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# Exploring Family-Centered Care from the Perspectives of Home-**Health Physical Therapists**

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# Walden University

College of Health Sciences

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James Mathews

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Walden University 2020

### Abstract

# Exploring Family-Centered Care from the Perspectives of Home-Health Physical Therapists

by

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DPT, AT, Still University, 2011

MBA, San Diego State University, 2006

BSPT, University of Wisconsin – Madison, 1998

BS, University of Wisconsin – Madison, 1996

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Health Services

Walden University

November 2020

#### Abstract

Older adults may need, or desire, caregiver and family involvement to avoid hospitalizations and institutionalizations. The caregivers of these older adults have the highest rates of burnout, injury, and turnover. Family-centered care (FCC) involves collaboration between healthcare practitioners, patients, family members, and caregivers. FCC is both established and effective in pediatric care settings. There is a paucity of evidence on how FCC is applied to older adult populations. Home health physical therapists (HHPTs) work with older adults in their homes and train both family members on how to safely handle and manage the care-dependent older adult. The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. Semi-structured interviews were used to interview each HHPTs. The interview responses were member checked for accuracy and analyzed on a coding table. Three main themes emerged with supporting subthemes. The first theme was that FCC is complex and practiced differently between HHPTs. The second theme was that FCC is used to impact the health factors defined by the International Classification of Functioning, Disability, and Health (ICF) model. The third theme was that contextual factors have the biggest impact on the delivery of FCC. The themes, and supporting subthemes, were conceptualized within the ICF model. Recommendations were made for additional FCC visits, expanded FCC education and training, and further FCC research. This study has the potential to lead to positive social changes through expansions in FCC education, training, and research; improved caregiver, family, and patient health outcomes; and higher patient, family, and caregiver satisfaction.

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# Dedication

I would like to dedicate this dissertation to my wife, Nili Mathews, who stood by me on this journey to becoming a Doctor of Philosophy. You helped me to raise two amazing boys, work fulltime, volunteer in the community, advocate for the profession of physical therapy, and thrive in a pandemic. Your faith and love gave me the strength and perseverance I needed. Wherever this journey takes us next, I am here for you too. Forever in your debt, *ani l'dodi v'dodi li*.

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# **Table of Contents**

List of Tables	V
List of Figures	vi
Chapter 1: Introduction to the Study	1
Background	5
Problem Statement	9
Purpose of the Study	10
Research Question	10
Conceptual Framework	10
Nature of the Study	11
Definitions of Terms	13
Assumptions	14
Scope and Delimitations	14
Limitations	15
Significance of the Study	16
Summary and Transition	17
Chapter 2: Literature Review	19
Literature Search Strategy	19
Historical Context of FCC	22
Conceptual Framework	28
Need and Desire for FCC	30
FCC and Aging in Place	31

Culturally Competent Care	40
Summary of Need and Desire for FCC	45
Case Study Design and Methods	45
Similar Single-Case Study Designs	46
Other Single-Case Study Designs and Methods	47
Summary and Conclusions	50
Chapter 3: Research Method	51
Research Design and Rationale	51
Narrative Design	52
Phenomenological and Ethnographic Designs	52
Grounded Theory Design	52
Summary of Designs	53
Role of the Researcher	53
Professional and Personal Relationships	53
Methodology	55
Participant Selection Logic	55
Instrumentation	56
Procedures for Recruitment, Participation, and Data Collection	59
Data Analysis Plan	61
Issues of Trustworthiness	62
Credibility	62
Transferability	62

	Dependability	63
	Confirmability	63
	Ethical Procedures	63
	Summary	65
Cha	pter 4: Results	66
	Setting of Study	66
	Demographics	67
	Data Collection	68
	Data Analysis	73
	Trustworthiness	79
	Results of Study	82
	Theme 1: FCC is Complex	82
	Theme 2: FCC Used to Impact Older Adults' Health Factors	91
	Theme 3: FCC is Impacted by Contextual Factors	98
	FCC in the ICF Model	107
	Summary	109
Cha	apter 5: Discussion, Conclusions, and Recommendations	110
	Interpretations of the Findings	110
	Theme 1: FCC is Complex	111
	Theme 2: FCC Used to Impact Older Adults' Health Factors	114
	Theme 3: FCC is Impacted by Contextual Factors	115
	ECC and the ICE Model	116

ICOPE, IOM-6, and FCC Competencies	117
Limitations of the Study	119
Recommendations	119
Additional FCC Visits	120
Expansions in FCC Education and Training	120
Continued Research on FCC with Older Adults	121
Implications	121
Expansions in FCC Education and Training	122
Additional Research on FCC with Older Adults	122
Improved Health Outcomes and Satisfaction for Older	Adults and
Families	
Conclusion	124
References	126
Appendix A: Confidentiality Agreement	187
Appendix B: E-Flyer	188
Appendix C: Final Interview Guide	189
Appendix D: Recruitment Tracker	191
Appendix E: Nvivo Generated Themes	192
Appendix F: NVivo Caregiver Theme with Subthemes	193

# List of Tables

Table 1. Search Strategy for FCC & Adults	20
Table 2. Search Strategy for the Need and Desire for FCC	21
Table 3. Search Strategy for Case Studies	21
Table 4. Quantitative Demographics	67
Table 5. Quantitative Demographics	68
Table 6. Sample of Coding Table for KQ1 and KQ2	72

# List of Figures

Figure 1. Pre-codes to code-mapping	74
Figure 2. Code-mapping to pattern coding	75
Figure 3. Pattern coding to first theme.	76
Figure 4. Pattern coding to second theme	77
Figure 5. Pattern coding to third theme	78
Figure 6. Themes in the context of the ICF model	108

## Chapter 1: Introduction to the Study

Family-centered care (FCC) is about collaborating with patients and their caregivers to deliver quality healthcare services. With FCC, patients can designate caregivers to be on their interdisciplinary team (IDT) for health care decisions (Capko, 2014; Moore & Kaplan, 2018; Truglio-Londrigan, 2016). Caregivers can also clarify, identify, and prioritize their collective needs (Jarrar, Minai, Al-Bsheish, Meri, & Jaber, 2019). The inclusion of caregivers makes FCC a shared approach to care over the widely accepted patient-centered care model (Creasy, Lutz, Young, & Stacciarini, 2015). FCC aligns to the principles of the open systems theory (Rousseau, 2015), the biopsychosocial model (Lehman, David, & Gruber, 2017), and servant leadership philosophy (Gersh, 2006; Parris & Peachey, 2013). The FCC approach is established and effective in pediatric care (Johnson & Abraham, 2012; Jolley & Shields, 2009; Zajicek-Farber, Long, Lotrecchiano, Farber, & Rodkey, 2017).

In pediatric care, FCC approaches have resulted in positive patient health outcomes and in improved caregiver satisfaction (Desai, Popalisky, Simon, & Mangione-Smith, 2015; Franck & O'Brien, 2019; Johnson & Abraham, 2012; Raphael, Mei, Brousseau, & Giordano, 2011). FCC has helped to reduces hospital readmissions in newborns as well (Bastani, Abadi, & Haghani, 2015; Desai et al., 2015; Flippo, NeSmith, Stark, Joshua, & Hoehn, 2015). Family centered approaches are proven to be part of best practices with families of children with special needs (Jarrell, Elias, & Kang, 2018; Kuhlthau et al., 2011; Raphael et al., 2011; Russell, Beckmeyer, & Su-Russell, 2018). Caregiver satisfaction surveys have demonstrated that families, and patients, are more

satisfied with FCC approaches to care (Bastani et al., 2015; Flippo et al., 2015). These improvements are encouraging and may be needed with older adults too.

Many older adults have a caregiver, designated as their durable power of attorney (DPOA) for healthcare decisions (Jarrell et al., 2018). When an older adult has a DPOA for healthcare decisions, FCC is needed (Bell, Whitney, & Young, 2019; Vloothuis, Depla, Hertogh, Kwakkel, & van Wegen, 2018). FCC ensures that the DPOA is involved with all decisions—a legal requirement (Jarrell et al., 2018). For other older adults, a DPOA may not be required but they may still depend on caregivers—formal paid caregivers or non-paid family members—to successfully age in place (van Lier et al., 2019). Family-centered approaches may allow for more effective training of older adults and their caregivers at home (Fairchild, 2003; Jones & Levy, 2019; Kuo et al., 2012; Scal & Ireland, 2005). This type of training is especially needed after a prolonged hospitalization (Alsharari, 2019).

Prolonged hospitalizations cause a significant number of older adults to be in a post-acute, care-dependent state of deconditioning, confusion, and weakness (Smith, Sreekanta, Walkeden, Penhale, & Hanson, 2020). This post-acute state can cause older adults to lose their independence with basic mobility tasks (function) and with activities of daily living (ADLs) (Smith, Sreekanta, Walkeden, Penhale, & Hanson, 2020). These losses are highly predictive of a hospital readmission (Fisher, Graham, Krishnan, & Ottenbacher, 2016; Kumar et al., 2017). To mitigate this problem with readmissions, many older adults are referred to home health physical therapy services for a time so that they and their caregivers are prepared to manage successfully (and safely) at home

(Falvey, Mangione, et al., 2019; Landers et al., 2016). Some older adults may not need FCC approaches to successfully age in place, but rather, desire caregiver involvement in their healthcare and healthcare decisions (Kuo et al., 2012).

Older adults that desire collaborative care approaches will benefit from FCC (Darnell & Hickson, 2015; Lovering, 2018; Moore & Kaplan, 2018). Collaborative care includes coordinating, communicating, and cooperating with patients and families on all aspects of care and allows for shared, group decisions (Fuks et al., 2008). With the FCC approach, the healthcare practitioner is more of a servant leader and puts the needs of the group—patient, family, and/or caregivers—first (Aij & Rapsaniotis, 2017). This approach makes FCC a more culturally competent approach (Butler et al., 2016; Kogan, Wilber, & Mosqueda, 2016; Lovering, 2018; Scal & Ireland, 2005). Whether older adults need or desire FCC, home health physical therapists can provide FCC.

Home health physical therapists (HHPTs) collaborate directly with families and patients at home (Brosco et al., 2018; Weeks, 2016). Most insurance policies cover the HHPT to conduct an assessment and follow-up visits during the first 30 days of returning home from a hospitalization (Centers for Medicare & Medicaid Services [CMS], 2019b; Squires et al., 2019). During this time, HHPTs will visit a couple of times per week to:

(a) provide physical therapy interventions; (b) make recommendations to the interdisciplinary team, patient, and caregivers; (c) modify equipment, and the home environment; and (d) train caregivers to manage the patient at home (Collins et al., 2019). Training includes, but is not limited to, progressive resistance exercises programs, transfer techniques, positioning, ambulation needs, and bed mobility tasks (Falvey et al.,

2016). The HHPT can also train physical therapist assistants how to provide maintenance care after services end (CMS, 2019).

Prolonged hospitalizations may cause older adults to become deconditioned, care-dependent, and without basic physical capacities (Falvey, Mangione, & Stevens-Lapsley, 2015). HHPTs are trained on how to assess, treat, and improve older adults' endurance, independence, and intrinsic capacities (O'Sullivan, Schmitz, & Fulk, 2019; Sahrmann, 2014). HHPTs also understand the need for family training and learn the basics of collaborative care during their professional education (Commission on Accreditation in Physical Therapy Education, 2017; Romanello, 2007). Despite the needs and desire for FCC approaches with older adults returning from prolonged hospitalizations, there is a paucity of evidence on how, and to what extent, HHPTs apply FCC.

This study explored how FCC is delivered to care-dependent older adults through the perspectives of HHPTs. These perspectives were used to create new understandings of how, and to what extent, FCC is practiced by HHPTs with older adults. These new understandings were conceptualized within the World Health Organization's (WHO) International Classification of Functioning Disability and Health (ICF) model (Abdi, Spann, Borilovic, de Witte, & Hawley, 2019) in order to expand the understandings within, and beyond, the profession of physical therapy. This study has the potential to lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction.

Chapter 1 introduces FCC as an effective care delivery approach that may be beneficial for older adults. HHPTs are introduced as integral to providing FCC approaches with older adults. The remaining sections of Chapter 1 include the background, problem statement, purpose statement, research question, conceptual framework, nature of the study, definitions, assumptions, scope, limitations, significance and implications for positive social change.

# **Background**

The number of older adults that need, or desire, FCC is extensive and growing (Jette, 2017). It is estimated that there are over 18 million older adults in America that are dependent on either their family or caregivers to function safely at home (Marcus-Aiyeku, DeBari, & Salmond, 2015). By 2060, this number is expected to double (Zissimopoulos, Tysinger, St. Clair, & Crimmins, 2018). HHPTs can use FCC approaches to help these older adults avoid hospitalizations and to help reduce issues with their caregivers (Falvey et al., 2016; Hesamzadeh et al., 2017; Mehra, Grover, Agarwal, Bashar, & Avasthi, 2019).

Hospital readmissions are costly, and they are an indicator of poor healthcare quality (Sentell, Ahn, Miyamura, & Taira, 2018). Nearly 20% percent of hospitalized older adults are readmitted to a hospital within 1 month of being discharged home (Jencks, Williams, & Coleman, 2009). These readmissions are often referred to as 30-day readmissions as they occur within the first 30 days of being discharged to home (Gadre, Shah, Mireles-Cabodevila, Patel, & Duggal, 2019). Thirty-day readmissions cost society more than \$20 billion annually; many of which are likely avoidable readmissions (Hines,

Barrett, Jiang, & Steiner, 2006; Polinski et al., 2016). These figures are conservative as they are limited to hospitals alone and not to other inpatient settings, such as skilled nursing facilities.

Chronic conditions that lead to frequent, and avoidable, readmissions are myocardial infarction, chronic obstructive pulmonary disease, heart failure, pneumonia, coronary artery bypass graft, and total hip and knee arthroplasties (CMS, 2019a). Each of these chronic conditions may result in care-dependency that may last a lifetime (Schnitzer, Blüher, Teti, Schaeffner, Ebert, Martus, ... & Kuhlmey, 2020). Care-dependent older adults with these conditions would likely age in place better if involved and receiving FCC approaches to care (de Vries et al., 2016; Jackson et al., 2013). Caregivers may also benefit if involved and desiring FCC approaches (Backman & Cho-Young, 2019).

Caregivers of older adults have the highest rates of injury, burnout, and turnover with care-dependent older adults (Dieterich & Divino, 2017; Mehra et al., 2019). These issues can result in family members becoming the caregivers or having to institutionalize the older adult in a long-term care facility (Huff & Cotte, 2016). When the family members become caregivers, they have the added burden of lost income, lost time, and increased family distress (Ankuda et al., 2017; Crespo, Santos, Tavares, & Salvador, 2016; Schiamberg et al., 2011). Older adults with dementia have the largest percentage of family involvement and caregiver issues at home compared to any other patient group and diagnosis (Brodaty & Donkin, 2009). Caregiver training and education are a main part of the HHPT's practice and are aligned well with the principles of FCC. These

trainings help prevent caregivers from getting new injuries and help to reduce flare-ups from preexisting conditions (World Health Organization, 2017). HHPTs may also consider treating caregivers directly during a home visit with the older adult.

Family doctors and family nurse practitioners are primary care clinicians trained to treat whole families (Bowman, Lucan, Rosenthal, Mainous, & James, 2017). These clinicians treat family members as separate individuals during scheduled outpatient appointments (Hardy, Thompson, Alto, Keppel, Hornecker, Linares, ... & Baldwin, 2016). Within nursing research, family nursing is described as a care delivery that seeks to treat the patient and caregivers through direct nursing interventions with both (Broekema, Paans, Roodbol, & Luttik, 2020; Mehri, Kinney, Brown, & Rajabi-Rostami, 2019). In home health physical therapy, the HHPT is encouraged to train and educate caregivers, but no study or source was located that looked at providing direct interventions to caregivers while treating the older adult patient (Commission on Accreditation in Physical Therapy Education, 2017; Piscitelli, Furmanek, Meroni, De Caro, & Pellicciari, 2018; ; Romanello, 2007).

Under direct access, HHPTs can care for family members individually, or as a group (Piano, Maselli, Viceconti, Gianola, & Ciuro, 2017). Direct access is, however, limited by reimbursement issues, Medicare rules, regulations on group sessions, attitudes, and understandings (Carvalho, Bettger, & Goode, 2017). These limitations may further add to the growing problem of untreated musculoskeletal injuries of caregivers (Mabry, Notestine, Moore, Bleakley, & Taylor, 2019). This study explored HHPTs perspectives

on the family physical therapy. The HHPTs reported both a need and desire to treat caregivers too, yet none of them did so directly.

The desire for FCC is on the rise as communities that value shared decision making expand (Morales, Lara, Kington, Valdez, & Escarce, 2002; Rassool, 2015; White, Plompen, Tao, Micallef, & Haines, 2019). These communities include Asian, Hispanic, and Muslim communities (Ezenkwele & Roodsari, 2013; Frey, 2018). HHPTs need to be prepared to provide FCC to these communities. As the need and desire for FCC rise, different models of home physical therapy are predicted that support FCC approaches.

HHPTs may one day play a critical role in assisting the patient's primary care physician, the patient, and the family to establish a patient-centered medical home (PCMHs) (Jackson et al., 2013). A PCMH utilizes telehealth, web meetings, and interdisciplinary care in real-time from the patient's home (Adaji et al., 2018; Zajicek-Farber, Lotrecchiano, Long, & Farber, 2015). PCMHs are considered ideal for managing older adults with chronic conditions (Whitehead, Jacob, Towell, Abu-qamar, & Cole-Heath, 2018). PCMH designs can reduce the burden of care, improve health management at home, and lead to a reduction of 30-day readmissions (McCovery & Matusitz, 2014; Pape & Muir, 2019). This study did not uncover any HHPTs involved in establishing or utilizing a PCMH. Limits in FCC in terms of treating families as a unit and establishing PCMHs may be related to significant barriers reported in home health and FCC delivery.

Educational barriers on FCC exist in physical therapy education. Accreditation takes more of an individualized approach to care and is limits family involvement to pediatric coursework (CAPTE, 2017; Romanello, 2007). Political, financial, and

attitudinal factors are other barriers reported in home health that may limit FCC approaches (Bamm & Rosenbaum, 2008). One study found that some HHPTs view FCC as out of their scope of practice (Warner & Stadnyk, 2014). Others saw FCC as incompatible with their home health agency (Mikołajewska, 2014; Warner & Stadnyk, 2014). There is a lack of understanding of what factors may impact the delivery of FCC by HHPTs. This study explores the perspectives of HHPTs on the factors that impact FCC. Multiple contextual factors were reported in this study, helping to fill in some of the gaps in understanding on FCC with older adults.

#### **Problem Statement**

There is a lack of understanding of how FCC is applied to older adults (Jette, 2017; National Alliance for Caregiving, 2019; Wolff & Boyd, 2015). Jette (2017) proposed FCC competencies that a physical therapist should apply when treating a care-dependent older adult. These competencies include recognizing a family's presence, knowing how to involve the family in the rehabilitation plan, engaging and sharing information with the family, helping caregivers with referrals to other services, and making culturally competent decisions with the family (Jette, 2017). HHPTs that competently use FCC may: (a) help to prevent 30-day readmissions of older adults; (b) reduce caregiver burden; and (c) improve culturally competent care (Butler et al., 2016; Darragh et al., 2015; Dodson et al., 2019; Vloothuis et al., 2018). This study provides new understandings in for the form of three main themes. The themes demonstrated new understandings on FCC with older adults from the perspectives of 14 HHPTs in a community in the western United States. This study has the potential to lead to positive

social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction.

# **Purpose of the Study**

The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States.

### **Research Question**

The research question was: How do HHPTs in a community in the western United States describe their perspectives on providing FCC to older adults?

## **Conceptual Framework**

The open systems theory and servant leader philosophy are connected to FCC but do not capture every health factor that HHPTs address (Abdi et al., 2019). For this reason, the WHO's International Classification of Functioning Disability and Health (ICF) model was the conceptual framework selected for this study. The ICF model defines a patient's health factors as their: (a) health conditions; (b) impairments of bodily function and structures; (c) activity limitations in routine daily activities; (d) participation restrictions in the ability to participate with others; and (e) contextual factors (Centers for Disease Control and Prevention, 2010; McDougall, Wright, & Rosenbaum, 2010). Contextual factors are further divided into environmental and personal factors, such as stairs at home and health literacy of the patient (Britto, Oliveira, Gomes, Pinto, & Guerra, 2018).

The ICF model is the conceptual model for physical therapy practice and identifies the patient's family as a contextual factor that can impact other health factors (Cesari et al., 2018; Commission on Accreditation in Physical Therapy Education, 2017; Falvey, Burke et al., 2019). For this study, each HHPT's interview response was coded on a coding table and conceptualized in the ICF model.

## **Nature of the Study**

The nature of this study was qualitative. This study is not mixed methods nor quantitative by nature. This is due to the pure inductive reasoning used with this study. The research design is the single-case study design. This design is ideal for answering the "how" research question of this study (Baxter & Jack, 2008; Yin, 2017). The main question of how FCC is applied by a group aligns well to this design. The main data collection tool is semi-structured interviews. Semi-structured interviews are considered ideal for gaining in-depth understandings from individuals in a group (Yin, 2017). This study seeks thematic saturation from HHPT responses (Baxter & Jack, 2008). The narrative, phenomenological, ethnographic, and grounded theory designs were ruled-out from this study.

The narrative design was ruled out because it seeks to obtain thick descriptions from one, or a few, individuals (Baxter & Jack, 2008; Patton, 2002). This design does not seek to establish an understanding from a group of persons. The phenomenological was also ruled out.

The phenomenological approach explores the essence of a traumatic lived experience, a significant experience, or the experience of a marginalized group (Creswell

& Creswell, 2017; Patton, 2002). FCC in this study was through the lens of HHPTs typical work experiences. Phenomenological studies seek to understand a significant lived experience of an individual or group. FCC with older adults was not considered a significant lived experience for this study. The ethnographic approach was considered and ruled out.

The ethnographic approach explores a culture through field research (Creswell & Creswell, 2017; Patton, 2002). This study did not seek to understand the culture of HHPTs, home health, or older adults. This study does provide descriptions that may help to understand these cultures, but that was not the aim of this study. Field research was also not a focus of this study, that is, no HHPT was observed during care with older adults. Grounded theory was that last research design to be ruled out.

Grounded theory inductively develops a theory during the data collection and data analysis phases of a study (Creswell & Creswell, 2017; Patton, 2002). This study did use inductive reasoning to develop themes. These themes supported the established ICF model. The grounded theory approach was not part of this study because the ICF model was not changed, nor was a new theory developed.

