IDENTIFYING SOLUTIONS TO ADDRESS ISSUES OF SAFETY IN HOME CARE ENVIRONMENTS FOR CHILDREN AND YOUTH

A Dissertation

by

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ABSTRACT

Many children and youth with special health care needs (CYSHCN) rely on home care and home health to have integrated and healthy lives in the community. For home care to be effective, it must also be safe. The purpose of this qualitative research study with a multiple case study approach was to explore what caregivers of CYSHCN perceive to be the safety issues in the home care environment and how they solve these issues.

I utilized convenience sampling to recruit fourteen formal, informal, and dual-role caregivers into the study. Caregivers participated in semi-structured interviews that discussed their safety concerns, how they addressed them, and what challenges remain. Multiple strategies (including member checking, peer debriefing, and creating an audit trail, among others) were incorporated throughout the study processes to maximize the credibility, dependability, confirmability, and transferability of the study. I used constant comparative analysis to generate findings.

The findings indicate that caregivers have many physical, mental/emotional, interpersonal, and spatial safety concerns in the home care environment. The most frequently cited safety concerns were injuries to the child/youth and the interactions between formal caregiver, informal caregiver, and the child/youth. To address these concerns, caregivers use training, preemptive activities (like cleaning and exercise), and several tools (devices, medical equipment, emergency bags, home modifications).

Caregivers recognized that becoming familiar with the environment and other caregivers was paramount to feeling safe and described various processes to do so. The use of solutions varies by type of caregiver, with formal caregivers more frequently using organizational supports. In contrast, informal caregivers turn to the internet or other parents to figure out what solutions work for them. Still, challenges remain in addressing safety, including training and devices that do not work for the caregivers or the home, costs of implementing solutions, and navigating formal services.

This study provides recommendations on defining and addressing safety based on the issues described by those with lived experience. Future safety interventions need to be comprehensive, realistic, and tailored to the child/youth to be effective and sustainable.

DEDICATION

To my biggest motivators - Jayson, Ellie, and Charlie.

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Professor Margaret Foster designed and conducted the database search for the scoping review utilized in Chapter 2. The student conducted all coding, analysis, and synthesis of the scoping review articles. All other work conducted for the dissertation was completed by the student independently.

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NOMENCLATURE

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADLs	Activities of daily living
BLS	Bureau of Labor Statistics
COVID-19	Coronavirus
CMS	Centers for Medicaid and Medicare Services
CR	Care recipient
CSHCN	Child with special health care needs
CYSHCN	Child/youth with special health care needs
ER	Emergency Room
FCG	Formal caregivers
HCBS	Home- and community-based services
IADLs	Instrumental activities of daily living
ICG	Informal caregivers
LTSS	Long-term supports and services
OASIS	Outcome and Assessment Information Set
PE	Physical environment
YSHCN	Youth with special health care needs

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CHAPTER I

INTRODUCTION TO STUDY

Millions of individuals in the United States receive home- and community-based services (HCBS) due to functional limitations or health conditions. When these services focus on assistance with daily tasks (such as bathing, dressing, and eating), they are referred to as *home care* or *personal care services* (Kaye & Harrington, 2015). When the tasks become more medically complex (therapies, nursing tasks), the term *home health care* is utilized. While the terms are often used interchangeably[1], together, they form a critical group of services that help individuals improve functioning and well-being, live with greater independence, and avoid hospitalization or admission to long-term care institutions (Hall Ellenbecker, Samia, Crushman, & Alster, 2008).

Background

Brief history of home care

The growth of home- and community-based services has been fostered, in part, by social justice movements and federal policies. Changing demographics, including the disappearance of the extended family, more women entering the workforce, lower birth rates, and longer life expectancy in general and particularly among people with disabilities, accelerated the growth of HCBS. Inspired by the civil rights movement in the 1960s, disability rights advocates demanded the agency previously stripped from

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[1] I use the term home care as broadly encompassing any assistance provided or the environment assistance is provided in. Home health care will refer to medical, nursing and other complex tasks when that distinction can be made.

people with disabilities by systems of care that placed care providers and institutions at the helm of services provision. As a result, in the 1970s and 1980s, the independent living movement arose (Mayerson, 2008). The independent living movement philosophy put forth that people with disabilities are experts on their own needs. As such, they should have more initiative in and control over their lives (both individually and as a collective group). Pressure from the independent living movement in the form of demonstrations at the Capitol was among the reasons that the American Disabilities Act (ADA) was signed in 1990 (Mayerson, 2008). The legislation is recognized as one of the most sweeping pieces of disability rights legislation, focusing on accessibility, accommodations, and utilizing a broad definition of disability.

Then in 1999, the Supreme Court ruled on *Olmstead v. LC.* This case centered around two women with disabilities initially admitted into a psychiatric hospital for care. While still institutionalized, the doctors decided the women could be treated effectively in the community instead of the hospital. However, the state healthcare system refused to reimburse community care, thus forcing the women to remain institutionalized against their wishes. The Supreme Court ruled in favor of the women stating they should be allowed to receive community care. The Court decided that if community services can be reasonably accommodated, the services are appropriate to care recipients' need, and the care recipients are not opposed to community care, then individuals should not remain in an institution (ADA.gov, 2014). This case opened the doors for individuals with disabilities to insist on HCBS.

