient therapies, there is much less evidence tying this concept to the pediatric home health therapy setting (Gallo et al., 2016).

Statement of the Problem

In the pediatric therapy settings, challenges arise while practicing FCC. Therapists must balance setting realistic outcome expectations through evidence-based practice and clinical expertise while avoiding defeat of a parent's hopes for their child (LeRoy et al., 2015). Therefore, the FCC approach to interventions in the home is not commonly or fully practiced (Kuo et al., 2012). To date, no studies have investigated how often FCC is utilized in the pediatric home health therapy setting. In addition, no studies have examined the use of FCC in the pediatric home health setting when cultural or language differences exist.

Purpose of the Study

The purposes of this study were to determine how many of the FCC concepts are being incorporated by therapists in the pediatric home health setting, to investigate the differences in incorporating FCC concepts among families with different cultures and different languages, and to explore parents' expectations of FCC within the home health pediatric therapy setting. Using a quasi-mixed methods approach, the study was able to generate new and useful information for pediatric home health therapists as they apply FCC principles. This information may also minimize challenges therapists face when incorporating FCC concepts during therapy sessions. Lastly, this study identified the

effect of language and cultural/ethnic differences when applying FCC concepts in this therapy setting.

Research Questions

The research questions addressed in this study were:

1. Which family-centered care concepts are being incorporated in the home health pediatric therapy setting?

2. Are there differences in incorporating FCC concepts when families are from cultures different from the therapists' or parents whose first language is not English?

3. What are parents' expectations of therapists regarding FCC concepts within the home health pediatric setting?

Research Hypotheses

The research hypotheses in this study were:

1. It was hypothesized that FCC concepts are inconsistently incorporated in the home health pediatric therapy setting.

2. It was hypothesized that FCC concepts are inconsistently incorporated with families from cultures different from the therapists or with families who are not fluent in the English language.

Operational Definitions

The following terms were used in this study and are presented in alphabetical order:

1. Cultural/ethnic differences: Homes in which the therapist is of different cultural/ethnic background than the family/child.

2. Family-centered care: The concept of including the provider, family and patient in all phases of the plan of care and treatment (Schreiber et al., 2011). FCC in this study was based on a combination of components from two models of FCC, Gallo et al. (2016) and the creators of the MPOC-20 (S. King, Rosenbaum, et al., 1996).

3. Language Differences: Homes in which Spanish is the primary language spoken; assuming that is different from the norm of English being the primary language of choice.

Assumptions and Limitations

Assumptions

The following assumptions were made for this study:

1. Parents/caregivers understood the term family-centered care.

2. Participants answered all survey questions honestly.

3. Parents who participated in the study were representative of the population of families receiving therapy services in the home.

4. Participants answering "0 = Not Applicable" truly feel it is not applicable and are not mistaking "0" for equal to or lower than a rating of "1 = Not at All".

Limitations

The following were limitations of this study:

1. Limited triangulation from closed- and open-ended question surveys without the use of interviews to probe further into each question.

2. Transferability may have been limited as this study was conducted on a group receiving pediatric home health therapy from agencies in Texas.

3. Due to the non-random, voluntary survey design, return rates were low, increasing the probability of self-selection bias.

4. Language barriers may also limit generalizability as the surveys were provided in English and Spanish but were not translated into any other language.

5. Due to the participation limited to families/caregivers that were currently enrolled in therapy services, the results may have been biased to more positive scores on the MPOC-20 (showing higher incorporation of FCC into services) as dissatisfied families may have terminated services with the agency prior to the study.

6. Another limitation of this study is the fact that the author relied on therapists employed by the agencies in the study to assist in disseminating the materials potentially resulting in biased answers as participants may have completed the surveys based on their relationship with the therapist or responding in a socially desirable manner.

7. Due to reliance on therapists employed by the agencies in the study to assist in disseminating the materials, the study may lack dependability as the author was not able to fully control how materials were disseminated by each therapist.

Significance of the Study

This project formally evaluated the current use of FCC principles in the home health pediatric therapy setting, identified which FCC concepts are incorporated when families have cultural differences and/or language differences, and determined parents' expectations of FCC in pediatric home health therapies. Data from this study may provide pediatric home health therapists with an understanding of what FCC entails in this

setting. Additionally, data may identify how culture and language impact FCC, as well as demonstrate the need for FCC to be a standard model when creating a plan of care for therapeutic interventions in the pediatric home health setting. The results may also highlight parents' expectations of FCC in this setting. Given the lack of studies in the pediatric home health setting, the results of this study will expand the literature on FCC, thereby improving patients' and families' quality of life through improved patient/parent satisfaction (G. King, King, et al., 1996; Ngui & Flores, 2006; Schreiber et al., 2011). The results may guide pediatric home health therapists as they implement FCC and adjust implementation with parents' expectations in mind.

CHAPTER II

REVIEW OF THE LITERATURE

The purposes of this study were to determine how many of the FCC concepts are being incorporated by therapists in the pediatric home health setting, to investigate the differences in incorporating FCC concepts among families with different cultures and different languages, and to explore parents' expectations of FCC within the home health pediatric therapy setting. In this chapter, the author discusses models of care used in pediatric therapy. There are two models of service delivery currently used to include: child-centered care and patient and family-centered care; and four models of developmental theories discussed: Bronfenbrenner's ecological systems, transactional model of development, dynamic systems theory, and family systems theory. Additionally, FCC will be defined, the history of this philosophy will be shared, and the importance of using a FCC model will be addressed. Finally, aspects of the methods used in this study such as a quasi-mixed methods design using quantitative and qualitative data collection and analysis, and survey development will be addressed.

Models in Pediatric Care

Over the years, models and theories of care for pediatric therapies have evolved. Traditionally, therapists relied on clinical reasoning and practice knowledge to provide care. Since then, clinicians have progressed towards using an evidence-based practice approach incorporating research evidence in their decision-making process when

formulating a plan of care (Campbell et al., 2012). Changes in the service delivery of pediatric therapies have also occurred (Tecklin, 2008). The developmental model has shifted from the reflex hierarchy model, development through primitive reflexes, to a systems model, which suggests that various systems affect each other and impact the child's development (Tecklin, 2008). In this model, the family is considered one of the systems (Tecklin, 2008). At the same time, child-centered services, a medical based model, has changed to family-centered services, initiating the family-centered care model (Tecklin, 2008). Furthermore, delivery of services has progressed from the traditional center-based delivery, in hospitals and clinics, to the natural environment where therapies are now taking place in the home and school environments (Tecklin, 2008).

According to the Early Intervention Special Interest Group of the Academy of Pediatric Physical Therapy, pediatric therapists can rely on principles from four models/theories to guide the practice of developing and cultivating relationships that involve the patient (2018). These models/theories include the bioecological systems theory, transactional model of development, dynamic systems theory, and the family systems theory (Academy of Pediatric Physical Therapy, 2018). Below, each of the four theories will be further explained.

The Bronfenbrenner ecological systems theory addresses different systems: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1977). The microsystem includes the person and the relationships between their immediate environment: home, school, work, etc.; as well as their specified role: family member, teacher, employee, etc. (Bronfenbrenner, 1977). The mesosystem, an extension of the

microsystem, includes the interrelations of a person at a specific time in their life (Bronfenbrenner, 1977). The exosystem is a further extension of the mesosystem that includes the society in which the person lives (Bronfenbrenner, 1977). This extension also includes other social structures that may affect interrelationships such as media, social media, governmental agencies, and transportation networks (Bronfenbrenner, 1977). Finally, the macrosystem is comprised of the previous systems in a general context and is important as it establishes the relationship and interactions between a child and their caregiver across all settings (Bronfenbrenner, 1977). For example, the macrosystem serves more as an implicit "blueprint" or prototype for everything occurring within the child's society/everyday life (Bronfenbrenner, 1977).

The transactional model of development involves a bidirectional relationship between the child and the experiences provided by the family or environment (Sameroff & Mackenzie, 2003). There is equal importance placed on the dynamic interaction of both parties (Sameroff & Mackenzie, 2003). Therefore, in this theory, it is believed that all experiences between the child and the environment are mutually essential in the development of the child (Sameroff & Mackenzie, 2003).

Dynamic systems theory consists of theoretical principles of the relationship between time and the complexity of the systems (Thelen & Smith, 2006). This theory challenges the oppositions of "either-or thinking" (e.g., nature versus nurture) and suggests all movements of the body are interactive within the person, and between the person and environment. At the same time, the processes are continuous in time, and functioning in the moment (Thelen & Smith, 2006).

9

The family systems theory has been used in early intervention practices of therapy. This theory shifted from a child-centered model and is now based on a systems model expanding from Bronfenbrenner's ecological systems model (Foster & Phillips, 1992). This model appreciates the connection between the child's individual functioning and the family's functioning as a whole (Foster & Phillips, 1992). Furthermore, this model believes that just as each person has a life cycle, a family has a life cycle with anticipated conditions over time (Foster & Phillips, 1992). Support for the family systems theory comes from studies that show better outcomes for a child when parents and family have been involved in the care (Foster & Phillips, 1992). The theory has helped develop FCC as it is known today and has resulted in more inclusion of the family in patient care (Foster & Phillips, 1992).

Essentially, the four theories previously described are similar as all systems show the connection of how the person as an individual and the environment interact to impact the person's development over time. These four theories create the systems theory replacing the previous reflex hierarchy model (Tecklin, 2008). While incorporating these theories of development to enhance relationships during interventions, therapists should embrace the systems models previously discussed with family-centered service models in the natural environment of care. Furthermore, the models have taken the medical model of child-centered services and expanded the model toward a family-centered model of care. When integrating all three aspects, systems theories, family-centered services and the natural environment, during therapy treatments, the therapist is demonstrating a family-centered care model.

Family-Centered Care

While many definitions of FCC exist, overall, the concept is to include families and patients in all aspects of the plan of care. Often times, patient-centered care (PCC) is used interchangeably with the term FCC; however, it is believed that FCC is most often the chosen term when referring to the care of pediatric patients (Kuo et al., 2012). FCC was defined more specifically by Schreiber et al. (2011), as a method of integrating all phases of healthcare treatment as an equal partnership among the provider, family, and patient.

Law, Rosenbaum, et al. (2003) further defined FCC as being:

> made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that **each family is unique**; that the family is the **constant in the child's life**; and that they are the **experts on the child's abilities and needs**. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered. (p. 2)

History of Family-Centered Care

FCC originated as early as the 1950s in the nursing profession (Newton, 2000), and evolved more during the 1960s' consumer movement when Wiedenbach published his book on maternity nursing (Dokken & Ahmann, 2006; Shelton & Stepanek, 1994). In 1975, the first special education law was passed, due in large part to family advocates

who were changing and promoting hospital-based care for children and their families (Kuo et al., 2012). After families became recognized as valuable advocates, a waiver was created in 1982 (the Katie Beckett Home and Community-Based Medicaid Waiver) allowing patients with special needs to be cared for at home (Kuo et al., 2012). In 1989, CanChild was founded as a non-profit education and research center located at McMaster University in Canada. CanChild continues today as a multidisciplinary team approach to research and education for children with lifelong disabilities.

Over the years, FCC has continued to evolve, and in 1992, the Institute of Patient- and Family-Centered Care organization was founded (Gallo et al., 2016). While there has been growth and progression in the area of FCC, implementation of FCC in the pediatric home health setting is still limited (Kuo et al., 2012). In addition, family and physician expectations regarding how best to assist families are often different (Kuo et al., 2012). Cultural and language differences may also account for variations in such expectations (Coker et al., 2010; Goode et al., 2009; Kuo et al., 2012).

Components of Family-Centered Care

FCC has been defined by different authors or groups. However, all models include some aspect of information sharing and support for the family with a child who has special needs. The first model reported by Gallo et al. (2016), contains five common core components of FCC: (a) Education by the Provider to the Patient and/or Family, (b) Information Sharing from the Family to the Provider, (c) Social-Emotional Support, (d) Shared Decision-Making, and (e) Adapting Care to Match the Family Background. The authors indicate that education provided to the patient includes information from the

healthcare provider regarding the diagnosis, treatment, and outcomes (Gallo et al., 2016).

Further, information the family might share consists of facts about the patient that do not

involve intervention or management, such as items and preferences the patient responds

to best. In addition, social-emotional support may include provider-initiated support to

the patient/family, whether direct or indirect, to assist in reducing stress and anxiety as

well as building confidence. This may include use of support groups or networking

opportunities. Their fourth component, shared decision-making, is a "collaborative

process" among the provider, family and patient, to negotiate and discuss all options

within care to include risks/benefits with an evidence-based approach and family

preference approach that will aid in family participation in care. Finally, when adapting

care to match the family background, a provider may obtain information from the family

to ensure needs are met with regard to culture, ethnicity, race, socioeconomic

background, as well as any past experiences of the patient/family (Gallo et al., 2016).

Another model of FCC was developed by the CanChild organization. The

CanChild group developed the Measure of Processes of Care (MPOC) to examine FCC

using five components: (a) Enabling and Partnership, (b) Providing General Information,

(c) Providing Specific Information about the Child, (d) Coordinated and Comprehensive

Care for the Child and Family, and (e) Respectful and Supportive Care (S. King,

Rosenbaum, et al., 1996). The authors state that enabling and partnership includes

parental input throughout the decision-making process of the child's medical care (S.

King, Rosenbaum, et al., 1996). Additionally, providing general information, states

parents will receive information from a healthcare provider that meets their needs for

general information on medical aspects of their child's condition or situation. Moreover,

providing specific information about the child, a healthcare provider will deliver

information to the family on details specific to the needs of their child's condition and

medical care. The authors further indicate that coordinated and comprehensive care of the

child and family takes into consideration the "holistic needs" of the patient/family

allowing providers to offer care that is consistent throughout the course of treatment

across all settings. Finally, when providing respectful and supportive care, providers will

ensure patients/families are treated equally, with respect, and feel valued as a team

member in the decision-making process of the child's care (S. King, Rosenbaum, et al.,

1996).

In still another model of FCC, Kuo et al. (2012) examined definitions and

principles of FCC identifying five common principles shared by four major groups

involved in pediatric care (Family Voices, the Maternal and Child Health Bureau, the

American Academy of Pediatrics, and the Institute for Patient- and Family- Centered

Care). These principles include: (a) Information Sharing, (b) Respect and Honoring

Differences, (c) Partnership and Collaboration, (d) Negotiation, and (e) Care in Context

of Family and Community (Kuo et al., 2012). The authors indicate that information

sharing consists of communicating information between providers and family/patients

that is unbiased and factual, a more general sharing of information (Kuo et al., 2012).

Next, respect and honoring differences include respecting the family/patient's care

preference, culture, and language differences even when different from that of the

provider. Their third concept, partnership and collaboration, states providers and

family/patients will join in making "medically appropriate decisions" that best fit the needs of all persons involved. Furthermore, a therapist who demonstrates the negotiation component is open to changing the plan of care and outcomes as necessary or as the child's progress changes. Finally, care and decisions are made taking the patient's lifestyle (including quality of life, family, environment, and activities) into consideration to achieve care in the context of family and community (Kuo et al., 2012).

For the current study, the components of FCC identified by Gallo et al. (2016), and S. King, Rosenbaum, et al. (1996) were combined. In this section, the components described by Kuo et al. (2012) are included for a comprehensive review of the literature. Several concepts parallel each other as shown in Table 1. However, the concept from Gallo et al. (2016), Social-Emotional Support, does not coordinate with any Kuo et al. (2012) principles. At the same time, the principle of Information Sharing from the Patient/Family to the Provider from Gallo et al. (2016) does not coordinate with any principle from S. King, Rosenbaum, et al. (1996) and is limited in comparison to Kuo et al. (2012) principles. To some degree, this concept coordinates with Information Sharing by Kuo et al. (2012) as they express this principle of sharing information as "between" providers and family, as well as being "general information sharing." Exploration of this component was necessary as it specifically emphasizes the importance of bidirectional information sharing; thus, it was included in the current research. Additionally, one concept identified by S. King, Rosenbaum, et al. (1996), Coordinated and Comprehensive Care for the Child and Family, that does not coordinate with the Gallo et al. (2016) or Kuo et al. (2012) principles. Gallo et al. (2016) and Kuo et al. (2012) are more focused

on the dyadic and triadic relationship of FCC while this particular S. King, Rosenbaum, et al. (1996) concept is more focused on how the organization or provider can facilitate the FCC process as a more unidirectional relationship. Therefore, this concept was only investigated in this study when using the MPOC questionnaire. See Table 1 for a list of corresponding components from each model.

Table 1

Comparison of FCC concepts across studies

Gallo et al. (2016)	S. King, Rosenbaum, et al. (1996)	Kuo et al. (2012)
Education by the Provider to the Patient and/or Family	Providing Specific Information about the Child Providing General Information	Information Sharing (general info sharing)
Information Sharing from the Patient/Family to the Provider	None	Information Sharing (general info sharing)
Social-Emotional Support	Respectful and Supportive Care	None
Shared Decision-Making	Enabling and Partnership	Partnership and Collaboration Negotiation
Adapting Care to Match the Family Background	Respectful and Supportive Care	Respect and Honoring Differences Care in Context of Family and Community
None	Coordinated and Comprehensive Care for the Child and Family	None

Note. FCC = family-centered care

Importance of Incorporating Family-Centered Care

In order to make positive health and behavioral changes, Gallo et al. (2016) noted that FCC practice requires more than just patient education. However, this group also recognized that there is a lack of evidence for ways to implement family-centered care in pediatrics (Gallo et al., 2016).

Despite the lack of studies, when FCC concepts are applied, some authors have reported positive outcomes with regard to patient health and satisfaction, and family/caregivers' psychosocial welfare (G. King, King, et al., 1996; Schreiber et al., 2011). Family-centered care not only improves parental satisfaction and psychosocial well-being, but also the child's psychological adjustment (G. King, King, et al., 1996; Schreiber et al., 2011). Gallo et al. (2016) also reported that FCC affects provider, patient, and/or family behavior and the overall experience for the patient. In a policy statement disseminated by the American Academy of Pediatrics (2012), Patient- and Family-Centered-Care not only improves patient and family satisfaction, overall outcomes, and experience, but also assists in decreasing healthcare costs and ease of use of healthcare resources (Eichner & Johnson, 2012). However, the evidence is elusive regarding the impact of FCC on a patient's health status due to inconclusive results in many studies reviewed by Gallo et al. (2016). Gallo et al. (2016) reviewed 68 studies, 27 of which did not report on the impact on health status and 20 that showed either mixed results or neutral/no impact.

At the same time, studies have shown further importance of incorporating FCC: satisfaction with, and the ease of use of healthcare services when language or

ethnic/cultural differences are considered. An increased dissatisfaction with care and difficulty with the use of health care services has been associated with the lack of incorporating sufficient FCC components (Ngui & Flores, 2006; Schreiber et al., 2011). Overall, studies have shown that patients with ethnicities/cultures and languages different from the healthcare providers were less likely to receive care provided with the FCC model (Coker et al., 2010; Ngui & Flores, 2006). Adjusting to these differences is important as the United States of America continues to grow in diversity. Estimates of our ethnic population by the year 2050 are as follows: 50% Caucasian, 15% African American, 24% Hispanic/Latino, and 8% Asian (Goode et al., 2009). Coker et al. (2010) show Latino, African American, multiracial and "other" ethnicities than Caucasian received significantly less FCC than Caucasian patients. Similarly, Coker et al. (2010) found that patients with non-English primary languages received FCC-based treatments significantly less than patients whose primary language was English. Furthermore, one-third of minority parents have reported dissatisfaction and difficulty with the use of healthcare services for their child with special needs, with language barriers being a key factor in causing the disparities (Ngui & Flores, 2006).

Although FCC is not a new concept, it remains unclear whether therapists are truly engaging in all aspects of FCC and are including patients and families in the plan of care within the home health pediatric therapy setting. There appear to be several contributing factors including lack of education on incorporating FCC principles, lack of evidence for interventions and ways to implement FCC (Gallo et al., 2016), as well as language and/or cultural/ethnic differences between the therapist and family. While there

is literature on FCC use in outpatient therapies (Schreiber et al., 2011), there is much less evidence tying this concept to the pediatric home health therapy setting. A study done by Dyke et al. (2006) assessed scores of the MPOC-56 from an organization in the early intervention and school settings to determine the use of FCC treatment in the pediatric population. Early intervention and school settings are potentially a closer comparison to home health therapies as interventions are often offered in the home; however, the study does not specify whether interventions took place in the home or clinic/school. Dyke et al. (2006) compared parents' and service providers' perceptions on inclusion of FCC behaviors in therapies using a quantitative research design. The authors concluded that it is important to identify areas of FCC that need improvement in order to provide "genuinely family-centered services" (Dyke et al., 2006, p. 175). Exploring FCC qualitatively in the current study allowed for further expression from parents/caregivers in areas of FCC that are less familiar to them, along with expectations of FCC in therapy to assist clinicians in providing better FCC services.