In summary, this study used a qualitative, case study design using a single case of 14 HHPTs. This design was appropriate because this study explored FCC with older adults from the perspectives of HHPTs in a community in the western United States. The HHPTs' perspectives on FCC with older adults constructed new understandings about FCC within and outside of the established conceptual model of practice (ICF model).

This study's purpose, nature, and design align to the research question and help resolve the research problem of limited understanding on FCC with older adults.

### **Definitions of Terms**

The following terms are operationalized for this study; they are not explicitly defined in other sections.

Aging in place. The ability to live in one's desired home, neighborhood, or community with the highest possible quality of life, for as long as possible (CDC, 2009).

Caregiver. A caregiver is a family member or person who assists an older adult at home with their impairments and activity limitations so that they may age in place successfully. Unpaid caregivers are referred to as informal caregivers and often includes family members and friends; caregivers who are paid are referred to as formal caregivers who sometimes are family and friend of the patient as well (Vaingankar et al., 2016).

Direct access. The term direct means that patients, family members, and caregivers seeking physical therapy services can do so directly without first seeing another health practitioner for a script, order, or referral for physical therapy services (Ojha, Snyder, & Davenport, 2014).

Durable power of attorney (DPOA). The DPOA for health care is the healthcare agent who makes care decisions for a person when the person is unable to do so for themselves and is recognized by the legal system as such (Glennon et al., 2019).

*Health practitioner*. A health practitioner is a health professional, or health provider, that provides interventions, training, and education to prevent, cure, or rehabilitate health conditions (McKimm & McLean, 2011).

Home health agency. A home health agency (HHA) is also often referred to as a home health organization or home health provider (HHP). The HHA is any licensed entity that provides home health services under Medicare A (Helbing, Sangl, & Silverman, 1992).

*Intrinsic capacity*. Intrinsic capacity includes the limits of physical and cognitive abilities that an individual has throughout their lifetime (de Carvalho et al., 2017). In the ICF model, IC refers (Lauffenburger et al., 2017) to body functions, body structures, and impairments.

## **Assumptions**

This study was based on four assumptions: (a) the HHPTs would be able to speak on how they deliver FCC openly and honestly; (b) the HHPTs had experience in providing FCC to older adults and their families; (c) the HHPTs would speak openly on how they provide FCC; and (d) the data collected will help to fill in some of the gaps in understanding FCC with older adults.

### **Scope and Delimitations**

The scope of this study is FCC with older adults; not patient-family care nor patient-centered care (Carman et al., 2013; Lawler, Taylor, & Shields, 2015; Street, Elwyn, & Epstein, 2012). FCC defines the caregiver and the patient as the unit of care, not just the patient (Wolff & Boyd, 2015). Unlike patient-centered care, FCC involves collaborating with families and caregivers. This collaboration occurs during the encounter with the older adults and may include: (a) caregiver training and education, (b) caregiver intervention through direct access; and (c) shared-decision making with the

caregiver (Jette, 2017; Kuo et al., 2012; Murrell, Crawford, Jackson, Lotze, & Wiemann, 2018). Shared decision-making with the caregiver and patient allows the family to make informed choices (Hendricks-Ferguson et al., 2018).

This study is delimited to the responses of 14 HHPTs treating older adults (over 64 years old) at home (any home setting) in a community in the western United States. The community and HHPTs were selected out of convenience and proximity. Also, HHPTs were given semi-structured interviews through a synchronous, web-based, meeting service. The platform for the interviews is RingCentral and all audio responses were recorded for transcription, member checked, coded, themed, peer-debriefed, and conceptualized.

The 14 HHPTs selected for this study are licensed in the State of California, have at least 1 year of experience in home health, and have access to RingCentral meetings.

The interview guide was field tested by two HHPTs with over 5 years of experience in home health, and the coding table was peer-debriefed twice by one HHPT for additional perspectives.

#### Limitations

The study is limited in transferability given the case-study design with 14 HHPTs in the same community in the western United States. The sample selected was not random, but used snowball, or chain sampling (Noy, 2008). This sampling technique limits generalizability (external validity) too (Palinkas et al., 2015). The scope of this study was limited to 14 HHPTs, one of which was a halftime home health registered nurse (RN) and the other was a halftime regional manager for a home health agency. This

study did not solicit the perspectives of older adult patients, family members, caregivers, or other health care practitioners.

During data collection, home health was being transformed due to the COVID-19 pandemic and due to major legislative changes from the newly adopted patient-driven group model (Warren, 2019). This study was limited in the triangulation strategies during data collection as well. I used semi-structured interviews to collect HHPTs' perspectives but did not triangulate with a second data collection tool. Last, this study was potentially limited by my influence. HHPTs may have answered more to impress me than in accordance with their true feelings due to my standing in the local physical therapy community. Given the strengths and limitations of this study further research was recommended.

# Significance of the Study

This study closed some of the gaps in understanding on how FCC is applied to older adults by HHPTs. These understanding may lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction. These new understandings could also guide future studies on FCC that assess the impact of FCC on older adults and their caregivers (Rigby, Gubitz, & Phillips, 2009). Future studies on FCC are needed to see to what extent health outcomes and customer satisfaction improve when applied to older adults (Jette, 2017; Kogan et al., 2016).

# **Summary and Transition**

Chapter 1 introduced the need for FCC research on older adults. Family-centered care (FCC) is a collaborative approach to care that is proven to improve health outcomes in pediatric care and improve caregiver satisfaction. This approach to care is not well understood in the care of older adults at home with caregivers. The need and desire for FCC is growing. There is a paucity of evidence on FCC with older adults at home. Home health physical therapists (HHPTs) are positioned and capable to meet these needs and desires. The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. Chapter 1 further introduced the ICF model, definitions, assumptions, scope, limitations, and significance of this this study.

Looking ahead, Chapter 2 constitutes a literature review of FCC with older adults. It begins with an explanation of the search strategy used and then provides a historical overview of FCC. The conceptual framework of the ICF model is analyzed in depth. The need and desire for FCC is explored further. Chapter 2 concludes by connecting the literature review to the remainder of the study.

Chapter 3 is a detailed account of the research methods and the role of the researcher in this study. The interview guide protocols, single-case study design, and purposeful sample strategy are expanded on further. The chapter includes an exploration of the potential ethical and trustworthiness issues related to this study.

Chapter 4 provides an account of the setting of the study being online and the data collection tools of the interview guide, coding table, NVivo software, and reflective notes

used in this study. Chapter 4 also provides the data analysis method of coding and thematic analysis to develop subthemes and themes. The three main themes that emerged were: (a) FCC is complex; (b) FCC used to impact older adults' health factors; (c) FCC is impacted by contextual factors. These themes and related subthemes were further conceptualized within the ICF model.

Chapter 5 provides an analysis of each of the three themes and the related subthemes. Chapter 5 also provides a deeper exploration of the limitation of this study and contains the recommendations by the lead researcher that: (a) additional FCC visits be granted to HHPTs; (b) FCC training and education be expanded; (c) further research on FCC be conducted. Chapter 5 provides the positive social change implications. This study has the potential to lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction.

# Chapter 2: Literature Review

The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. This study fills in knowledge gaps surrounding FCC and home health physical therapy with older adults. These understandings have the potential to lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction. Chapter 2, a review of current literature, presents an exhaustive investigation into the available peer-reviewed articles on the history of FCC, the conceptual framework of the ICF model, the need and desire for FCC, and a review of the case study design. The first section of this chapter presents the search strategy used. The second section presents the historical context that is foundational to this study. The third section provides the underpinnings of the need and desire for FCC. The fourth section analyzes the case study design and methods planned for this study.

# **Literature Search Strategy**

The first phase of the literature review involved searching for available peerreviewed journals within the databases of CINAHL, Medline, Political Science Complete
& Business Source Complete (EBSCO), Psychology Database (EBSCO), APA
PsycTESTS, Thoreau, ProQuest Nursing Allied Health, PubMed, SAGE Journals, Allied
Health Evidence, Gale PowerSearch, Ovid Emcare, Wiley Library, and PTJ. A variety of
search terms, abbreviations, and Boolean phrases were used within these databases to

produce over 1110 articles covering the main sections of Chapter 2 (see Tables 1-3).

These articles were used for the second phase of the literature review.

Table 1
Search Strategy for FCC & Adults

Search Terms	Database	Articles
Family centered care or family-centered	Allied Health	95
care or FCC, [TI Title],	Evidence	
NOT	APA PsycTESTS	4
pediatric or child or children or	CINAHL & Medline	30
pediatrician or children's or infant or	Combined Search	
adolescent or NICU or neonatal intensive	Gale	249
care unit [TI Title]	Ovid ECCare	10
AND	Political Science	3
adults or adult or aged or elderly or	Complete &	
geriatrics or older adults or elderly [AB	Business Source	
Abstract]	Complete (EBSCO)	
Family-centered care [Anywhere]	Psychology Databases (EBSCO)	8
	ProQuest Nursing	20
	Allied Health	
	PTJ	125
	PubMed	11
	SAGE Journals	9
	Thoreau	89
	Wiley Library	4

Table 2
Search Strategy for the Need and Desire for FCC

Search Terms	Databases	Articles
TI (30 day readmissions or 30-day	ProQuest	25
readmissions or thirty day readmissions)		
AND AB (older adults OR elderly OR		
senior OR aging adults OR geriatric)	CINAHL & Medline	20
TI (informal caregivers) AND (geriatric	PTJ	18
OR older adults OR aging adult OR	ProQuest	166
elderly) NOT ab (ped* OR children)	CINAHL & Medline	29
TI (caregiver AND reduce or decrease or	PubMed	72
minimize or prevent)		
((cult*[Title]) AND family [Title]) NOT		
(children or pediatric or paediatric)		

Table 3
Search Strategy for Case Studies

Search Terms	Databases	Articles
perspectives or views or perceptions or attitudes or opinion [TI Title]	CINAHL & Medline	21
AND phys* ther* AND case study AND qualitative (((case study) AND perspectives) AND attitudes) AND (healthcare professional or	PubMed	30
doctor or healthcare professional of phys*ther*) AND (qualitative) NOT (student*)		
Therapist AND case study AND qualitative AND themes	PTJ	45

The second phase of the literature review focused on excluding irrelevant articles from the first phase. The articles from the first phase were loaded into EndNote.

Duplicate articles from the first phase were removed. The remaining articles were reviewed by title. Titles that did not relate to this study, like cellular biology, were

excluded. The abstracts from the remaining articles were reviewed. The abstracts that did not relate to this study were excluded. The remaining 237 articles were organized. Eighty articles were classified as supporting the historical context and frameworks of FCC, 130 supported the need and want for FCC, and 27 supported the case study design.

#### **Historical Context of FCC**

The 12th-century physician, and scholar, Maimonides understood the importance of collaboration with the patient (Bloch, 2001; Glick & Jotkowitz, 2014). Medical practitioners ignored Maimonides' teachings for centuries and were benevolent towards the patient (Yeoman et al., 2017). Nine-hundred years after Maimonides, the first article on patient-centeredness was published in a medical journal (Balint, 1969). By 1990, the term patient-centered care (PCC) first appeared (Creasy, Lutz, Young, & Stacciarini, 2015). PCC was about the patient having the locus of control over their healthcare delivery and making informed decisions through collaborations with the health practitioner. FCC allows for a shared locus of control (Coyne, Holmström, & Söderbäck, 2018; Moore & Kaplan, 2018).

Family-centeredness to care developed from changing societal expectations for hospitalized children after World War II (Jolley & Shields, 2009). The traditional paternalistic approaches were ineffective, insincere, and disingenuous (Oates, Weston, & Jordan, 2000). Pediatric nurses responded by collaborating more closely with the families of hospitalized children (Oates et al., 2000). The 1960s brought about consumer and family movements that pushed for family-centric approaches to care. These movements were based on social justice theories and spanned decades of growth, research, and

development (Lor, Crooks, & Tluczek, 2016). By 1987, the Association for the Care of Children's Health (ACCH) developed the first FCC guidelines (Bruce et al., 2002, p.410).

The 1990s saw expansions in FCC with the establishment of the Institute for Patient- and Family-Centered Care (DeRosa et al., 2019). This organization collaborates with consumer groups, accreditors, researchers, healthcare trusts, hospitals, and policymakers to advance the understanding and practice of FCC (Institute for Patient- and Family-Centered Care, 2019). In 2001, the Institutes of Medicine backed family-centric approaches to care in a series of quality care reports (Dhurjati, Sigurdson, & Profit, 2019). The general principles of FCC reported in current literature includes information sharing, respect, honoring differences, partnerships collaborations, negotiations, and providing care in the context of the patient and their family (Kuo et al., 2012).

Family-centered care continues to grow and continues to be considered the same as, or part of, patient-centered care. FCC is unique given the needed collaborations with the patient and their caregivers (Lor et al., 2016; Marcus-Aiyeku et al., 2015; Meyer, Scarinci, Ryan, & Hickson, 2015; Shields, 2015). Much of the growth and advocacy for FCC has been in pediatric settings; with little understanding, research, and advocacy in adult populations (Feeg et al., 2016). In Western medicine, self-autonomy and privacy laws make FCC collaborations with adults challenging (Joseph-Williams et al., 2017). Collaboration is challenging but is important for, and effective with, older adults and their caregivers (LaVela et al., 2016).

### **FCC Research on Adults**

FCC and caregivers of older adults. Studies on older adult care transitions have looked at caregiver satisfaction and preparedness with FCC approaches (Desai et al., 2015; Dhurjati et al., 2019; Kokonya, 2018). These studies found that FCC approaches improved satisfaction, and improved preparedness for the care transitions of older adults. A patient and family who are more prepared to return to home from the hospital should positively impact their initial assessment with the HHPT. During an episode of care, the HHPT should also consider FCC to transition care from home health to outpatient care, community care, or self-management (Falvey et al., 2016; Smith & Bemis-Dougherty, 2015). A landmark, mixed-methods study by La Vela et al. (2016) looked at caregiver and family perceptions of FCC during home health services with an older adult.

Over 2000 caregivers participated in the La Vela et al. study (2016). The caregivers completed the Family-Centered Care Survey and answered one open-ended question. The survey was a 20-item survey that assessed three FCC domains of respect, collaboration, and support (Wang, Feng, Wang, & Chen, 2016). The authors determined that younger caregivers scored significantly lower scores on their perception of all three FCC domains compared to older caregivers (LaVela et al., 2016). The main theme of the open-ended question was age differences. Younger caregivers needed more information and feelings of acknowledgment from the home health services. Older caregivers reported needing more help navigating care transitions and outpatient services (LaVela et al., 2016).

Families that have older adults with mental health issues, end of life diagnosis and wellness issues were the subjects of recent FCC inquiries. Multiple studies demonstrated

that FCC improved family caregiver satisfaction and competencies with caring for older adults with mental health issues (Bui, Han, Diwan, & Dao, 2018; Haigh, Bogucki, Sigmon, & Blazer, 2018; Hinton et al., 2019; Rhee & Rosenheck, 2019; Wong, Wan, & Ng, 2016). FCC was also demonstrated to be more effective for working with families dealing with end of life situations at home by reducing caregiver, family, and patient stress through collaboration (Chen et al., 2016; Dallas et al., 2016; Kimmel, Wang, Scott, Briggs, & Lyon, 2015; Williams, Donovan, Stajduhar, & Spitzer, 2015; Wittenberg, Buller, Ferrell, Koczywas, & Borneman, 2017). Wellness issues like smoking cessation (Kim et al., 2015) and weight loss (Duncan et al., 2016) were also found to be effective with FCC approaches. These studies found that FCC produced better adherence to wellness and improved family satisfaction. HHPTs should benefit from these understandings. Studies looking to improve the understanding of FCC by health professionals were explored further.

FCC understandings. Improving FCC understandings with older adult applications was the subject of recent studies. One study demonstrated that FCC training during physician grand rounds at a hospital was effective at increasing FCC awareness and use with older adult patients and their families (Fagan, Wong, Carnie, Ashley, & Somerville, 2015). Another study assessed how cardiologists and nurses performing FCC with families present during grand rounds would rate FCC (Ludmir et al., 2018). Cardiologists and nurses reported that FCC was a less efficient use of their time, but FCC benefited families more through improved communication and patient safety (Boztepe &

Kerimoğlu Yıldız, 2017; Ludmir et al., 2018). Other studies have recently experimented with more novel FCC approaches.

FCC experimentation. One study experimented with customized baseball cards to help patients and their families identify surgical-unit team members (Demehri et al., 2015). Another study experimented with using health libraries and information specialists to help families cope with hospitalized older adults (DeRosa et al., 2019). The results of these two studies were that FCC experimentation was safe and improved caregiver recall and coping. The literature on FCC with adults is limited but demonstrated that there are significant barriers to delivering FCC to this population.

#### **FCC Barriers**

FCC barriers with older adults were reported as limiting the consensus on FCC approached with older adults (Coyne, Murphy, Costello, O'Neill, & Donnellan, 2013; Jette, 2017). These barriers included documentation, travel conditions, reimbursement, authorization, family involvement, and cultural sensitivity (Shamus, Fabrizi, & Hogan, 2018). For HHPTs specifically, an additional barrier was a lack of understanding around FCC and older adults (Haines, 2018; Jette, 2017; Warner & Stadnyk, 2014). Additional barriers were reported in the literature related to FCC.

Family care approaches, in which the older adult and their caregivers are treated at home together, was not widely practiced (Mainous, Porter, Agana, & Chessman, 2018; Rosser, 2002). According to one study, few doctors received quality training on older adults (Portela Romero, Bugarin Gonzalez, & Rodriguez Calvo, 2017; Raetz, Unwin, & Andrilla, 2016). The barriers of high caseloads and health practitioner burnout were

found to further limit the time needed for FCC with older adults (Ramos, Romero, Ortiz, & Brizuela, 2015; Weidner, Phillips, Fang, & Peterson, 2018). Additional barriers were identified in pediatric and critical care settings.

Bruce et al. (2002) and Johnson (2000) summarized the barriers to FCC reported in pediatric settings. These barriers were reported as a reluctance to delegate care by health practitioners, limited time for FCC, a lack of understanding of FCC, difficulties with conflict management with families, and difficulties with role negotiations within the IDT (Bruce et al., 2002; Johnson, 2000). In critical care settings, FCC was considered a research, and clinical, priority for older adults and their families (Oczkowski et al., 2017; Rojas Silva, Padilla Fortunatti, Molina Munoz, & Amthauer Rojas, 2017).

FCC in critical care settings with older adults had significant barriers. A recent systematic review summarized multiple studies on FCC applications in critical care (Frank, Shah Jahan, & Agbele Alaba, 2019). The main findings were that FCC has four main barriers in critical care settings. The findings included a lack of understanding of FCC, organizational barriers, personal biases of healthcare practitioners, and a lack of an interdisciplinary approach to care (Frank et al., 2019).

FCC and the HHPT. Family-centered care is philosophically aligned with the servant leadership philosophy (Nyborg, Danbolt, & Kirkevold, 2017). Multiple core physical therapy practice and educational documents support the servant leadership approach and FCC (Gersh, 2006). Servant-leadership focuses on the needs of others (patients and their families) and fosters the growth and empowerment of patients and families (CAPTE, 2017; de Zulueta, 2016).

### **Conceptual Framework**

## **Theoretical Underpinnings**

The traditional medical model, the biomedical model, defined health as being dependent on a person's biology and physiology (Maier, al'Absi, & Persad-Clem, 2018). External environmental factors were considered independent of health and were ignored (Williams, Priest, & Anderson, 2016). The human body, and health, were considered a closed system that doctors could impact, independent of the external environment (Maier et al., 2018). The biomedical model did not provide a theoretical foundation for understanding the impact FCC had on patients.

The systems theory traces back to 19<sup>th</sup> century sociologists who saw biology and societal status as influencing a person's well-being (Perrin, 1995). The systems theory evolved into business management. In business management, the systems theory was used to visualize a business as a living organization that could be influenced by, or change, the surrounding environment. (Sun, Wu, & Yang, 2018). The systems theory was revolutionized in health care by Von Bertalanffy (1950), who proposed that the health of a person was impacted by contextual factors such as finances and caregiver support (Von Bertalanffy, 1950). Systems theory was also used to understand complex healthcare delivery systems (Khan et al., 2018; McCovery & Matusitz, 2014). The systems theory is grounded within the main conceptual framework used in this study—the ICF model.

#### The ICF Model

The ICF model developed from the biopsychosocial model which is rooted in systems theory. George Engle used the systems theory to develop the biopsychosocial

(BPS) model (Engel, 1977). In this model, social and psychological factors influence health positively or negatively. Access to healthcare and affordability are prime examples of social issues affecting the health of millions of Americans (Anderson, 2016). In the BPS model, families were considered social factors that impact health. Supportive families were considered as affecting both the morbidity and mortality of care-dependent individuals. The BPS model was considered too limited to be the conceptual model for this study (Prescott & Logan, 2019).

The BPS model lacked newer concepts that may impact health and healthcare approaches. These factors included, but were not limited to, spiritual, cultural, and ecological factors. The BPS model did not account well for the impact that a person's intrinsic capacities had on their health either. Improvements in intrinsic capacities were considered essential for successful aging in place (Cesari et al., 2018). The BPS model was, however, considered foundational to the development of the ICF model (Abdi et al., 2019).

The ICF model developed from the BPS model and conceptualized a person's health as a combination of multiple internal and external health factors (FitzGerald et al., 2018). These factors included the intrinsic capacities, societal roles, environmental factors, and personal factors of the patient (World Health Organization, 2001). The ICF model accounts for any current and future contextual factors—both environmental and personal (Prodinger et al., 2016). The ICF model was important to consider for this study given this flexibility and the changing definitions of families and caregivers (Huff & Cotte, 2016).

The ICF model went beyond the patient's medical diagnosis and physiology and considered a host of other factors. The family and the IDT, as environmental factors, directly link the ICF model to FCC approaches (Abdi et al., 2019). Outside of the ICF model, few models are validated and support FCC well (Alemayehu, 2019). The ICF model is the conceptual framework for many health professions, including physical therapy (Peters-Brinkerhoff, 2016). Given these connections to FCC and the profession of physical therapy, the ICF model was selected for this study.

Other models were also considered. These models included the family-centered care model, patient-centered care model, strength-based model, and universal model of family-centered care (Alemayehu, 2019; Christon & Myers, 2015; De Beer & Brysiewicz, 2019; MacFarlane, 2011; Tanenbaum, 2015). The universal model of family-centered care (UMFCC) model was the only model to align with FCC and older adults (Kokorelias, Gignac, Naglie, & Cameron, 2019). This model was connected to the general principles of FCC reported by Ku. The model strived for the creation of an FCC plan of care by the health practitioner—a must for family medicine. The UMFCC model was not validated or understood within physical therapy at the time of this study and lacked the depth of the ICF model. The ICF model supports the need and desire for FCC.

#### **Need and Desire for FCC**

Improving the quality of healthcare delivery is considered essential for reducing costs and improving health outcomes (Bilimoria et al., 2017; Burstin, Leatherman, & Goldmann, 2016). For over 30 years the Institutes of Medicine (IOM) provided guidance and literature supporting the need for improved safety, effectiveness, timeliness, patient-

centeredness, efficiency, and equitability of healthcare (Newton, Baxley, & Lefebvre, 2019). These quality aims are referred to as the IOM-6 and are present in most health policy initiatives (Newton et al., 2019). The IOM-6 provides a framework for quality improvement for older adults (Abbasi, 2016; Dharmarajan et al., 2017; McPhail, 2016; Newton et al., 2019; Wells et al., 2018). FCC approaches by the HHPT with older adults can achieve the IOM-6, improve aging in place, and lead to culturally competent care (Butler et al., 2016; Picco et al., 2016; Polinski et al., 2016; Regenbogen et al., 2017).

### FCC and Aging in Place

Keeping older adults out of hospitals, and in their preferred place of residence, is considered a priority for older adults and policymakers (Jette, 2017; Kogan et al., 2016; Lovering, 2018; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Thirty-day readmissions are problematic for both seniors and society (Regenbogen et al., 2017). Unplanned readmissions account for nearly 12% of all hospitalizations (Berry et al., 2018). In 2012, the Affordable Care Act included the Hospital Readmissions Reduction Program (CMS, 2019a). This program lowers payments to hospitals in the form of a penalty for 30-day readmissions. The program was effective at reducing avoidable readmissions and forced hospitals to experiment with care delivery models (Angraal et al., 2018; Boltz, Chippendale, Resnick, & Galvin, 2015; Occelli et al., 2016). Other initiatives like Patient-Centered Medical Homes, changes in care transitions, and interdisciplinary collaborations have had positive impacts on reducing 30-day readmissions (Adaji et al., 2018; Almkuist, 2018; Alvarez, Ginsburg, Grabowski, Post, &

Rosenberg, 2016). Still, many of the root causes of 30-day readmission need to be further addressed (Ameh et al., 2017; Dharmarajan et al., 2016).

The World Health Organization's Department of Ageing and Life Course established clinical practice guidelines to address many of the root causes of readmissions for older adults (WHO, 2017). These guidelines are referred to as the Integrated Care for Older People (ICOPE) guidelines. These guidelines are designed for home-based care, community-based care, and IDT approaches.

Home-based care includes insurance covered services, like home health physical therapists, volunteer, and private-pay services. Community-based care includes adult day centers that help with aging in place (Christon & Myers, 2015). Interdisciplinary approaches in all of these settings are important because they assist the family to monitor medical issues that lead to readmissions and caregiver burnout (Kolte et al., 2017; Robinson, 2015). The HHPT is considered as an IDT member too. The HHPT played a major in achieving ICOPE guidelines that improve or maintain an older adult's intrinsic capacities, urinary continence, and fall risk (WHO, 2017). The HHPT is at the forefront of preventing readmissions and promoting successful aging in place with older adults (Jette, 2017).

Intrinsic capacities and exercise programs. The first ICOPE guideline is to improve the intrinsic, physical, capacities of older adults (WHO, 2017). Improvements in the intrinsic capacities of care-dependent older adults reduce the risk for readmissions significantly, and with a high level of evidence (Galloway et al., 2016). ICOPE recommends a progressive, multimodal exercise program that would be self-managed at

home to improve intrinsic capacities (WHO, 2017). These programs include activities that improve the strength, balance, flexibility, and aerobic capacity of older adults (WHO, 2017). Tai chi and the Otago exercise programs are supported by research as being effective with older adults (Hwang et al., 2016; Stevens & Lee, 2018). Standardized exercises programs like these, unfortunately, do not work well in practice (Worum, Lillekroken, Ahlsen, Roaldsen, & Bergland, 2019). Individualized exercise programs may allow for better adherence to a program by both the patient and their caregivers.

The safety of the exercise program needs to be balanced against increasing exercise intensity. Higher intensity exercise programs should be the goal for the older adult. Higher intensity exercises are more predictive at reducing 30-day readmissions rates with older adults (Andrews, Li, & Freburger, 2015). This is true for even the frailer older adults with common readmission conditions like myocardial infarction (Belga et al., 2016; Carlson et al., 2017). HHPTs should consider progressing the exercise program intensity while avoiding triggers, like shortness of breath, that lead to hospital readmissions (Borkenhagen et al., 2018). To achieve self-management safely with the exercise program, the caregiver will need training by the HHPT.

Urinary incontinence. Urinary incontinence affects almost a third of all older adults and can lead to social isolation, depression, disuse atrophy, skin breakdown, and infection (Tamanini et al., 2018; Vaughan, Fitzgerald, & Markland, 2019). These problems are considered another cause to hospital admissions and readmissions (WHO, 2017). To better manage urinary incontinence, the ICOPE guidelines call for prompted voiding and pelvic floor muscle training (WHO, 2017). Prompted voiding is a behavior

management strategy that the HHPT can train the older adult and the family through FCC. Prompted voiding is effective at any cognitive level of the older adult (Averbeck, Altaweel, Manu-Marin, & Madersbacher, 2017). HHPTs can assess the home situation to determine what modifications to the environment are needed to optimize and comply with voiding schedules. They can also provide interventions to improve urinary continence.

Interventions include basic pelvic floor muscle training that is effective for both males and females (Masterson et al., 2017). Advanced pelvic floor muscle training is considered more effective, but requires certification and equipment (Hagen et al., 2019; Herman and Wallace, 2019). HHPTs can train families on how to locate a certified specialist for the pelvic floor if they do not possess advanced skills. Given the need for modesty, privacy, and collaboration with the family, FCC approaches are important when engaging in pelvic floor training at home. FCC approaches are also ideal for reducing falls at home.

Fall risk. Falls are highly predictive of 30-day readmissions in older adults (Hughes & Witham, 2018). In the older adult population, falls and fall-related injuries are growing exponentially (Galet, Zhou, Patrick Ten, & Romanowski, 2018). HHPTs must consider other contributing factors with care-dependent older adults when assessing fall risks (Collins et al., 2019). These contributing factors were defined by ICOPE as medication management and fall-hazards. Well-managed medications and home modifications to reduce hazards are highly effective at reducing falls and readmissions (Stevens & Lee, 2018).

*Medication reviews*. Medication errors are prevalent at home and increased fall risks significantly for care-dependent older adults (Brody et al., 2016; Park, Satoh, Miki, Urushihara, & Sawada, 2015). Park et al. (2015) found that sedatives, hypnotics, and antidepressants, significantly increase the risk of falls in older adults. Supplements and other over-the-counter medications increase the fall risk further (Qato, Wilder, Schumm, Gillet, & Alexander, 2016). Some supplements, like Vitamin D, were found to reduce fall risk (Stevens & Lee, 2018). One study showed a positive correlation between the number of medications an older adult takes, the rate of falls, and the rate of 30-day readmissions (Basnet et al., 2018). ICOPE recommends that the home health practitioner (the HHPT) review the medications with the patient and caregivers. It is also recommended that the home health practitioner discuss with the family, patient, and doctor, any medication side-effects (Collins et al., 2019).

Home environment assessments. ICOPE guidelines recommend that a home environment assessment, and subsequent home modifications be made, to eliminate fall hazards and promote safe mobility at home (WHO, 2017). Multiple standardized tools were reported in the literature that identify fall hazards at home (Romli, Mackenzie, Lovarini, Tan, & Clemson, 2018). Home modifications and recommendations to reduce these hazards by the HHPT can significantly reduce the fall risks at home (Stevens & Lee, 2018).

**The IOM-6**. The FCC approach aligns to the IOM-6 aims of relevance, timeliness, efficiency, and safety (Clay & Parsh, 2016). A recent systematic review demonstrated that the FCC approach to exercise training improved the relevance of an

exercise program and improved compliance over time (Bachmann, Oesch, & Bachmann, 2018). Through FCC approaches, HHPTs get a good understanding of the medications, supplements, and alternative approaches to care that may affect balance. Last, by working with the family and the care-dependent older adult, the HHPT can find solutions that are relevant to the patient and caregiver needs and desires.

Home-based FCC by the HHPT was found in one study to save time and money over outpatient visits (Hwang et al., 2016). With outpatient services, care-dependent older adults and their caregivers needed to arrange for transportation and visit many providers. Home-based services by the HHPT allowed services to be bundled such as PMEP training, bladder retraining, and home modifications. When the HHPT provides FCC at home after a hospitalization, it is timely and efficient for the family to transition back home. This is important for older adults with chronic conditions that cause them to decompensate rapidly (Goto, Faridi, Camargo, & Hasegawa, 2018). HHPTs may also need to train older adults and caregivers on the use of smart home technology to manage their care and exercise programs as well (Majumder et al., 2017).

FCC approaches require extra time to train and help caregivers become experts in caring for older adults (Wilkinson et al., 2018). The time invested in this training is considered important at reducing the risk of a 30-day readmissions and caregiver issues (Backman, Chartrand, Dingwall, & Shea, 2017; Dieterich & Divino, 2017; Mehra et al., 2019). Caregiver burnout occurs when a stressor leads to the inability to care for others over an extended period (Ankuda et al., 2017; Snyder, 2009). Caregiver burnout is the highest with caregivers of older adults that have more than two chronic conditions or e a

progressive neurological disorder like dementia (Ploeg et al., 2018). This burnout can lead to posttraumatic stress disorder (Vranceanu, 2019). The three main stressors that lead to burnout are reported as depersonalization of work, a reduced sense of personal accomplishment, and emotional exhaustion (Gharakhani & Zaferanchi, 2019). Understanding and responding to the needs of families and caregivers is part of the FCC approach. The HHPT needs to prioritize the patient's needs, as well as the caregiver's needs when assessing a care-dependent older adult for the first time (Hagedoorn et al., 2017; Rose et al., 2007). Preventing caregiver burnout is critical.

Support services are effective at preventing caregiver burnout. The ICOPE guidelines encourage health practitioners to help family members find support services to avoid burnout (WHO, 2017). Caregiver support options existed for both families and older adults (Donath et al., 2019). These options include web-based, telephone, and outpatient support services (Caunca, Simonetto, Hartley, Wright, & Czaja, 2018; de Oliveira et al., 2019; Egan et al., 2018; Fänge et al., 2017; Fowler, Haney, & Lemaster, 2016; Garand et al., 2019; Ploeg et al., 2018). Some of these options, like telephone sessions, were limited in their success at reducing burnout levels (Heckel et al., 2018).

In addition to psychological support, other services were reported as effective at reducing caregiver burnout. Respite care is a service reported as effectively helping caregivers (Wolff, Mulcahy, & Kasper, 2017). In-home support services are effective too (Jutkowitz et al., 2019). Family care approaches via telehealth were reported as effective too (Winders Davis, Myers, Logsdon, & Bauer, 2016). The HHPT needs to use FCC

approaches to collaborate with caregivers to find the right services and approaches to reduce caregiver burnout.

One way that the HHPT can directly reduce burnout is to set clear expectations around home health services at the beginning of an episode of care. Hospitals have used new technologies, like virtual reality (Jütten, Mark, & Sitskoorn, 2018) to better transition families to home. At times, these transitions were not in alignment with what home health agencies provided. This mismatch caused caregivers and patients additional stress (Jones et al., 2019). HHPTs using FCC approaches can set clear expectations early-on with families and address mismatches promptly. The HHPT can also provide caregiver education and training with FCC which helps to reduce burden (Terayama et al., 2018). Educating and allowing caregivers to participate in HHPT sessions is an effective FCC approach to care (Fiest et al., 2018).

Caregiver injury. Caregivers often have physical injuries that are acute, subacute, or chronic (Darragh et al., 2015). These musculoskeletal injuries often limit the caregiver's intrinsic capacities to care for the older adult. Injuries were found to be more prevalent with higher frailty and caregiver burnout (Maxwell et al., 2018). The HHPT needs to consider addressing caregiver injuries directly, like a family-medicine approach, to prevent further injury to the patient or caregiver. Assistive devices were found to reduce injuries too.

One study found that assistive devices and adaptations at home reduced physical injuries to caregivers significantly (Budarick, Lad, & Fischer, 2019; Hwang, Kuppam, Chodraju, Chen, & Kim, 2019). Another study demonstrated that aerobic exercise

reduced stress of, and injuries to, caregivers (Puterman et al., 2018). HHPTs may need FCC approaches to help set-up exercise programs for both patients and the caregiver. These family programs have barriers that will require collaboration (Sun et al., 2019). One study on caregivers with chronic osteoarthritic knees demonstrated that a total knee arthroplasty with exercises significantly reduced their preoperative burdens at work (Zadzilka et al., 2018). Musculoskeletal injuries respond well to manual therapy by the HHPT (Leininger et al., 2016). Exercises are important for patients and for their caregivers (Chan et al., 2016). The HHPT can create an exercise program that benefits all parties and is performed during a singular visit.

HHPTs are uniquely trained to address musculoskeletal injuries, functional declines, and intrinsic capacity of any patient at any age and can be a valuable resource to the caregiver. Treating the caregiver and patient at home is legal, on a limited basis, under direct access. Direct access is legal in all 50 states, however, is seldom reimbursed by Medicare (American Physical Therapy Association, 2019). This creates a large barrier to directly treating caregivers at home.

Caregiver turnover. Caregiver turnover is related to burnout and injury. FCC strategies used to reduce burnout and injury can reduce turnover (Roth, 2018). Measuring how effective FCC approaches are is an important, quality control measure of FCC. The Family-Centered Care Assessment Scale (FCCAS) was designed and validated to assess caregiver perceptions and ongoing needs with FCC (Wells, Bronheim, Zyzanski, & Hoover, 2015). Meeting caregiver expectations and providing high-quality collaboration may be one effective way to reduce turnover.

# **Culturally Competent Care**

Culturally competent care is described as care that adapts to, and respects, a patient's language, communication styles, values, beliefs, and behaviors (Butler et al., 2016; Cuevas, O'Brien, & Saha, 2017). This type of care is considered an institutional priority for healthcare organizations (American Hospital Association, 2013; Whealin et al., 2017). Multiple theories exist that support culturally competent care such as the social justice, cultural care, and the sunrise enabler theories (McFarland & Wehbe-Alamah, 2019). Culturally competent health practitioners promote health-literacy, address underserved needs, and design targeted interventions (Butler et al., 2016). This care is aligned well to FCC (Lor et al., 2016). For this study, FCC is considered a facet of culturally competent care.

Culturally competent care and FCC. Culturally competent care is supported by FCC approaches when a patient wants (values) their family, community, or caregivers to be involved with their care. Many cultures in America, like African, Chinese, Latino, and Muslim cultures, desire FCC approaches and shared decision making (Edge & Grey, 2018; Huang et al., 2018; Morales et al., 2002; Rassool, 2015; White et al., 2019). FCC approaches with cultures that desire FCC is a culturally competent approach to care (Weerasinghe & Maddalena, 2016). This type of care includes humility, self-reflection, and a desire to be caring (Fahlberg, Foronda, & Baptiste, 2016; Nino, Kissil, & Davey, 2016). HHAs have a role in providing culturally competent care initiatives (Xiao et al., 2017). One initiative is improved health literacy.

Culturally competent care and health literacy. Health literacy is one aspect of care that HHPTs can assess of patients and families (Hughson et al., 2018). Health literacy is a concerted effort to have all materials in the language and communication style of the patient and include culturally relevant interventions (Mackert, Mabry-Flynn, Champlin, Donovan, & Pounders, 2016). HHPTs can provide training and education with materials in the patient's native language and educational levels (Arlandis Guzman et al., 2017; Rojas Silva et al., 2017; Vasli, 2018). Improving health literacy is a priority because low levels of health literacy are predictive of 30-day readmissions (Bailey et al., 2015). For the HHPT, cultural factors can differ greatly when it comes to rehabilitation goals and needs at home (Norup et al., 2015). Therapeutic alliances are also considered a way for the HHPT to provide CCC through FCC (Harris & Panozzo, 2019).

Culturally competent care and therapeutic alliances. A therapeutic alliance represents ongoing collaboration with patients and their families, agreement of treatments and goals, and an *affective bond*, that is, caring and trusting (Arnow & Steidtmann, 2014). FCC is aligned with creating therapeutic alliances (Bell, 2014). Therapeutic alliances were found to foster healthier family dynamics and positive health outcomes (Brown & Weisman de Mamani, 2018; Fernandes & Horta, 2018). Therapeutic alliances are vital for patients with chronic conditions (Giuliano, Danesh, & Funk, 2016; Hu, Amirehsani, Wallace, McCoy, & Silva, 2016; Turrise, 2016). For these patients, FCC and therapeutic alliances reduce hospital readmissions and improve the quality of care (Deek et al., 2016; Hu et al., 2016; Huang et al., 2018).

Culturally competent care and cultural targeting. Cultural targeting relates to providing education, training, and services that align with the culture of the family, and it goes beyond health literacy (Shukri, Jones, & Conner, 2016). Culturally targeted interventions allow for improved aging in place (Weisman de Mamani, Weintraub, Gurak, & Maura, 2014). HHPTs need to be aware of unhealthy biases and stigmatisms that can form when formulating culturally targeting interventions. Research can even foment these biases. For example, a study found that younger White caregivers needed significantly more time to train than their Asian counterparts (Speirs, Huang, & Konnert, 2017). This may not be the case for all White, or all Asian, caregivers. Addressing cultural stigmatism and biases, such as attitudes on mental health, diabetes, and smoking is needed as well (Bui et al., 2018; Kim et al., 2015).

It is recommended to respect a culture's differences, yet, still inform a family of any contradictory evidence as it relates to health outcomes (Chen, Lam, Deng, Corrigan, & Yau, 2018; Patel et al., 2015). One study cautioned that families did not always act in the patient's best interests (Wusten & Lincoln, 2017). HHPTs are obligated to report to the appropriate authorities any abuse or neglect (Dong & Simon, 2014; Siddiqui, 2017). Unsupportive or abusing families is a barrier. Therefore, each family should be considered its own micro-culture that the HHPT needs to be familiar with and adapt to appropriately.

Barriers to culturally competent care. Triscott, Szafran, Waugh, Torti, and Barton (2016) reported that culturally competent care is difficult for implementing because of the cultural differences people have (Lawlor & Mattingly, 1998). Verbal and

nonverbal communication, gender norms, family conflicts, personal space differences, boundary issues, and differences in personal struggles make for challenging barriers (Benson, Parker Oliver, Demiris, & Washington, 2019; Squires et al., 2019; Triscott, Szafran, Waugh, Torti, & Barton, 2016; Valizadeh, Mirlashari, Navab, Higman, & Ghorbani, 2018). In addition to this, health disparities reported by non-whites outside of homecare are another barrier to receiving and benefitting from HHPT services (Zajicek-Farber et al., 2017). Practitioners can minimize these issues by using interpreters, sharing information with community advocates, and maintaining a flexible work schedule (Bouye, McCleary, & Williams, 2016; Frist, 2005; Knox, Lehmann, Vogelgesang, & Simpson, 2018; White et al., 2019). Health educational changes are recommended to better prepare clinicians as well (Campos & Kim, 2017; Frist, 2005; Vick et al., 2018).

Nursing students were identified as needing more education on interviewing patients of diverse backgrounds (Brown, 2017). Brown (2017) found that the need for more open-ended questions, restatements, and summarizations during initial assessments. Physical therapy students were identified as not being prepared for cultural differences (Blackwood & Sweet, 2017; Kraemer, 2001). Kraemer (2001) found that student physical therapists lacked adequate preparation in school, exposure from fieldwork, and awareness of cultural differences. Medical students were also identified as not being adequately prepared to engage in CCC (Ortiz et al., 2019; Raetz et al., 2016). Given these educational shortcomings, issues with cultural competence remain. Marginalized groups, like Native Americans, suffer when new clinicians cannot perform FCC in a culturally

competent manner (Garwick, Jennings, & Theisen, 2002). Attitudes can also be a barrier to culturally competent care.

In Western medicine, the autonomy of the patient to make their own health decisions, and the privacy of health information are highly valued (Alden et al., 2018). FCC can seem contrary to these values and regulations. Family involvement is *only* appropriate when the patient, or DPOA, want them to be involved. Some patients may desire FCC but prefer non-disclosure when they have a terminal diagnosis, like cancer, (Chittem & Butow, 2015). Other cultural attitudes regarding the interpretation of pain and gender roles are potential barriers to forming therapeutic alliances (Fantini, 2016; Hong, 2018; Kizilhan, 2016).

Cultures with differing socially accepted responses to pain require the HHPT to adjust their FCC approaches. For example, some older adults were embarrassed to show pain to their families or to the opposite gender (Kizilhan, 2016). This required the practitioner to engage in more individualized care methods. The methods reported were:

(a) closely monitoring the patient's nonverbal responses to pain when the family is present; (b) working alone with the patient; or (c) finding the same gender therapist to work with patient (Kizilhan, 2016). The current healthcare system continues to be a barrier to culturally competent care and the FCC approach.

Insurance policies, home health agencies, patients, and caregivers can further limit FCC and culturally competent care (Frist, 2005; Richards & Schmitt, 2018).

Insurance policies do not reward the HHPT for quality family training, improved customer satisfaction, or improved aging in place (Anderson et al., 2018; Jette, 2017).

Home health agencies provide limited training on FCC and may also limit the number of visits by the HHPT (Bender, Lui, & Holyoke, 2017; Okeke et al., 2019). Patients and caregivers that do not comply with the plan of care, or are unwilling to learn new information, are also barrier (Frist, 2005; Partridge, Gallagher, Freeman, & Gallagher, 2018). This occurs when patients do not attend to their home exercise program, caregivers miss therapy sessions, and families refuse to invest in home modifications (Maddison et al., 2019; Partridge et al., 2018; Talboom-Kamp, Verdijk, Kasteleyn, Numans, & Chavannes, 2018).

### **Summary of Need and Desire for FCC**

In summary, HHPTs will need FCC approaches and interventions when delivering care to care-dependent older adults and their caregivers. HHPTs using FCC approaches may allow the care-dependent older adults to better maintain (or improve) their intrinsic capacities, urinary continence, and fall risk. HHPTs using FCC approaches allow caregivers to manage or avoid injuries, burnout, and turn-over. FCC approaches have the potential to result in more successful aging in place, higher customer satisfaction, and more culturally competent care (Bastani et al., 2015; Vanleerberghe, De Witte, Claes, Schalock, & Verté, 2017).