Qualitative Data Collection and Analysis

Over the last 30 years, qualitative research has evolved and expanded in clinical practices encompassing social and biomedical sciences including psychology, sociology, physical therapy and occupational therapy among others (Sandelowski et al., 2006). Investigators have fought to have qualitative research referred to as evidence-based practice as this design allows for the study of certain aspects of human nature, using "culturally-sensitive" methods that quantitative data cannot reveal (Sandelowski et al., 2006). Qualitative research is built on paradigms and philosophical frameworks that are

emergent, focusing on the context in the most natural setting, and is often used in social and human science research (Creswell, 2007; Marshall & Rossman, 2011). There are several forms of data collection in qualitative research to include various forms of interviewing (i.e., face-to-face interviews, phone interviews, etc.) and participant observation (i.e., observing individuals or groups to analyze behaviors and interactions in a certain setting) (Creswell, 2007; Marshall & Rossman, 2011). Brief open-ended surveys have also been used in qualitative research to obtain rich data while maintaining anonymity (Jackson & Trochim, 2002).

Creswell (2007) defines five approaches to qualitative research that drive the form of data collection including: (a) narrative research, (b) phenomenological research, (c) grounded theory research, (d) ethnographic research, and (e) case study research. Narrative research is the narration of an individual's lived and told experiences of events in a chronological manner. Research that examines lived experiences by a group of individuals to correlate concepts and commonalities of a phenomenon experienced by the group is considered phenomenological research. In grounded theory research, the researcher aims to generate a theory from the analysis of the lived experiences of a larger group of participants. Ethnographic research examines the meaning of shared patterns in groups larger than those considered in grounded theory research that identifies with the same ethnic or cultural values, languages or behaviors. Case study research generally incorporates various sources of information to describe a particular case within a particular context over time (Creswell, 2007). The qualitative portion of this study

incorporated a phenomenological research approach as the author investigated similarities and differences in the participants' expectations of FCC.

When analyzing qualitative data, there are several typical phases of the process: (a) organizing the data, (b) generating categories and themes through coding, (c) providing interpretation or "story-telling" through analytic memos, (d) searching for alternative understandings ensuring saturation and sufficiency, and (e) compiling a discussion to present the results (Creswell, 2007; Marshall & Rossman, 2011). To organize the data the researcher will arrange the data into a manageable system for further analysis (Creswell, 2007; Marshall & Rossman, 2011). Coding the data is a process that will then group datum into reoccurring themes or categories (Creswell, 2007; Marshall & Rossman, 2011). Interpreting the data allows the researcher to create analytic/theoretical memos that are notes throughout the process of analysis that allow self-reflection and tell the story while cross-referencing categories and themes (Creswell, 2007; Marshall & Rossman, 2011). When searching for alternative understandings the researcher will ensure any further answers will result in similar findings (saturation) and ensure that the data provide answers that fully describe the categories (sufficient) (Marshall & Rossman, 2011). Finally, compiling the results allows for further discussion of the findings (Marshall & Rossman, 2011).

A similar approach to the previously described qualitative data analysis is thematic analysis as defined by Braun and Clarke (2006). Thematic analysis is a flexible approach as it does not follow any specific theoretical method, is easy to use for novice researchers, and can provide rich, thick description of larger data sets (Braun & Clarke,

2006). Thematic analysis follows six steps: (a) familiarizing oneself with the data, (b)

generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and

naming themes, and (f) producing the report, which allows for a "recursive" versus linear

approach to analysis as the steps can be repeated as necessary (Braun & Clarke, 2006).

The author used a thematic analysis approach of qualitative analysis to take advantage of

the flexibility and allow the data to provide a well-rounded and comprehensive outcome.

Coding data and creating themes is an important phase of the qualitative analysis

process. Coding methods can be broken into two cycles: first cycle coding methods—

used initially to code the data based on the need of the study, and second cycle coding

methods—used to reorganize and reanalyze the codes and themes (Saldana, 2013). The

coding methods used in a study can be chosen based on the paradigmatic/theoretical

approach, conceptual framework, or methodological needs of the study or a mixture of all

based on the collected data and research questions (Saldana, 2013). There are seven

methods to choose from in the first cycle coding methods: (a) grammatical methods, (b)

elemental methods, (c) affective methods, (d) literary and language methods, (e)

exploratory methods, (f) procedural methods, and (g) themeing the data (Saldana, 2013).

There are six methods to choose from in the second cycle coding methods: (a) pattern

coding, (b) focused coding, (c) axial coding, (d) theoretical coding, (e) elaborative

coding, and (f) longitudinal coding (Saldana, 2013).

This study used the first cycle coding method of elemental method, a primary

method with simple but focused filters allowing the data to create a blueprint or

foundation, with initial (open) coding, comparing and contrasting different parts of the

information to allow the data to show the direction and remain open to all possibilities of development (Saldana, 2013). The author utilized pattern coding, developing main codes and sub-codes from patterns found during initial coding, as a second cycle coding method to reorganize and reanalyze the data (Saldana, 2013). Focused coding (Saldana, 2013) was also used as a second cycle coding method after pattern coding for questions 1 and 2 of the survey as the author then re-coded a main code into pre-generated sub-codes created from the FCC concepts. The author chose these coding methods to allow the data to guide the direction of codes while using thematic analysis. This method is in contrast to allowing a theoretical framework to formulate preconceived codes or themes as seen in other coding strategies such as structural coding which applies a restructured phrase that represents a specific topic found in the research question (Saldana, 2013).

Computer-assisted analysis software can be used to organize, manage, and query data and is most useful for sorting through large quantities of data (Creswell, 2007). Computer-assisted analysis serves as a tool for coding into themes and creating analytic memos (Marshall & Rossman, 2011). It can also assist the researcher in questioning of the data when themes are created to assist in finding further information on specific themes or new research questions that may be elicited from the current data (Marshall & Rossman, 2011). Four commonly used computer-assisted analysis programs are ATLAS.ti, QSR NVivo, HyperRESEARCH, and MAXqda (Creswell, 2007). All four programs allow the researcher to analyze the data similarly; however, each has slight differences and advantages of their own. For example, ATLAS.ti requires less storage memory as it compiles the data into one link and also allows multiple users to work on

the same project (Creswell, 2007). ATLAS.ti also allows the researcher to use a variety of languages as well as "mix" languages within the project and allows for mixed methods and can be used on a Windows PC or Macintosh computer (ATLAS.ti, 2020). QSR NVivo allows researchers to use different languages and has a user-friendly appearance (Creswell, 2007). QSR NVivo can be used on a Windows PC or Macintosh computer and also allows the researcher to ask questions and explore data further for patterns or comparisons by running queries of their data (QSR International, 2020). HyperRESEARCH is a program that is available on Windows PC and Macintosh computers and can also be used to work with graphics and audio sources (Creswell, 2007). Finally, the MAXqda allows the researcher to assign a weight to segments of the data ranking the relevance and also allows for image and video sources of data to be analyzed (Creswell, 2007). MAXqda can be used on a Windows PC or Macintosh computer, is available in 15 different languages, and allows for mixed methods analysis (VERBI GmbH, 2020). For the purpose of this study, the researcher used QSR NVivo to assist in managing the qualitative data as the author expects to receive data in English and Spanish and this program supports multiple languages. Also, this program is the data management software that is currently supported by Texas Woman's University.

In this section, the researcher discussed qualitative research, qualitative data analysis, thematic analysis, coding methods, and the use of computer-assisted analysis programs for qualitative data. In the next section, the researcher discusses a mixed methods approach using qualitative research with quantitative research for a more

25

rounded approach to research. The researcher describes five styles of mixed methods designs to be considered when using a mixed methods approach to research.

Mixed Methods Design

When referring to a mixed methods research design, quantitative and qualitative methods are combined, and can obtain a more holistic comprehension of the research questions as data findings may be complementary or contradictory (Bazeley, 2006; Onwuegbuzie & Johnson, 2006). Mixed methods design in research is becoming more widely used as qualitative data can be beneficial in strengthening and expanding the importance of quantitative results (Creswell et al., 2006; Sandelowski et al., 2006).

As discussed by Onwuegbuzie and Johnson (2006), there are five approaches to mixed methods designs that include parallel, concurrent, conversion, sequential, or fully mixed designs. In parallel mixed methods designs, quantitative and qualitative data are collected separately but concurrently, analyzed separately but concurrently, inferences are made separately but concurrently, and there is no attempt to draw meta-inferences integrating the quantitative and qualitative data and findings (Onwuegbuzie & Johnson, 2006). The advantages of the parallel mixed methods design are that the influence of time would be minimized and the influence of the quantitative questions on qualitative answers would be lessened. A disadvantage of this approach is that quantitative and qualitative data are reached separately to answer separate research questions, thus, lacking the ability for each type to build and strengthen one another. There are differing opinions on this parallel approach being a true mixed methods design as meta-inferences

are not drawn between the qualitative and quantitative findings. While some researchers agree this approach is a mixed methods design (Onwuegbuzie & Johnson, 2006), other researchers such as Creswell et al. (2006) and Yin (2006) state that, for a study to truly be mixed methods meta-inferences should be drawn between qualitative and quantitative methods. At the same time, some researchers consider a parallel approach as defined by Onwuegbuzie and Johnson (2006) to be a "quasi-mixed" methods design (Teddlie & Tashakkori, 2006).

In a concurrent design, quantitative and qualitative data are collected separately but concurrently, analyzed separately but concurrently, inferences are made separately but concurrently (Onwuegbuzie & Johnson, 2006). However, different from parallel designs, a meta-inference is drawn integrating the quantitative and qualitative data and findings (Onwuegbuzie & Johnson, 2006). The advantages of the concurrent mixed methods design are similar to a parallel approach in that the influence of time would be minimized. However, unlike the parallel approach, inferences between the quantitative and qualitative data allow for increased strength of the findings being confirmed or disproved.

In a conversion mixed methods design, one data set (qualitative or quantitative) is converted into the other and then analyzed to draw inferences (Onwuegbuzie & Johnson, 2006). Transforming qualitative data into data that can be analyzed quantitatively is known as "quantitizing" (Driscoll et al., 2007). At the same time, transforming quantitative data into data that is able to be analyzed qualitatively is known as "qualitizing" (Driscoll et al., 2007). For example, qualitative data are collected and then

converted via "quantitizing" the data into quantitative data. Concurrently, quantitative data is collected and converted via "qualitizing" the data into qualitative data. Finally, both sets of data will be analyzed, and inferences will be drawn (Onwuegbuzie & Johnson, 2006). The advantage of a conversion design is increased strength of results due to full integration of qualitative and quantitative styles. Again, the influence of time is minimized as there is a collection of one data set to obtain results of each qualitative and quantitative finding.

In a sequential design, data are analyzed before all data have been gathered as one data set (qualitative or quantitative) is analyzed and used to shape the next phase of data collection (qualitative or quantitative) (Onwuegbuzie & Johnson, 2006). The advantage of a sequential mixed method design is the high level of integration between qualitative and quantitative data and results. A disadvantage of this method is that time is a factor in obtaining final results because one data set must be collected before the next collection phase can begin.

Fully mixed designs are fully integrated and interactive throughout each stage of the study, as all data, quantitative or qualitative, are used to shape the creation of the next phase, whether qualitative or quantitative, throughout the entire study (Onwuegbuzie & Johnson, 2006). The advantage of fully mixed designs is the data are fully intertwined throughout the study. A disadvantage of this approach would be when answering separate research questions that would not benefit from both qualitative and quantitative research approaches for each question.

In this research study, a parallel mixed methods design as defined by Onwuegbuzie and Johnson (2006), or quasi-mixed methods design as defined by Teddlie and Tashakkori (2006), was used with the purpose of expansion as defined by Caracelli and Greene (1993), because separate instruments were implemented specifically to answer each research question to gain a full perspective on the topic. The quantitative data in this study were collected using a previously created survey instrument that has established validity and reliability, and then analyzed using non-parametric tests. The qualitative data in this study were collected using a survey newly created and piloted by the author, and then analyzed via thematic analysis using a qualitative software program to code the data into themes. The quantitative and qualitative data were collected separately, but concurrently, and analyzed separately, but concurrently. The results from each set remain separate as the results were used to investigate separate research questions; thus, meta-inferences were not drawn to integrate the quantitative and qualitative data.

Major justifications for the use of mixed methods design have been presented by Caracelli and Greene (1993) as triangulation—the use of quantitative and qualitative methods to seek convergence between the results, compensatory—the use of qualitative and quantitative methods to enhance or clarify the results, and expansion—the use of quantitative and qualitative methods separately to expand the significance of the topic (Caracelli & Greene, 1993; Chen, 2006). According to Caracelli and Greene (1993) there are two additional purposes of mixed methods design to include: development—the use of results of one method (qualitative or quantitative) to inform the method of the

remaining method (qualitative or quantitative), and initiation—the use of integrated

qualitative and quantitative methods to generate new perspectives on the topic. The

author chose a quasi-mixed methods design for authentication of the data through

compensatory and expansion reinforcement.

Survey Development and Response Rates

Data collection using a survey is helpful in a mixed methods design as the

information gathered can often be formulated into quantitative and qualitative data. Using

quantitative and qualitative data together may produce differing, but corresponding

information that will provide more insight into the topic of interest than quantitative data

alone (Erickson & Kaplan, 2000). In a qualitative design, surveys can offer rich, thick

data while receiving more honest feedback when using open-ended questions (Jackson &

Trochim, 2002). Rich, thick data is "thick," or descriptive in the sense that the reader can

fully feel the detail of the situation with evoking emotion as if he or she could potentially

experience the events described (Creswell, 2007). However, rich data also poses the

difficulty of slower analysis of the data, as well as a potential threat to validity and

reliability when coding the data (Jackson & Trochim, 2002). Despite that, using a survey

for data collection is often a lower cost method, allowing for a larger sample size,

anonymity, and a reduction in interviewer biases (Greer et al., 2000; Jackson & Trochim,

2002; Rea & Parker, 1995).

When designing survey questions, the researcher should ensure questionnaire

clarity, comprehensiveness, and acceptability (Rea & Parker, 1995). The questions in the

survey should be clear and understandable, have an inclusive range of choices, and be

appropriate in length while remaining ethically and morally correct (Rea & Parker, 1995).

The author determines the structure or formatting of the questions (i.e., closed-ended or open-ended). Closed-ended questions have a set list of responses to choose from while open-ended questions allow for greater depth and variability from respondents without structuring responses (Rea & Parker, 1995). When designing a qualitative open-ended survey, wording of questions is particularly important. The author should ensure appropriate level of word choice based on the typical level of education of their audience, eliminate ambiguity of words or phrases, exclude double-barreled questions, avoid the use of biased or manipulative information in the questions that may skew or influence responses, and strive for neutral wording to avoid inappropriately provoking emotion (Rea & Parker, 1995). To adequately investigate the proposed research questions, a previously designed closed-ended questionnaire, and a newly designed qualitative open-ended survey were used in this study.

A common disadvantage of surveys is a low response rate (Greer et al., 2000). When creating a survey, multiple factors must be addressed in order to receive the best possible response rate. These factors include the day of the week the survey is distributed, length of the questionnaire, inducement factors (i.e., content, sponsorship, paid postage, privacy, and incentives), questionnaire design (i.e., aesthetic appearance, structure of questions, and nature of responses), and prenotification/follow-up of the study (Greer et al., 2000). Increased response rates allow for increased reliability and validity of the study.

31

According to Fincham (2008), researchers using survey instrumentation for data collection should strive for a 60% response rate. Using a multimodal administration method (web-based and mail-in surveys) has been shown to achieve a 60% response rate (Fincham, 2008; Schaefer & Dillman, 1998). Minimum response rates within the literature tend to vary. As cited by Baruch and Holtom (2008), some studies suggest an adequate minimum response rate of 50% (Babbie, 1990; Dillman, 2000; Rea & Parker, 1992; Roth & BeVier, 1998), whereas Fowler (1984) recommended 60% and De Vaus (1986) proposed 80% as a minimum response rate. The study by Schreiber et al. (2011) using the MPOC-20 survey achieved a 35% return rate of the survey, while Myrhaug et al. (2016) had a 34% return rate when using a postal survey design with the MPOC-20 survey. Lastly, Cook et al. (2000) suggested a minimum response rate is not necessary as long as the data provide adequate representation of the population (Baruch & Holtom, 2008; Fincham, 2008).

Summary

In this chapter, the researcher explained FCC and discussed the working definition of FCC in this study. The researcher also provided information on the origin of FCC, which originated in as early as 1950 and continues to evolve through today. Components of FCC were presented, including those created by Gallo et al. (2016), those created by S. King, Rosenbaum, et al. (1996) of the Canadian organization CanChild, as well as the components from Kuo et al. (2012). Furthermore, the researcher addressed the importance of incorporating FCC into pediatric home health therapies as there has been a lack of evidence stating whether or not therapists are including FCC into their plan of

care. Next, the researcher provided information on qualitative research data collection and analysis methods, and mixed method designs in research showing that adding qualitative data to quantitative data can enhance the overall product with a more holistic conclusion. Lastly, the researcher discussed survey development and the key components required when creating a sound survey to use in a research study, as well as survey response rates.

CHAPTER III

METHODS

FCC is a model that includes families and patients in all aspects of the plan of care and treatment of the patient. While there has been growth and progression in the area of FCC over the years, implementation of FCC in the pediatric home health setting is still limited (Kuo et al., 2012). The purposes of this study were to determine how many of the FCC concepts were being incorporated by therapists in the pediatric home health setting, to investigate the differences in incorporating FCC concepts among families with different cultures and different languages, and to explore parents' expectations of FCC within the home health pediatric therapy setting. This chapter describes the methods that were used in the study. It will start with a discussion on the quasi-mixed method design. Next, the researcher will address inclusion/exclusion criteria and sampling plans for participants of the study. Instrumentation will be introduced and discussed, followed by the data collection procedures, concluding with information on the data analysis processes.

Research Design

This study used a quasi-mixed (parallel mixed) methods design to meet the purposes of the study. Quantitative analysis of Measure of Processes of Care-20 (MPOC-20) scores was used to determine the number of FCC components incorporated in the home health setting and to determine differences in use of FCC components when

language or cultural/ethnic differences exist. Qualitative analysis using a thematic analysis approach was used to define family expectations regarding FCC in the pediatric home health setting.

Participants

Parents/caregivers of children with special needs who were currently receiving physical, occupational, and/or speech therapy were recruited from two pediatric home health agencies through a grassroots method. To be included in this study, each participant must have had a child, aged 0 to 21 years, who was currently receiving therapy services (minimum of two therapy sessions from at least one discipline) for any diagnosis through the home health agencies across six regions of the state of Texas (Central Texas, Dallas, East Texas, Fort Worth, Houston, and West Texas). Participants who did not understand or speak English or Spanish were excluded from the study. Written informed consent was signed by the participant prior to engagement in the study in the form of a printed statement at the top of each survey.

Instrumentation

Two survey instruments were used to carry out this study, an author-constructed survey and the MPOC-20, each described below.

7-Item Qualitative Survey

A 7-item qualitative survey (see Appendix A) that included demographic questions (preferred language, age, ethnicity/culture, gender, child's age, child's diagnosis, child's current therapy disciplines, and time on service) and seven open-ended questions regarding parents' expectations of FCC were developed using the five core

components of FCC identified by Gallo et al. (2016). Content experts reviewed the qualitative questions and provided feedback, primarily editorial in nature. The 7-item qualitative survey was translated from English to Spanish via AG Linguistics, Inc. (see Appendix B for biography of linguist) and back-translated by a native Spanish speaker. Prior to distribution, the survey was pilot tested on eight participants (four English- and four Spanish-speaking) whose children were currently receiving therapy services to ensure face validity of the survey. Piloting this qualitative survey allowed for clarity of the survey questions, exposed problems with instructions, as well as indicated areas for further examination. If a specific question on the survey was consistently misinterpreted, as shown by inconsistent codes and themes during the pilot portion of the study, that question was corrected or clarified before the study.