## **Case Study Design and Methods**

This study sought to solve the research problem related to the paucity of evidence on FCC with older adults through HHPTs' perspectives. The research design was a holistic, single-case study design looking at a single case of HHPTs in a Western community in the United States. The data collection tool was semi structured interviews

and data analysis via coding for themes. Themes were conceptualized within the ICF model. The nature of this study was qualitative using exploratory questions, thick descriptions, and constructed themes (Yin, 2017). Twenty-six case studies were identified during the literature review that measured case-studies on health practitioner perspectives. These cases were compared to this study.

#### **Similar Single-Case Study Designs**

The holistic single-case study design, also referred to as the Type 1 design, was described well by Holt, McCool, Nosa, and Thorne (2018). The authors employed purposeful sampling to find 12 otitis media experts. They used semi-structure interviews to collect data from these experts (Holt, McCool, Nosa, & Thorne, 2018). The authors coded the data from the interviews, used thematic analysis to form themes, and conceptualized these themes in a Venn diagram. Multiple similar studies were revealed in the literature review to have used the Type 1 design effectively across healthcare professions to develop themes around a single unit of analysis (Boztepe & Kerimoğlu Yıldız, 2017; Dewhirst, Ellis, Mandara, & Jette, 2016; Díaz de León-Castañeda, Gutiérrez-Godínez, Colado-Velázquez, & Toledano-Jaimes, 2019; Hughson et al., 2018; Karvande, Sonawane, Chavan, & Mistry, 2016; Nguyen, Bauman, Watling, & Hahn, 2017; Patel et al., 2015; Sarin & Maria, 2019; Teruya, Sunagawa, Sunagawa, & Toyosato, 2019). Boztepe and Kerimoğlu (2017) interviewed 18 nurses from three departments within a hospital and sought to summarize nursing perspectives as single, not multiple, case design. Toivonen, Lehtonen, Ahlqvist-Björkroth, and Axelin (2019) interviewed nurses and nurse managers selected from eight different neonatal intensive

care units (NICUs). For these authors, there was no distinction in the unit of analysis, nor was there between NICUs, making the NICU a single case. Other authors used different data collection methods or used multiple methods. None reported being a phenomenological study.

Analysis. The literature search revealed multiple single case studies that used similar methods to this study. A deeper understanding of the common case from the perspectives of a single unit of analysis can be done effectively this way. These findings support the design and methods used with this study. Other methods and designs are analyzed further.

# Other Single-Case Study Designs and Methods

Carlson (2016), Blackwood and Sweet (2017), and McCann (2015) used focus groups with their case study. Carlson (2016) transcribed focus groups to obtain deeper meanings on nursing-faculty perspectives (Blackwood & Sweet, 2017; Carlson, 2016; McCann et al., 2015). Blackwood and Sweet coded the nonverbal responses of participants and used a team of researchers to code responses. McCann et al. (2015) used a second researcher to code the focus groups' responses. One advantage of focus groups was that they captured nonverbal communication. Nonverbal communication is estimated to account for over 50% of all communication (Anders, 2015). A team of researchers exposed a study to more biases given more persons involved, but if biases were controlled properly, a team increased the trustworthiness of the data analysis (Creswell & Creswell, 2017; Ravitch & Carl, 2015).

Bonsu et al. (2017) used unstructured open-ended interviews and coded the data using a software package (NVivo). Unstructured interviews allowed for more natural conversations to occur but had disadvantages. Unstructured interviews were time-consuming and difficult to compare to other participant responses (Creswell & Creswell, 2017; Rubin & Rubin, 2011). The authors assessed the perspectives of healthcare officials to judge the satisfaction of patients with tuberculosis (Bonsu, Afutu, Hanson-Nortey, Ahiabu, & Amo-Adjei, 2017). These authors should have considered an embedded single-case design that also looked at the perspectives of patients with tuberculosis.

Oliver, Geniets, Winters, Rega, and Mbae (2015) used semi structured interviews to code for themes and used field observations. Field observations allowed the authors to have detailed first-hand experiences to enrich their understanding and develop more robust themes. Challenges with field observations included getting clearance to be in the field and creating unnatural, biased responses from those being observed. Other authors conducted a single case study longitudinally.

Longitudinal case studies were considered more effective at measuring change over time. Lawford et al. (2018) tracked perceptions of the physical therapist at two points in time, pre- and post-PCC training on patients with osteoarthritis. This study demonstrated major qualitative improvements in all three themes. Lñvesque, Levine, and Bedos (2015) did a similar study on a dental team in Canada. The authors sought qualitative changes in attitudes and understanding over time (Lñvesque, Levine, &

Bedos, 2015). Like longitudinal studies, the multiple-case study designs had additional benefits.

Multiple-case designs are bound by one over-arching rationale, replication (Yin, 2017). Pelaez, Hendricks, Merry, and Gagnon (2017) conducted a holistic, multiple-case study. The authors compared the perspectives of healthcare professionals on the maternal care of new immigrants (unit of analysis) at four different hospitals (multiple four cases). They were seeking literal replication and found similar barriers to care across the cases (Oliver, Geniets, Winters, Rega, & Mbae, 2015). Worum, Lillekroken, Ahlsen, Roaldsen, and Bergland (2019) used this same design. The authors found that across multiple cases, physical therapists were aware of the benefits of the Otago exercise program but found it too cumbersome in clinical practice (Worum et al., 2019). This demonstrates preliminary evidence that the Otago may not be an effective program for the physical therapist to implement in the field. Another multiple case study compared three nursing homes to each other on how well the transitioned patients from the nursing home to home (Toles, Colón-Emeric, Naylor, Barroso, & Anderson, 2016). The results of this study were that care transitions were more successful at nursing homes that involved families in the transition process.

Analysis of other types of qualitative designs. Focus groups, unstructured interviews, and field observations all have their advantages. Focus groups were ruled-out of this study because keeping HHPTs separated from one another allowed for confidentiality between participants. Unstructured interviews were also ruled-out of this study. Some control over the interviews, and comparison across participants was done

with this study. Field observations were ruled out given the intimate nature of home settings and potential barriers related to privacy laws. Last, a multiple case study design would have been used if additional perspectives around FCC were being sought with this study. Time and resources limited this study to one case, that is HHPTs in a Community in the western United States.

## **Summary and Conclusions**

Family-centered care developed after World War II in pediatric hospitals to be a more humanistic, care-delivery method. This approach to care is different from patientcentered care and developed out of the social justice movements of the 1960s. The FCC approach has surged over the past 20 years. FCC is well studied in pediatric settings, where it is effective at reducing 30-day readmissions and at improving caregiver satisfaction. Limited evidence exists as to how FCC is applied to older adults. Involvement of caregivers with care is supported by and conceptualized within the ICF model. HHPTs can provide FCC approaches to improve older adults' intrinsic capacities, incontinence, fall risk, and health outcomes. The HHPT is most effective when they design interventions within the context of the micro-culture of the patient and their family without bias. This study uses a case study design of a single case of 14 HHPTs in a western community of the United States. Similar studies were able to construct themes and new understanding in this manner about healthcare delivery and approaches to care. The single-case study design is supported by the literature review in Chapter 2. Chapter 3 proposes the methodologies, role of the researcher, and potential areas of trustworthiness related to this study.

### Chapter 3: Research Method

The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. Chapter 3 presents the research design, rationale for the design, role of the researcher, overall methodology, and issues with trustworthiness.

## **Research Design and Rationale**

The central research question of this study was: How do HHPTs in a community in the western United States describe their perspectives on providing FCC to older adults? The phenomenon of interest was HHPTs' perspectives on providing FCC to older adults. The single-case study design was used because the case studies explore a specific issue faced by a group of participants within a defined boundary (Creswell & Creswell, 2017). For this study, 14 HHPTs in a community in the western United States represented the single case.

Case studies are considered one of the main qualitative research designs (Creswell & Creswell, 2017). They can be quantitative or mixed method (Yin, 2017). For this study, a constructivist approach was used to allow themes and concepts to emerge inductively from interviews with the HHPTs to gain a deeper understanding about FCC with older adults. This study did not seek to test a theory, find causation, collect measurable data, or be inflexible in the interpretation of collected data (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007). For these reasons, mixed methods were ruled out. Other qualitative designs were considered, as described below.

### **Narrative Design**

The narrative design is an effective qualitative design when an in-depth story is researched from the written (or oral perspective) of a single participant (Creswell & Creswell, 2017). For example, Lang and Pinder (2017) wrote a narrative study that told the story of a wrongly accused athletic coach. Through this narrative, the anguish of being wrongly accused of child sexual abuse was explained and provided a unique, new perspective (Lang & Pinder, 2017). This understanding provided an alternative view to reality and gave a voice to the interviewee. Such an in-depth understanding of a single HHPT was not the phenomenon of interest in this study.

# Phenomenological and Ethnographic Designs

The phenomenological and ethnographic designs explore a phenomenon of interest within a group of people. The phenomenological design relates to exploring a lived experience (Creswell & Creswell, 2017). Ethnographic designs explore how a certain group (or culture) of people interact in real-world situations (Ravitch & Carl, 2015). Both designs seek to interpret the participants' feelings, emotions, actions, interactions, reactions, and opinions (Creswell & Creswell, 2017). The main data collection tools for both designs are interviews, reflections, and direct observations. This study did not seek to explore a phenomenon within a group nor the culture of home health.

#### **Grounded Theory Design**

The purpose of grounded theory design is to inductively create a theory from the data collected during a study (Creswell & Creswell, 2017). This is done to update an

existing theory, establish a new theory, or provide a conceptual model. Data is generally collected during the study, but can also be collected retrospectively (Fulton, Pullen Sansfaçon, Brown, Graham, & Ethier, 2018). This study did not seek to create a theory. This study sought to place findings within an established conceptual model – the ICF model.

## **Summary of Designs**

This study was qualitative and used the single-case study design. Quantitative and mixed-method designs were ruled-out as they do not align with the pure inductive, and constructivist, nature of this study. The case-study design allowed the phenomena of interest, FCC with older adults, to be within a small group of HHPTs. Other qualitative designs did not align well to either the purpose or scope of this study.

### Role of the Researcher

The main roles I had was that of the lead researcher and a participant. I recruited 14 HHPTs through snowball sampling and participated as the interviewer in all interviews with the HHPTs. I guided every step of the study. As the lead researcher, participating in the study, I needed to disclose my professional and personal relationships with each HHPT.

## **Professional and Personal Relationships**

My career has been in the same Western community as this study for the past 21 years. From 1999 to 2012, I worked full-time in multiple inpatient facilities as a Physical Therapist (PT), Director of Rehabilitation, and Area Manager. In 2012, I became a full-time physical therapist educator and part-time PT for an adult-day healthcare center. I

served on the executive committee of the western community district of the American Physical Therapy Association (APTA) since 2016. In late 2017 I was promoted from full-time Academic Coordinator of Clinical Education (ACCE) to Assistant Program Director (APD). I have taught, worked, and collaborated with hundreds of physical therapists (PTs) and student physical therapists (SPT) within the Western community and beyond. I have not worked in a home-health setting as an HHPT, but I have conducted multiple predischarge home assessments when working for nursing homes. As an SPT in 1997, I completed a two-week internship in home health in rural Wisconsin and have both friends and colleagues in the home health industry. I am a middle-aged, well-educated, white male, that lives in a middle-to-upper class neighborhood. I consider myself fiscally conservative and socially liberal. I controlled for positionality and social location through criticality, reflexivity, and collaboration (Ravitch & Carl, 2015).

Criticality and rigor plan. Positionality issues were minimized through criticality and rigor. Criticality demanded that I maintained the fidelity of each participant. Fidelity was important to avoid ethical issues like peer pressure, employer bias, and employment repercussions. I retained my private reflexive notes after each interview. I described how privacy is managed upfront on the consent form and repeated this verbally at the start of each interview. All HHPTs were provided written consent before the interview and verbal consent at the onset of the interviews. During recruitment, I employed rigor to deal with positionality. I set the selection criteria for HHPTs. I avoided interviewing HHPTs that worked for the university I worked at. Rigor

was further managed by being transparent at every stage of the study and seeking feedback from my research committee, experts, and peers.

Reflexivity and collaboration. In terms of my social identity, I used self-reflection and collaboration to control my biases. I reflexively journaled my experiences with each interview. I actively collaborated in confidence with my *thought-partners* (Ravitch & Carl, 2015) to help me reflect on my work at each stage of the study. These thought-partners included fellow scholars at Walden, faculty at Walden, peers, family, and work colleagues. Collaborating with these thought-partners helped me challenge my biases, assumptions, and interpretations during the data collection and analysis stages.

# Methodology

This study included a purposeful sampling strategy of snowball sampling. This strategy resulted in 14 HHPTs being interviewed. The data from the interview transcripts were analyzed for deeper meanings and conceptualized within the ICF model. Participant selection logic, instrumentation, procedures with recruitment, participation, and data collection, and data analysis are explained further.

## **Participant Selection Logic**

This researcher sought to recruit enough HHPTs from the Western community to achieve thematic saturation. In qualitative research, purposeful sampling does not have a steadfast rule for the number of persons to interview to achieve saturation (Guest, Bunce, & Johnson, 2006). It is generally accepted that the goal of qualitative interviewing is to reach the saturation point when no new information or new themes are emerging (Rubin & Rubin, 2011). One landmark study found that it takes between 6-12 participants to

reach data saturation with interviewing (Guest, Bruce, & Johnson, 2006). Six interviews will likely produce 80% saturation and twelve interviews will likely produce over 90% saturation (Guest et al., 2006). The goal set of this study was to interview a minimum of 12 HHPTs. What made the HHPTs qualified to participate in this study was a set of selection criteria.

The first selection criterion was that the HHPTs will have worked a minimum of one-year (12 months) as an HHPT. The second criterion was that the HHPTs must have 50% of their present caseload be with older adults. These first two criteria were verified in writing by the participant and asked during the interviews. One of the HHPTs selected had signed the consent, but during the interview disclosed working less than one year as an HHPT. The third criterion was that each HHPT held a valid PT license. The fourth criterion was that the HHPTs have a computer with access to the web and some form of microphone and speaker. The fifth criterion was that the HHPT be able to interview in a quiet area for approximately one hour during the available timeframes provided by the lead researcher.

#### Instrumentation

The lead researcher was the main instrument for this study. The lead researcher used a variety of researcher-developed, data collection tools. These tools included interview protocols, emails, a reflexive journal, a coding table using Microsoft Word, and a computer-assisted qualitative data analysis software (CAQDAS). The following sections provide detailed explanations of these tools and the sources of data.

Tool 1: Interview protocols. A semi-structured interview design was selected for this study because this type of interview allows for a mix of closed-ended and open-ended questions (Rubin & Rubin, 2011). The close-ended questions created were designed to obtain the background and demographic information on each HHPT. The open-ended questions were created to obtain a thick description of FCC with older adults. All questions were field rested by two expert HHPTs that did not participate in the interviews.

Protocol 1: Scripted guide. The first interview protocol used was the creation of a scripted guide that has an opening statement, introduction with consent and privacy explained, closed-ended demographic questions, main phase (key questions), and closing statement (Myers & Newman, 2007; Qu & Dumay, 2011). Following a script reduces the overall ambiguity of language, keeps the interviewer on track, and builds trust with the interviewees (Myers & Newman, 2007). Scripted openings help to initiate conversation and establish rapport (Patton, 2015). The scripted introduction and conclusions help to ensure that privacy, consent, and post-interview follow-up were understood by each HHPT (Rubin & Rubin, 2011). A scripted interview guide helps to ensure consistency between the interviews (Patton, 2015). The second interview protocol was to use a variety of questions types.

**Protocol 2:** Use of a variety of question types. The interview guide included both closed- and open-ended questions. Closed-ended questions were used as icebreakers and collected some demographic information on each HHPT before the key questions (Whiting, 2008). These types of questions were useful during the opening, introduction,

and closing phases of the interview. Open-ended interview questions were used as the key questions. The key questions helped to explore the phenomenon of interest (FCC with older adults). Scripting the interviews and using a variety of questions should affect the nature of interviews (Myers & Newman, 2007). To promote a more conversational tone, two additional protocols were used.

Protocols 3 and 4: Conversational. The third protocol used was verbal probes during interviews. Emerging probes were used to build trust, rapport, understandings, and produced a more natural form of conversation (Rubin & Rubin, 2011; Schober & Conrad, 1997; Yeong, Ismail, Ismail, & Hamzah, 2018). The fourth protocol used was to follow normal social rules. This included being polite, respectful, and gracious with each HHPT (Castillo-Montoya, 2016). The participants could respond at all phases of the interview, time was kept to one-hour maximum, and the interview guide was free of grammatical and spelling errors. Conversations and connectedness with interviewees were important to ensure good responses. A fifth protocol used was to align the central research question (CRQ) of this study to the questions.

Protocol 5: Alignment with the CRQ. The fifth interview protocol used was to ensure that the interview questions aligned well to the central research question (CRQ) of how HHPTs describe FCC with older adults (Castillo-Montoya, 2016). HHPTs were asked about their understandings of FCC and what FCC means to them when seeing older adults at home. HHPTs were asked when they believe FCC is needed, and when patients would want FCC. Questions were asked about cases they recall seeing with FCC, and their perspectives on treating families/caregivers at home (family-therapy). Last, the

HHPTs were asked about the barriers and facilitators with FCC and older adults.

Responses to these questions aligned well to understanding how FCC through HHPTs' perspectives.

**Tool 2: Emails**. Email communications were used to get expert review on the interview guide, recruit participants, obtain consents and confidentialities, member check transcripts, and obtain peer debriefing.

**Tool 3: Reflexive journal.** Field notes are an important part of qualitative research (Patton, 2015; Phillippi & Lauderdale, 2018). Field notes were taken in the form of reflective journal entries made after each interview.

**Tool 4: Coding table**. For this study, a coding table was used on a Microsoft Word document. The coding table was the main instrument for data analysis. Coding tables are recognized tools for organizing and creating codes (Basit, 2003).

Tool 5: CAQDAS. CAQDAS is often as an alternative to hand-coding and is considered useful with large data sets for organizational purposes (Leech & Onwuegbuzie, 2011). For this study, NVivo, a CAQDAS program was used to triangulate further the themes and subthemes from the coding table.

**Sufficiency of tools**. This study produced consistent results with each interview and reached thematic saturation using the interview tool alone. The other tools supported the interviews and did not produce new information.

#### **Procedures for Recruitment, Participation, and Data Collection**

The main recruitment strategy was snowball sampling. A second planned strategy was to post an IRB-approved, e-flyer (see Appendix C) on a professional association

webpage. Each perspective was planned to receive the IRB-approved consent email (see Appendix A). HHPTs that consented to be in the study, and met the selection criteria, were selected on a first-come, first-serve, basis. Participation was voluntary. Email communications were sent out with the confidentiality agreements (see Appendix B) with available times and days over a two-week window.

The main source of data came from the audio recordings of the web-based interviews. Each interview was less than one hour and done once with each participant. The participants were informed of the plan to follow-up verbally and by email. Although face-to-face interviews have advantages, web-based were used (Deakin & Wakefield, 2014; Janghorban, Roudsari, & Taghipour, 2014; Lo Iacono, Symonds, & Brown, 2016; Seitz, 2016).

Although online interviews can be less authentic over true face-to-face interviews, they are still effective (Lo Iacono et al., 2016). Given the large geographical area, long commute times, and busy schedules of the HHPTs, interviews could occur wherever the participants needed them to. All data from these interviews were recorded and transcribed. The transcripts were reviewed and edited for errors by hand. The edited interview transcripts were sent to each HHPT for member checking. Participants were given until August 1, 2020, to return the transcripts – all met this deadline and provided their edits. The HHPTs were thanked for their participation by email after the member checking ended.

The other data collection tools used were reflexive journal notes, emails, a coding table, and peer-debriefing. The peer debriefing was done during the development of codes and again after thematic analysis of the codes.

## **Data Analysis Plan**

Data analysis led to the development of codes and themes that connected back to the (CRQ).

Connection of data to the CRQ. Each section (opening, main phase, closing) of the interview guide was used. The opening section (opener, introduction, and transition) provided the HHPTs with a mental understanding of the purpose of the study, the definition of FCC, a chance to establish rapport, consent, and some limited demographic information. The demographic data were analyzed separately and complemented the CRQ.

The main section of the interview was comprised of eight key questions (KQ1-8). The seven KQs asked HHPTs about their perspectives on a variety of things related to FCC with older adults and addressed the CRQ directly. The KQs asked *who* would need (KQ2) or want (KQ3) FCC, *what* FCC meant to the HHPTs (KQ1), *where* the HHPTs would document FCC (KQ5), *when* did the HHPTs use FCC (KQ4), *why* do HHPTs use FCC, (KQ6), and *how* the HHPTs would describe barriers (KQ7) and facilitators (KQ8) of FCC. To dive deeper into the HHPTs' perspectives, probes and clarification statements were used, and developed, as the interviews progressed. After the main phase, the closing section provided closure, a follow-up plan, and a request for member-checking.

Coding methods. Summary statements were planned on the coding table to reduce the member-checked responses to each of the eight key questions (KQs). From these summarizations, short descriptions were to be generated, and the results were alphabetized as pre-codes. The pre-codes were planned to go through multiple coding phases. Discrepant cases were also planned to be accounted for on the coding table.

#### **Issues of Trustworthiness**

This study addressed the main areas of trustworthiness and explored ethical procedures (Nowell, Norris, White, & Moules, 2017).

## Credibility

Credibility in qualitative research is considered equivocal to internal validity in quantitative research (Ravitch & Carl, 2015; Rooney et al., 2016). One strategy used was triangulation. This study triangulated data between each interview by checking the consistency of the responses to the key questions between each HHPT. This study also triangulated the HHPTs interview responses to the response of a home health manager (Renz, Carrington, & Badger, 2018). This study enhanced credibility by having the interview guide reviewed by two experts, transcripts member-checked, and coding table peer debriefed.

## **Transferability**

Transferability in qualitative research is considered equivocal to external validity in quantitative research (Morse, 2015). This study collected thick descriptions on FCC from each HHPT to improve transferability. Thick descriptions refer to the detailed account of participants on their experiences with the phenomenon of interest (Patton,

2015). For this study, the open-ended questions during the main section of the interviews were probed further for high levels of detail. The details provided the evidence needed to be more transferable. The HHPTs had some variation on their experience, training, workload, and case-mix (percent of work with older adults). This variety of demographic data improved transferability (Tracy & Hinrichs, 2017). To enhance trustworthiness further, dependability was considered.

## **Dependability**

Dependability is considered equivocal to reliability in quantitative research (Hadi & Closs, 2016). Detailed descriptions of the methods, data collection, and data analysis helped to improve the dependability of this study. Audio-recordings and member-checked transcripts helped to also ensure dependability. Thematic saturation through diverse participants and triangulation of the data using NVivo further enhanced dependability. Confirmability was also accounted for.

## **Confirmability**

Confirmability assures that the findings are based on the HHPT's perspectives and not based on biases (Nowell et al., 2017). Reflexive journaling was used after each interview to identify biases and make corrections. Direct quotations were used to generate codes and support the themes generated in this study. These strategies helped enhance confirmability.

#### **Ethical Procedures**

This study followed a series of ethical procedures to further enhance trustworthiness. First, the Walden University Research Ethics Approval Checklist

(Planning Worksheet) was completed. This forty-item checklist detailed the minimal, ethical information needed by Walden University's Institutional Review Board (IRB). This included a detailed account of the data collection methods, privacy plans during data collection, data security, and anonymity. The main tools for these being the consent email and confidentiality agreement. The second, and main ethical procedure, was to obtain ethical approval for a doctoral study by the IRB. The consent email contained the Walden University Institutional Review Board (IRB) approval, that is, IRB# 04-13-0661874, with an expiration date of April 12, 2021. The third ethical procedure was to respect each HHPT.

To show respect the professional attire was worn in a semi-private clean space without distractions. HHPTs were given opportunity and time to respond to the consent email, confidentiality agreement, and member checking. Interviews were scheduled respectfully with preferred times and days accounted for.

The fourth ethical procedure was to assign each HHPT a coded name. The code was the term 'HHPT' followed by an assigned number. For example, the first HHPT was HHPT1 and second HHPT2. These coded names are retained in a password-protected document. This document, and all documents related to this study, are kept in a locked safe—they will remain locked away for 5 years and then be destroyed.

The fifth ethical procedure was to minimize this power imbalances. To do this each HHPT was assured in the introduction and consent email of the procedures for confidentiality. The HHPTs were assured that the interview was a safe place and reminded that they could stop the interview at any point.

## **Summary**

Chapter 3 explained how this study is qualitative in nature and how the design choice for this study was a single-case study design. The chapter further detailed: (a) the role of the researcher as the lead researcher and participant; (b) the sampling technique of snowball sampling with contacts in the community; (c) the recruitment techniques of direct emailing of consents, confidentiality agreements, and interview times; (d) the data collection tools with instrumentation techniques like field testing; (e) the member checking process; and (f) triangulation strategies of peer debriefing and NVivo software comparisons. Ethical procedures that targeted respect, confidentiality, and power equality with the HHPTs was also provided in preparation for the data collected and analyzed in Chapter 4. Chapter 4 provides data collection methods, data analysis methods, and results of the study.

## Chapter 4: Results

The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. The research question was: How do HHPTs in a community in the western United States describe their perspectives on providing FCC to older adults? This research study was qualitative in nature and used a single-case study design. The data collection tool was an interview guide that was used during semi structured, private interviews with 14 HHPTs. In this chapter, the setting, demographics, data collection, data analysis, evidence of trustworthiness, results, and summary of the study are provided.

### **Setting of Study**

This study used remote, web-based interviews through a web-meeting service called RingCentral. This setting was ideal for data collection during the COVID-19 pandemic. At the time of data collection, the pandemic was transforming the practice of some of the HHPTs interviewed. As HHPT14 put it, "during the pandemic things have just gotten increasingly more difficult because everybody's stressed." HHPT5 reported that, "volume numbers are way down for all of us...with the Covid-19 pandemic". HHPT1 attributed the change to fear: "I had several patients when all of this pandemic stuff started that were fresh post-ops that became very nervous about having outside visitors". One modification to the setting occurred. The pandemic closed the lead researchers' work office, which required the RingCentral meetings to be conducted from the researcher's home office.

# **Demographics**

The participants in this study were asked demographic information. This information pertained to their: (a) years worked as an HHPT; (b) percentage of workload that was older adults; (c) percentage of older adults seen under Medicare A, or a Medicare A equivalent; (d) type of home health agency (HHA) they worked for; (e) employment status; (f) formal trainings on FCC; (g) board certifications, and (h) their familiarity with the ICF model. Table 4 and Table 5 visualize demographic data collected in this study into quantitative and qualitative responses.

Table 4

Quantitative Demographics

	Years Worked as in	% of Workload	% of Older Adults on
	Western Community	Older Adults	Medicare A
HHPT1	5.5	95	75-80
HHPT2	6	90-95	90
ННРТ3	.5	90	90
HHPT4	5	100	100
HHPT5	2.5	90-95	80
ННРТ6	17	95	70
HHPT7	4	95	40
HHPT8	3	95-99	90
HHPT9	3	95	45-50
HHPT10	7	80-90	80
HHPT11	3	98	95
HHPT12	10	90	80
HHPT13	8	95	100
HHPT14	3	90	90
Averages	5.5 years	94%	81%

Table 5 *Quantitative Demographics* 

	California License	HHA Type	Employed	FCC Trained	Board- Certified	Familiar with ICF-Model
HHPT1	Yes	For-profit	Fulltime	No	No	Yes
HHPT2	Yes	For-profit	<b>Fulltime</b>	No	Yes	Yes
HHPT3	Yes	For-profit	<b>Fulltime</b>	No	No	Yes
HHPT4	Yes	For-profit	<b>Fulltime</b>	No	No	No
HHPT5	Yes	For-profit	<b>Fulltime</b>	Yes	No	Yes
ННРТ6	Yes	For-profit	Fulltime	Yes	No	No
HHPT7	Yes	For-profit	Fulltime	No	No	Yes
HHPT8	Yes	For-profit	<b>Fulltime</b>	No	No	Yes
HHPT9	Yes	For-profit	<b>Fulltime</b>	No	No	Yes
HHPT10	Yes	For-profit	Part-time	Yes	No	No
HHPT11	Yes	Nonprofit	<b>Fulltime</b>	No	No	Yes
HHPT12	Yes	For-profit	Fulltime	No	No	No
HHPT13	Yes	For-profit	Part-time	No	No	No
HHPT14	Yes	Nonprofit	Fulltime	No	No	Yes
Ratio	14:14	12:14	12:14	3:14	1:14	9:14

The following section explains the data collection process used with this study.

#### **Data Collection**

On April 13, 2020, this study was approved by the Walden University

Institutional Review Board (IRB) as IRB# 04-13-0661874 with an expiration date of

April 12, 2021. To obtain IRB approval the plans in Chapter 3 were modified slightly.

These changes included the elimination of visual recordings of HHPTs and a \$25 gift

card. Edits were also required on the researcher-generated documents of the interview

guide, consent email, confidentiality agreement, and e-flyer. Appendices A-D contain the

final version of the documents used in this study. Field tests were done on the interview

guide prior to data collection.

Two experts were used to field test the interview guide. Each expert was an HHPT with over 5 years of home health experience in the western U. S. community of the study. Each expert was a Doctor of Physical Therapy (DPT), had a valid California license, and a Board-Certified Geriatric Specialist (GCS). One of the experts, referred to here as Expert 1, was used later in the study to do peer-debriefing of the codes and themes during data analysis. This expert had the additional credential of Doctor of Philosophy (PhD) and experience with qualitative research. The experts were sent the IRB-approved interview guide for review on April 20, 2020, and both completed their review by April 27, 2020.

The first expert suggested breaking up the seventh key question (KQ7) into two different key questions. This feedback was accepted and KQ7 became KQ7 (barriers to FCC) and KQ8 (facilitators of FCC). This same expert provided additional feedback to move the definition of FCC from the introduction and place between KQ1 and KQ2. KQ1 asked the HHTPs to define FCC in their own words. This feedback was accepted, and the FCC definition was moved between KQ1 and KQ2 with the addition of a probe that assessed HHPT reactions to the researcher's definition compared to their response to KQ1. The second expert, Expert 2, recommended a demographic question be modified to ask about formal training on FCC versus training on family care. This feedback was also accepted, and the demographic question was modified. The final, expert-reviewed interview guide used with this study is in Appendix D.

After this process, each expert was asked to provide the contact information of other HHPTs to start the snowball sampling process. The experts referred five HHPTs,

two of whom participated full in this study (HHPT1 and HHPT8), and three were retained as reserves.

Snowball sampling began with the expert reviewers providing five contacts. Their colleagues included four physical therapists (PTs) and one occupational therapist (OT) with over 15 years of working experience with older adults. Each HHPT interviewed was asked to provide an additional contact after each interview. The IRB-approved e-flyer was posted on a local professional website and produced no referrals. A total of 20 HHPTs were identified from the snowball sampling technique. Of these 20 HHPTs referred, 14 were interviewed to ensure saturation and gain additional perspectives. Three were not contacted and set aside as reserves; three did not respond to the invitation to be in the study.

Each HHPT was sent an invitation with consent via email. Each HHPT that replied with, "I consent" was sent a second email with the confidentiality agreement and schedule of available times for interviews. HHPTs were asked to return the signed confidentiality and pick their top three choices of available interview times and days. After the signed confidentiality agreement was received, one of the preferred interview times and days was scheduled in a third email with a calendar invite. The calendar invite had the data and time of the RingCentral meeting along with instructions on how to use the meeting. Each HHPT was present on RingCentral and recorded. Audio files were saved onto a password-protected USB drive. To track the progress of the recruitment and member-checking, a recruitment tracker was made—see Appendix E. During the

interview the lead researcher took notes on a Microsoft Word document and afterward reflexively journaled each interview experience.

Following the interviews, the audio recordings were collected and transcribed using a free software program. These generated transcripts were not accurate, and this required edits to each transcript by hand while listening to each audio file. The sound quality of the audio file was good, and the revised transcript was transferred to a Microsoft Word document. The transcribed interviews were sent to the HHPTs for member-checking. The HHPTs returned the member-checked transcripts by the August 1, 2020 deadline, and data from each transcript was transferred to the coding table.

The coding table proposed in Chapter 3 was modified by eliminating demographic (background) information from the table, expanding the coding cycles used, and eliminating the field notes. The elimination of demographic information and field notes was done because neither source produced codable data that directly answered the research question. Both sources were retained for trustworthiness and analyzed separately.

More coding cycles were added to the coding table too. This was done to manage the volume of data collected. The conceptualization in the ICF model was also removed from the coding table. This was done to instead create an image of how the themes fit into the ICF model (see Figure 6). Table 6 is a sample of the revised coding table. To understand the meaning of the data collected, and how the coding process led to themes and conceptualizations, a detailed data analysis is provided.

Table 6
Sample of Coding Table for KQ1 and KQ2

Key	Respons	Paraphras	Pre-	Holisti	Code-	Secon	Thematic
Questio	es from	es and	Codes	C	Mapping	d-	Analysis
n	Member	quotes		Codes		Cycle	
17.01	S THIDE1					Codes	
KQ1	HHPT1	<b>D</b> 1	G 1	G 1	G	G 1	TT1 1
	HHPT2	Paraphras	Codes:	Codes:	Category1	Codes	Theme 1
	ННРТ3	es &					
	HHPT4	Quotes			Category 2		
	HHPT5						
	ННРТ6				Category 3		
	HHPT7						Theme 2
	ННРТ8						
	HHPT9						
	HHPT10						
	HHPT11		-		-		Theme 3
	HHPT12		Peer	Peer	Peer		
	HHPT13		Debrief	Debrie	Debrief		
	HHPT14		Notes	f Notes	Notes		
KQ2	HHPT1					Peer	
11.02	HHPT1	Paraphras	Codes:	Codes:	Category1	Debri	
	HHPT2	es &	Codes.	Coucs.	Cutegory	ef	Peer
	HHPT3	Quotes			Category 2	Notes	Debrief
	HHPT4	20000			2000		Notes
	HHPT5				Category 3		
	ННРТ6						
	HHPT7						
	ННРТ8						
	ННРТ9						
	HHPT10						
	HHPT11						
	HHPT12		Peer	Peer	Peer		Other
	HHPT13		Debrief	Debrie	Debrief		Discrepa
	HHPT14		Notes	f Notes	Notes		nt Cases

### **Data Analysis**

Thematic saturation of the eight key questions appeared by the 10<sup>th</sup> interview and was determined met by the thirteenth interview with no additional themes emerging.

Two HHPTs provided different professional perspectives. HHPT4 was also a home health nurse, and HHPT 14 was also a home health administrator. These two HHPTs improved the overall trustworthiness of the data collected and analyzed. The member checked interview data was transferred to a coding table for coding.

The coding of HHPT responses began with a pre-coding phase. During the pre-coding phase, paraphrases and quotes were created from each of the HHPTs' responses to the KQs and probes. This data was alphabetized and referred to as pre-codes on the table. Pre-codes went through a first-cycle coding method called holistic coding (Saldaña, 2015). Holistic codes were mostly organized within each KQ they originated from. An exception to this was if a holistic code was additionally deemed as a barrier or facilitator. Any code deemed a barrier was moved to the codes in KQ7, and as a facilitator to KQ8. If a coded response to KQ7 or KQ8 was not considered a barrier or facilitator, it was moved to one of the other applicable KQs—no variant cases were seen. The coding table was then sent off for peer-debriefing.

Peer-debriefing was done by Expert 1 from the field test of the interview guide. The feedback received from the peer-debriefing was used to revise some of the pre-codes and the holistic codes in the coding table. These edits were added to the coding table in red font. After peer-debriefing, the data went through an after first-cycle coding method called code-mapping. Chapter 3 predicted the need for code-mapping to create categories

to organize the data, and this was needed. Code-mapping produced 23 categories and 108 related codes. Figure 1 provides a sample of the data from pre-codes to holistic codes and from holistic codes to code-mapping with related codes.

Pre-Codes	Holistic Codes (First Cycle)	Code-Mapping (After-First Cycle)
- Active caregiver - 1, 2, 8, 3, 9 - Active Listening - 10 - Adapts to type of home settings - 1 - Adapts to a type of assistance needed -1 - Adjusting PT agenda - 8, 1 - Balancing how and when PT communicates with the family - 10, 8 - Based on patient and family goals - 8, 9 - Based on the conglomerate goals - 2, 12 - Build rapport -10 - Cannot decide for themselves - 2, 9, 3 - Caregiver education - 4 - Caregiver training - 4 - Coaching families to participate in care 4, 8, 10 - Cognitive declines 4, 17 - Collaboration with patient and family -2 (full list on the coding table)	FCC Defined (1-13)  Holistic Codes  1. Adaptable 2. Coordinated / Collaborative 3. Inclusive 4. Family/ Caregiver Training/ Education 5. Interdisciplinary Team 6. Novel 7. Qualifying Criteria 8. Respectful to Individual Needs 9. Shared-Decision Making 10. Skilled Communication 11. Team based 12. Therapeutic 13. Timebound  Peer Debriefing: - "Q1 – I wonder if your codes 5 and 11 are similar and could be combined." – done	Category 1: Team focus on patient, family, caregivers.  Related codes: - Family/ Caregiver Training/ Education - Interdisciplinary Team - Shared-decision making - Inclusive - Referral to community services  Category 2: Situational  Related codes - Adaptable - COVID-19 Effects - Qualifying Criteria - Respectful to Individual Needs - Re-evaluation and extend if rapid progression - Timebound  Category 3: Skilled  Related codes: - Coordinated / Collaborative - Customer satisfaction sought - Documentation Styles Vary - Electronic Documentation - Family and caregiver goals are set and measured too - Novel - Psychology of being a therapist - Skilled Communication - Therapeutic

Figure 1. Pre-codes to code-mapping. Peer-debriefing occurred after first cycle coding and before code-mapping. This debriefing resulted in edits to the original list of holistic codes.

The code-mapping process revived early excluded pre-codes that were lumped into some of the holistic codes. These pre-codes added deeper meaning to the new

categories and related codes. The need for an additional coding cycle was evident given that the data was still massive and not fully organized. The data went through a secondcycle coding method called pattern coding.

Pattern coding reduced the data to 12 pattern categories and 55 related codes.

Codes identified as barriers and facilitators were condensed into pattern codes and proceeded with a '+/-' symbol. This symbol meant that the code could impact FCC as a barrier if present *and* as a facilitator if absent. This was done because the responses from HHTPs had this duality. For example, HHPT9 said, "they [caregivers] care for their family or their loved ones, and they're very much involved, but then, right when you think that that's how it's going to be all the time, it flips on you and you encounter a situation where it's not the case". In this case, attitudes about care had both a positive and a negative impact on the HHPT's ability to provide FCC. Figure 2 demonstrates a sample from the coding table of this process.

Code Mapping	Pattern Coding
Category: External Needs	•
Related codes:	CAREGIVER IMPACT
CAREGIVER/ FAMILY/ OR PATIENT CONCERNS	+/- ABILITIES
CULTURAL DIFFERENCES	+/- ATTITUDES,
REFERRAL RESPONSES	+/- AVAILABILITY
UNSAFE ENVIRONMENTS	+/- BELIEFS
Category: Cultural Wants	
Related codes:	
CULTURAL DIFFERENCES	
LARGER FAMILIES	
Category: Team Preferences	
RELATED CODES:	
SPECTRUM OF CAREGIVER/FAMILY WANTS	

Figure 2: Code-mapping to pattern coding. The pattern code beliefs was patterned from related codes on the code-map. This association was demonstrated in grey shading. The patten code category of caregiver impact was generated from a combination of code-mapped categories and related codes and was displayed in bold font.

After the pattern coding phase, the pattern codes and categories were thematic analyzed to form subthemes. The process of pattern coding to subthemes produced the three themes of this study. Figure 3 displays the process to form the first theme that FCC is complex, Figure 4 displays the process to form the second theme that FCC impacts older adult health factors, and Figure 5 displays the process to form the third theme that FCC is impacted by contextual factors.

THEME 1: FCC IS COMPLEX Pattern Coding Sub-themes INTERDISCIPLINARY **INTERDISCIPLINARY** - FAMILY/ CAREGIVER TRAINING/ EDUCATION - INTERDISCIPLINARY TEAM - SHARED-DECISION MAKING **SITUATIONAL** SITUATIONAL - ADAPTABLE TO NEEDS - QUALIFYING CRITERIA - TIMEBOUND SKILLED SERVICE **SKILLED** - SKILLED DOCUMENTATION - SKILLED COMMUNICATION - SKILLED INTERVENTIONS **DEVELOPING DEVELOPING** - FAMILY MEDICINE - NOVEL TERM FCC

*Figure 3:* Pattern coding to first theme. The pattern codes were organized into the subthemes of developing, interdisciplinary, situational, and skilled service. These sub-themes formed the first theme of the study that FCC is complex.

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#### THEME 2: FCC IMPACTS OLDER ADULT HEALTH FACTORS

Pattern Coding Sub-themes **HEALTH CONDITIONS** - CARDIAC - ORTHOPEDIC **HEALTH CONDITIONS** Cardiovascular, Neurological, - NEUROLOGICAL Orthopedic, Other - TERMINAL - VASCULAR - OTHER CONDITIONS (cancer, renal, terminal unspecified surgeries, and wounds) **BODY STRUCTURE & FUNCTION** - COGNITIVE IMPAIRMENTS **BODY STRUCTURES / FUNCTIONS IMPAIRMENTS** - PHYSICAL IMPAIRMENTS (balance, endurance, pain, sensory, range of motion, Cognitive, Physical, and Other and strength) - OTHER IMPAIRMENTS (Constipation, Pain, and Wounds) **ACTIVITY LIMITATIONS** - LOSS OF FUNCTION **ACTIVITY LIMITATIONS** - LOSS OF INDEPENDENCE WITH Functional Mobility and ADLs WALKING, TRANSFERS AND BED **MOBILITY** - SIGNIFICANT CHANGE PARTICIPATION RESTRICTIONS - CHANGE/ LOSS OF FAMILY/ PARTICIPATION RESTRICTIONS RELATIONSHIP ROLE(S) Family and Community - PSYCHOLOGY OF BEING A THERAPIST **CONTEXTUAL FACTORS CONTEXTUAL FACTORS** - HOME SET-UP - CAREGIVER ISSUES Environmental and Personal

Figure 4: Pattern coding to second theme. The pattern codes were organized into the subthemes of health conditions, body structures/functions impairments, activity limitations, participation restrictions and contextual factors. These sub-themes formed the second theme that FCC impacts older adult health factors.

#### THEME 3: FCC IMPACTED BY CONTEXTUAL FACTORS

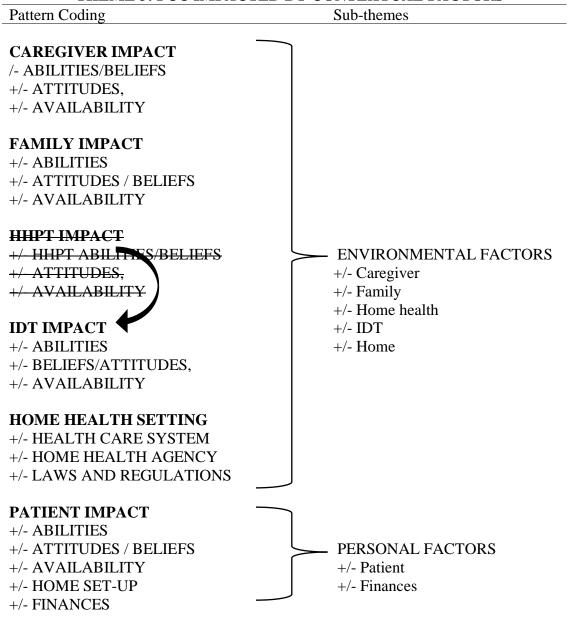


Figure 5: Pattern coding to third theme. The pattern codes were organized into the subthemes of contextual factors environmental and personal factors. The subthemes had +/-impact on how FCC was delivered by the HHPT. These sub-themes formed the third theme that FCC is impacted by contextual factors.

The coding table was then reviewed a second time by the peer-debriefer.

Additional feedback from Expert1was collected and synthesized into the coding table.

This feedback helped to revise pattern codes, subthemes, and themes. Three themes emerged. A deeper discussion of these themes with examples of supporting evidence from the HHPTs' responses is provided in the results section. The conceptualization of the themes in the ICF model is provided in the results as well. The trustworthiness of the methods used to collect and analyze the data is assessed further.