Measure of Processes of Care

The MPOC is a valid and reliable survey allowing self-report on the perception of the extent that FCC is addressed or used in services (S. King et al., 1995; Schreiber et al., 2011). The survey assesses healthcare providers' use of FCC behaviors (S. King et al., 1995). Initially created in 1995, the MPOC was a 56-question survey with good internal consistency of Cronbach's alpha of 0.63 to 0.96 and test-retest reliability with interclass correlation coefficients of 0.78 to 0.88 (S. King, Rosenbaum, et al., 1996). To show good validity, the MPOC was positively correlated with a measure of satisfaction (0.40 to 0.64) and negatively correlated with a measure of stress (-0.47 to -0.55) when dealing with a child's treatment in an ambulatory rehabilitation center (S. King, Rosenbaum, et al., 1996). S. King et al. (2004) created a shortened version of the MPOC-56, the MPOC-20,

which was later refined in 2004. The MPOC-20 shows similar and consistent

psychometric properties and reflects the same five concepts as the MPOC-56 (S. King et

al., 2004). These concepts include: (a) Enabling and Partnership, (b) Providing General

Information, (c) Providing Specific Information about the Child, (d) Coordinated and

Comprehensive Care for the Child and Family, and (e) Respectful and Supportive Care

(S. King, Rosenbaum, et al., 1996). More specifically, the MPOC-20 has good internal

consistency of Cronbach's alpha of 0.83 to 0.90, good test-retest reliability of 0.81 to

0.86, and moderate to high construct validity with intercorrelation coefficients of 0.56 to

0.87 (S. King et al., 2004). The MPOC-20 is comprised of 20 closed-ended questions

with a range of scores from 0 to 7 with a score of 0 = *Not Applicable*, 1 = *Not at All*, up to

a score of 7 = *To a Very Great Extent*. When separated into FCC concepts, Questions 4,

7, and 8 comprise Enabling Partnership, questions 16-20 comprise Providing General

Information; Questions 2, 14 and 15 comprise Providing Specific Information about the

Child; Questions 5, 6, 10 and 12 comprise Coordinated and Comprehensive Care for the

Child and Family; and Questions 1, 3, 9, 11, and 13 comprise Respectful and Supportive

Care. Validated English and Spanish versions of the MPOC-20 were used in this study.

Appendix C lists the MPOC-20 questions and the scoring definitions.

Procedures

The author obtained approval through the Texas Woman's University (TWU)

Institutional Review Board (IRB; see Appendix D) and obtained a signed agency

approval letter (see Appendix E) from participating pediatric home health agencies. An

education module (see Appendix F) was created and presented to the therapists employed

by the participating agencies to ensure each therapist was educated about their role in the process of disseminating the research materials throughout the study. The education module was available to the therapists as a reference throughout the duration of the study. The agencies' employed therapists delivered a recruitment flyer (see Appendix G) to all qualified patient families receiving therapy services. The flyer provided information about the purpose of the study and how to participate in the study if desired. There were approximately 2,250 patients on the current therapy caseload for the identified agencies at the start of the study. To ensure adequate sampling from each region, 20% of the patient census from each service region of the state was included, totaling 450 participants. Four hundred and fifty parents/caregivers of these patients were randomly selected for participation. Convenience sampling occurred as therapists disseminated surveys at the first X number of treatment sessions in each area beginning on the study start date until all surveys were handed out. The researcher uses the term "X number" as the regions had varying numbers based on the 20% sample per region, per agency. Good survey response rates vary from 30–80%, but most often, a survey rate of 34–41% is achieved in the pediatric population when using the MPOC-20 (Dyke et al., 2006; Myrhaug et al., 2016; Schreiber et al., 2011). Therefore, the researcher used a mail-in method of the surveys and strived for a 30% return rate to ensure adequate sample size, reduce type 2 errors, and improve external validity of the study.

The researcher determined the overall start date of the project prior to disseminating the informational recruitment flyer. Employed therapists were given the flyer to hand deliver to the primary family member of all patients on the agencies'

therapy caseload seven to 10 days before the surveys were to be distributed. The researcher provided a research packet to the agency's employed therapists containing the MPOC-20 survey, the qualitative survey with an informed consent statement and general information, the address sheet (see Appendix H), and a self-addressed and stamped envelope. Employed therapists only hand-delivered the packets to potential candidates. The treating therapists gave the packet of materials to the primary family member of the first 20% of patients on the agencies' therapy caseload per region as previously described. Participants were asked to return the completed surveys in the self-addressed and stamped envelopes within 30 days of the start date specified in the materials provided. Due to a low return rate, the researcher extended the study for 2 weeks totaling 44 days. By extending the end date by 2 weeks, the return rate rose by 2.45%. Employed therapists were to inform candidates that completing the survey was voluntary, and if they were interested, participants could complete the surveys and return them to the researcher via the self-addressed and stamped envelopes. Therapists were not to answer any questions regarding the study. If any participant had questions, they were asked to contact the researcher directly via the contact information provided with the survey. Each packet provided all information in English and Spanish to ensure Spanish-speaking participants had an appropriate version of the surveys.

Fifteen days after the survey packets were initially distributed, the researcher asked treating therapists to hand deliver a reminder letter (see Appendix I) in English and Spanish to all participants to increase participation and return of the survey. Due to a low return rate at the end of the 30 days, the researcher extended the end date by 2 weeks. At

this time, the treating therapists reached out to all participants via phone calls, text messages, or while in person at the therapy sessions to remind participants to complete and return the survey. All participants who completed and returned the entire survey packet to the author within the allotted timeframe, to include the 2-week extension, were entered into a drawing for a chance to win a $50 gift card. A total of 10 $50 gift cards were awarded to qualified participants. In order to retain the privacy of the survey answers, a separate sheet was provided in the survey packet for home address to be listed should the participant wish to be entered into the drawing for a gift card. An individual, not involved in the study in any other way, received the returned packets and separated the surveys and address sheets. The address sheets received with qualifying surveys were stored separately from the surveys as they were received. The individual delivered the completed surveys to the researcher. When the study timeframe ended, the individual, with the researcher's supervision, randomly drew 10 address sheets and mailed each of those 10 participants a $50 gift card as an incentive for participating in this research study. When the 10 gift cards were mailed, all address sheets were immediately shredded.

Data Analysis

Quantitative analysis included descriptive statistics from both surveys. The Statistical Package for Social Sciences (SPSS 25.0 statistical software package, IBM Corporation, Chicago, IL) was used to analyze the quantitative data. Means and standard deviations were used to present demographic information (child's age) and frequencies were shared on remaining demographic information (participant's gender, preferred language, ethnicity/culture, child's diagnosis, and child's current therapy discipline(s)).

Time on service was eliminated from analysis as it was used solely to ensure inclusion

criteria was met. Means and standard deviations were used to present demographic

information (child's age) and frequencies were shared on remaining demographic

information (participant's gender, preferred language, ethnicity/culture, child's diagnosis,

and child's current therapy discipline(s)) for all data. Descriptive statistics were used to

analyze the results of the MPOC-20. To further analyze the MPOC-20, the score of 0

(Not Applicable) was removed to calculate medians and IQRs per scoring instructions to

avoid unnecessary skewing of the data, and the score was treated as if the data were

missing. Median scores were calculated on each item of the MPOC-20. The percentiles of

the MPOC-20 data were used to show the quartiles with the central tendency from the

interquartile range (IQR) in the box-and-whisker plot. The IQR identified the spread of

the middle 50% of the data, and any outliers in the data. The IQR was also used in this

study to compare findings to a previous study by Schreiber et al. (2011) that analyzed

their data using the median and IQR of each S. King, Rosenbaum, et al. (1996) FCC

concept. The responses of this study were then analyzed using the median scores to

determine how many of the S. King, Rosenbaum, et al. (1996) FCC concepts were being

utilized within the participants' child's pediatric home health therapy.

Participants were grouped by preferred language (English or Spanish) and the

culture/ethnicity they best identified with. The researcher anticipated there would be four

levels for this grouping variable, (a) Caucasian American, (b) African American, (c)

Hispanic: Mexican, South American, and Spain, and (d) Asian: Indian, Middle Eastern,

Vietnamese, Japanese, and Chinese. However, after data were collected there were five

levels for this grouping variable, (a) Caucasian American, (b) African American, (c) Hispanic (Mexican, South American, and Spain), (d) Other (Asian, Native American, and multiracial), and (e) Unknown. A Mann-Whitney U analysis was conducted to determine variability in MPOC-20 scores between people whose preferred language is English or Spanish. Kruskal-Wallis analysis was conducted to determine variability in MPOC-20 scores among the five cultural/ethnic groups.

Qualitative data were gathered based on a phenomenological approach using a validated 7-question open-ended survey created by the author to obtain the participants' expectations of FCC in pediatric home health therapies. The Gallo et al. (2016) FCC concepts were used when creating the qualitative survey. Using an elemental method with initial coding as a first cycle coding method, and pattern coding as a second cycle coding method (Saldana, 2013), the researcher, two other licensed physical therapists, who also served as mentors, and one non-licensed person read and re-read the survey answers. Each item was categorized into main codes and then re-coded generating themes based on a thematic analysis approach (Braun & Clarke, 2006) using qualitative software (QSR NVivo) for the coding of all qualitative data. After re-coding via pattern coding, Questions 1 and 2 of the survey were re-coded via focused coding to sub-code into FCC concepts. The thematic analysis approach was also conducted on Questions 1 and 2 of the survey to generate themes.

To address the overall rigor (internal and external validity, and reliability) of the study, credibility, transferability, dependability, and confirmability were addressed. To ensure trustworthiness of this aspect of the research, credibility was addressed through a

review of the 7-question survey by three content experts. Additionally, data triangulation was ensured by using a wide range of participants from various locations across the state, applying tactics to ensure participants answer honestly by completing the surveys in their own home at their leisure. Finally, four additional licensed physical therapists (who also served as mentors) provided feedback on the study's methods and data analysis throughout the study. Transferability was addressed by using a large sample size across six areas of the state and incorporating multiple languages within the study. A detailed description of the methods used in the study was presented to aid in reproducibility and dependability, and display integrity of the results to the extent that others may confirm the study's results. Confirmability was also addressed as the author stated any predisposed assumptions as well as kept a detailed audit trail throughout the process describing the methods used, raw data collected, analytic notes created, and a detailed process of the analysis and interpretation of the data.

Summary

This chapter explained the methodology chosen for this study. To summarize, the author used a quasi-mixed (parallel mixed) methods research design. The author described inclusion and exclusion criteria for participation in the study. Next, the surveys, a 7-question qualitative survey and the MPOC-20 survey, were discussed with information provided on the reliability and validity of these instruments. A detailed description of the study's procedures was presented. Lastly, the techniques used for data analysis were defined and the researcher discussed the overall rigor of the study.

CHAPTER IV

RESULTS

The purposes of this study were to determine how many of the FCC concepts are being incorporated by therapists in the pediatric home health setting, to investigate the differences in incorporating FCC concepts among families with different cultures and different languages, and to explore parents' expectations of FCC within the home health pediatric therapy setting. The results of this study provide a description of the sample, quantitative outcomes and qualitative findings to address the research questions. The quantitative results indicate which FCC concepts are being incorporated in home health pediatric therapies as well as define the differences in incorporating FCC concepts when there are language or cultural differences. The qualitative results provide themes reviewing parents' expectations of therapists incorporating FCC concepts within home health pediatric therapies.

Description of the Sample

Four hundred and fifty survey packets were disseminated to six areas across the state of Texas through two home health agencies. Metropolitan areas included Dallas, Fort Worth, and Houston, Texas. More rural areas included east west, and central Texas. To standardize sampling, 20% of the current patient census in each location per agency was obtained totaling 450 participants for the study. Of the 450 eligible participants, there were 76 packets returned for a return rate of 16.9%.

Participants were the parent or primary caregiver of a child currently receiving

therapy services with one of the two participating agencies. Participants in the study

consisted of a greater number of females than males, with a small percentage who did not

indicate their sex. A majority of the returned surveys were English. Originally, there were

four ethnicities/cultures anticipated. However, after the conclusion of the study, there

were five ethnicities/cultures including: Caucasian, Hispanic, African American, Other

(consisting of Asian, Native American, and Multiracial), and Unknown. The majority of

participants were Caucasian (38%), Hispanic (21%) and African American (17%). See

Table 2 for descriptive information on ethnicities/cultures.

From the 76 surveys, 67 provided the child's age. The mean age of the children

was 4.8 years old, ranging from 0.6 years (7 months) to 19 years old, with a standard

deviation (SD) of 3.7 years. Reported diagnoses of the children varied greatly and

included speech or feeding delays, autism, congenital disorders, cerebral palsy, genetic

disorders, and developmental delay among others. There were many children with

multiple diagnoses creating difficulty with calculating frequencies within distinct

categories. For children with multiple diagnoses, the child was categorized by the main

diagnosis for which the child was receiving care. For descriptive purposes, children were

grouped into six main diagnosis categories: autism, genetic/chromosomal disorders,

neurological/spinal disorders, speech delays, other, and unknown. The "other" group

included children that had specific diagnoses that did not fall within the other categories.

The 14 children in this group included children with attention deficit hyperactive disorder

($n = 2$), prematurity ($n = 4$), developmental delays ($n = 2$), prematurity with

45

developmental delays ($n = 1$), torticollis ($n = 1$), sensory processing disorder ($n = 1$), laryngomalacia with hearing problems and asthma ($n = 1$), medulloblastoma ($n = 1$), and severe combined immunodeficiency (SCIDS; $n = 1$). See Table 2 for diagnoses frequencies. The therapy disciplines received were physical therapy (PT), occupational therapy (OT), speech therapy (ST) or a combination of the three disciplines. The participants received various combinations of therapy services with the largest combination being PT, OT, and ST services (28.9%). See Table 2 for the combinations of therapy services. Although the amount of time on service was included on the survey as a screening to ensure eligibility, very few surveys included detailed information. Therefore, this item was omitted from analysis in regard to participant's demographic information.

Table 2

Sample Characteristics

Characteristic (*N* = 76)	*n* (%)
Participant Gender	
Female	41 (61.8%)
Male	24 (31.6%)
No Response	5 (6.6%)
Language of Survey Returned	
English	69 (90.8%)
Spanish	7 (9.2%)
Diagnoses	
Other	14 (18.4%)
Unknown	14 (18.4%)
Genetic/Chromosomal	13 (17.2%)
Autism	12 (15.8%)
Speech Delays	12 (15.8%)
Neurological/Spinal	11 (14.5%)
Therapy Services Receiving	
Single Discipline	36 (47.4%)
ST	17 (22.4%)
PT	11 (14.5%)
OT	8 (10.5%)
Multiple Disciplines	40 (52.6%)
PT/OT/ST	22 (28.9%)
OT/ST	13 (17.1%)
PT/OT	4 (5.3%)
PT/ST	1 (1.3%)
Self-reported race/ethnicity/culture	
Caucasian	29 (38.2%)
Hispanic	16 (21.1%)
African American	13 (17.1%)
Unknown	11 (14.5%)
Other	7 (9.2%)

Note. OT = occupational therapy, PT = physical therapy, ST = speech therapy

Quantitative Outcomes

Quantitative results include median scores on each MPOC-20 question to describe the perceptions of the extent that FCC is used in therapy services in pediatric home health in Texas. Furthermore, the MPOC-20 data were analyzed by FCC concepts to show the quartiles with the central tendency from the interquartile range (IQR). Table 3 shows medians and interquartile ranges for each of the five S. King, Rosenbaum, et al. (1996) FCC domains and individual questions within domains for the complete sample of participants.

The IQR of median scores of each FCC concept can be seen in Figure 1 for a better visual as a boxplot with outliers. Outlier criteria were determined by SPSS using a step (M) of 1.5x the IQR signified by dots on the figure. While each dot is represented by participant response, each dot is not necessarily signified by one single response. Numbers adjacent to the dot indicate the case for each participant response. For example, under Enabling Partnership, a median score of 4 has seven outlier responses, case numbers 13, 24, 26, 34, 41, 60, and 74, whereas a median score of 3.5 has one outlier response, case number 51; under Coordinated/Comprehensive Care, a median score of 4 has two outlier responses, case numbers 13 and 41, while a median score of 3.5 has one outlier response, case number 76. Finally, under Respectful/Supportive Care, a median score of 4 has three outlier responses, case numbers 13, 41, and 51. Of note, case number 41 resulted in outlier responses for three of the five FCC concepts, while case numbers 13 and 51 resulted in outlier responses for two of the five FCC concepts. There was a total of

nine participants with outlier responses. Demographic information of the outlier

respondents is shown in Table 4.

Table 3

MPOC-20 Descriptive Statistics, Median, and IQR on Family-Centered Care Concepts ($n = 76$[a])

FCC Concept	Median Score	IQR
Enabling Partnership	**7**	**1**
Q4. Let you choose when to receive information and the type of information you want?	6[b]	
Q7. Fully explain treatment choices to you?	7	
Q8. Provide opportunities for you to make decisions about treatment?	7[a]	
Providing General Information	**6**	**3**
Q16. Give you information about the types of services offered at the organization or in your community?	6[b]	
Q17. Have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	6[b]	
Q18. Provide opportunities for the entire family to obtain information?	6[ab]	
Q19. Have information available to you in various forms, such as a booklet, kit, video, etc.?	6[b]	
Q20. Provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	6[b]	
Providing Specific Information about the Child	**6**	**3**
Q2. Provide you with written information about what your child is doing in therapy?	6[b]	
Q14. Provide you with written information about your child's progress?	6[b]	
Q15. Tell you about the results from assessments?	7[b]	
Coordinated and Comprehensive Care for the Child and Family	**7**	**1**
Q5. Look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	
Q6. Make sure that at least one team member is someone who works with you and your family over a long period of time?	7	
Q10. Plan together so they are all working in the same direction?	7	
Q12. Give you information about your child that is consistent from person to person?	7[b]	
Respectful and Supportive Care	**7**	**1**
Q1. Help you to feel competent as a parent?	7	
Q3. Provide a caring atmosphere rather than just give you information?	7	
Q9. Provide enough time to talk so you don't feel rushed?	7	
Q11. Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "mom" or "dad")?	7[ab]	
Q13. Treat you as an individual rather than as a "typical" parent of a child with a disability?	7[b]	

Note. [a]$n = <76$ due to no response for that question. [b]$n = <76$ due to response of 0 (not applicable), IQR = interquartile range

Figure 1

IQR of the MPOC-20 scores listed by FCC concept domains

InterQuartile Range (IQR) of MPOC-20 by Family-Centered Care (FCC) Concept
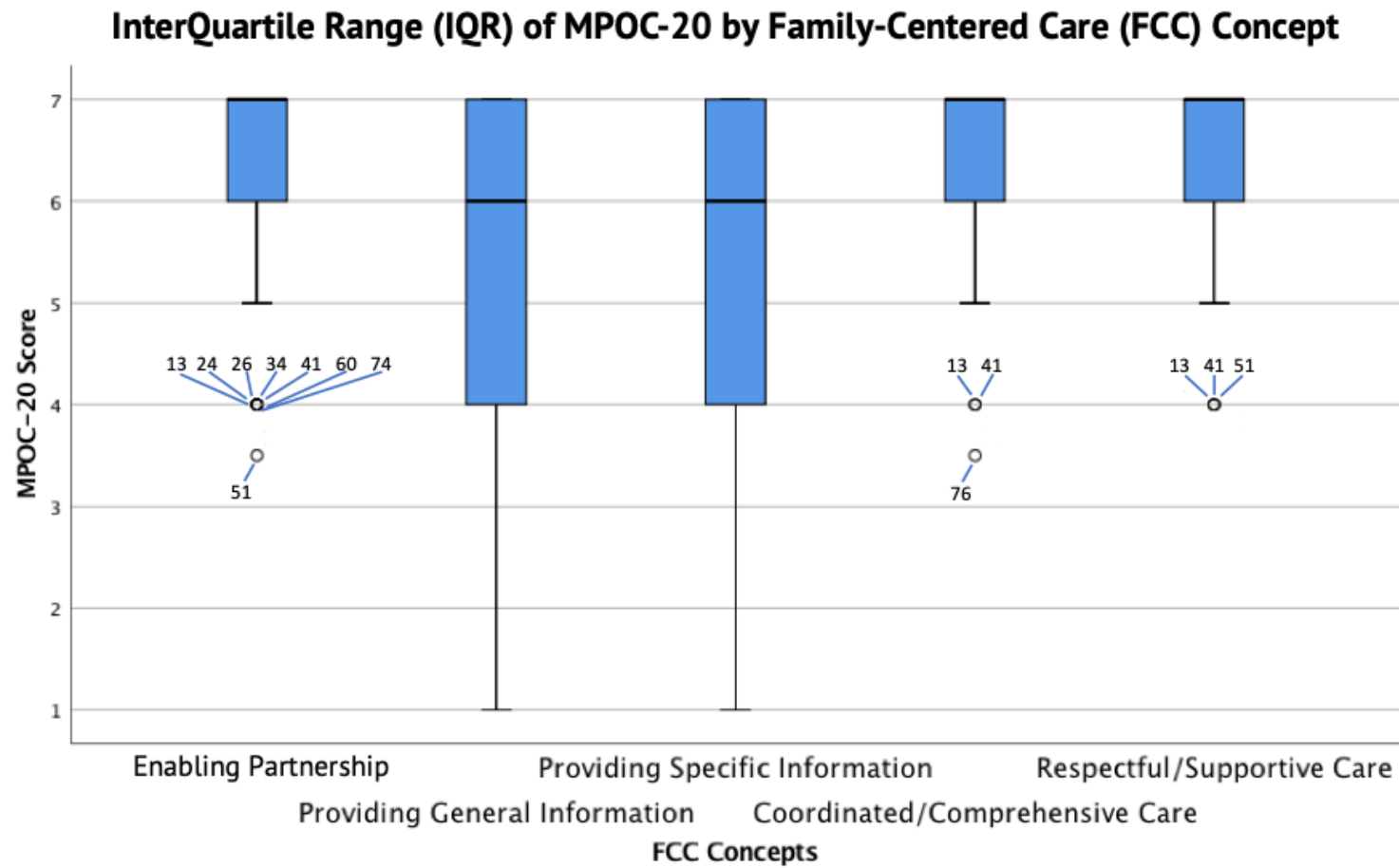
Table 4