#### **Trustworthiness**

In Chapter 3 the strategies used for trustworthiness were outlined in terms of credibility, transferability, dependability, and confirmability strategies. A summary of each strategy with deviations from Chapter 3 is discussed further.

## Credibility

In Chapter 3, credibility was planned for data collection through triangulation and member-checking. Triangulation was planned through a variety of data collection methods, an expert review of the interview guide, member checking of interview transcripts, coding of responses on a coding table, and peer-debriefing of the coding table.

The data collection methods were the interview guide, field notes of nonverbal communication, and reflexive journaling. Nonverbal data was not collected, and the reflexive journal notes did not produce codable data. Therefore, the main data collection method was semi-structured interviews with HHPTs. Semi-structured interviews are a recognized data collection technique in qualitative research. Expert reviews helped improve credibility further before initiating the interviews. Last, interview responses

were member checked. Every member had reviewed and made edits to the transcripts sent to them. Member checking helped to improve credibility further.

During data analysis, a coding table was used, and multiple phases of coding were used. Selecting multiple coding techniques is a recognized strategy for reducing large amounts of data into smaller, meaningful themes. To further enhance the credibility of the codes and themes selected, peer debriefing was done on the coding table after the first-cycle coding and again after thematic analysis.

#### **Transferability**

The plan in Chapter 3 was to improve transferability by detailing how each step of this study was done, the assumptions of the researcher, and the context of this study. This study collected thick descriptions from each HHPT. During the study, the HHPTs had variations in their work experiences, FCC training, workload, case-mix, board certifications, and knowledge of the ICF-model. This variety in demographic improves transferability within and outside of the western community of HHPTs. During the interview with HHPT4, it was disclosed that HHPT4 was a halftime home-health nurse and half-time HHPT. HHPT14 was half-time HHPT and half time Regional Manager. These two HHPTs may have added transferability to others. Last, the themes generated in this study were conceptualized within the ICF model (see Figure 6). Other health professionals familiar with the ICF model, like occupational and speech therapists, could have transferable findings.

## **Dependability**

Dependability, like reliability in quantitative research, looks at the consistency of the data collection methods. In this study, the data collection method of semi-structured interviews using a reviewed guide, planned for in Chapter 3, was dependable at eliciting thick descriptions by HHPTs. Additional questions were asked about COVID-19 effects on their care. The data collected in this study reflects three HHPTs who were negatively affected by reduced work as result of the pandemic. Thematic saturation occurred through interviewing multiple HHPTs with differing backgrounds which helped to ensure the dependability of the data. The coding table was expanded to allow more coding of data to occur for this reason and the results of the coding table were compared to the themes generated in NVivo.

The original interview transcripts were loaded into NVivo to triangulate the themes, organize the data differently, and explore for new meanings. An aggregated coding method was used with NVivo by assessing the whole responses of each question by each participant. From this analysis NVivo generated 12 themes (Appendix F). These themes did not alter the themes or findings generated from the coding table. Appendix G displays further analysis of the NVivo generated theme of caregiver and the resulting subthemes. These subthemes did not alter the subthemes generated from the coding table and further triangulated the findings of this study.

#### Confirmability

Confirmability was based on the findings being from the HHPT's perspectives and not on researcher-bias. The words and meanings of the first-cycle codes came

directly from the HHPTs. The data in the coding table was reviewed by and experts, and feedback helped to avoid critical losses of data with holistic coding. As codes were analyzed further, words familiar to the lead researcher from the ICF model, literature, and professional knowledge were added. The results are supported by multiple quotations from the HHPTs.

### **Results of Study**

The central research question for this study was answered through an analysis of the perspectives of 14 HHPTs working in a community in the western United States. This analysis led to the development of the three main themes and eleven subthemes that are conceptualized in the ICF model (see Figure 6). The resulting themes were that FCC is complex, FCC is used to impact older adults' health factors, and FCC is impacted by contextual (environmental and personal) factors. These three themes are supported by HHPTs' responses to the eight key questions (KQs), professional knowledge, expert review, and FCC literature.

# **Theme 1: FCC is Complex**

Patient care that is centered on both the patient and the caregiver requires a complex conceptualization of the practitioner's relationships and roles (Reach, 2016). The theme FCC is complex was supported by four subthemes. The subthemes were that FCC is developing, interdisciplinary, situational, and skilled service.

**FCC is developing.** FCC is full of complexities and is developing. All 14 HHPTs reported educating and training both caregivers and families. Their FCC training was designed to minimize injuries and centered on the patient. Each HHPT supported the

notion of shared decision making at some level. HHPT4 stated, "maybe I just take it [FCC] for granted that I always incorporate it." Others felt HHPT applied to every diagnosis. HHPT3 stated, "I can't think of a diagnosis it [FCC] doesn't apply to. It seems like all of them equally." HHPTs had developed skills to train, educate, and collaborate. Despite this, some of the HHPTs had not heard of FCC before. HHPT5 said, "I've never heard of this before". HHPT9 said, "I'm just not familiar with that name family-centered". Of the 14 HHPTs interviewed only one reported formal training on FCC. One area not practiced by any of HHTPs, nor supported by most of them, was family medicine.

None of the HHPTs interviewed reported practicing with family medicine techniques when visiting a patient and family at home. That is to say, they did not treat other patients under a plan of care outside of the patient being referred to them by their HHA. When asked about family medicine, HHPT7 said, "[n]o, I would not.... [i]t's kind of a fine line, you don't want to not help, because you could be negligible." Others, like HHPT12 said, "the home health agency sent me to this home for this patient, then that's the only patient that I have to treat, but a caregiver? Then that's on them". Every HHPTs reported too many legal, financial, and regulatory barriers.

When probed if the HHPTs would do family medicine without these barriers a few HHPTs said they would. HHPT14 said, "if your treatment went from patient-specific to family-centered and that included any potential issues that the family has, and then we were all cool with that, right, legally we had the orders from that physician, insurances are going to kick-up the reimbursement because now we're treating a family, not a

patient, and then obviously, your employer would have to comply with that because that's the new world that we would be living in... I would love to do that". Some were still reluctant even with the external barriers removed. HHPT4 said "they would be on two separate plans", while HHPT3 said, "that sounds overwhelming for me". Oddly enough some of the barriers described are more perceived.

Direct access allows HHPTs to treat and bill a family member at home privately for up to 12 visitations in a community in the western United States without a diagnosis or referral. It would be unethical to bill their time with the HHA for this if the HHPT is collecting private payment, and it would violate individual care if doing a group session at the same time with the older adult and the caregiver.

The issue with no family medicine at all in practice is likely due to the knowledge gaps around direct access and how to work with families and home health agencies. For example, HHPT2 reserved their direct access to their pro-bono work alone stating, "I don't do direct access that way. I mostly do pro-bono direct access for senior members in our church". HHPT9 was unsure and said, "I think it would be a contradiction to do direct access for a patient while I'm working for a company to see that family member." HHPT13 was not familiar with how to use direct access and stated, "I'm not as familiar with direct access with patients and treating patients that way". FCC is developing and is made more complex by the need for interdisciplinary approaches.

FCC is interdisciplinary. Interdisciplinary teams (IDTs) s are more complex for the HHPT to work with than working in isolation (Ambrose-Miller & Ashcroft, 2016; McGill et al., 2017). FCC, families, and caregivers are included in these teams which

adds complexity. HHPTs reported using FCC with older adults and their families/caregivers to training and education. HHPT2 said, "I've been doing family training and I incorporate family training or caregiver training with my patient interventions." HHPT12 said FCC is, "caregiver education, family education on how to take care of the patients". Other complexities to FCC included interdisciplinary communication.

HHPTs reported the need to collaborate with a variety of health professionals in the care of their older adults besides families and caregivers. HHPT1 said, "[i]t's something I [use to] communicate to the doctor." HHPT 10 said, "let's say there's a concern from the patient, then we do a care conference with the nurse, the doctor, and all the home health disciplines that are involved with the patient... [and] [s]o, they're all in the loop on what's going on." HHPT12 said FCC is, "a collaborative thing with other disciplines helping with the patient." In addition to the IDT, HHPTs practicing FCC reported making referrals to community services for families.

HHPT5 reported referring a family member out to a community program. HHPT 5 stated, "I worked with his spouse to identify a Parkinson's group where they do boxing exercises". Other HHPTs reported needing to contact social workers or refer families to private caregiver agencies. For example, HHPT10 said, "I have to take care of it from day one so that I can make a concrete plan and recommendation if I have to get caregiver support, outside caregiver support, if none of the family members are there or available to take care of the patient. If there's social worker needed for them to get some resources on where to get the needs that they have to be able to be home safe." Communicating with patients and families about community services is another complexity to FCC.

Ultimately, families and patients must decide for themselves what to do and will need to be well-informed. This form of information sharing, and autonomy of the patient and family to make choices, is shared decision making.

HHPTs demonstrated an understanding of the legal obligations to involve any existing Durable Power of Attorney (DPOA) with shared decision making. The HHPTs recognized the value of involving other people. HHPT3 said, "I'll try to have that conversation with the caregiver present, and so we all talk about it and we try to get us to agree on what's reasonable that they could do with the caregiver there to help and go over the exact, you know, hand placement, etc. of whatever we're going to do and then get all parties to agree on it and then come up with a system to keep track of it." HHPT5 supported the notion of sharing decisions as well and stated, "if you can give them that full picture, they're more apt to have a better understanding and then make better decisions overall for patient care." HHPT12 demonstrated mastery of shared decision making by stating, "our responsibility is to take care or share with a patient and a family to decide on the care, what they need to have, you know. So, it's... helpful, but it's still in-line with what physical therapist functions to be with them also."

Shared decision making also relates to preparing families for what to do or expect when HHPT services end. HHPT1 reported this handing off care is a shared decision.

HHPT1 stated, "incorporating the family members to a point where we're involving them in the patient's care from the point of disease management, as well as to physical management". Shared decision making aligns well with the idea of servant leadership.

HHPT3 espoused servant-leader philosophy by stating, "your focus [is] on putting the

families and the patient's goals above your agenda and taking it into consideration when you come up with the plan of care."

Collaborating with the IDT, families, patients, and caregivers increase the complexities of FCC. Referring to community resources and being able to discuss these options to patients, families, and caregivers increase the complexities of FCC with older adults. Last, FCC is not available, or for everyone. This situational nature of FCC makes it more complex than patient-centered care.

**FCC** is situational. Patient, caregiver, and family needs were varied in this study. Some patients did not require FCC. HHPT13 reported, "I mean, we have a fair number of patients who just don't have anybody to help them, and the care is patient-centered is the only option". Other HHPTs adapted FCC to meet a certain situation. HHPT3 said FCC requires patience as sometimes families are, "too busy and too tired... just uninformed... adapting to it in the last second and they're not really in a good place to be dealing with all of it". HHPT13 reported the need to go into homes with an open mind about FCC, "you just never know what you're going to encounter, whether it's over-involvement or under involvement, so just going in with an open mind, that, in home health, really like whoever is living in the home or is in the home is all part of the package". In addition to adapting to situations, HHPTs reported that some patients may not qualify for FCC. HHPT5 spoke to the criteria of receiving HHPT in general. HHPT5 said, "sometimes we don't have the home health order, sometimes which we don't have the H&P, a lot of times it's H&P that causes lagging because you're waiting for a doctor's office to send it over and that can lag and cause you delays." Other HHPTs reported trying to identify the

responsible party as an issue as well. HHPT6 spoke of the challenges of, "needing somebody to sign their consent forms, just kind of logistics of who is empowered." HHPT12 said that even though certain family members present as the caregivers and actively involved it may be that, "the DPOA is the one we need to train on how to take care of them." HHPT 13 felt that FCC is, "not for everyone". HHPTs adapted to whatever the situation was by providing FCC as needed. Time-constraints add further complexity to FCC.

Time constraints were reported in the form of the duration of an episode of care. HHPT3, when referring to an episode of care stated, "you're just there for a little bit." HHPT5 mirrored this time constraint by stating, "in home health, it's really about just getting them as functional as you can in a short period as you can, and you're done." HHPT11 also reinforced the notion of limited time and related it to changing environments and contextual factors. HHPT 11 stated, "sometimes a patient will be in the home temporarily with the family, and so I'm requesting medical equipment changes or environment changes in the home for safety. So, of course, I need to collaborate with the family on that to make changes to their environment and to make it safe temporarily." Knowing how to titrate FCC based on qualifying factors and time constraints makes FCC complex. FCC is also complex given the skilled nature of the FCC approaches described by the HHPTs.

**Subtheme: FCC is Skilled**. The term skilled means the skills of a therapist are necessary to safely and effectively provide services that improve a patient's impairments and functional limitations. A service is considered skilled if medical complications and

safety concerns require a therapist to perform, or supervise, the service. Documentation must be kept that supports the service as being skilled. HHPTs reported many dimensions to their communication, documentation, and interventions that supported the theme that FCC is Skilled.

In terms of communication, HHPTs must be open to conversations wherever and with whoever they come from. HHPT4 demonstrated this when they said, "somebody will follow me out of the car and go, hey, you know, I know what she said about that, but in reality, this is what we're seeing in the house". HHPT11 recognized that communicating with caregivers and families is vital when making recommendations. HHPT11 stated, "so communicating with them on the transfers and finding out what they're able to do and what they're not able to do, both physically as well as, time-wise, you know, making sure that I'm not giving them too many activities to do... that are unrealistic." Many other aspects of skilled communication were present through the interviews with HHPTs.

HHPT14 stated, "I treat everybody individually, I treat every family individually, I'd like for as many people to be there as possible so that I can get all of the information that I need, because if I don't get all the information, if I don't get the full story, then my plan of care might not end up being appropriate, or achievable." HHPT14 went on to discuss the merits of active listening evidence-based responses and the 'psychology of being a therapist'. HHPT14 stated, "I tell them [families and patients] my job in the first visit is to listen and assess, and then we as a group come up with a plan of care that we can agree

on...let's sit down, let's be firm, let's go to science, let's educate with an accurate hopeful outcome with diseases that just don't have those, and I think part of that is the psychology of being a therapist." This level of professionalism, trust, rapport, and critical thinking is a part of the skilled communication that HHPTs reported doing when performing FCC approaches. It is also in alignment with the recommendation from a study in Chapter 2 to set clear expectations. This type of skilled care must be documented; each HHPT reported extensive documentation.

Multiple places were reported as areas for documenting FCC, however, no documentation section was referred to as FCC or family care section. HHPT5 discussed documenting in multiple areas. HHPT5 stated, "sometimes [FCC] will go into my care coordination note... sometimes it will go into my assessment or goals...where we'll talk about caregivers going to get trained on this, this and this...it might go into the subjective [section of a daily note] if I'm getting information from the patient's caregiver or spouse or family member." HHPT10 reported skilled documentation as it related directly to the Outcome and Assessment Information Set (OASIS) – a required Medicare outcome assessment (CMS, 2019c). HHPT10 stated, "there's a portion on our OASIS where we see the type of patient-caregiver training, education and then what type of exercises we provide". HHPT12 also reported skilled documentation by establishing measurable goals for FCC. HHPT12 stated, "we put it by percent attained, the return demonstration, how to do that, we document that in a way it is measurable." Other skilled services that HHPTs reported providing were skilled interventions.

Skilled interventions were reported by each HHPT. The establishment of a home exercise program (HEP) was one such service. HHPT2 stated, "I started seeing him too for right knee osteoarthritis and established a home exercise program". Range of motion programs were included with this. HHPT7 discussed the skills needed to train a caregiver on range of motion (ROM) activities. HHPT7 stated, "I'm teaching about a turning schedule [and] range of motion... showing them... this is kind of what it feels like where the joints stop, don't try to stretch them past that because you can avulse the tendon." Many more interventions were reported too. For example, HHPT6 reported doing, "therapeutic exercises, diabetic training, and caregiver training on symptom management".

### Theme 2: FCC Used to Impact Older Adults' Health Factors

HHPTs reported the benefits of FCC approaches with each health factor of the ICF model. In this study, the five ICF model health factors (HCs, IMPs, ALs, PRs, and CFs) represent the five subthemes supporting the second theme that FCC is used to impact older adults' health factors.

**Health conditions (HCs)**. Multiple HCs were described when the HHPTs were asked about the needs of FCC. No HHPT reported pulmonary conditions in the interviews, however, deconditioning was brought up a few times. The main types of health conditions reported by the HHPTs were cardiac, orthopedic, neurological, terminal, vascular, and other conditions.

The common cardiac conditions reported were heart attack and heart failure. For example, HHPT8 stated they used FCC approaches commonly for, "people who have had

a stroke or a heart attack, or something that kind of takes them out of their home, into their family's home or their home, their family coming to stay with them". HHPT9 reported the later stages of heart disease requiring FCC approaches. HHPT9 stated, "especially in the late stages... of CHF or just heart failure". FCC was also applied by HHPTs to patients with orthopedic conditions.

Orthopedic conditions included amputations, joint replacements, fractures, and spine surgeries. For example, HHPT6 stated that FCC tends to be short-lived with orthopedic patients, "I see a lot of total joint replacements that... gain independence quite quickly." HHPT11 alluded to spine surgery or spine injury like fractures when they stated, "I need the training to be performed by the caregivers, making sure that they understand the safety precautions, whether it be spine precautions or total hip precautions". HHPT12 described an experience with a patient with a hip fracture, while HHPTs 4, 11, and 14 reported using FCC with older adults with total knee replacements. The most-reported condition needing FCC, as reported by all 14 HHPTs, were neurological conditions.

Neurological conditions included neurological diseases and central nervous system injuries. HHPT1 stated that FCC is used most often when the patients have, "diagnoses that involve some kind of neurological disease process where it's something that is going to be progressive and the patient won't completely recover from." HHPT7 reported that on the need for FCC when the patient has a spinal cord injury (SCI) or a cerebral vascular accident (CVA). HHPT7 stated, "I've used a lot of family-centered approaches with my spinal cord and a CVA, any type of neural involved patients, where

the point of function is, we're kind of got them where we we've got them". FCC was reported by a couple of HHPTs as being a large part of their care at home when an older adult is on hospice at home with a terminal condition.

HHPT5 and HHPT9 both reported using FCC with terminal conditions. HHPT5 stated, "I've had several terminal patients that I've worked with up to the end of life, and the family members have been just so supportive and the patient themselves just really enjoyed." HHPT9 reinforced this by stating that FCC is important for, "any kind of carcinoma or any kind of end of life diagnosis...is part of the decision making with the family." Vascular diseases were also reported by the HHPTs in this study.

FCC was also used by HHPTs to address vascular diseases and amputations. HHPT6 described the need to perform FCC with "any sort of peripheral vascular disease". HHPT14 described the complexity of working with FCC and an older adult with vascular disease. They stated that an older adult was, "going to be amputated and the patient was in denial... I could see that the niece who's the primary caregiver... was overwhelmed... she walked me out to the car and we spent a good 40 minutes talking and going through the process of medically what it might mean for her uncle and what it's going to mean for her and her mom who was taking care of him, and so in that instance, my therapy visit had nothing to do with the patient." Cancer was also reported.

Cancer was reported by HHPT8 who stated, "I have a patient that due to cancer has a generalized weakness, and we're just working a lot with the family on finding that balance of helping them". Surgery, in general, seemed to trigger a need for FCC by HHPT10 who stated, "after surgery or after hospitalization, it's usually 90 percent of the

time, recovery, it's not to prior level of function." Last, HHPT alluded to renal conditions when they discussed the challenges of meeting patients in their homes due to outpatient visits. For example, HHPT stated the patient had, "dialysis three days a week."

**Body structures/functions and impairments (IMPs)**. HHPTs used FCC to helps families and caregivers cope with a variety of IMPs. Cognitive impairments, physical impairments, and other impairments of bodily structures and functions were reported.

Cognitive impairments were mentioned by each HHPT as being a reason for the need for FCC approaches with families and caregivers. For example, HHPT1 reported, "maybe it's cognitive impairment or maybe it's just tough getting them motivated... when I want to involve the family member, I want to do what I can to try to improve that compliance". HHPT12 also reported cognitive impairments needing FCC approaches. HHPT12 reported, "if the patient is not functional, well and cognitively well, then [the family] is actually a team partner with the medical profession for medical personnel to help them." HHPT9 reinforced the notion that families may also be caregivers when it comes to cognitive impairments. HHPT9 stated, "depending on how the patient or what the diagnosis is, what their cognitive levels are, there needs to be caregiver support, and caregiver could mean family". Physical impairments were also reported.

Balance, endurance, pain, sensory, range of motion, and strength impairments were reported. HHPT12 related balance to falls when they stated, "it's very important for the family to be involved" in learning how to work on balance deficits and reducing fall risk. HHPT5 discussed deconditioning with patients returning from the hospital during COVID-19. HHPT 5 stated, "they've been recently quarantined for six or seven days

[and] haven't done anything... they're deconditioned [and] are going to need more care, more patient-centered care, and more family-centered care". Similarly, HHPT10 stated that older adults returning from the hospital can get a condition called post"hospitalization state" and will need FCC approaches to improve their physical impairments. Range of motion and strengthening, hallmarks of physical therapy interventions, were also identified as impairments needing FCC approaches to care.

HHPT7 and HHPT8 report teaching families and caregivers how to perform, "basic passive range of motion". HHPT8 reported teaching families and caregivers, "kind of what it feels like where the joint stops" to prevent injuries to the patient. HHPT1 reported engaging in FCC approaches when they had "been doing more just general strengthening like low extremity strengthening exercises and some balance activities type things at the countertop". Six of the HHPTs reported doing a home exercise program for strengthening with FCC approaches. Other impairments were reported too.

A few HHPTs reported using FCC techniques with constipation, pain, and wound care. HHPT2 discussed an FCC approach that had a positive outcome. After training a family on how to do knee exercises with a patient, the patient's "right knee pain was gone, his back was much stronger and he was able to do those things that, you know, that he wants to do".

Activity limitations (ALs). ALs are losses in independence with basic functional mobility tasks, or loss in activities of daily living, that are essential for survival at home. Losses in basic function like bed mobility (rolling and sitting up), transfers from sitting to standing or onto a chair, and locomotion in the form of walking or going upstairs were

reported. Losses in the ability to do activities of daily living like hygiene, eating, bathing, and dressing were also reported.

This study had multiple ALs reported by HHPTs that required FCC approaches to care. HHPT 12 summarized the need for FCC with ALs well. HHPT12 stated that they, "have to educate the family to take care of the patients, to get used to their home, to practice how safe to go, you know, getting up from the bed, going through the bathroom safely, how to navigate the stairs, you go to the living room, you know, get their mail and how to walk". HHPT 2 also summarized activity limitations and FCC well when she said, "So I discussed it with the son, and I told him she at least needs help with ADLs…I was able to train her enough that she was able to get to the bathroom, but she was a higher risk for falling because she likes to keep almost all of her stuff near her bed". Six of the HHPTs reported that losses in prior level of function as being activity limitations.

Participation restrictions (PRs). The transition to home for an older adult can be a traumatic one for the patient and family as they attempt to navigate new realities. One area that was interesting in this study was the loss or change of family roles that were identified by multiple HHPTs. For many families the older adult now needed care, and for their adult child, there was an expectation to now be their caregiver. HHPT14 referred to this as making, "pseudo-therapists". When these roles change, FCC is highly needed to determine if the person is accepting and ready for this change. HHPT11 reported that "communicating with [family members] on the transfers and finding out what they're able to do and what they're not able to do, both physically as well as, time-wise, you know, making sure that I'm not giving them too many activities to do with her that are

unrealistic". HHPT8 summarized this reality when they said, "sometimes you just have that family member that greets you at the door and then steps out of your life...you just can tell they're overwhelmed."

Participation restrictions are also on the patient who no longer has their traditional role as the parent and care provider. A few HHPTs noted, there are times when social workers are needed as are private caregivers. Patients do not always want family members to care for them and can be quite resistant to care from family members.

HHPT2, 5, and 14 all reported issues with this, saying that patients do not always want to see the role they have with loved ones to change.

Contextual factors (CFs). Contextual factors include environmental factors and personal factors. More discussion on the impact of contextual factors on FCC by HHPTs is provided in the third theme that FCC is impacted by contextual factors. In this study, HHPTs used FCC approaches to address CFs. Environmental factors that were reported as needing the FCC approach included working with families to make home modifications, purchase equipment, and reduce fall hazards. For example, HHPT9 reported using FCC approaches to address, "safety in terms of having adaptive equipment around the home, in terms of bathrooms, also in terms of what they can do to make the narrow walkways a little bit bigger or to tack down, you know, if you will, some throw rugs and so forth and so on". Personal factors were also reported as benefitting from FCC approaches to care.

Personal factors were address by HHPTs using FCC approaches. Some families and patients were not trusting of HHPTs when they arrived at their homes for the first

time. FCC approaches of being a servant leader, explaining everything, and using shared decision making were reported as part of the process of building rapport and trust with these families. HHPT9 reported, "you have to build up your rapport and then you have to present yourself and then you need to gain that confidence that what you're doing is what's best for the patient". HHPT6 reported that FCC approaches support culturally competent care. HHPT6 stated that they, "have to respect their [the family and patient] wishes regardless of whether [they] think that's the best...safest decision". FCC was used by every HHPT to impact older adults' health factors. The HHPT's ability to provide FCC was largely determined by a variety of contextual factors – both personal to the patient and environmental (surrounding the patient).

# Theme 3: FCC is Impacted by Contextual Factors

The third theme that FCC is impacted by contextual factors, relates to the barriers and facilitators HHPTs have with delivering FCC to older adults. CFs were divided into recognized subthemes of environmental factors (EFs) and personal factors (PFs) (WHO, 2002). The subthemes of EFs and PFs were coded with a +/- symbol to indicate facilitator (+) and barrier (-).

**Environmental factors (EFs)**. EFs had four related codes that were reported to impact FCC by HHPTs. These related codes were caregivers, families, IDT, and home health.

Caregivers and families. The related codes of caregivers and families were supported by the codes of abilities, attitudes, beliefs, and availability. The codes are related because caregivers may be considered by the older adult as part of their family,

and family members may serve as caregivers to the patient. Families, for coding purposes, are people who are not caregivers, or are transitioning to be caregivers, when the HHPTs encounter them with the older adult. The level of education, spoken languages, attitudes about HHPTs, stress levels, injuries, cultural and personal beliefs, and scheduling conflicts of caregivers and families impacted FCC by the HHPT.

For example, HHPT1 reported on availability "I want to do what I can [and] there's just either nobody there or nobody there that's willing to be involved". HHPT12 reported on scheduling issues and education levels. HHPT12 said their biggest barriers to FCC were caregiver and family problems with "scheduling and also educational attainment". HHPT3 expressed frustration over caregiver availability when it was said that, "a lot of times I do see that they get recurring hospitalizations because you don't have the follow through with the family when you leave". HHPT4 reported a concern for caregiver and family burnout when they stated that caregivers and families report, "I don't want to deal with this person right now. I'm so angry with them." According to HHPT, "you know that is going to put a hitch in the giddy-up of my training when I have this kind of caregiver burnout. They're just at their max. You know, especially with somebody who is at a high acuity of care." On the flipside, caregiver abilities, attitudes, beliefs, and availability could positively impact the HHPTs ability to provide FCC to older adults.

On a more positive note, HHPT2 reported that having a consistent, available, caregiver or family member made a difference with FCC approaches. HHPT2 stated, "when there is the same family member or the same caregiver caring for that patient, then

the follow through with my training is much easier." HHPT7 stated that being present and active facilitates FCC approaches with them and the older adults. HHPT7 stated, "any kind of family member that is an active caregiver or is participating in an active role with maintaining function or increasing independence with the patient that I am working with." HHPT4 summarized these ideas of how families and caregivers facilitate and support FCC:

You know, you just see the families where it's like they just generally care so much about them. Usually, it's like the parents or whatever or the grandparents or something like that. And it's like there's just they just definitely want to know how they can help them, how they can support them because they just mean they love that person so much that they just want to be so involved in their care. And then, yes, they're there. They're genuinely concerned about the patient's safety or well-being. And so, they want to know how it is. And they also want to make sure that they don't hurt the patient, too.

Family dynamics and some cultural differences were reported to also impact FCC. Cultures such as Asian, Hispanic, and Chaldean cultures were reported, at times, as being overprotective, but this did not impact the FCC approach with them. Caucasians were also reported by HHPT2 and HHPT14 as often being less involved and using caregivers more often. Each HHPT said these generalizations with caution, noting that culture was not as important as observed family dynamics and caregiver dynamics. IDT members were also reported as also having a +/- impact on the HHPT's ability to provide FCC to older adults.

impact on FCC and older adults. HHPT2 saw the primary care physician (PCP) as having the ability to positively impact FCC when families have the same PCP. HHPT2 reported, "since they have the same PCP, I asked him to discuss with the PCP about getting PT too". Others saw the PCP as a barrier to FCC. HHPT5 stated that, "everybody still almost always is going through their primary care physician, and that creates a bottleneck and that creates delays and then that creates patients that are worse off". HHPT7 expressed frustration with collaborating with nursing. The HHPT7 reported that with nursing, "there have been isolated incidents where I have done more than what I feel like I should have done... it's really frustrating sometimes." HHPT10 described nurses as an essential part of their FCC and IDT. HHPT reported, "let's say there's a concern from the patient, then we do a care conference with the nurse, the doctor, and all the home health disciplines that are involved with the patient". Within the IDT is the HHPT themselves.

*Home health*. HHPTs' attitudes, beliefs, abilities, and availability have an impact on FCC with older adults. HHPT14 alluded to this problem when they reported:

Whether they're physicians or nurses or rehab therapists, they just get in, they treat the patient, they get out, and they might be really good at treatment, but if they're not good at communicating with the family, especially with elderly, because a lot of elderly might not be diagnosed with dementia, but they've got forgetfulness, or they're confused in new situations. Right, so that's what we are. We're coming to the house and it's a new situation. So, if you don't involve the

family, even if it's remotely, I personally don't feel that you're doing 100 percent of your job.

Expert1 commented that therapists may be avoiding doing family medicine and scheduling around families and caregivers as an avoidance strategy. The code of therapist avoidance was generated. Therapist avoidance was sensed in the comments of HHPT13 who stated, "because I work part-time I can kind of flex my schedule to what works for me personally". This suggested to that HHPT13 may avoid working later hours and weekends that many other HHPTs reported doing out of convenience. HHPT9 stated, "I think it would be a contradiction to do direct access for a patient while I'm working for a company to see that family member". This too may be an avoidance strategy. During the Chapter 2 literature review one study reported that FCC may be in part due to a lack of interest on the part of the practitioner to engage in FCC approaches with older adults (Dall'Oglio et al., 2018; Fiest, McIntosh, Demiantschuk, Leigh, & Stelfox, 2018; Frank et al., 2019; Jette, 2017; Kiwanuka, Shayan, & Tolulope, 2019). FCC is complex and weighs into the HHPT as +/- EF.

FCC is likely enhanced when HHPTs have a good understanding of FCC, practice it frequently, and are open to the idea of family medicine without barriers. Some HHPTs espoused the value of FCC. For example, HHPT12 stated, "you have to finish the education—even if it if it means you will be there one and a half hours; you have to complete all the education." HHPT11 reported being open to scheduling on weekends, "I can see the patients at times when family members can be present, so, if I have working

family members, I even work on Saturdays". HHPT7 responded to KQ7 with an attitude that is very supportive of FCC approaches:

I feel like it's kind of almost part of the definition of what we do in the title of home health, physical therapy. So our job is to address every entity in the home, whether it's poor safety with clutter and things that need to be moved or rearranged to, you know, getting the people that live there with the patient to play a part in their recovery. So, I feel like it's my job, as long as I have a willing participant, to at least strike up that conversation with.

In addition to the IDT members, home health as a setting had an impact on the HHPTs ability to provide FCC to older adults. Home health agencies were both positively and negatively impacting FCC by HHPTs.

HHPT2 stated that their home health agency (HHA) had a good relationship with their PCP which allowed them to communicate more openly with issues that families and caregivers were having. HHPT2 reported that their HHA trusted her input and allowed her to be more autonomous. HHPT2 stated that three of the HHAs she has worked for, "trust my clinical decisions so when I say I need more or I don't need as much, they are fine with it". Others reported that HHAs as a barrier to FCC, HHPT1 reported, "when it's busier when we have a high census, I do feel I'm being pressured to go see more visits, in those situations, yes, that does kind of impede my ability to spend more time with some patients and families. HHPTs also reported on the impact of home health laws and regulations like the Patient-Driven Grouping Model (PDGM) which took effect on January 1, 2020.

https://doi.org/10.1016/j.com/10.2016/j.com/

HHPT4 summarized difficulties with home health in general that impact FCC. HHPT4 stated:

Home health, in general, is a difficult field. It's difficult to go into, especially if you come right out of college and you don't have a lot of experience because you are by yourself and there's a lot of dynamics. I don't I have found that the training in home health is lacking significantly, and a lot of it and you just have to kind of figure out as you go into it. I feel like there should be more exposure probably while they're in their degree programs, and then also there should just be a better training system in place. A lot of these home health agencies, more so with the smaller one, and even with the larger ones, do have the training, or it's just inadequate for what you, what you deal with out there.

Home health in general, according to HHPT 7 and HHPT13, did not offer the tools that outpatient care does. As HHPT13 put it, "our place in home health is we're making them safe to be in their home while they are homebound... once they're really no longer homebound, even if that means that a family member has to drive them to outpatient, I think they should be going to outpatient". HHPT 10 felt home health encourages FCC approaches. HHPT10 stated, "I have to wait for that time for the caregiver to be available to do all of those training, and what else... you have to accommodate all this time when you're in the home health setting". HHPT6 stated that the advantage to home health is that, "it's real life, and real-life goals, it's easy to make those goals, it's easy to measure progress towards those goals based on the family's responses and feedback". HHPT1 reported that home health, in general, encouraged her to perform FCC approaches because home health is, "literally why I love my job is because it is so personal". Caregivers, family members, the IDT, and the home health environments are all EFs that have an impact on how FCC is delivered to older adults by HHPTs. Personal factors (PFs) of the patient were also reported as impacting FCC.

## **Personal Factors (PFs)**

Personal factors in this study refer to non-health-related factors that apply to the patient that can impact the delivery of FCC by the HHPT. PFs are described as the related codes of a patient, the home, and finances. The patients in this study had attitudes, beliefs, abilities, and availability that either promoted or inhibit the HHPT from engaging in FCC with them. PFs like patient abilities are not considered impairments, like cognitive issues, described in the second theme.

PFs identified in this study included native language, coping strategies, and educational levels. Native language was considered both a barrier and facilitator. Each HHPT reported that families and patients that can speak English were easier to educate and collaborate with followed by Spanish. Outside of these two languages, other languages presented some of them with unease. As HHPT3 stated:

The times that I spoke with Arabic families, I had a family member translate. But those are the times that I tell you, like I feel the most uneasy about it because it's like that with the families telling me, the patients saying it doesn't feel right, but I don't know it could be the culture that I don't understand that.

HHPT7 reported, "I've also had patients that are deaf, and I don't know how to sign, so I do rely on a family member that way". Educational attainment of the patient was reported as impacting FCC. HHPT12 stated that, "the family needs to be there, especially with a patient that has a you know, their educational attainment is not really that high". HHPT6 implied that educational levels and the ability to read can impact FCC. HHPT6 stated, "whether you give [education] to them verbally, written, or through demonstration, you have to be really cognizant of their level of being able to retain that information in order for them to process it". In addition to PFs of educational attainment and language, attitudes and beliefs were both reported to impact FCC by HHPTs.

HHPT12 reported that attitudes about physical therapy affected their care.

HHPT12 stated, "even if you educate the family to understand the process of training and what's the reason why you're there, some family members feel like they don't need a physical therapy intervention for their parents". Other HHPTs, like HHPT4, felt that

patient motivation helped them to achieve better outcomes with FCC. HHPT4 said, "sometimes they're more motivated and they enjoy, you know, the work that we do and they want to get better and they want to be more stable and they want to be able to get around and be more independent". Patient beliefs impacted FCC too. Some patients preferred the same gender HHPT or an older HHPT. These beliefs were reported as being a facilitator or a barrier if the HHPT represented, or did not represent, what the patient wanted. HHPT8 stated, "people feel burdened and they just don't understand why their family member isn't just back doing it and other ones just don't want their family member to stand-up because they are terrified". Patient availability was reported as impacting FCC as well.

According to HHPT 14, "although patients in home health are technically homebound, they've got oncology infusions, they've got doctors' appointments, dentist appointments, religious things that they go to.". Other times, patients had arranged for their scheduling needs. As HHPT5 said, "that's usually a big plus because they're handling all the doctor's appointments, they're handling all the scheduling". HHPT5 felt this allowed them to arrive at a preset time and have the time needed to work on FCC with the patient and family.

### **FCC** in the ICF Model

The themes and subthemes generated by this study where conceptualized in relation to the ICF model as displayed in Figure 6.

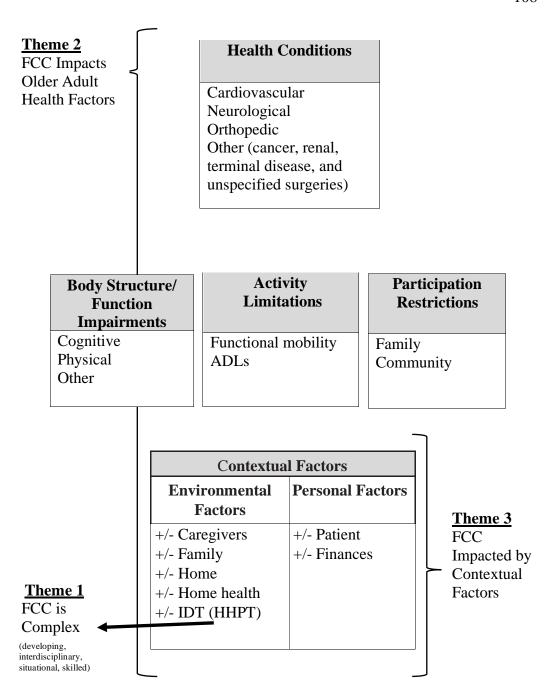


Figure 6. Themes in the context of the ICF model. Theme 1 demonstrates that FCC is complex in nature. Theme 2 demonstrates that FCC is used by HHPTs in this study to address all five health factors. Theme 3 demonstrates that the ability of the HHPTs to deliver FCC is dependent on the impact (+/-) of contextual factors; one of which is their own abilities to navigate FCC complexities. Note: This is an adaptation of original work, "International Classification of Functioning, Disability, and Health. Geneva: World Health Organization (WHO); [2001]. License: CC BY-NC-SA 3.0 IG".

## **Summary**

Chapter 4 detailed the expert review process, demographic information collection, data collection process, coding process, peer debriefing and issues with trustworthiness. The results of this study were that: (a) HHPTs provided FCC to older adults and their caregivers to impact all five ICF model health factors; (b) FCC is complex due to the skilled services required, lack of uniform understanding, and variability in practice; and (c) FCC is impacted by multiple contextual factors which include both environmental and personal factors. Within the environmental factors, the HHPT was considered as having an impact (positive or negative) on how, or if, FCC would be used. A visual conceptualization of how these three relate to the ICF model was also given in the chapter. The results of this study answered the research of how HHPTs perform FCC with older adults. These new understandings have the potential to create positive social change within the profession of physical therapy and beyond. As HHPT2 put it, "FCC can help older adults stay at home and be part of their community".

Chapter 5 provides an in-depth interpretation of the findings, limitations of the study, recommendations for future practice and research, implications of the findings, and a conclusion to the study. This study has the potential to lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction.

## Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of 14 HHPTs in a community in the western United States. This study was conducted to close the knowledge gaps in the literature on FCC with older adults, the use of FCC in home health physical therapy, and the understandings of FCC within the context of the ICF model. FCC is important to understand with older adults because of the many benefits FCC has in pediatric settings (Desai et al., 2015; Franck & O'Brien, 2019; Johnson & Abraham, 2012; Raphael et al., 2011). These benefits include higher quality health outcomes, best practices, reduced caregiver issues, and higher family satisfaction.

Three main themes emerged from this study. The first main theme was that HHPTs reported FCC as being complex. The second main theme was that HHPTs used FCC to address the five health factors of the ICF model with older adults. The third main theme was that HHPTs reported multiple contextual factors (environmental and personal) that impact their delivery of FCC. Chapter 5 provides details on these themes and on other findings. The chapter also describes the limitations, recommendations, implications, and conclusion of the study.

### **Interpretations of the Findings**

Interpretations of the themes of this study were conceptualized within the ICF model and related to the review of the literature in Chapter 2.

# Theme 1: FCC is Complex

The reported differences in how developed each HHPT was in their understandings and practices of FCC varied. The different interdisciplinary teams and situations that HHPTs encountered complicated FCC. Last, the levels of skilled service varied as well.

Understandings and practices. FCC understandings were reported as problematic among health professionals before this study (Boztepe & Kerimoğlu Yıldız, 2017; Fagan et al., 2015; Ludmir et al., 2018). The HHPTs in this study considered FCC in practice to be caregiver education and training alone. The HHPTs did not see FCC as group therapy, collaborative interventions, or family medicine. The HHPTs' belief may prevent them from expanding their knowledge and practice of FCC in the modern era of direct access, collaborative care, bundling of services, and telehealth.

There was evidence in the literature that caregiver issues can be effectively addressed directly by HHPTs. These issues included training and providing exercises and skilled physical therapy to caregivers (Puterman et al., 2018). There was a lack of understanding among the HHPTs around direct access and family medicine during a single episode of care. Two HHPTs saw more than one person as intimidating and out of their scope of practice, much like the HHPT described in the Warner and Stadnyk study (2014). In the literature, a lack of understanding and the personal biases of healthcare practitioners were found to limit the extent to which FCC approaches were used (Campos & Kim, 2017; Franck & O'Brien, 2019). This study confirmed that the knowledge gaps and self-limiting beliefs reported in studies (Haines, 2018; Jette, 2017; Warner &

Stadnyk, 2014) may have impacted the level at which HHPTs practiced FCC with their older adult patients.

None of the HHPTs interviewed reported using FCC guiding principles, best practices, or source materials. These resources are part of pediatric practice settings (Bruce et al., 2002; Kuo et al., 2012). FCC resource awareness remains problematic amongst many health professionals (Boztepe & Kerimoğlu Yıldız, 2017; Fagan et al., 2015; Ludmir et al., 2018). This study confirms the need to expand best practices, guiding principles, and source documents on FCC with older adults.

Interdisciplinary approaches. Seven of the HHPT interviewed referred to the primary care physician (PCP) as a barrier to interdisciplinary care. This was related to PCPs having limited time to conduct additional tasks. Other HHPTs complained that the PCP caused too many bottlenecks. These bottlenecks were not discovered during the literature review and provided new understandings. Patients experiencing a bottleneck were reported as waiting too long for an outpatient follow-up visit with their PCP. These long visits were reported as burdensome outings that could negatively impact sessions with HHPTs. The patient care medical home, described in Chapters 2, was not mentioned by the HHPTs interviewed despite the potential for improve outcomes (Jackson et al., 2013). Furthremore, the PCP was removed from direct communication with the HHPTs who reported having to collaborate with the nursing staff to get information relayed to the PCP. This was not seen during the literature review and adds new understandings. In terms of culturally competent care (CCC), there was a variety of complex issues addressed by this study.

Culturally competent care (CCC) aligns with shared decision making and seeks to adapt to, and respect, a patient's language, communication styles, values, beliefs, and behaviors (Butler et al., 2016; Cuevas, O'Brien, & Saha, 2017). In this study, some HHPTs used language applications on their cellphones, others spoke some Spanish and attempted to use some Spanish, others used a family member to translate, and others used translation services over the phone. Some seemed to avoid translation altogether and relied more on nonverbal and visual demonstrations. None of the HHPTs interviewed reported bringing materials in other languages as suggested in the literature review (Arlandis Guzman et al., 2017; Rojas Silva et al., 2017; Vasli, 2018). The patient and caregiver may not be equal partners on the IDT or form therapeutic alliances if the language difference is not accommodated for (Deek et al., 2016; Hu et al., 2016; Huang et al., 2018). A lack of this alliance may result in a lost chain of communication that could prevent re-hospitalization.

**Situational needs**. Some of the HHPTs interviewed identified Asian and Hispanic family caregivers as being overly involved. Others reported some Caucasian family caregivers as under-engaged. LaVela et al. (2016) found that Caucasian adult children felt the need for the most training. Under-engagement may be indicative of needing increased training and adjustment time.

Black and Native American races were not mentioned by the HHPTs in this study yet do have a presence within the western community of this study. Reduced access to HHPTs may be part of this problem, as could be geographical differences. To this extent, the findings are less transferable (Garwick et al., 2002). Many HHPT stated that an

assessment of the family is needed and to always avoid pre-conceived notions about a race, culture, or religion. Gender was not considered a factor per the HHPTs interviewed. One HHPT reported multi-generational families living under one roof as caring more for each other. This HHPT reported training both grandchildren and great-grandchildren to care for the older adult. Training younger adult and minors was not addressed in the literature review. This study adds depth to the understanding of who HHPTs may need to incorporate FCC approaches with.