Sample Characteristics of Outlier Responses

Characteristic ($N = 9$)	n (%)
Participant Gender	
Female	6 (66.7%)
Male	9 (33.3%)
Language	
English	9 (100%)
Spanish	0 (0%)
Diagnoses	
Neurological/Spinal	3 (33.3%)
Genetic/Chromosomal	2 (22.2%)
Autism	1 (11.1%)
Speech Delays	1 (11.1%)
Other	1 (11.1%)
Unknown	1 (11.1%)
Therapy Services Receiving	
Single Discipline	3 (33.3%)
OT	1 (11.1%)
PT	1 (11.1%)
ST	1 (11.1%)
Multiple Disciplines	6 (66.7)
PT/OT/ST	5 (55.6%)
OT/ST	1 (11.1%)
PT/OT	0 (0%)
PT/ST	0 (0%)
Self-reported race/ethnicity/culture	
Caucasian	4 (44.4%)
Unknown	2 (22.2%)
African American	1 (11.1%)
Hispanic	1 (11.1%)
Other	1 (11.1%)
Age	Years
Mean (SD)	5.97 (4.05)[a]
Range (min – max)	11 (1-12)[a]

Note. [a] $n = 8$ due to no response. OT = occupational therapy, PT = physical therapy, ST = speech therapy

The Mann-Whitney U, a non-parametric test, was used to analyze differences in incorporating FCC concepts between individuals who spoke different languages. The null hypothesis (H_0) states there are no differences between English- and Spanish-speaking families in regard to incorporation of FCC concepts. Differences were analyzed for the entire sample ($n = 76$) with an alpha level of 0.05, using the median scores of each set of grouped questions forming each FCC concept (see Table 5). Analysis of median scores ($n = 76$) indicated that there was no difference in incorporating FCC concepts for individuals who spoke Spanish compared to individuals who spoke English for all concepts (see Table 6).

Table 5

Mann-Whitney U Mean Ranks Between English and Spanish for Total Data

	Language	n	Mean Rank	Sum of Ranks
Enabling Partnership	English	69	37.79	2607.50
	Spanish	7	45.50	318.50
	Total	76		
Providing General Information	English	68	36.54	2485.00
	Spanish	7	52.14	365.00
	Total	75		
Providing Specific Information	English	69	37.05	2556.50
	Spanish	7	52.79	369.50
	Total	76		
Coordinated/ Comprehensive Care	English	69	37.64	2597.50
	Spanish	7	46.93	328.50
	Total	76		
Respectful/ Supportive Care	English	69	38.19	2635.00
	Spanish	7	41.57	291.00
	Total	76		

Table 6

Mann-Whitney U Test Between English and Spanish for Total Data

$n = 76$	Enabling Partnership	Providing General Information[a]	Providing Specific Information	Coordinated/ Comprehensive Care	Respectful/ Supportive Care
Mann-Whitney U	192.50	139.00	141.50	182.50	220.00
Wilcoxon W	2607.50	2485.00	2556.50	2597.50	2635.00
Z	-.97	-1.89	-1.93	-1.21	-.45
Asymptotic Sig. (2-tailed)	.333	.059	.054	.228	.655

Note. [a] $n = 75$

The mean ranks were higher with Spanish-speaking participants in all five domains. With this finding and noting there were significantly fewer Spanish surveys returned ($n = 7$), the author re-analyzed this data with a smaller matched sample ($n = 14$) from Spanish surveys ($n = 7$) and English surveys ($n = 7$) using location, gender, discipline, diagnosis, and age as matching variables (see Table 7). Analysis of median scores for the matched sample (see Tables 8 and 9) indicated there were still no differences for all concepts.

Table 7

Demographic Data for Matched Samples

	Location	Gender	Discipline	Diagnosis	Age
Spanish	Houston	F	OT	Autism	5
English	Houston	F	OT/ST	Autism	4
Spanish	Dallas	F	PT/OT/ST	Unknown	Unknown
English	Dallas	F	PT/OT/ST	Genetic	1
Spanish	Dallas	M	PT/OT/ST	Other	2
English	Dallas	M	PT/OT/ST	Genetic	2
Spanish	Houston	M	PT/OT	Unknown	Unknown
English	Houston	F	PT/OT	Genetic	2
Spanish	Houston	M	OT	Unknown	Unknown
English	West TX	M	OT/ST	Unknown	3
Spanish	East TX	M	OT	Autism	6
English	East TX	F	OT/ST	Autism	6
Spanish	East TX	M	OT	Autism	8
English	East TX	M	OT	Other	Unknown

Table 8

Mann-Whitney U Mean Ranks Between English and Spanish for Matched Data

	Language	n	Mean Rank	Sum of Ranks
Enabling Partnership	English	7	7.00	49.00
	Spanish	7	8.00	56.00
	Total	14		
Providing General Information	English	7	6.36	44.50
	Spanish	7	8.64	60.50
	Total	14		
Providing Specific Information	English	7	6.50	45.50
	Spanish	7	8.50	59.50
	Total	14		
Coordinated/ Comprehensive Care	English	7	7.14	50.00
	Spanish	7	7.86	55.00
	Total	14		
Respectful/Supportive Care	English	7	7.07	49.50
	Spanish	7	7.93	55.50
	Total	14		

Table 9

Mann-Whitney U Test Between English and Spanish for Matched Data

$n = 14$	Enabling Partnership	Providing General Information	Providing Specific Information	Coordinated/ Comprehensive Care	Respectful/ Supportive Care
Mann-Whitney U	21.00	16.50	17.50	22.00	21.50
Wilcoxon W	49.00	44.50	45.50	50.00	49.50
Z	-.52	-1.14	-1.12	-.44	-.45
Asymptotic Sig. (2-tailed)	.60	.25	.26	.66	.65
Exact Sig. [2*(1-tailed Sig.)]	.710[a]	.318[a]	.383[a]	.805[a]	.710[a]

Note. [a] Not corrected for ties.

The Kruskal-Wallis was used to analyze differences in incorporating FCC concepts among cultures/ethnicities. The null hypothesis (H_0) states there are no differences among cultures/ethnicities in regard to incorporation of the FCC concepts. Differences were analyzed with an alpha level of 0.05, using the median scores of each set of grouped questions forming each FCC concept. Analysis of median scores indicate there were no differences in incorporating FCC concepts among cultures/ethnicities for all concepts (see Table 10).

Table 10

Independent-Samples Kruskal-Wallis Test Summary by FCC Concept

$n = 76$	Enabling Partnership	Providing General Info[a]	Providing Specific Info	Coordinated/ Comprehensive Care	Respectful/ Supportive Care
Kruskal-Wallis H	1.26	2.16	4.28	3.19	1.73
Asymptotic Sig.	.87	.71	.37	.53	.79

Note. [a] $n = 75$; degrees of freedom = 4

Qualitative Outcomes

The qualitative seven open-ended question survey was included to gather information about parents' expectations regarding therapists incorporating the FCC concepts defined by Gallo et al. (2016) during their child's home health pediatric therapies. These FCC concepts include: (a) Education by the Provider to the Patient and/or Family, (b) Information Sharing from the Family to the Provider, (c) Social-Emotional Support, (d) Shared Decision-Making, and (e) Adapting Care to Match the Family Background. Qualitative analysis was conducted to investigate each survey

question individually and to create themes for each FCC concept. The elemental method with initial coding was used as first cycle coding, followed by pattern coding for second cycle coding (Saldana, 2013). This process was completed with the use of NVivo 12 Mac to code and re-code each response into themes using the thematic analysis approach for each question individually.

The data from each of the survey questions yielded one predominant theme per question. The themes discussed below summarize the participants' responses to each of the survey questions along with the rationale for each identified theme. While 76 participants returned surveys, a few questions were left blank. It was assumed that answers left blank were done so because the participant was not sure how to answer the question. When reviewing responses by code/sub-code, the readers will notice that n does not equal 76 as some responses were coded into multiple codes based on the relevance and are listed as "frequency" in each code/sub-code. Codes for all open-ended questions were generated using an open-coding or bottom-up approach of initial coding, then re-coded using pattern coding. After codes were generated for Questions 1 and 2, the data were re-coded again to identify which FCC concepts were being expressed in the participants understanding and expectations of FCC. This top-down approach of focused coding used the five pre-generated sub-codes of Gallo et al.'s FCC concepts (2016) and one FCC concept from S. King, Rosenbaum, et al. (1996). While Coordinated and Comprehensive Care for the Child and Family is a S. King, Rosenbaum, et al. (1996) FCC concept, it was included as a sub-code as it was the most relevant concept for particular participant responses that did not fit into Gallo and associates' model of FCC.

58

Braun and Clarke's (2006) thematic analysis approach was used in generating the themes

by capturing the most significant patterns and relationships.

**Parental Understanding of Family-Centered Care**

The first question of the survey was intended to explore parents'/caregivers'

understanding of FCC. See Table 11 and Figure 2 for results of codes/sub-codes for this

question.

Table 11

Parental understanding of family-centered care

	Q1: In your words, define what Family-Centered Care (FCC) means to you, or what you know about FCC.		
Initial Code	Code Definition	Representative Quote from Participants	Frequency
Great Quotes	Responses taken from internet sources	"I looked it up. It's a partnership to health-care decision making as a philosophy of care."	2
Not Sure	Answered not sure what FCC entailed or not sure how to answer the question; Left blank	"I have no idea."	15
Off Topic	Responses did not directly answer the question	"I like it."	8
Therapy	Participants interchanging FCC with the typical practice of PT/OT/ST services	"Family-centered care is an agency that helps many different people with many different needs."	6
In-Home Therapy	Similar to Therapy but referring to therapy in the home setting	"Providing services in the comfort of your home."	11
Involving Family	Responses stating FCC involves the family in some way		49
• Background		• "I assume it is referring to providing care to my child that fits within our family needs."	14
• Info Sharing		• (None)	0
• Provider Education		• "I would guess that it would refer to care that includes parent education and participation."	13
• Shared-Decision Making		• "The therapist and family (parents) work together to meet the child's needs by working in concert to assess, intervene, and evaluate his progress."	22
• Social-Emotional		• "Family-Centered Care means to me that they help the family through a process of a child's diagnosis."	2
• Coordinated and Comprehensive Care		• "It is an approach to healthcare in which the family gets support from all disciplines needed to help the child in need. It involves physicians, therapists, and others centered on the child to help him or her achieve their highest potential intellectually, physically, mentally, and spiritually"	1

Figure 2

Parental understanding of family-centered care
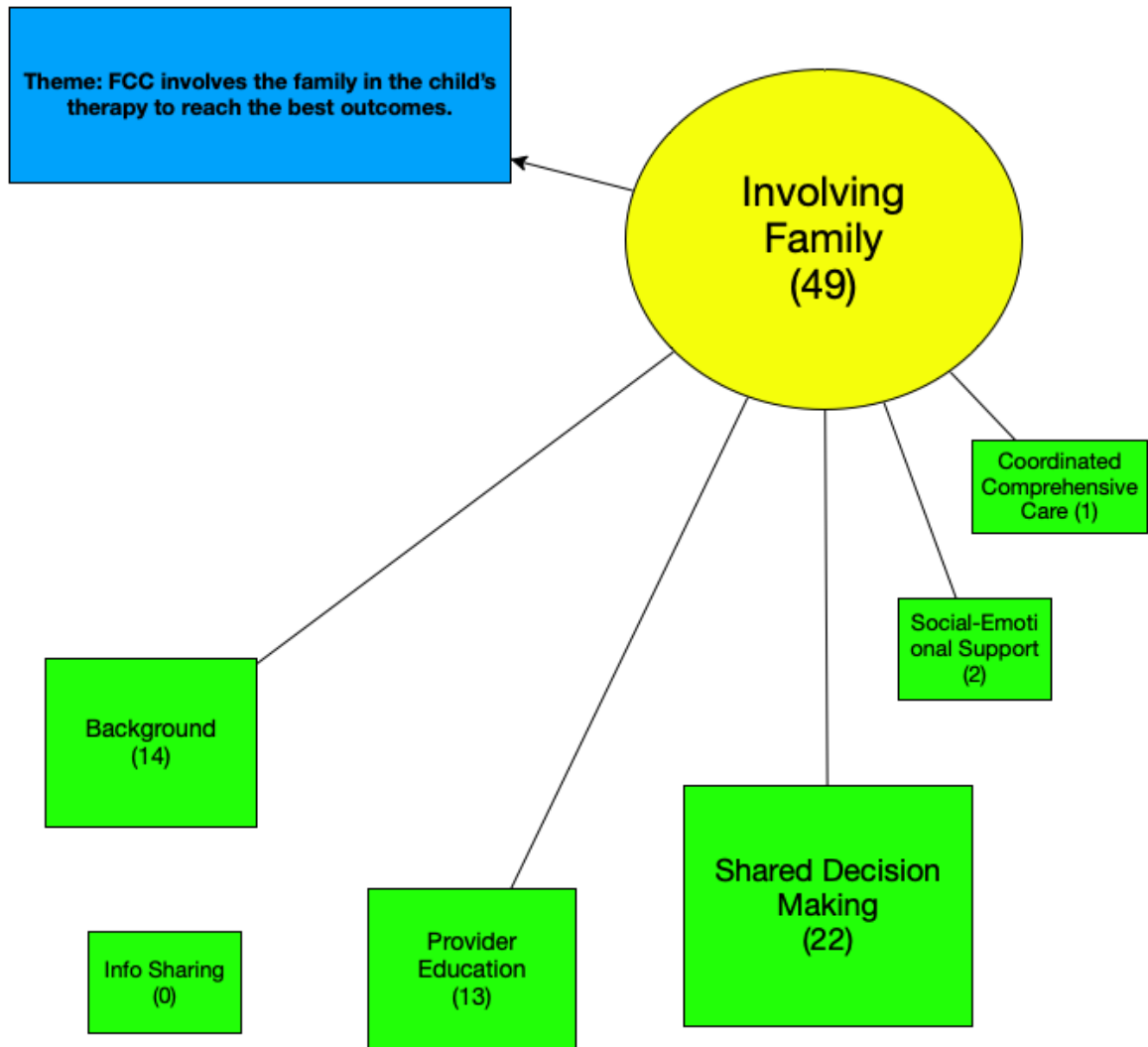
Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 1. The direction of the arrow signifies the relationship between the code and theme. *Involve Family* was recoded into sub-codes matching five FCC concepts indicated by solid lines.

It is important to note that a number of participants did not know what FCC was or did not understand the question ($n = 23$). Of those that did have some understanding and were able to express what FCC meant to them, two responses were likely taken from an internet source verified by web search or participant stating they searched the internet when generating their response.

Nevertheless, the majority of participants ($n = 49$) contributed to the theme for this question: FCC involves the family in the child's therapy to reach the best outcomes. This involvement includes the therapist adapting to match the child/family's background, providing education to the family, sharing the decision-making process, providing social-emotional support, or creating a coordinated and comprehensive plan of care. Interestingly, no participants directly or indirectly mentioned information sharing.
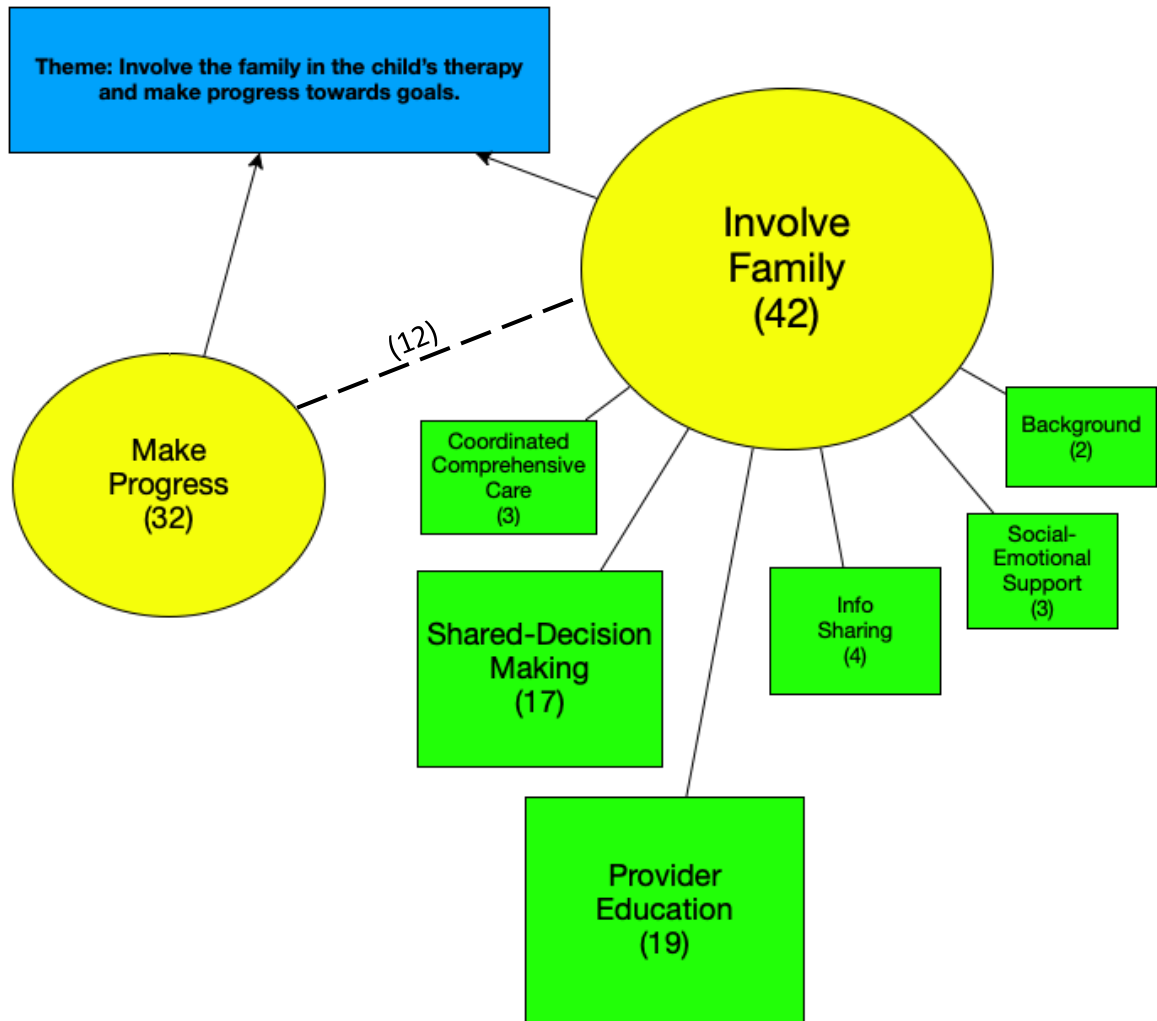
Parental Expectations of FCC in Therapies

The second question of the survey was intended to explore parents/caregivers' expectations of incorporating FCC concepts into their child's therapies. See Table 12 and Figure 3 for results of codes/sub-codes for this question.