**Skilled service**. The HHPTs reported communicating with families at many levels. This included basic training on home exercise programs, better understandings of their loved one's prognosis, death and dying issues while on hospice at home, and care transitions. Servant leadership was present in many of the responses by the HHPTs. This supports studies in Chapter 2 that aligned servant leadership with FCC approaches on critical care settings with adults (de Zulueta, 2016; Gersh, 2006). Servant leadership is also a preferred strategy for providing CCC (Chittem & Butow, 2015).

## Theme 2: FCC Used to Impact Older Adults' Health Factors

HHPTs reported using FCC to address all five health factors in the ICF model. Much of the target factors were IMPs and ALs. Targeting the performance of the body and independence with functional mobility confirms that the HHPTs in this study did focus on intrinsic capacity changes. The Integrated Care for Older People (ICOPE) guidelines (WHO, 2017) were not referred to by name specifically. Still, almost every HHPT described some level of caregiver training and education on a progressive, individualized multimodal exercise program. In this study, only one HHPT dealt with

incontinence. This suggests this type of training and education may not be part of the average HHPT's assessment and plan of care.

Most of the HHPTs interviewed reported reviewing medications, providing some form of a home environment assessment, reviewing their fall risk concerns, and helping patients regain or cope with their changing roles. These reports support the ICOPE guidelines further and likely benefit the patient and their family by reducing medication errors and impairments, improving functional mobility, preventing falls, changing the environment, and adjusting to new realities (Basnet et al., 2018; Romli et al., 2018). The types of assessments were not discussed in the literature. The HHPTs in this study also reported practicing in a manner that aligns well with the Institute of Medicine's six aims for improving health care quality (Clay & Parsh, 2016).

Terminal diseases have increased complexities with FCC due to the end of life issues and stress as reported in Chapter 2. FCC is effective with reducing stress on families dealing with an older adult with a terminal disease (Bui, Han, Diwan, & Dao, 2018; Haigh, Bogucki, Sigmon, & Blazer, 2018; Hinton et al., 2019; Rhee & Rosenheck, 2019; Wong, Wan, & Ng, 2016). This study provided additional evidence that FCC with older adults with terminal diseases was being used and was effective from the perspectives of HHPTs interviewed.

# Theme 3: FCC is Impacted by Contextual Factors

The FCC barriers reported in the literature included documentation, travel conditions, reimbursement, authorization, family involvement, and cultural sensitivity (Shamus, Fabrizi, & Hogan, 2018). In this study, the HHPTs reported the abilities,

attitudes, beliefs, and availability of the caregivers, family members, home health agency, patient, and IDT as impacting their ability to provide FCC with older adults. This study confirmed most of the barriers cited in the literature with the exception of documentation. Additional barriers were reported on in this study including the primary care physician, home health nurse, home health administrator, HHPT, home environment, patient health literacy, and patient personal finances.

### FCC and the ICF Model

The ICF model is considered versatile and supportive of IDT approaches, changing definitions of family, and changing contextual factors. This study added new understandings on how FCC can be visualized within the ICF model. FCC was visualized through three main themes.

The first theme, FCC is complex, was attached to the HHPT – a contextual (environmental) factor to the older adult patient. This provided new understandings on FCC and the ICF model. In addition, the second theme, FCC is used to impact older adults' health factors provided new understandings on the ICF model and FCC too.

The second theme demonstrated that HHPTs used FCC to address all five of the ICF defined health factors. Previous studies found connections between FCC and health conditions (1), impairments (1), and activity limitations (1) (Christon & Myers, 2015; Hwang et al., 2016; Stevens & Lee, 2018; WHO, 2017)). These first three factors are more bio-physiological in nature. This study found psychosocial factors to also be addressed with FCC approaches by including participation restrictions (PRs) and contextual factors (environmental and personal). In terms of HCs, neurological conditions

were consistently reported as needing FCC the most—this too is a new understanding on FCC with older adults.

## **ICOPE, IOM-6, and FCC Competencies**

The HHPTs in this study demonstrated some of the World Health Organization's Integrated Care for Older Adult People (ICOPE) guidelines, Institute of Medicine's Six Aims for Improving Health Care Quality (IOM-6) (Newton, Baxley, & Lefebvre, 2019), and the FCC competencies for physical therapists (Jette, 2017).

ICOPE guidelines. Multiple HHPTs in this study used FCC approaches that aligned with some of the ICOPE guideline. Some of HHPTs reported issuing multimodal exercise programs, working on fall prevention through exercises and home modifications, and supporting caregivers through caregiver training and education. Two HHPTs used FCC to design multifactorial interventions. One HHPT used FCC to give supplemental nutritional advice. None of the HHPTs reported using FCC approaches to address vision or hearing losses, assess the psychological well-being of the patients and caregiver, or engage in strategies that address urinary incontinence.

IOM-6. FCC approaches were incorporated by the HHPTs to prevent falls, meet the patient and families need, and ensure continuity of care. This met the IOM-6 aims of safe and patient-centered care. There was no reported scientific basis reported for using FCC approaches. This may be related to FCC being novel, complex, and confused with patient-centered care. Three HHPT reported that too many disciplines were called out at once, and at times, they were called out to the home too soon. This prevented coordination of care and time for adjustment to being home. This demonstrated quality

concerns of the home health system related to coordinated and effective care (Newton, Baxley, & Lefebvre, 2019).

Most of the HHPTs reported that FCC with caregivers was less efficient but led to better outcomes with willing caregivers. Two HHPTs reported that personal finances of the patient limited the home modifications they could make or recommend. Three HHPT reported finding ways to get things paid for via alternate community resources. Equity in care seemed to differ as well, with non-English or Spanish cultures having less resources and meaningful engagements.

FCC competencies. The competencies needed for FCC per Alan M. Jette (2017) were not fully demonstrated. One HHPT called ahead and set clear, and agreed, expectations to caregivers. Most arrived without doing this. Two HHPTs reported that the agencies (HHAs) arranged largely for when the patient would be present, but that this did not ensure caregiver presence. Some HHPTs felt frustration over caregivers and families unwilling to participate in FCC and the rehabilitation plan. If caregivers did not have the supporting presence that the HHPTs was seeking, FCC was less likely to be initiated.

Working with negative attitudes and challenging caregivers seemed to present a problem for some of the HHPTs in providing FCC. Eight of the 14 HHPTs reported referring out to appropriate services to assist caregivers and family members. Most of the HHPTs also reported approaching each family as a unique micro-culture. Some of the HHPTs demonstrated good cultural competence by learning to adjust to the needs of the patient and family, such as removing shoes, or coming at certain times of the day.

## **Limitations of the Study**

The study is limited in generalizability given the design used of a single-case study of 14 HHPTs in the same Community in the western United States. The sample selected was not done so at random, but rather through snowball, or chain, sampling (Noy, 2008). This sampling technique further limits the generalizability (external validity) of this study (Palinkas et al., 2015). This study is limited in scope which affects the overall transferability of this study. This study interviewed 14 HHPTs, one of which was a halftime home health Registered Nurse (RN) and the other a halftime Regional Manager for an HHA. This study did not obtain additional perspectives of older adult patients, family members, caregivers, and other health practitioners. This study is also limited to the timeframe in which the data was collected.

During the time of data collection, home health was transforming due to the COVID-19 pandemic and due to major legislative changes from the newly adopted Patient-Driven Group Model (Warren, 2019). This study is limited in the triangulation strategies during data collection as well. This study used semi-structured interviews to collect HHPTs' perspectives but did not seek to triangulate with a second data collection tool. Last, HHPTs may have answered in a manner that masked their true feelings due to a power imbalance, ego, or job concerns. Given the strengths and limitations of this study, further research is recommended.

#### Recommendations

This study provided new understandings on FCC with older adults from a limited perspective of 14 HHPTs. From these understandings three recommendations were

developed. These recommendations are for additional FCC visits; expansions in FCC education and training, and additional research studies on FCC with older adults.

### **Additional FCC Visits**

One area that was repeatedly reported as a challenge to the HHPTs was having enough visits and time to conduct FCC. In addition, some HHPTs reported multiple caregivers needing to be trained and retrained. Other HHPTs reported scheduling conflicts with families, patients, and caregivers. It is recommended that home health agencies and healthcare insurance carriers allow HHPTs to have additional FCC visits that do not compete with the direct interventions needed with the patient. More education and training are also recommended.

# **Expansions in FCC Education and Training**

It is recommended that healthcare educational programs expand education on FCC beyond pediatric care settings. This study established new understandings on FCC with older adults in the context of the ICF model. The ICF model is recognized by the professions of nursing, physical therapy, occupational therapy, and speech-language pathology. This study provides real world examples of FCC with older adults that could be simulated in the classroom, developed into case studies, and assessed by faculty. Twelve of the 14 HHPTs interviewed stated that they would practice family medicine if allowed. Continuing education on working with more than one individual in their home is needed and specifically on how to navigate direct access. Expanding education and training on FCC was also recommended by Jette (2017).

### **Continued Research on FCC with Older Adults**

Continued research on FCC is needed to fill in more of the gap in the FCC literature with older adults. One recommended study is a quantitative study that looks at what effects FCC has on aging in place over patient-centered care approaches. Another recommended study is a quantitative study looking at the effects treating a caregiver at home has on the patient versus referring out. Last, a large scale mixed-methods study is recommended to assess patient and caregiver satisfaction with FCC compared to patient-centered care. To do these studies, HHPTs would need to be competent in a set of FCC standards (Jette, 2017) and have clearance from the home health agencies, patients, and families. Further research is needed to get professional agreement on a set of standards related to FCC.

## **Implications**

This study fills in a portion of the knowledge gaps in understanding surrounding FCC and older adults. This study also adds knowledge to the gaps on the relation of FCC with the ICF model. The three themes that emerged were developed from the perspectives of 14 HHPTs, the literature review on FCC, expert review of the interview guide, conversations with thought-partner, and the researcher's professional knowledge of the field of physical therapy. These themes, and supporting subthemes, have the potential to impact positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction.

# **Expansions in FCC Education and Training**

FCC is about shared decision making and the goal of the HHPT should be to ensure successful aging in place of the older adult. Caregiver and family education were reported as the main form of FCC provided by HHPTs. This study goes further and provides a figure and explanation of how FCC is conceptualized in the ICF model. In this manner, FCC is applied to handle all the ICF health factors as an intervention approach to care. Future positive social change may include specific education on how to manage impairments, activities of daily living, functional mobility, societal roles, personal, and environmental barriers through FCC. Other future education and training that may develop from this study may include skill training on how to deal with the various dynamics of families, caregivers, patients, and the IDT when performing FCC.

### **Additional Research on FCC with Older Adults**

More research is needed to determine the best practices, professional guidelines, and standards of care for FCC with older adults. This study provides a window into the need for such guidelines as practice and understanding varied between HHPTs. Family medicine approaches are one example of this need. Of the 14 HHPTs interviewed, none reported doing true family medicine, yet 12 of the 14 said they would do it without any of their reported barriers. More guidance on this and clarity is needed from licensing, professional organizations, and Medicare. The potential is there with direct access being legal in all 50 states. Future research that establishes these guidelines may be possible from this study leading to positive social change of providing a point of service delivery to the patient, and when needed, to their family or caregivers.

# Improved Health Outcomes and Satisfaction for Older Adults and Families

FCC is not exclusive to HHPTs and is for any health practitioner to apply. It was encouraging to see that FCC, at some level, was a part of the practice of every HHPT interviewed. This study provides some evidence that FCC is manageable in practice currently and could encourage new graduates and future clinicians to engage in FCC approaches.

FCC was reported in this study to be limited by the number of visits authorized by insurance and family, caregiver, or HHPT availability. The current pandemic is forcing some of the HHPTs in this study to pivot their practice to telehealth and working with families online while working with older adult patients. As the Baby Boomer generation grows and ages so too does the need for their adult children to assist them at home. These adult children were reported as often needing copious amounts of training and education (LaVela et al., 2016). This study may support the future changes in regulations and reimbursement needed for more effective delivery of FCC to these populations.

This study provides no causation as to whether FCC with older adults leads to the same positive social changes that FCC has on pediatric patients. This study does provide some evidence into why FCC is utilized by HHPTs that may indirectly demonstrate that FCC is more effective for improving health outcomes.

The first piece of evidence came from the fact that each ICF health factor was addressed through FCC approaches at some level by the HHPTs interviewed. The second piece of evidence is that most of the HHPTs connected the FCC approach to improved aging in place. As HHPT6 stated, "[FCC] means including, if possible, and if allowed by

the patient, the patient's goals as well as the family goals in terms of what their goals are with the patient to reduce the burden of caregiver care and to just see what the whole picture is of the entire family dynamics and what is needed to keep the patient home safely". HHPT10 echoed this when they stated that FCC, "involves the family members to make sure that there's enough or adequate support for the patient to be able to stay well and stay home and promote the continuation of care". The third piece of evidence is that Medicare recognizes the importance of caregiver and family training with older adults enough to include this as part of the regular documentation by the HHPT. This study adds to the evidence that FCC approaches may lead to improved health higher quality health outcomes, reduced caregiver issues, and higher customer (patient, family, and caregiver) satisfaction as seen in pediatrics may result from this future work.

### Conclusion

This study filled in some of the gaps in understand FCC with older adults, within the context of the ICF model, from the perspectives of 14 HHPTs in a western community of the United States. The findings were: (a) FCC with older adults is complex; (b) FCC was used by the HHPTs interviewed to treat all five health factors; and (c) the delivery of FCC by the HHPT was impacted by multiple contextual factors. Based on these findings and the limitations of this study it was recommended that additional FCC visits be granted, educational and training on FCC be expanded, and additional research be conducted on the effects that FCC has on older adult and caregiver health outcomes and satisfaction.

This study has the potential to lead to positive social changes of expansions in FCC education, training, and research; improved caregiver, family and patient health outcomes; and higher patient, family and caregiver satisfaction. It is encouraging to see new studies emerging on FCC with adults. At the conclusion of this study, two peer reviewed journal articles on FCC with adult populations were identified. One study explored the best practices of FCC with hospitalized adult patients (Kaslow, Dunn, Henry, Partin, Newsome, O'Donnell, ... & Schwartz, 2020). Another study looked at FCC with adult patients during the COVID-19 pandemic (Hart, Turnbull, Oppenheim, & Courtright, 2020). Both studies, like this study, help to fill in the gaps in understanding FCC outside of pediatric settings and have the potential for positive social changes.

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# Appendix A: Confidentiality Agreement

#### CONFIDENTIALITY AGREEMENT

### Name of Signer:

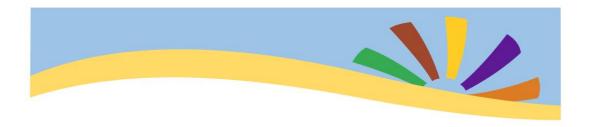
During the course of my activity in collecting data for this research: Exploring Family-Centered Care from the Perspectives of Home-Health Physical Therapists, I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

## By signing this Confidentiality Agreement, I acknowledge and agree that:

- 1. I will not disclose or discuss any confidential information with others, including friends or family.
- 2. I will not in any way divulge, copy, release, sell, loan, alter, or destroy any confidential information except as properly authorized.
- 3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
- 4. I will not make any unauthorized transmissions, inquiries, modification, or purging of confidential information.
- 5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
- 6. I understand that violation of this agreement will have legal implications.
- 7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:	Date:
0	



# Research Study

Hello,

My name is Jim Mathews, PT. I am graduate student seeking to interview qualified, home health physical therapists from San Diego County on their perspectives with Family-Centered Care and older adults. For more information please email me at:

james.mathews@waldenu.edu



# Appendix C: Final Interview Guide

# **Opening Phase**

Hello and thank you for your willingness to participate in today's interview with me, Jim Mathews, a Ph.D. student at Walden University and a physical therapist. Thank you for agreeing to do this interview today and returning the informed consent. The information gathered today will be recorded and transcribed in confidence for the purposes of my dissertation alone. Your name and company will not be identified in this study and every effort will be made to keep your responses in complete confidence. This is a safe, private place and your responses will not be judged in any manner. Do I have your permission to proceed?

#### **Introduction Phase**

**Purpose Statement**. I would like to restate the purpose of this study. The purpose of this single-case study was to explore the perspectives of HHPTs on the delivery of FCC to older adults using a purposeful sample of HHPTs. This study will be used in my dissertation toward obtaining a Ph.D. in Health Care Administration with Walden University. Your participation is voluntary, and you may stop at any time. I will be recording the audio during today's meeting. Do you have any further questions before we proceed? I will start recording now. Now that we are recording, for the record, do you consent to participate in this study as previously explained? If so, please state, "I consent". Thank you

#### **Transition Phase**

# **Demographic and Ice-Breaker Questions**

I'd like to get to know a little bit about you before we plunge into the main questions.

- 1. How many years have you worked fulltime in home-health?
- 2. If you know, is your current home health agency for-profit or not-for-profit?
- 3. Are you currently working fulltime in home-health?
- 4. What percent of your workload is with older adults, i.e. adults over the age of 64?
- 5. Have you ever attended any training related to family-centered care delivery?
- 6. Do you have a GCS?
- 7. Are you familiar with the International Classification of Functioning, Disability, and Health Model, also known as the ICF model?
- 8. Do you have any questions?

Are you ready to proceed to the main questions related to FCC and older adults?

#### The Main Phase

KQ1: How would you define family-centered care with older-adults at home?

# **FCC Definition After HHPT Response**

I would like to take a moment to define family-centered care as it relates to physical therapy services. Family-centered care, unlike patient-centered care, involves

collaborating with families and caregivers. This collaboration occurs during the encounter with the older adults and includes family and caregivers training, family and caregiver PT interventions through direct access, family or caregiver's participation in interventions, and engaging in shared decision making with physical therapy services. Shared decision-making means that care decisions are shared between the patient and their family and the role of the PT is to provide informed choices.

**Probe1**: Do you have any questions about family-centered care with older adults?

**KQ2**: Can you please describe what situations and diagnoses would need family-centered care with older adults and their families at home? Family can mean caregivers, friends, and neighbors too.

**KQ3**: Can you think of who would want, or who would prefer family-centered approaches to care with older adult patients at home?

**KQ4**: Can you please describe a time when you have engaged in family-centered care with older adults and their families at home?

**KQ5**: Where in your plan-of-care or documentation can you address family-centered care approaches and interventions?

**KQ6**: Have you ever, or would you ever, treat a care-dependent older adult patient and treat a family member in pain simultaneously? If so, describe what you did or why you would. If not, why would you not treat someone simultaneously with their family?

**KQ7**: What factors, if any, would you describe as barriers, or challenges, to providing family-centered care to older adults at home?

**KQ8**: What factors would you describe as facilitators that allow you to provide family-centered care to older adults at home?

#### **Closing Phase**

That concludes my main questions, thank you. Do you have any questions or anything you would like to say now before we end?

I will be transcribing the audio recordings of these interviews to define some common themes related to delivering FCC with older adults at home. Please review the transcript for accuracy and send me any edits, and any additional information you would like to include. I will notify you in the next two weeks if any further action is needed beyond this. Do you have any questions?

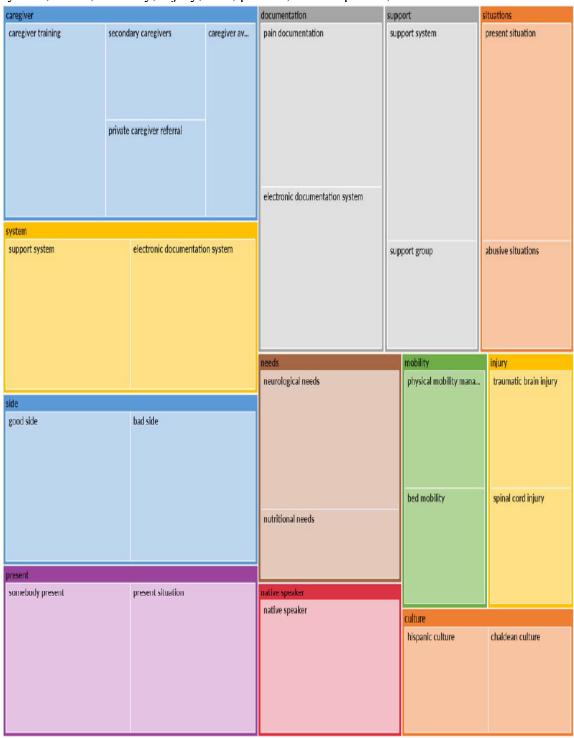
Thank you for helping, feel free to contact me if you need any assistance.

Appendix D: Recruitment Tracker

Snowball Sampling	ННРТ	Contact	Consent Returned	1	Interview Scheduled	Transcript Sent	Member Checked	Thank You Sent
Expert Reviewer	HHPT1		Yes	Yes	Yes	Yes	Yes	Yes
	ННРТ8		Yes	Yes	Yes	Yes	Yes	Yes
HHPT5	HHPT7		Yes	Yes	Yes	Yes	Yes	Yes
PT1	HHPT6 (self- referral)		Yes	Yes	Yes	Yes	Yes	Yes
ННРТ6	HHPT5		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT9		Yes	Yes	Yes	Yes	Yes	Yes
PT2	HHPT10		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT4		Yes	Yes	Yes	Yes	Yes	Yes
PT3	HHPT3		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT2		Yes	Yes	Yes	Yes	Yes	Yes
HHPT10	HHPT11		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT12		Yes	Yes	Yes	Yes	Yes	Yes
PT4	HHPT13		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT14		Yes	Yes	Yes	Yes	Yes	Yes
	HHPT Reserve		Yes	Yes	No	N/A	N/A	Yes
	HHPT Reserve		Yes	Yes	No	N/A	N/A	Yes
	HHPT Reserve		Yes	Yes	No	N/A	N/A	Yes
	HHPT No Response		Yes	No	No	N/A	N/A	N/A
	HHPT No Response		Yes	No	No	N/A	N/A	N/A
	HHPT No Response		No	No	No	N/A	N/A	N/A

# Appendix E: Nvivo Generated Themes

The twelve NVivo generated themes were caregiver, documentation, support, situations, system, needs, mobility, injury, side, present, native speaker, and culture.



Appendix F: NVivo Caregiver Theme with Subthemes

Each NVivo generated theme had subthemes related to it. Below is a different visualization of the theme 'caregiver' broken into four subthemes. The subthemes were private caregiver referral, secondary caregiver, caregiver training, and availability.