Table 12

Parental expectations of family-centered care in therapies

Initial Code	Code Definition	Representative Quote from Participants	Frequency
Q2: What are your expectations regarding incorporating Family-Centered Care concepts into your child's therapies?			
None	Responses stating they have no expectations	"We have no expectations."	8
Not Sure	Answered not sure what to expect or not sure how to answer the question; Left blank	"I don't know what to expect."	6
Off Topic	Responses did not directly answer the question	"Therapists are very good people who do what they provide and fulfill it."	3
Make Progress	Responses where they expect incorporating FCC concepts will improve progress in child's abilities or towards therapy goals	"That they can help my son in areas that he needs help in and try to help improve his way of life, to help his development."	32
Involve Family	Responses where expectation is family to be involved in the plan of care		42
• Background		• "It needs to be at the forefront of every session. Family life affects a child just as much as an adult. The therapist should use anything pertinent in the session to be able to relate better to the child."	2
• Info Sharing		• "Being able to communicate openly with therapists during the good and the bad."	4
• Provider Education		• "I expect the therapists to inform family of goals and teach/inform them of how to help reach them outside of 'therapy'."	19
• Shared-Decision Making		• "We expect to be able to work together to develop a plan to help my little guy reach his full potential."	17
• Social-Emotional		• "Establishing a relationship and not feeling like 'another client'."	3
• Coordinated and Comprehensive Care		• "I have been fortunate to have a pediatrician, OT, PT, and Speech along with neurologist and brace facility that all work together. I have had the same people for many years."	3

Figure 3

Parental expectations of family-centered care in therapies

Theme: Involve the family in the child's therapy and make progress towards goals.

Involve Family (42)

Make Progress (32)

(12)

Coordinated Comprehensive Care (3)

Background (2)

Social-Emotional Support (3)

Info Sharing (4)

Shared-Decision Making (17)

Provider Education (19)

Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 2. The direction of the arrow signifies the relationship between the code and theme. The dashed line indicates there is a shared connection between the codes *Make Progress* and *Involve Family* for 12 of the responses. *Involve Family* was recoded into sub-codes matching six FCC concepts indicated by solid lines.

The theme for this question was Involve the family in the child's therapy and make progress towards goals. The two main codes generating this theme were Involve Family and Make Progress. Participants felt their child making progress towards their goals was important. This expectation was clearly seen with 12 responses indicating they expect involvement of the family and to ensure progress was made, with seven of those responses further implying involving the family will improve the child's progress in therapy. Of those 12 responses, eight participants expected the therapists to share the decision-making process in order to make progress. To make progress toward goals, two additional responses expected the therapist to provide education to the family and child. The final two responses indicated to make progress, they expected coordinated and comprehensive care be provided. However, there were 32 responses that stated involving the family is preferred but did not imply the need to make progress.

**Parental Expectations on Education from the Provider**

The third question of the survey was intended to explore parents/caregivers' expectations of provider education to the child/family. See Table 13 and Figure 4 for results of codes/sub-codes for this question.

Table 13

Parental expectations on education from the provider

	Q3: What are your expectations about how your child's therapist teaches you things?		
Initial Code	Code Definition	Representative Quote from Participants	Frequency
None	Responses stating they have no expectations	"We have no expectations."	1
Off Topic	Responses did not directly answer the question	"I feel my therapists are great."	9
Have Patience	Expressed expectation that therapist should have respect, have patient or be kind when teaching	"That they will be kind, courteous, and understanding. They must have patience with me."	10
Easy to Understand	Expectations that things taught by the therapist are easy to understand by the family/child	"Teach in a way/technique and language that I can understand. For example, use terms that are general and not medical."	5
Preferred Mode of Interaction	Expectation that teaching was done in a certain manner or mode of instruction		46
• Give Examples		• "I expect my son's therapist to educate me on how I can also do things to help improve my son's speech."	18
• Hands-On Demonstration		• "I personally like to be shown hands on and see how he and his therapist interact."	9
• Visual Instruction		• "Just by showing me how they do things with him exactly so that I could keep doing it."	16
• Written Instruction		• "Provide written example"	3
Type of Interaction	Expectation that therapists teach the family/patient based on their preferred level of participation		24
• Active Participant		• "I write it down for myself to remember. I expect to be an active member, alongside the therapist. A partner."	20
• Passive Participant		• "Keeps me updated on progress, what they are working on, methods they are working."	4

Figure 4

Parental expectations on education from the provider
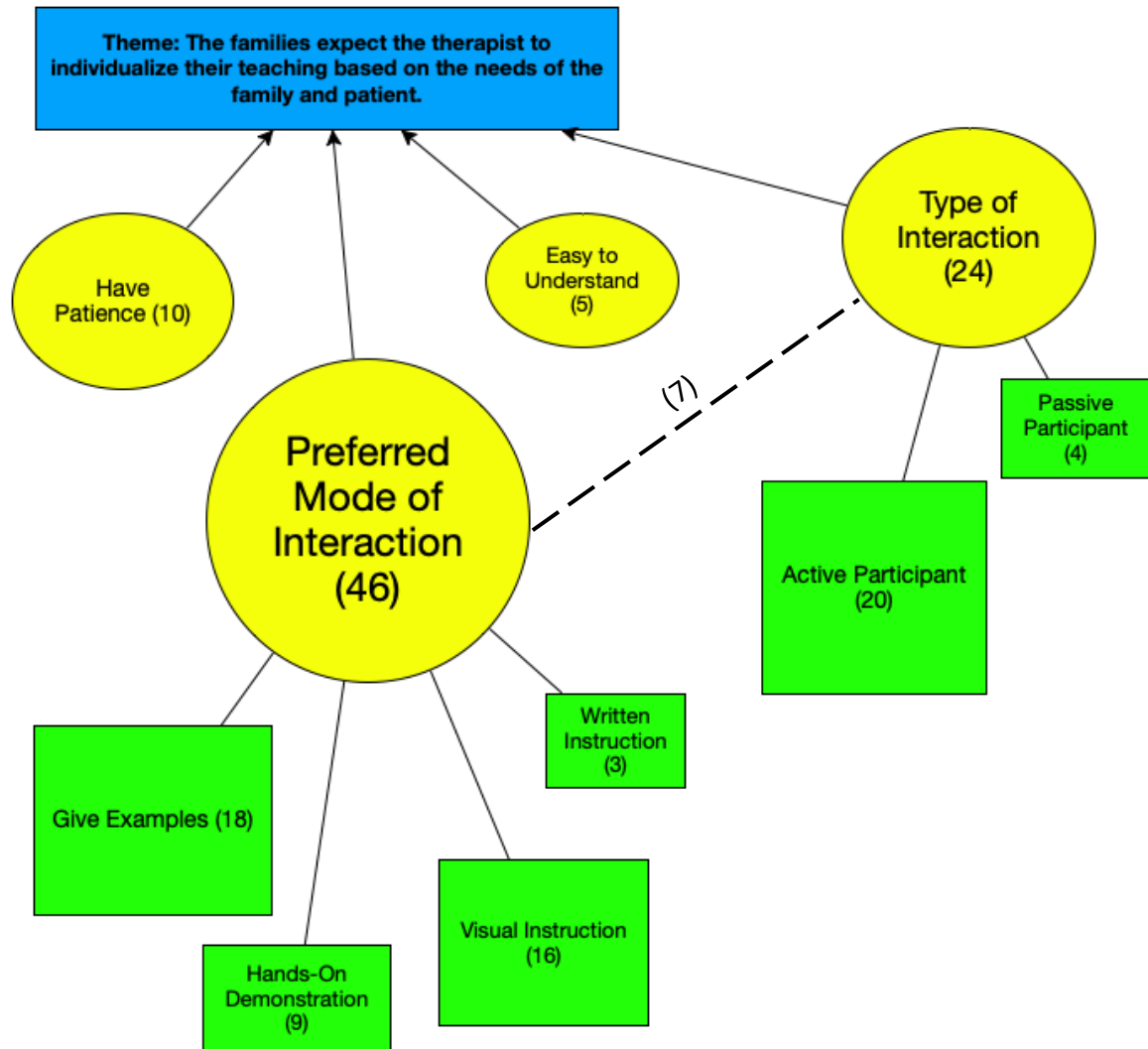
Theme: The families expect the therapist to individualize their teaching based on the needs of the family and patient.

Have Patience (10)

Easy to Understand (5)

Type of Interaction (24)

Passive Participant (4)

Preferred Mode of Interaction (46)

(7)

Active Participant (20)

Give Examples (18)

Written Instruction (3)

Visual Instruction (16)

Hands-On Demonstration (9)

*Note.*Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 3. The direction of the arrow signifies the relationship between the code and theme. The dashed line indicates there is a shared connection between *Type of Interaction* and *Preferred Mode of Interaction* for seven of the responses. Solid lines indicate sub-codes generated from codes.

The theme for this question was The families expect the therapists to individualize their teaching based on the needs of the family and patient. Overall, participants expected therapists to modify their teaching to accommodate the patient/family's preferred way of learning. Participants wanted the therapists to adapt their teaching style to the family and patients' preferred learning style and modify instructional strategies that enhance the family and patient's learning. When modifying their teaching, families expected therapists to be kind, display patience and positivity, and teach in such a way that was easy to understand. There were seven responses from participants who preferred to be an active participant in their child's therapy who also indicated their preferred mode of interaction. No other connections were generated from the remaining responses.

**Parental Expectations on Sharing Information**

The fourth question of the survey was intended to explore parents/caregivers' expectations of sharing information to the therapist. See Table 14 and Figure 5 for results of codes/sub-codes for this question.

Table 14

Parental expectations on sharing information

	Q4: What are your expectations on sharing information with your child's therapist?		
Initial Code	Code Definition	Representative Quote from Participants	Frequency
None	Responses stating they have no expectations	"I don't have any specific expectations."	5
Not Sure	Answered not sure what to expect or not sure how to answer the question; Left blank	"Not sure I understand this question."	1
Off Topic	Responses did not directly answer the question	"We are confident for the good work of the doctors."	4
Mode of Sharing	How the participant expects to share the information with the therapist	"Text and therapy notebook."	1
Use of Information	Expresses expectation that family/caregivers prefer the therapist use the information they provide to better their child	"I expect them to use info I share to improve the quality and outcome of therapy." "That she would use the information to better care for my child. That she would respond with ideas or information for our family to use. Example: son struggling to listen and obey."	9
How Information Should be Received	Responses stating expectation of how the therapist should receive the information provided by the family/child.		13
• Be Open-Minded		• "I expect our therapist to be open minded and flexible or adaptive without deviating from goals to achieve for my child.	5
• Be Respectful		• "I also expect confidentiality and a sense of trust in our child-therapist relationship."	8
Types of Information Shared	Responses state what type of information they expect to share with therapists.		53
• All Information		• "Communication is key for any relationship. I expect to share all that is happening with my child in all areas, because I know each area is not isolated and therefore pertinent to all disciplines. Everything is interdependent upon one another."	24
• Selective Information		• "I share information whenever it seems appropriate. Since my son is very young and is doing fairly well, I share about his appointments or specific things that may impact his behavior or responses during therapy sessions."	29

Figure 5

Parental expectations on sharing information
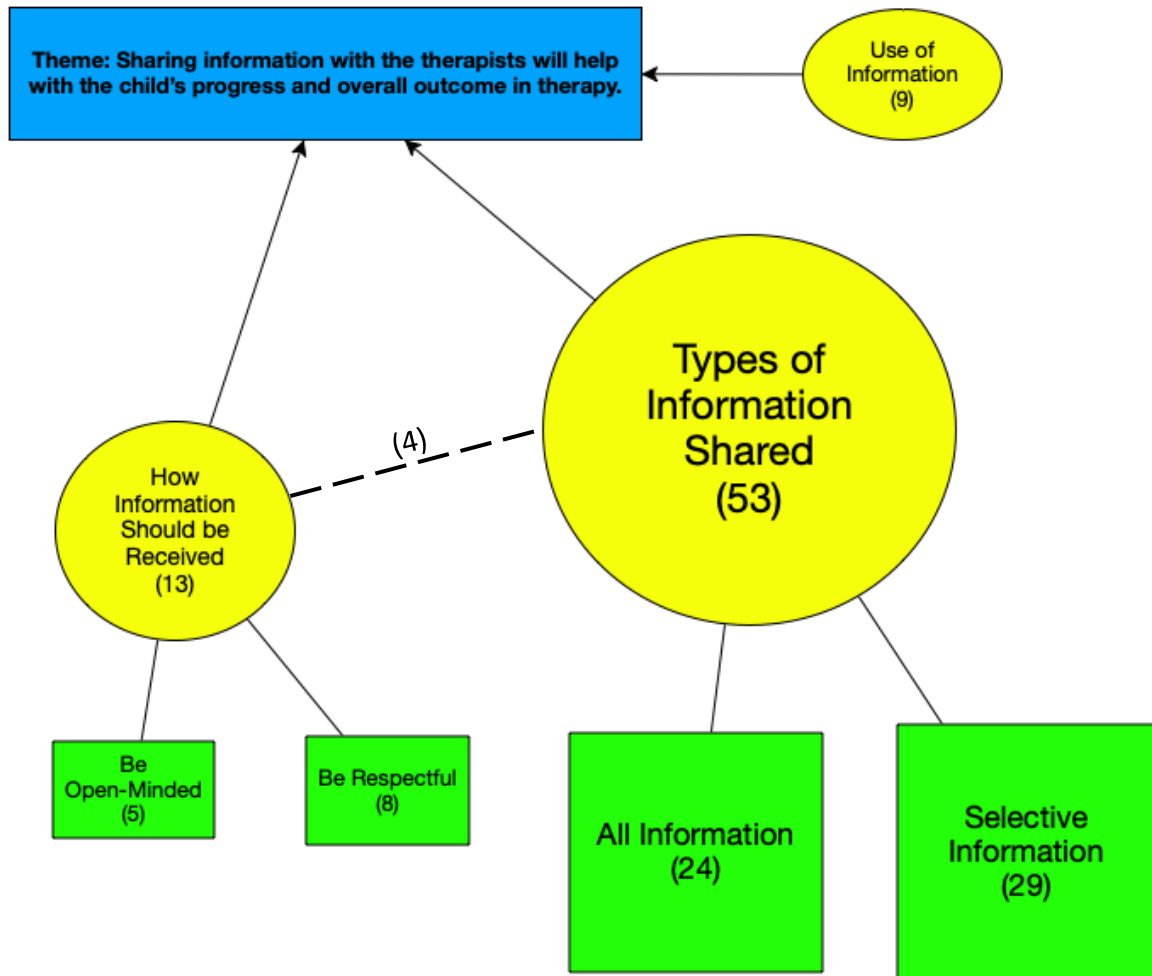
Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 4. The direction of the arrow signifies the relationship between the code and theme. The dashed line indicates there is a shared connection between *How Information Should be Received* and *Types of Information Shared* for four responses. Solid lines indicate sub-codes generated from codes.

The theme for this question was Sharing information with the therapists will help with the child's progress and overall outcome in therapy. When families share information, participants expected the therapists to be open-minded and respectful. Further, whether families chose to share all information or only selective information about their child, the therapist should accept the information as provided. Lastly, families expected therapists to use the shared information to assist the child in reaching the best possible outcomes from home health therapy services.

Although some participants included types of information shared and how information should be received in their response, there were only four who responded with both expectations. Of these four, two participants preferred to share all information about their child and wanted the therapist to be respectful when receiving the information. The remaining two participants preferred to share selective information about their child and wanted the therapist to be open-minded (non-judgmental, flexible or adaptative) when receiving the information the family shared.

**Parental Expectations on Social-Emotional Support**

The fifth question of the survey was intended to explore parents/caregivers' expectations of the therapist providing social-emotional support to the family or child. See Table 15 and Figure 6 for results of codes/sub-codes for this question.

Table 15

Parental expectations on social-emotional support

Q5: What are your expectations about the social-emotional support your child's therapist provides to you and/or your child regarding your child's condition?			
Initial Code	Code Definition	Representative Quote from Participants	Frequency
None	Responses stating they have no expectations	"No expectations on this topic."	7
Not Sure	Answered not sure what to expect or not sure how to answer the question; Left blank	<LEFT BLANK>	1
Off Topic	Responses did not directly answer the question	"He's always happy to see her."	17
Interaction	Responses express the expectation that the therapists will educate them in some way		16
• Educates		• "To a very great extent, she is very supportive with many great ideas to do with him, for example when we first started the program she showed me some home activities I could do with my son."	11
• Provides Resources		• "They are always willing to try new things and help find resources for any new equipment or adaptive toys."	5
Therapist's Attributes	Expecting that the therapist displays positive attributes while providing social-emotional support to family/child		59
• Be Caring, Compassionate, Understanding		• "That they be understanding that the child's condition can be new to the parents or a sensitive subject." & "Show empathy and show that my child is not a number but that they really care about the outcome and meeting goals."	18
• Be Competent		• "They can control her when she is not wanting to do something."	11
• Be Honest		• "Honest feedback about whether the child is capable. Honest feedback on family/caregiver follow up. Honest about progress."	2
• Be Respectful		• "I expect my child's therapist to respect my child as a human."	7
• Be Supportive or Encouraging		• "My child's therapist's so supportive of my child by always having a positive and encouraging demeanor regardless of my child's behavior. With myself as well, she is very positive and encouraging even if a concept is confusing to me."	22

72

Figure 6

Parental expectations on social-emotional support
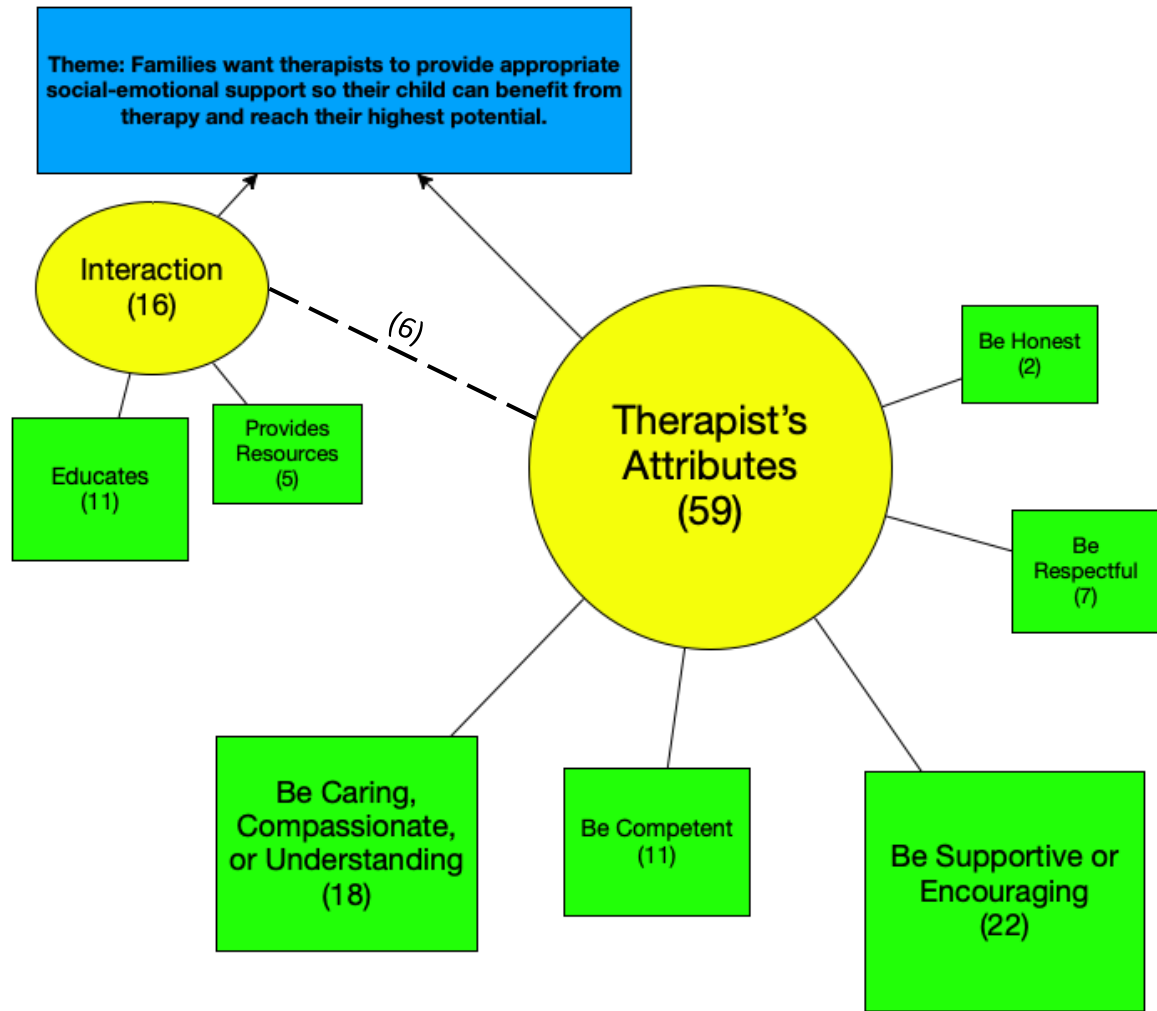
Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 5. The direction of the arrow signifies the relationship between the code and theme. The dashed line indicates there is a shared connection between *Interaction* and *Therapist's Attributes* for six responses. Solid lines indicate sub-codes generated from codes.

The theme for this question was Families want therapists to provide appropriate social-emotional support so their child can benefit from therapy and reach their highest potential. In order to provide social-emotional support, participants expected that therapists possess positive attributes that will facilitate learning and progress in the child's care. Additionally, families expected positive interactions where the therapists educate or provide resources to the patient and family.

Of the 76 responses, six participants commented on the therapist attributes and the interaction with the therapist. There were three combined responses among the sub-codes: one response combined education with competence, a second response combined providing resources with being supportive or encouraging, and four other responses combined education with being supportive or encouraging.

**Parental Expectations on Matching the Patient/Family's Background**

The sixth question of the survey was intended to explore parents/caregivers' expectations of the therapist adapting to or matching the family or child's background. See Table 16 and Figure 7 for results of codes/sub-codes for this question.

Table 16

Parental expectations on matching the patient/family's background

	Q6: What expectations do you have on your child's therapist adapting to match your family's background?		
Initial Code	Code Definition	Representative Quote from Participants	Frequency
None	Responses stating they have no expectations	"I have zero expectations for this."	18
Not Sure	Answered not sure what to expect or not sure how to answer the question; Left blank	"None?" <LEFT BLANK>	3
Off Topic	Responses did not directly answer the question	"My child is very well adored, he is a very good and affectionate child."	9
Don't Understand	Participants did not understand the question	"My apologies, I do not understand how to answer this question."	4
No Need (Therapist/Family match)	Participants do not feel there is a need for therapists to match or they already match their background	"I have not had to deal with this issue." "They do not need to match my family's background."	9
Positive Therapist Attributes	Expectations that therapists should be positive, encouraging, or respectful	"That's hard. As long as the therapist is patient and kind, adapting will come the more the therapist is around our family."	18
Adapting to Needs	Expect that the therapist adapt to the family or patient's needs	"I see the therapist working with the family- meeting them where they are. Ex. Time of visits, place of visits, accommodating flexible schedules, rescheduling when something unexpected happens, using techniques and ideas that work for the parent in the therapy sessions."	18
Appreciates Differences	Expect that the therapist adapt by appreciating differences whether those differences are cultural or non-cultural beliefs		18
• Cultural Differences		• "The expectations will always be to provide a culturally competent life style adaptation."	10
• Non-Cultural Differences		• "They need to support my family the way I discipline my child," and "I think it's important to consider background- e.g. Single parent home, how many siblings, parent at home or working."	8

Figure 7

Parental expectations on matching the patient/family's background
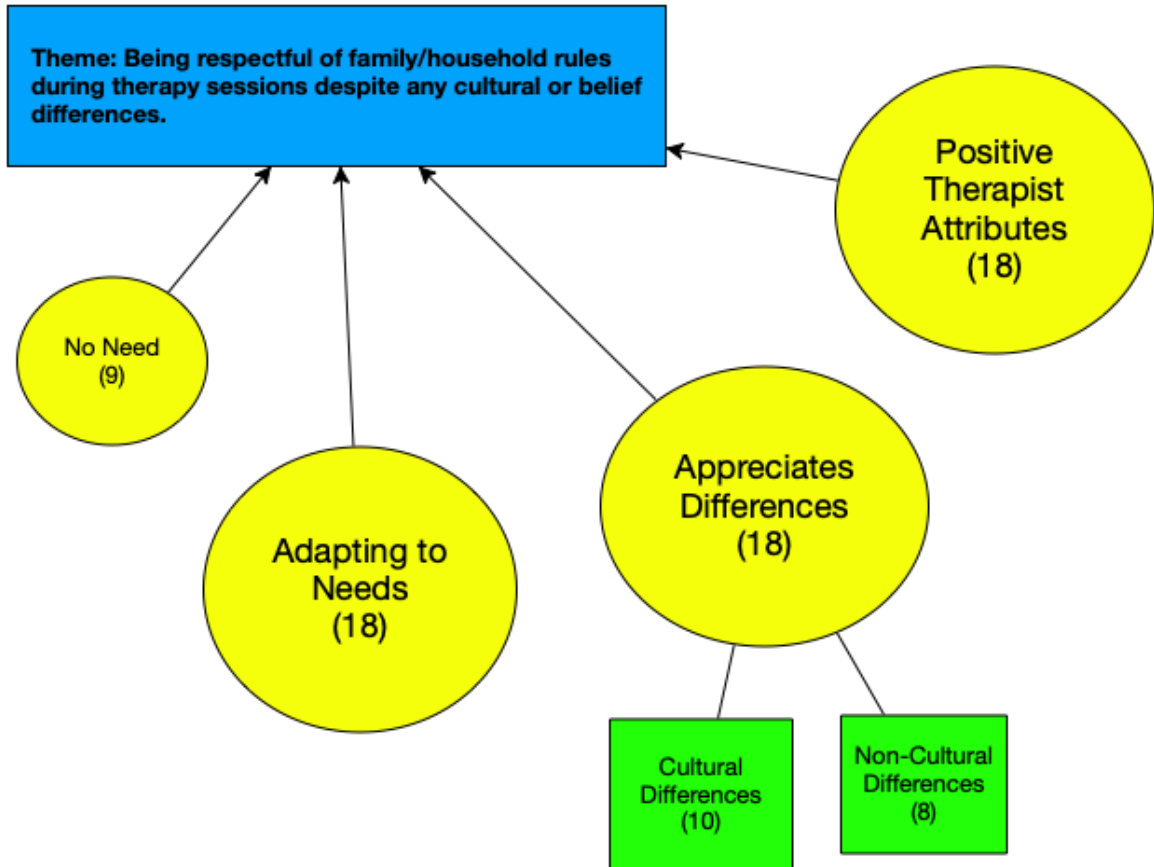
Theme: Being respectful of family/household rules during therapy sessions despite any cultural or belief differences.

Positive Therapist Attributes (18)

No Need (9)

Appreciates Differences (18)

Adapting to Needs (18)

Cultural Differences (10)

Non-Cultural Differences (8)

Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 6. The direction of the arrow signifies the relationship between the code and theme. Solid lines indicate sub-codes generated from codes.

The theme for this question was Being respectful of the family/household rules during therapy sessions despite any cultural or belief differences. Overall, participants preferred therapists to display positive attributes while adapting to the needs of the child and family. Furthermore, therapists should appreciate differences regardless of their own personal cultural and non-cultural beliefs.

**Parental Expectations on the Shared Decision-Making Process**

The last question of the survey was intended to explore parents/caregivers' expectations of the therapist sharing the decision-making process with the family/child throughout the process of creating the therapy plan of care. See Table 17 and Figure 8 for results of codes/sub-codes for this question.

Table 17

Parental expectations on the shared decision-making process

Q7: What do you expect your child's therapist to share with you in the decision-making process when creating your child's plan of care for therapy?

Initial Code	Code Definition	Representative Quote from Participants	Frequency
None	Responses stating they have no expectations	"We have nothing to expect."	3
Not Sure	Answered not sure what to expect or not sure how to answer the question; Left blank	"There really hasn't been any decision making as far as I am aware."	1
Off Topic	Responses did not directly answer the question	"Could not ask for better girls."	5
Be Supportive	Participants expect that the therapists are supportive when creating the plan of care	"Compassionate and empathetic decision-making process as if they are caring for one of their loved ones."	3
Level of Involvement	States expectation of the type of interaction they prefer within decision-making process		73
• Active Participant		• "I do not want to be surprised on decisions that the therapist makes by herself. I expect the therapist to get my input as well because I know my child better than anyone does." & "I think it needs to be bi-directional information sharing in order to best meet my kid's needs."	27
• Passive Participant		• "Goals, how and why they are using the tools they do. What they hope to accomplish. What exactly are they working."	46

Figure 8

Parental expectations on the shared decision-making process
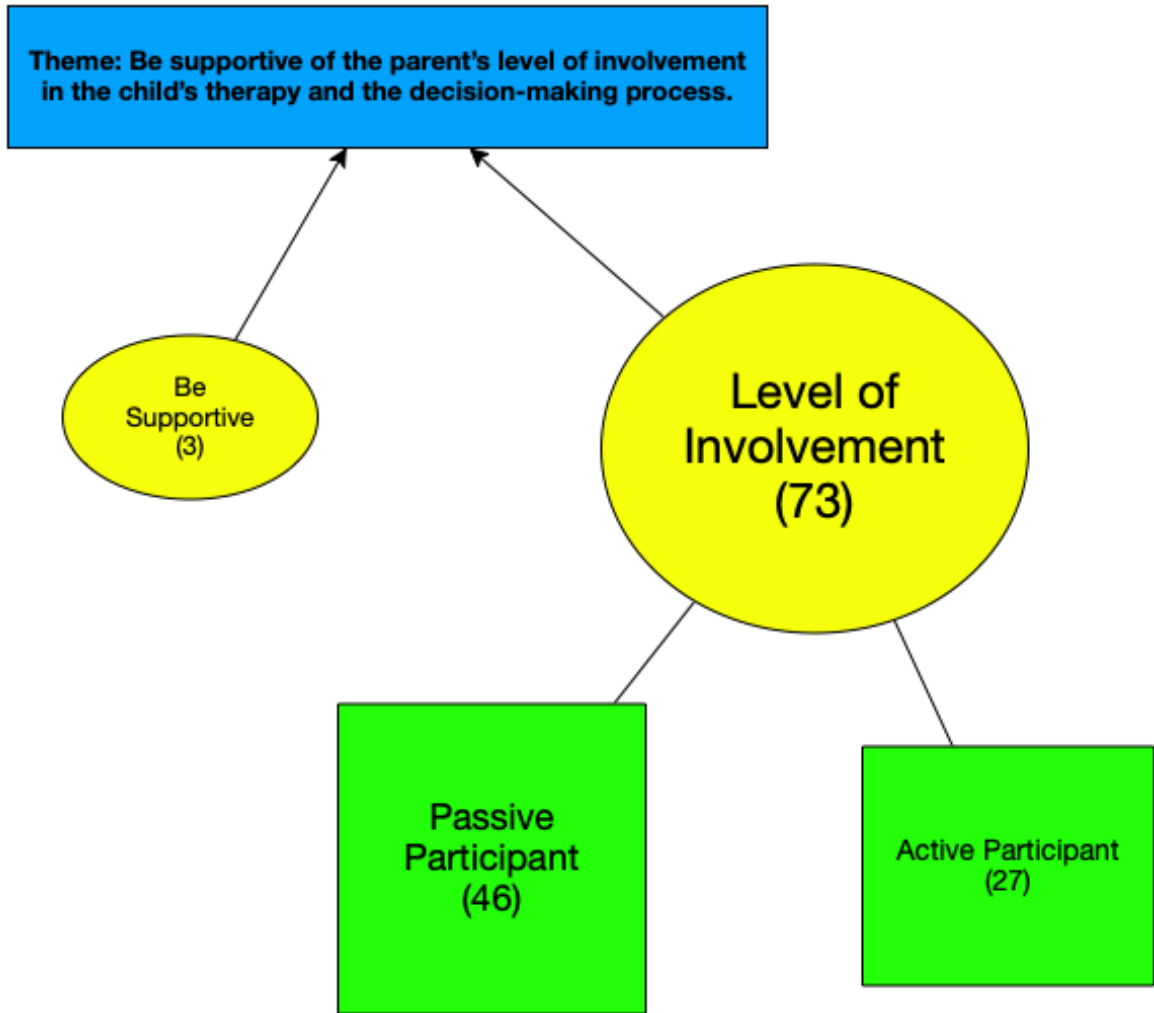
Theme: Be supportive of the parent's level of involvement in the child's therapy and the decision-making process.

Be Supportive (3)

Level of Involvement (73)

Passive Participant (46)

Active Participant (27)

Note. Diagram of codes (yellow) and sub-codes (green) essential in generating the theme (blue) for Question 7. The direction of the arrow signifies the relationship between the code and theme. Solid lines indicate sub-codes generated from codes.

The theme for this question was Be supportive of the parent's level of involvement in the child's therapy and the decision-making process. Participants expected therapists to be supportive and to accept whether the family wanted to be actively or passively involved in the decision-making process of their child's care.

Summary

In this chapter, the author reported the results for the quantitative and qualitative findings of this study. When analyzing scores from the MPOC-20, results revealed that all five FCC concepts were incorporated to a great extent or higher. In addition, no significant differences were found between English and Spanish-speaking respondents, nor were there any differences found among cultures/ethnicities regarding the incorporation of FCC concepts in home health pediatric therapies. For the qualitative portion of the study, participants were able to express their expectations in regard to incorporating FCC in their child's home health pediatric therapies. Following analysis, one theme, along with various codes and sub-codes, was developed for each question. In the next chapter, the researcher discusses the results and clinical implications of the results generated in this study.

CHAPTER V

DISCUSSION

Many definitions of FCC exist; simply put, FCC involves including the provider, family and patient in all phases of the plan of care and treatment (Schreiber et al., 2011). Parents/caregivers in this study defined FCC in the context of pediatric home health as involving the family in some aspect of the child's therapy. Just as there are several definitions of FCC, there are various studies identifying specific components of FCC. Research on FCC has been completed in different healthcare settings; however, no previous studies have assessed FCC in the pediatric home health therapy setting. This study examined the FCC concepts identified by S. King, Rosenbaum, et al. (1996) using the MPOC-20 in the quantitative portion of the study. The five FCC concepts identified by Gallo et al. (2016) were used to generate a seven open-ended question survey to gather data for the qualitative portion of the study. The quantitative portion of the study was designed to assess how often FCC concepts were being used in the pediatric home health setting, while the qualitative portion of the study focused on family/caregiver expectations about incorporating FCC in their child's therapy.

Data from this study provides an understanding of what FCC entails in this setting and insight into how language and culture might impact FCC. The findings demonstrate why FCC needs to be a standard part of the plan of care for therapeutic interventions in the pediatric home health setting. The results also highlight parents' expectations of FCC

in this setting and expand the literature on FCC. Additionally, results may guide pediatric home health therapists to implement FCC and adjust care with parents' expectations in mind. In this chapter, the author provides a summary and discussion of findings along with limitations and recommendations for future research.

Summary and Discussion of Findings

The first purpose was to identify which FCC concepts are being incorporated in the home health pediatric therapy setting. Prior to the study, based on personal practice in this setting, observing other therapists, and reviewing the literature on this topic, the author hypothesized that FCC concepts are inconsistently incorporated in the home health pediatric therapy setting. However, the results demonstrate a median range of 6 to 7 for each MPOC-20 question, suggesting that parents/primary caregivers perceive that therapists incorporate these items/behaviors "to a great extent" or more. In fact, only nine participants scored any question 4 or below. Therefore, FCC concepts were consistently incorporated by therapists who provided therapy for children of the participants in this sample. Such findings are similar to those found by Schreiber et al. (2011) who used the MPOC-20 to determine parent perceptions of how often FCC concepts were implemented in a pediatric outpatient rehabilitation facility. IQR for each domain was used to identify outliers and compare findings in the present study with those from the Schreiber et al. (2011) study. For both studies, outliers existed in the same three MPOC-20 domains: (a) Enabling and Partnership, (b) Coordinated and Comprehensive Care for the Child and Family, and (c) Respectful and Supportive Care. Further inferences about these outliers cannot be drawn because Schreiber et al. (2011) did not provide more detailed

information about their outliers. For the present study, all outlier responses were from

English-speaking participants with the majority being female respondents. While all

ethnicity/cultural groups were represented in the outlier responses, the majority were

Caucasian. Similarly, all diagnosis groups had at least one outlier response; however, the

diagnosis group with the majority of outlier responses was neurological/spinal disorders.

There were no obvious identifying characteristics of the outlier respondents; therefore, it

appears outlier responses may be due to the individual therapist/family relationships.

Further inferences cannot be drawn as specific information was not collected on the

family/therapist relationships in this study.

The least frequently incorporated domains in the present study were (a) Providing

General Information and (b) Providing Specific Information About the Child. These

findings are consistent with published studies in the inpatient and outpatient settings by

Almasri et al. (2017), Dyke et al. (2006), S. King et al. (2004), Raghavendra et al. (2007),

and Schreiber et al. (2011), who all reported these domains as the least frequently

incorporated FCC domains. According to Almasri et al. (2017), a possibility for low

incorporation could be due to family/provider's lack of recognizing informational "needs

and concerns." At the same time, Dyke et al. (2006) suggest therapists' low level of

experience using the FCC model as a possibility for the lack of information provided in

their services. Limited resources to print written materials in the home health setting may

be a potential explanation for the lack of written education provided to the families in this

study. However, when compared to responses from the qualitative portion of this study,

there were only three participants that expected to receive written information as

education from their provider. In yet another study by Hummelinck and Pollock (2006), parents' expectations on informational needs were assessed. They found that many parents did want general and specific information about their child; however, to avoid stress and information over-load, it is important to provide information that is individualized and at the most appropriate time for the child/family. This is also consistent with the current study as the qualitative portion showed that parents expect education from the provider be delivered based on their preferred level of involvement and preferred mode of interaction.

For frequently incorporated concepts, prior studies suggested that Respectful and Supportive Care was most often incorporated in the inpatient and outpatient settings (Almasri et al., 2007; Dyke et al., 2006; S. King et al., 2004; Raghavendra et al., 2007; Schreiber et al., 2011). To further clarify the issue of FCC, Schreiber et al. (2011) supplemented their quantitative MPOC-20 results with a qualitative interview. Their results showed an increased satisfaction in Respectful and Supportive Care on the MPOC-20 correlated with parents indicating the importance of a good family/therapist relationship and therapists possessing positive attributes. Qualitative results from the present study also show a majority of respondents indicate the expectation that therapists possess positive attributes when providing social-emotional support. As a reminder, Social-Emotional Support corresponds with Respectful and Supportive Care (see Table 1). In contrast, in the present study, Coordinated and Comprehensive Care for the Child and Family was the most often incorporated domain in pediatric home health by a very slim margin. However, Respectful and Supportive Care was the next frequently

incorporated concept. The qualitative portion of the current study assessed

parent/caregiver expectations on FCC concepts created by Gallo et al. (2016), not the S.

King, Rosenbaum, et al. (1996) concepts, nor did this study assess the specific

family/therapist relationship of the participants. As previously seen in Table 1,

Coordinated and Comprehensive Care for the Child and Family does not correspond with

any of the Gallo et al. (2016) concepts. Therefore, further inferences cannot be drawn on

why certain FCC concepts are incorporated more or less often than others.

The second purpose was to determine if there were differences in incorporating

FCC concepts when parents whose first language was not English, or families were from

cultures different from the therapists'. Based on personal experience and previous

research highlighting inconsistencies in FCC when language barriers or cultural

differences are present (Coker et al., 2010; de Moissac & Bowen, 2019; Ngui & Flores,

2006), the researcher hypothesized that FCC concepts would be inconsistently

incorporated with families whose culture was different from the therapists', or with

families who were not fluent in the English language. Such mismatch is likely due to

therapists in the United States being predominately Caucasian, with the assumption that

their first language is English (DATAUSA.io, 2021). Furthermore, of the nearly 24

million people in Texas 5 years of age or older, almost 7 million speak Spanish at home

(United States Census Bureau, 2020). Yet in this study of parents of children receiving

one or more therapies in home health, English-speaking participants outnumbered

Spanish speakers almost 10 to 1. Therefore, to address the study's second purpose, the

data were analyzed using the total sample ($n = 76$), and a matched sample of English-

speaking ($n = 7$) and Spanish-speaking ($n = 7$) participants. For both, the total sample and the matched sample, there were no differences in incorporating FCC concepts between English and Spanish-speaking families. While these results may be surprising, they indicate that therapists working in the pediatric home health therapy setting were incorporating FCC concepts regardless of language differences. In contrast, Coker et al. (2010) reported inconsistencies of FCC usage due to language differences.

In addition to language differences, the incorporation of FCC concepts among families with different ethnic/cultural identities was also assessed. Once again, there were no significant differences due to ethnicity or culture. Although unexpected, these results suggest the therapists in the pediatric home health therapy setting were incorporating FCC concepts regardless of any ethnic/cultural differences. In contrast, Coker et al. (2010) described inconsistencies in FCC based on ethnic/cultural differences. Similarly, Ngui and Flores (2006) reported dissatisfaction in healthcare among African Americans because care provided was not family centered. In the United States, diversity is increasing, and cultural and linguistic competencies continue to evolve. However, as late as 2009, Goode et al. concluded that challenges in delivering and receiving FCC continue. Differences between the finding of this home health based study and previous studies may be due to the changes in society. It is important to note, these early studies were conducted more than 10 years ago. Increased focus on cultural and linguistic competencies over the last 10 years (Jernigan et al., 2016) may have eliminated barriers to providing FCC when differences exist.

While it is possible barriers still exist, families may not expect the therapist to adapt to the family's culture. From the qualitative portion of this study, the Gallo et al. (2016) FCC concept, Adapting Care to Match the Family Background, had the highest response rating ($n = 18$) in the None code indicating families did not expect therapists to adapt to the family background. One possible explanation is Texas has such a diverse population (United States Census Bureau, 2020) that differences in background are readily accepted. Another possibility is the therapists' background may have matched the child/families' background, thus no adaptation was required. However, in looking at the demographic data of the therapy professions, the majority of therapists tend to be white non-Hispanic females (DATAUSA.io, 2021) so the likelihood of matching backgrounds is small. Nonetheless, from the qualitative portion of this study, families expected therapists to appreciate differences regardless of personal cultural or non-cultural beliefs.

The third purpose was to explore parents' expectations of therapists regarding incorporating FCC concepts within the home health pediatric therapy setting. Similar to information found in the quantitative portion of this study indicating Providing General Information and Providing Specific Information about the Child as the least frequently incorporated FCC concepts, it was noted that many parents/caregivers did not have an understanding of FCC prior to this study. A study by Law, Hanna, et al. (2003), indicated families' beliefs about FCC influenced their perceptions about FCC. They also stated that families who perceived they were receiving family-centered services had higher satisfaction in their services. Therefore, further highlighting opportunities for education to therapists on proper implementation of FCC in their practice as well as better

information sharing to the family to ensure families are fully educated on FCC. While participants did not appear to be formally educated about the meaning of FCC or the different FCC concepts, many were able to express their expectations regarding the FCC concepts throughout the survey. Overall, parents/caregivers expected a cohesive and collaborative relationship with the therapists so the child would receive individualized and optimal care in order to make the best progress in his or her home health therapies. Similar to the studies by MacKean et al. (2004), and G. King and Chiarello (2014), the respondents communicated their expectations of a collaborative family/therapist relationship and described FCC as using an individualized approach to care. At the same time, participants of this study indicated FCC should help the child make progress towards his or her therapy goals as seen in the themes generated from four of the seven qualitative questions. When specifically asked of expectations of incorporating FCC in therapy, some parents/caregivers implied incorporating the family will cause the child to have better progress and outcomes in therapy.

To the researcher's knowledge, this is the first study to explore parents/caregivers' expectations about incorporating FCC concepts in the pediatric home health therapy setting. Information on what families expect from FCC in their child's services assists therapists when building their mission statement and practice model that incorporates FCC in the home. Studies by G. King and Chiarello (2014), and Law, Hanna, et al. (2003) stated that organizations and therapy practices should adopt a family-centered culture to properly implement the FCC model as it has been shown to increase families' satisfaction with services and improve the outcomes for the child. Ideally,

parents should be included in the care process from initiation of care through discharge, pointing out roles and expectations of the provider/family, to engage and empower families (G. King & Chiarello, 2014). By understanding family expectations found in this study, specifically preferred level of involvement and preferred mode of interaction, therapists are better equipped to individualize therapy services and provide education at the most appropriate time. Enhancement of family-child-therapist relationships is expected by families. Better relationships will occur when therapists provide education appropriate to the family and child's preferred modes of interaction while using the information shared from the family to improve the quality and outcome of therapy. Again, the qualitative findings from this study show many families do not formally know the meaning of FCC highlighting an opportunity for therapists to initiate discussion with families. These discussions will assist families in better understanding FCC, allowing families to inform therapists of personal and individualized expectations, thus, building a more cohesive and collaborative relationship. Along with building a more collaborative relationship, better communication between the families and therapists improves family-centered services increasing parent satisfaction, decreasing parental stress and anxieties, and increasing the child's progress in therapy (G. King & Chiarello, 2014; Law, Hanna, et al., 2013).

Despite the outcomes differing from the original hypotheses, the results of this study are positive and suggest that FCC was being implemented appropriately in the pediatric home health therapy setting. Findings indicate that while parents may not be formally educated on what FCC entails, therapists in the home health pediatric therapy

setting are incorporating FCC concepts to a great extent regardless of language or cultural

differences. Information generated from parents/caregivers' expectations of incorporating

FCC concepts is important to therapy professions as it further validates the professional

associations' direction to utilize a FCC approach in therapies across all settings, again,

reiterating family-centered culture at the organizational level. With previous studies

showing language barriers and cultural differences as a cause for dissatisfaction in

healthcare services and lack of FCC usage (Coker et al., 2010; Ngui & Flores, 2006), this

study allows reassurance of adequate FCC implementation. Thus, educational programs

should continue to instruct therapy students on FCC and how to effectively incorporate

FCC concepts into their practice.

Limitations

There were several limitations in this study, some anticipated prior to the study's

initiation that could not be mitigated and others where steps were taken to minimize

limitations to some extent. One limitation is the lack of triangulation from closed- and

open-ended question surveys without the use of interviews to probe further into each

question. Due to the non-random, voluntary survey design, return rates were relatively

low, increasing the probability of self-selection bias. Language barriers may also limit

generalizability as the surveys were only provided in the English and Spanish languages,

the two most common languages spoken in Texas. Transferability and generalizability

may have been limited as this study was conducted on a group receiving pediatric home

health therapy from agencies in Texas. Due to participation limited to families/caregivers

that were currently enrolled in therapy services, the results may be biased to more

positive scores on the MPOC-20 (showing higher incorporation of FCC into services) as dissatisfied families may have terminated services with the agency prior to the study. Another limitation of this study is the researcher relied on therapists employed by the agencies in the study to disseminate the surveys and materials. Therefore, potentially resulting in biased answers as participants may have completed the surveys based on their relationship with the therapist and/or responding in a socially desirable manner. To mitigate this potential bias, therapists were reminded to tell the families that they were not involved in the study. Further, therapists were instructed to assure participants their answers would be confidential, only seen by the researcher, and would not affect the treatment sessions in any way. Families were also instructed to reach out to the researcher with any questions or concerns. Lastly, the study may lack dependability as the researcher was not able to fully control how materials were disseminated by each therapist. Education was provided to the therapists to reduce this limitation.

After analyzing the demographic information, three additional limitations were identified. First, there were no questions in the demographic questionnaire about the therapists involved in the child's care other than their discipline. The therapists' language or ethnicity/culture is unknown; therefore, it is not certain whether the therapists involved had a culture or language different than that of the family/child. Therapists in this study were licensed to practice in Texas and thus if educated outside of the United States must be proficient in the English language (Executive Council of Physical Therapy and Occupational Therapy Examiners, 2021). The demographics of therapists in general tend to be white, English-speaking women (DATAUSA.io, 2021), some mismatch in language

and culture is expected, but the extent cannot be described, or any differences statistically tested. Second, responses to the question on participant's gender suggests this question was misinterpreted. Based on an assumption of handwriting and written language, some respondents appeared to provide the child's gender and not their own. Future surveys should explicitly make it clear whose gender the question applies to. Lastly, respondents provided a wide variety of answers or no answer for child's diagnoses. The researcher left this as an open-ended question to avoid excluding diagnoses or limiting parents' responses. However, categorical choices as well as an "other" category would make the reporting and analysis of diagnoses data easier.

Future Research

The results of this study show there were no significant differences in incorporating FCC concepts in pediatric home health therapies between the English and Spanish languages, as well as among cultures/ethnicities. While this finding may be due to the setting itself (the family's home versus a medical provider's workplace), these results should be considered with caution given the low response rate from Spanish-speaking participants, the lack of demographic information about therapists involved in the care of the children in home health, and unknown language and/or culture mismatch. Therefore, future research may target underrepresented populations specifically and explore any inconsistencies of FCC incorporation with language and ethnic and cultural differences. Due to the overall low response rate in this study, further research would be beneficial on a wider population at the national level to ensure increased response rate as well as greater diversity in language and culture. Partnering with national pediatric home

health agencies could also provide opportunities to include underrepresented minority groups to further investigate cultural and ethnic differences at a national level. While studies have shown consistent findings of higher and lower incorporated FCC concepts, most studies do not specify why these concepts are incorporated more or less frequently. Therefore, future research may be warranted to investigate reasons and identify opportunities to therapists to provide adequate information to families as this tends to be the least incorporated concept seen in multiple research studies. This author hypothesizes a possible reason for more or less frequently incorporated FCC concepts may be due to the family/child/therapist relationships. Thus, future research should be aimed to focus on this triadic relationship and perceptions to FCC incorporation. As the FCC model continues to evolve, additional research investigating language and cultural differences and patient and caregiver expectations in the adult home health therapy setting should be conducted to ensure therapists are incorporating FCC concepts across all settings along the continuum of life.

Conclusion

The MPOC-20 (S. King et al., 2004) was used to investigate how often FCC concepts are incorporated in the pediatric home health therapy setting. It was found that therapists were incorporating FCC concepts "to a great extent" or higher. This finding may be related to the setting in which care is provided. Home health therapists come to the family's home and as a guest, may automatically conform to the family's social and cultural norms. At the same time, the MPOC-20 was utilized to explore whether or not language and cultural/ethnic differences impact the incorporation of FCC concepts in this

setting. Statistical analysis indicated no differences between languages or among

ethnicities in how often FCC concepts are incorporated in the pediatric home health

therapy setting as measured by the MPOC-20. While these finding also may be due to the

setting itself (the family's home versus a medical provider's workplace), the reader must

be cautious given the low response rate of participants from underrepresented

populations. Lastly, an open-ended survey was used to gather information on parents'

expectations of FCC, with specific interest in expectations of five FCC concepts

identified by Gallo et al. (2016). While participants did not fully understand the FCC

model or concepts, they were able to share expectations when prompted by each

question. Overall, parents/caregivers expect a collaborative relationship with the

therapists ensuring the child receives individualized and optimal care in order to make the

best progress in his or her home health therapies.

REFERENCES

Almasri, N. A., An, M., & Palisano, R. J. (2017). Parents' perception of receiving family-

centered care for their children with physical disabilities: A meta-analysis.

Physical & Occupational Therapy in Pediatrics, *38*(4), 427–443.

https://doi.org/10.1080/01942638.2017.1337664

ATLAS.ti. (2020). *ATLAS.ti qualitative data analysis* (Version 9). Scientific Software

Development GmbH. https://atlasti.com/product/what-is-atlas-ti/

Babbie, E. (1990). *Survey research methods* (2nd ed.). Wadsworth.

Baruch, Y., & Holtom, B. C. (2008). Survey response rate levels and trends in

organizational research. *Human Relations*, *61*(8), 1139–1160.

https://doi.org/10.1177/0018726708094863

Bazeley, P. (2006). The contribution of computer software to integrating qualitative and

quantitative data and analysis. *Research in the Schools*, *13*(1), 64–74.

http://msera.org/docs/rits-v13n1-complete.pdf

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative*

Research in Psychology, *3*(2), 77–101.

https://doi.org/10.1191/1478088706qp063oa

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development.

American Psychology, *32*(7), 513–531. https://doi.org/10.1037/0003-

066x.32.7.513

Campbell, S. K., Palisano, R. J., & Orlin, M. N. (2012). *Physical therapy for children*

(4th ed.). Elsevier Saunders.

Caracelli, V. J., & Greene, J. C. (1993). Data analysis strategies for mixed-method

    evaluation designs. *Educational Evaluation and Polices*, *15*(2),195–207.

    https://doi.org/10.3102/01623737015002195

Chen, H. T. (2006). A theory-driven evaluation perspective on mixed methods research.

    Research in the Schools, *13*(1), 75–83. http://msera.org/docs/rits-v13n1-

    complete.pdf

Coker, T. R., Rodriguez, M. A., & Flores, G. (2010). Family-centered care for US

    children with special health care need: Who gets it and why? *Pediatrics*, *125*(6),

    1159–1167. https://doi.org/10.1542/peds.2009-1994

Cook, C., Heath, F., & Thompson, R. L. (2000). A meta-analysis of response rates in

    web- or internet-based surveys. *Educational and Psychological Measurement*, *60*,

    821–836. https://doi.org/10.1177/00131640021970934

Creswell, J. (2007). *Qualitative inquiry & research design: Choosing among five*

    approaches (5th ed.). SAGE Publications, Inc.

Creswell, J. W., Shope, R., Plano Clark, V. L., & Green, D. O. (2006). How interpretive

    qualitative research extends mixed methods research. *Research in the Schools*,

    13(1), 1–11. http://msera.org/docs/rits-v13n1-complete.pdf

DATAUSA.io. (2021, March 28). *Occupational therapists, physical therapists.*

    https://datausa.io/profile/soc/occupational-therapists?compare=physical-

    therapists#demographics

de Moissac, D., & Bowen, S. (2019). Impact of language barriers on quality of care and patient safety for official language minority Francophones in Canada. *Journal of Patient Experience*, *6*(1), 24–32. https://doi.org/10.1177/2374373518769008

De Vaus, D. A. (1986). *Surveys in social research*. George, Allen & Unwin.

Dillman, D. A. (2000). *Mail and internet surveys: The tailored design method* (2nd ed.). Wiley.

Dokken, D., & Ahmann, E. (2006). The many roles of family members in "family-centered care"- Part I. *Pediatric Nursing*, *32*(6), 562–565.

Driscoll, D. L., Appiah-Yeboah, A., Salib, P., & Rupert D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology*, *3*(1), 19–28. http://digitalcommons.unl.edu/icwdmeea/18

Dyke, P., Buttigieg, P., Blackmore, A. M., & Ghose, A. (2006). Use of the measure of process of care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting. *Child: Care, Health & Development*, *32*(2), 167–176. https://doi.org/10.1111/j.1365-2214.2006.00604.x

Early Intervention Special Interest Group of the American Pediatric Physical Therapy Group. (2018). *Weaving relationship-based practices into interventions: A guide for physical* therapists [Fact Sheet]. https://pediatricapta.org/includes/fact-sheets/pdfs/18%20Relationship%20based%20Approach%20to%20Intervention%20FS.pdf

Eichner, J. M., & Johnson, B. M. (2012). Patient- and family-centered care and the

    pediatrician's role: Committee on hospital care and institute for patient- and

    family-centered care. *Pediatrics*, *129*(2), 394–404.

    https://doi.org/10.1542/peds.2011-3084

Erickson, P. I., & Kaplan, C. P. (2000). Maximizing qualitative responses about smoking

    in structured interviews. *Qualitative Health Research*, *10*, 829–840.

    https://doi.org/10.1177/104973200129118859

Executive Council of Physical Therapy and Occupational Therapy Examiners. (2021,

    March 28). *Foreign-trained applicants.* https://www.ptot.texas.gov/page/foreign-

    trained-applicants

Fincham, J. E. (2008). Response rates and responsiveness for surveys, standards, and the

    journal. *American Journal of Pharmaceutical Education*, *72*(2) Article 43, 1–3.

    https://doi.org/10.5688/aj720243

Foster, M. A., & Phillips, W. (1992). Family systems theory as a framework for problem

    solving in pediatric physical therapy. *Pediatric Physical Therapy*, *4*(2), 70–73.

    https://doi.org/10.1097/00001577-199200420-00004

Fowler, F. F. (1984). *Survey research methods*. SAGE.

Gallo, K. P., Hill, L. C., Hoagwood, K. E., & Olin, S. S. (2016). A narrative synthesis of

    the components of and evidence for patient- and family-centered care. *Clinical

    Pediatrics*, *55*(4), 333–346. https://doi.org/10.1177/0009922815591883

Goode, T. D., Haywood, S. H., Wells, N., & Rhee, K. (2009). Family-centered,

    culturally, and linguistically competent care: Essential components of the medical

home. *Pediatric Annals*, *38*(9), 505–512. https://doi.org/10.3928/00904481-20090820-04

Greer, T. V., Chuchinprakarn, N., & Seshardri, S. (2000). Likelihood of participating in mail survey research: Business respondents' perspectives. *Industrial Marketing Management*, *29*, 97–109. https://doi.org/10.1016/s0019-8501(98)00038-8

Hummelinck, A., & Pollock, K. (2006). Parents' informational needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling*, *62*, 228–234. https://doi.org/10.1016/j.pec.2005.07.006

Jackson, K. M., & Trochim, W. M. K. (2002). Concept mapping as an alternative approach for the analysis of open-ended survey responses. *Organizational Research Methods*, *5*(4), 307–336. https://doi.org/10.1177/109442802237114

Jernigan, V. B. B., Hearod, J. B., Tran, K., Norris, K. C., & Buchwald, D. (2016). An examination of cultural competence training in US medical education guided by the tool for assessing cultural competence training. *Journal of Health Disparities Research and Practice*, *9*(3), 150–167. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5091804/

King, G., & Chiarello, L. (2014). Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. *Journal of Child Neurology*, *29*(8), 1046–1054. https://doi.org/10.1177/0883073814533009

King, G., King, S., & Rosenbaum, P. (1996). Interpersonal aspects of care-giving and client outcomes: A review of the literature. *Ambulatory Child Health*, *2*, 151–160.

King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: Development of a refined measure of processes of care (MPOC-20). *Children's Health Care*, *33*(1), 35–57. http://dx.doi.org/10.1207/s15326888chc3301_3

King, S., Rosenbaum, P., & King, G. (1995). *The measure of processes of care: A means to assess family-centred behaviours of health care providers.* Hamilton, ON: McMaster University, Neurodevelopmental Clinical Research Unit.

King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of caregiving: Development and validation of a measure of processes. *Developmental Medicine and Child Neurology*, *38*(9)*,* 757–772. https://doi.org/10.1111/j.1469-8749.1996.tb15110.x

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, *16*, 297–305. https://doi.org/10.1007/s10995-011-0751-7

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: care, health, and development*, *29*(5), 357–366. https://doi.org/10.1046/j.1365-2214.2003.00351.x

Law, M., Rosenbaum, P., King, G., King, S., Burke-Gaffney, J., Moning-Szkut, T., Kertoy, M., Pollock, N., Viscardis, L., & Teplicky, R. (2003). *FCS Sheet #1: What is family-centred service?* [PDF document].

https://www.canchild.ca/system/tenon/assets/attachments/000/001/266/original/FCS1.pdf

LeRoy, K., Boyd, K., De Asis, K., Lee, R. W. T., Martin, R., Teachman, G., & Gibson, B. E. (2015). Balancing hope and realism in family-centered care: Physical therapists' dilemmas in negotiating walking goals with parents of children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, *35*(3), 253–264. https://doi.org/10.3109/01942638.2014.925028

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2004). Bridging the divide between families and health professionals' perspectives on family-centered care. *Health Expectations*, *8*(1)*,* 74–85. https://doi.org/10.1111/j.1369-7625.2005.00319.x

Marshall, C., & Rossman, G. B. (2011). *Designing qualitative* research (5th ed.). SAGE Publications, Inc.

Myrhaug, H. T., Jahnsen, R., & Østensjø, S. (2016). Family-centred practices in the provision of interventions and services in primary health care: A survey of parents of preschool children with cerebral palsy. *Journal of Child Health Care*, *20*(1), 109–119. https://doi.org/10.1177%2F1367493514551312

Newton, M. S. (2000). Family-centered care: Current realities in parent participation. *Pediatric Nursing*, *26*(2), 164–168. https://csds.qld.edu.au/sdc/Provectus/GAPP/Impact%20of%20childhood%20illness/files/Newton%20Parent%20participation%202000.pdf

Ngui, E. M., & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: The roles of

race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*, *117*(4), 1184–1196. https://doi.org/10.1542/peds.2005-1088

Onwuegbuzie, A. J., & Johnson, R. B. (2006). The validity issue in mixed research. *Research in the Schools*, *13*(1), 48–63. http://msera.org/docs/rits-v13n1-complete.pdf

QSR International. (2020). *NVivo* (Version 12). QSR International. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/about/nvivo/who-its-for/academia

Raghavendra, P., Murchland, S., Bentley, M., Wake-Dyster, W., & Lyons, T. (2007). Parents' and service providers' perceptions of family-centered practice in a community-based paediatric disability service in Australia. *Child: Care, Health, and Development*, *33*(5), 586–592. https://doi.org/10.1111/j.1365-2214.2007.00763.x

Rea, L. M., & Parker, R. A. (1992). *Designing and conducting survey research: A comprehensive guide*. Jossey-Bass.

Roth, P. L., & BeVier, C. A. (1998). Response rates in HRM/OB survey research: Norms and correlates,1990–1994. *Journal of Management Studies*, *24*, 97–117. https://doi.org/10.1177/014920639802400107

Saldana, J. (2013). *The coding manual for qualitative* researchers (2nd ed.). SAGE Publications, Inc.

Sameroff, A., & Mackenzie, M. (2003). Research strategies for capturing transactional

    models of development: The limits of the possible. *Development and*

    Psychopathology,*15*(3), 613–640. https://doi.org/10.1017/S0954579403000312

Sandelowski, M., Voils, C. I., & Barroso, J. (2006). Defining and designing mixed

    research synthesis studies. *Research in the Schools*, *13*(1), 29–40.

    http://msera.org/docs/rits-v13n1-complete.pdf

Schaefer, D. R., & Dillman, D. A. (1998). Development of a standard e-mail

    methodology. *Public Opinion Q*, *62*(3), 378–397. https://doi.org/10.1086/297851

Schreiber, J., Benger, J., Salls, J., Marchetti, G., & Reed, L. (2011). Parent perspectives

    on rehabilitation services for their children with disabilities: A mixed methods

    approach. *Physical & Occupational Therapy in Pediatrics*, *31*(3), 225–238.

    https://doi.org/10.3109/01942638.2011.565865

Shelton, T. L., & Stepanek, J. S. (1994). *Family-centered care for children needing*

    specialized health and developmental services. Association for the Care of

    Children's Health. https://files.eric.ed.gov/fulltext/ED381926.pdf

Tecklin, J. S. (2008). *Pediatric physical therapy* (4th ed.). Lippincott, Williams &

    Wilkins.

    https://books.google.com/books?hl=en&lr=&id=YX8pztQHX0MC&oi=fnd&pg=

    PA1&dq=models+of+pediatric+physical+therapy&ots=ec1IpNoMJg&sig=tP6gfE

    L1qteKHdGJThKUaj6bPCU#v=onepage&q&f=true

Teddlie, C., & Tashakkori, A. (2006). A general typology of research designs featuring mixed methods. *Research in the Schools*, *13*(1), 12–28. http://msera.org/docs/rits-v13n1-complete.pdf

Thelen, E., & Smith, L. B. (2006). Dynamic systems theory. In R. M. Lerner & W. Damon (Eds.), *Dynamic systems theories* (pp. 258–312). John Wiley & Sons Inc. https://cogdev.sitehost.iu.edu/labwork/handbook.pdf

United States Census Bureau. (2020, October 6). *Detailed languages spoken at home and ability to speak English for the population 5 years and over: 2009-2013.* https://www.census.gov/data/tables/2013/demo/2009-2013-lang-tables.html

VERBI GmbH. (2020). *MAXQDA The Art of Data Analysis* (Version Standard). VERBI GmbH. https://www.maxqda.com/products/maxqda-standard

Yin, R. K. (2006). Mixed methods research: Are the methods genuinely integrated or merely parallel? *Research in the Schools*, *13*(1), 41–47. http://msera.org/docs/rits-v13n1-complete.pdf

APPENDIX A

7-Item Qualitative Survey

The return of your completed questionnaire constitutes your informed consent to act as a participant in this research.

Please complete these surveys even if you have just started services with this agency. Please fully complete and return both surveys and address sheet to be eligible for one of ten $50 gift cards.
Return by:

Demographic Questions
Today's Date:
Gender: ___F ___M
Preferred/Primary Language:
Culture/Ethnicity you best identify with (i.e. Caucasian, African-America, Asian, Hispanic, Multiracial; if multiracial please list which you identify with):

Child's Age:
Child's Diagnosis:
Date you started services with this agency:

Please mark X for all disciplines your child is currently receiving:
____Physical Therapy
____Occupational Therapy
____Speech Therapy
Others: _____

Questionnaire (7 Qualitative Questions):
1. In your words, define what Family-Centered Care (FCC) means to you, or what you know about FCC.

2. What are your expectations regarding incorporating Family-Centered Care concepts into your child's therapies?

3. What are your expectations about how your child's therapist teaches you things? Give an example or please explain.

4. What are your expectations on sharing information with your child's therapist? Give an example or please explain.

5. What are your expectations about the social-emotional support your child's therapist provides to you and/or your child regarding your child's condition? Give an example or please explain.

6. What expectations do you have on your child's therapist adapting to match your family's background? Give an example or please explain.

7. What do you expect your child's therapist to share with you in the decision-making process when creating your child's plan of care for therapy? Give an example or please explain.

2

El regresar su encuesta contestada constituye su consentimiento informado para participar en este estudio. Por favor, complete estas encuestas aunque lleve poco tiempo recibiendo los servicios de esta agencia. Le pedimos que complete y devuelva todos los documentos, tanto las encuestas como la hoja de dirección para ser elegible para participar en una rifa y ganar una de diez tarjetas de regalo de $50.
Devuelva antes del:

Preguntas sobre datos demográficos
Fecha de hoy:
Sexo: ___F ___M
Idioma principal/preferido:
Cultura/etnia con la que más se identifica (por ejemplo, caucásico, afroamericano, asiático, hispano, multirracial; si elige multirracial, enumere las culturas con las que se identifica):

Edad del niño:
Diagnóstico del niño:
Fecha en que comenzó a recibir servicios de parte de esta agencia:

Marque con X todas las disciplinas que está recibiendo su hijo actualmente:
____Fisioterapia
____Terapia ocupacional
____Terapia del habla
Otros: _____

Cuestionario (7 preguntas cualitativas):
1. En sus propias palabras, defina qué significa para usted el cuidado centrado en la familia o FCC (por sus siglas en ingles, Family Center Care), o lo que sabe sobre el FCC.

2. ¿Qué expectativas tiene usted en cuanto a la incorporación de los conceptos de cuidado centrado en la familia en las terapias de su hijo?

3. ¿Cuáles son sus expectativas en relación con la forma en que el terapeuta de su hijo le enseña cosas? Denos un ejemplo o explíquenos.

4. ¿Qué expectativas tiene usted en relación a compartir su información con el terapeuta de su hijo? Denos un ejemplo o explíquenos.

5. ¿Cuáles son sus expectativas sobre el apoyo socioemocional que le proporciona el terapeuta de su hijo a usted, o a su hijo, en relación con la condicion de su hijo? Denos un ejemplo o explíquenos.

6. ¿Cuáles son las expectativas que usted tiene del terapeuta de su hijo, para adaptar su servicio en relación a la etnicidad de su hijo? Denos un ejemplo o explíquenos.

7. ¿Qué espera que comparta con usted su terapeuta en el proceso de toma de decisiones al crear el plan de terapia de su hijo? Denos un ejemplo o explíquenos.

2

APPENDIX B

AG Linguistics, Inc. Biography

Adrienne Grunau is a Spanish language translator and educator who partners with schools, non-profit groups and companies to provide Spanish language materials. Adrienne has not only taught in K-12 classrooms but has also worked extensively around the country to provide professional development and curriculum design assistance for educators in bilingual classrooms as well as needs assessments for museums, non-profit organizations, medical groups and large companies to design relevant materials to be provided for non-English-speaking individuals. Adrienne holds a BA in both Spanish and International Relations as well as an MBA from the University of New Mexico.

APPENDIX C

Measure of Processes of Care-20 (MPOC-20)

Indicate how much this event or situation happens to you. 0 = Not Applicable, 1 = Not at All, 2 = To a Very Small Extent, 3 = To a Small Extent, 4 = To a Moderate Extent, 5 = To a Fairly Great Extent, 6 = To a Great Extent, 7 = To a Very Great Extent

In the past year, to what extent do the people who work with your child. . .
1. Help you to feel competent as a parent?
2. Provide you with written information about what your child is doing in therapy?
3. Provide a caring atmosphere rather than just give you information?
4. Let you choose when to receive information and the type of information you want?
5. Look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?
6. Make sure that at least one team member is someone who works with you and your family over a long period of time?
7. Fully explain treatment choices to you?
8. Provide opportunities for you to make decisions about treatment?
9. Provide enough time to talk so you don't feel rushed?
10. Plan together so they are all working in the same direction?
11. Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?
12. Give you information about your child that is consistent from person to person?
13. Treat you as an individual rather than as a "typical" parent of a child with a disability?
14. Provide you with written information about your child's progress?
15. Tell you about the results from assessments?
16. Give you information about the types of services offered at the organization or in your community?
17. Have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?
18. Provide opportunities for the entire family to obtain information?
19. Have information available to you in various forms, such as a booklet, kit, video, etc.?
20. Provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?

APPENDIX D

IRB Approval Letters

Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: February 7, 2019

TO: Ms. Courtney Quinn-Scott
               Physical Therapy - Dallas

FROM: Institutional Review Board (IRB) - Dallas

Re: Exemption for Language Barriers, Cultural Differences, and Parents' Expectations of Family-Centered Care in Pediatric Home Health Therapy (Protocol #: 20384)

The above referenced study has been reviewed by the TWU IRB (operating under FWA00000178) and was determined to be exempt from further review.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. Because a signed consent form is not required for exempt studies, the filing of signatures of participants with the TWU IRB is not necessary.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc.   Dr. Mark Weber, Physical Therapy - Dallas
       Dr. Ann Medley, Physical Therapy - Dallas

TWU
TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

DATE: May 31, 2019

TO: Ms. Courtney Quinn-Scott
             Physical Therapy - Dallas

FROM: Institutional Review Board - Dallas

Re: *Notification of Approval for Modification for Language Barriers, Cultural Differences, and Parents' Expectations of Family-Centered Care in Pediatric Home Health Therapy (Protocol #: 20384)*

The following modification(s) have been approved by the IRB:

1. The sample size has increased.
2. ███████████████ has been added as a recruitment site.
3. The survey has been modified due to feedback from the pilot survey.
4. The estimated completion date will now be December 6, 2019.

cc. Dr. Ann Medley, Physical Therapy - Dallas

116

APPENDIX E

Agency Approval Letters

12-18-18

To Whom It May Concern,

We understand that Courtney Quinn-Scott, PT, DPT, PhD(c) the author/principle investigator, and research assistants in collaboration with Texas Woman's University would like to conduct research as part of the primary researcher's education entitled, "Language Barriers, Cultural Differences, and Parents' Expectations of Family-Centered Care in Pediatric Home Health Therapy". We understand that this project will measure family-centered care concepts utilized during pediatric home health therapies. We give our permission for this research to be conducted through ███████ patients/families as outlined in the research proposal. We also understand that this research will be conducted only if approval is obtained from Texas Woman's University Institutional Review Board. We ask that the Agency(s) name(s) not be published or released/disclosed to anyone other than those conducting and analyzing the results, without express written permission from the agency. If you have any questions, or if you require additional information, please do not hesitate to reach me at ███████ or via email at vanessa.richardson@███████

Vanessa Richardson

Vanessa Richardson

Executive Director of Clinical Excellence and Quality Assurance

4/23/19

To Whom It May Concern,

We understand that Courtney Quinn-Scott, PT, DPT, PhD(c) the author/principle investigator, and research assistant in collaboration with Texas Woman's University would like to conduct research as part of the primary researcher's education entitled, "Language Barriers, Cultural Differences, and Parents' Expectations of Family-Centered Care in Pediatric Home Health Therapy". We understand that this project will measure family-centered care concepts utilized during pediatric home health therapies. We give our permission for this research to be conducted through ███████████ patients/families as outlined in the research proposal. We also understand that this research will be conducted only if approval is obtained from Texas Woman's University Institutional Review Board. We ask that the Agency(s) name(s) not be published or released/disclosed to anyone other than those conducting and analyzing the results, without express written permission from the agency. If you have any questions, or if you require additional information, please do not hesitate to reach me at ████████ or via email at vanessa.richardson@████████
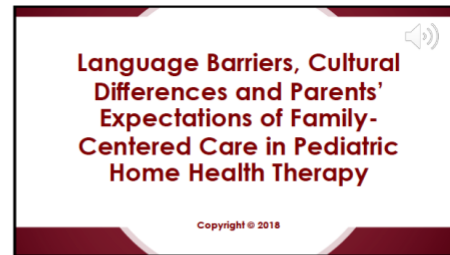
Vanessa Richardson

Vanessa Richardson

Executive Director of Clinical Excellence and Quality Assurance

APPENDIX F

Education Module

Slide 1

TEXAS WOMAN'S
UNIVERSITY

Courtney Quinn-Scott, PT, DPT, PhD(c)
Dissertation Research Study

1

Slide 2

Language Barriers, Cultural Differences and Parents' Expectations of Family-Centered Care in Pediatric Home Health Therapy

Copyright © 2018

2

Slide 3

Objectives

By the end of this presentation you should:
- Have a brief overview of the purpose and research questions of the study
- Understand how this study will be conducted
- Know your role in the participation in this study

TEXAS WOMAN'S
UNIVERSITY

3

Slide 4

Introduction

This is a research study to investigate family-centered care

What is Family-Centered Care (FCC)?
- A method of integrating all phases of healthcare treatment as an equal partnership among the provider, family and patient. (Schreiber et al., 2011)
- Including families/patients in all aspects of their care

TEXAS WOMAN'S
UNIVERSITY

4

Slide 5

FCC Concepts

Gallo et al. (2016):
- Education by the Provider to the Patient and/or Family
- Information Sharing from the Family to the Provider
- Social-Emotional Support
- Shared Decision-Making
- Adapting Care to Match the Family Background

TEXAS WOMAN'S
UNIVERSITY

5

Slide 6

Purpose/Research Questions

- Which family-centered care concepts are being incorporated in the home health pediatric therapy setting?
- Are there differences in incorporating FCC concepts when families are from cultures different from the therapists' or parents whose first language is not English?
- What are parents' expectations of therapists regarding FCC concepts within the home health pediatric setting?
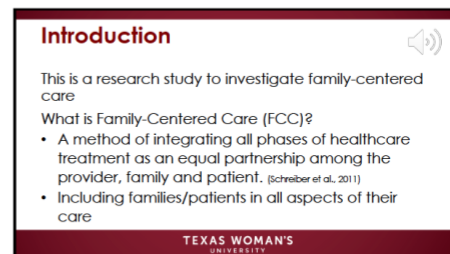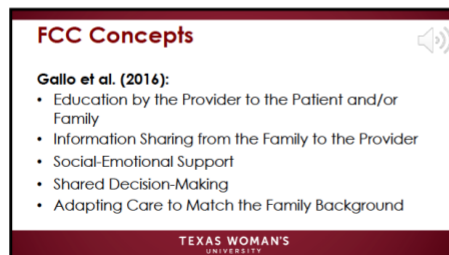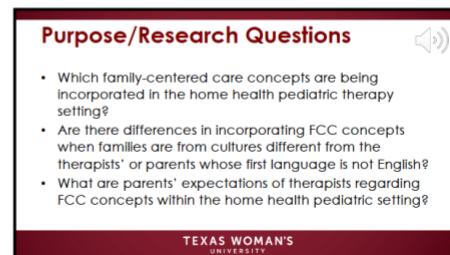
TEXAS WOMAN'S
UNIVERSITY

6

Surveys

- Quantitative: MPOC-20 survey
- Qualitative: 7-Question survey
- All participants who return both surveys fully completed within 30days will be eligible to win 1 of 10 $50 gift cards through a drawing

7

Your Role

To facilitate this research study you will:
- Hand out a research flyer to all of your patients' families
- Disseminate the research packets to all eligible participants 7-10 days after the flyer
- Pass out a reminder card to all participants who received the research packets 15 days after providing the packet

8

Eligible Participants

- Have a child aged 0 to 21 years, who is currently receiving therapy services (minimum of 2 therapy sessions from at least one discipline)
- Child may have any diagnosis
- Excluded if they do not understand/speak English OR Spanish

9

Participants by Area

- Total of 450 surveys
- 6 regions
- 20% of current caseload
- Goal of 30% return rate

10

DOs and DON'Ts

DO
- Provide all materials
- Provide my contact information
- Contact me with any questions
- Direct all questions to me
- Explain that their participation in the study does not affect their services from you in any way

DON'T
- Assist families in filling out surveys
- Answer any questions about the surveys

11

Items in Research Packets

- MPOC-20 survey
- 7-Question Qualitative survey (with information and demographic questions included)
- Address sheet (to enter into gift card drawing)
- Self-addressed & Stamped envelope (to return surveys)

ALL items in each packet will be in English & Spanish

12

Contact Information

It is important that you do not attempt to answer questions about this research study

Direct all questions to the primary investigator (myself)
- **Email:** cquinn@twu.edu (if they leave phone number I can call them back)
- **Mailing Address:**

Courtney Quinn-Scott
P.O. Box 326
Suamico, WI 54173

13

APPENDIX G

Recruitment Flyer

Volunteers needed for research study on Family-Centered Care in Pediatric Home Health Therapy

We are looking for volunteers to complete a survey on their perceptions of Family-Centered Care. As a participant in this survey, you would be asked to: answer 2 brief surveys; one 20 question rank ordered survey and one 7 open-ended question survey. The study will take approximately 15-25 minutes for you to complete. In appreciation of your time, you will be placed in a drawing for a chance to win one of ten $50 gift cards if both surveys are returned fully completed.

Thank you!

**This study has been reviewed and approved by the
Research Ethics Review Board, Texas Woman's University**

Se necesitan voluntarios para un estudio de investigación en Family-Centered Care en Pediatric Home Health Therapy

Estamos buscando voluntarios para realizar una encuesta de su percepción sobre Family- Centered Care. Al participar en esta encuesta, se le pedirá que: responda 2 encuestas breves; una encuesta ordenada de 20 preguntas y una encuesta abierta de 7 preguntas. El estudio tomará aproximadamente 15-25 minutos para su realización. En agradecimiento por su tiempo, será incluido(a) en un sorteo para tener la oportunidad de ganar una de diez tarjetas de regalo de $50 si ambas encuestas son devueltas totalmente llenas.

¡Gracias!

**Este estudio ha sido revisado y aprobado por la
Junta de Revisión de Ética de la Investigación, Texas Woman's University**

APPENDIX H

Address Sheet

Do not write your name on this form.

ADDRESS

Street: _____

Apartment/Lot #: _____   City: _____

State: _____   Zip Code: _____

NO escriba su nombre en este formulario.

DIRECCIÓN

Calle: _____

Núm. de apartamento/Lote: _____ Ciudad: _____

Estado: _____ Código Postal: _____

APPENDIX I

Reminder Letter

This is a reminder to please complete and return the surveys on Family-Centered Care in the Pediatric Home Health Therapy before (10/4/19).

If you fully complete and return both surveys, you will be eligible to be entered into the gift card drawing. If you would like to be entered into the drawing for one of ten $50 gift cards, please be sure to fill out and return the address sheet provided with your surveys. Please, **DO NOT** write your name on the address sheet.

La presente es para recordarle que debe llenar y devolver las encuestas sobre Family-Centered Care en Pediatric Home Health Therapy antes del (10/4/19).

Si llena y devuelve ambas encuestas, será elegible para ingresar al sorteo de la tarjeta de regalo. Si desea ingresar al sorteo para una de diez tarjetas de regalo de $50, asegúrese de llenar y enviar la hoja de direcciones que se proporciona con sus encuestas. Por favor, **NO** escriba su nombre en la hoja de direcciones.