The judgment also led to the requirement that state Medicaid programs cover nursing services in the home as part of their long-term supports and services (LTSS). States cover additional services in the home through Medicaid waivers. As many states recognized the service needs are similar for both elderly and those with a disability, LTSS programs are often combined for the aged and disabled, extending the effect of the Olmstead decision to other populations. Support for this decision was reenergized in 2009, as President Obama launched the Year of Community Living, prioritizing enforcement of the Supreme Court decision and its execution (Milne, 2012).

Changing landscape of home care

Home care has gained further support over the years because it is seemingly more cost-effective than other care settings. Expenditures per recipient for HCBS are equal to one-fifth of the spending per nursing home care recipient ($1069 and $5243, respectively). The differing care needs or functional abilities between the two populations did not fully explain the difference in expenditures. More work is needed to understand better the root of these differences (Kaye, Harrington, & LaPlante, 2010),

Advances in technology and medical device design further augment care provision in the home, allowing new populations to be cared for in the home. This increased use of home care generates variable care populations, each individual having unique and often multidimensional care and service needs (Henriksen, Joseph, & Zayas-Caban, 2009). Furthermore, caregivers provide services and care in the home that were historically limited to formal health care settings (Gershon, et al., 2009). Considering that 30% of those who receive assistance in the community are also considered eligible for institutional care (Kaye & Harrington, 2015), ensuring the home environment remains an effective and safe place to receive care is necessary to avoid transfer to institutional care.

Home care team

Three key members of the home care team - the care recipient, the formal caregiver, and the informal caregiver – become important in safety discussions. These groups can both be affected by and affect safety in the home care environment. Each member has specific needs based on their role and experience in the home.

Care recipients

One challenge in understanding the home care environment is describing the population within it. Numerical estimates and descriptions of care recipients do not always clearly delineate populations; the counts vary depending on many characteristics such as what type of care is needed, the type and intensity of care provided, the reasons for care, and who pays for care. The descriptions below offer some perspective.

Approximately eight million individuals in the United States receive assistance and support to perform activities of daily living (ADLs), such as eating and bathing, or instrumental activities of daily living (IADLs) such as preparing meals in their home. Over half of this population is under 65 years old, and most are female (60%) (Kaye, Harrington, & LaPlante, 2010). Ninety percent of care recipients receive assistance from family or friends; only a quarter receive further assistance from a paid caregiver (Kaye & Harrington, 2015) for these home care tasks.

Five million individuals receive assistance from a home health agency (Centers for Disease Control and Prevention, 2016). These individuals can qualify for home health and can receive home care if eligible. Medicare covers the majority (70%) of these care recipients (approximately 3.5 million) (Centers for Medicare and Medicaid Services, 2018).

Children/youth with special health care needs

One in five families in the United States has a child (under 18) with special health care needs. These approximately 13 million children "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (Health Resources & Services Administration Maternal & Child Health, 2019). Children and youth with special health care needs (CYSHCN) face functional limitations that hinder their abilities to participate in activities. These children can and often do receive home care services.

Previous research for CYSHCN in Texas's Medicaid program highlights some of the characteristics of this population. Approximately two-thirds have both a medical and psychiatric/developmental/behavioral health condition. Common diagnoses include intellectual disability (48%), epilepsy/chronic seizure disorder, asthma/respiratory disorder, cerebral palsy, and ADHD (24-28% each) (Phillips, et al., 2012).

Caregivers

The term "caregiver" designates those who provide care (in either a formal or informal capacity) to the individual who receives home care services.

Formal caregivers

Formal caregivers represent home care workers paid to provide care in the care recipient's home. Home care workers include a range of professionals - nurses, home health aides, personal care assistants - all providing varying levels of care in the home aligned with their skills and expertise. Home care is considered a rapidly growing field in the United States, with approximately three million home health and personal care aides (Kaye & Harrington, 2015).

Informal caregivers

An informal caregiver is an individual who provides unpaid care for a home care recipient (McMaughan, Ohsfeldt, Miller, & Phillips, 2012). Typically, this duty falls to a family member who may or may not live with the care recipient. Informal caregivers are a critical component of home care, as they provide the majority of care. Without them, many care recipients would be otherwise institutionalized

The American Association of Retired Persons (AARP) estimated 43.5 million adults in the United States acted as informal caregivers to another adult or a child with special health care needs at some point in 2015. According to their estimation, almost 80% of informal caregivers provide care to an adult aged 50 or older. Caregivers in the United States spent an average of 24.4 hours a week providing care. These caregivers often assisted with ADLs or IADLs (59% of caregivers) (AARP, 2015).

Problem statement

Safety in home care is a complex issue. Unlike other health care settings, homes are not explicitly constructed for providing health care. Physical barriers and inaccessible layouts may impede mobility, primarily when a care recipient utilizes a wheelchair or other device. Lack of safety equipment (such as grab bars in the bathroom) can lead to slips and falls. Furthermore, substandard housing conditions pose safety risks. Beyond the physical environment limitations, the human component of safety plays a unique role in home care (Henriksen, Joseph, & Zayas-Caban, 2009). Care recipients rely on caregivers for their needs. The care recipient may have one caregiver who works in isolation or multiple caregivers who must work together to provide this care. Because of the overlapping and relational nature of home care, a growing amount of research suggests approaching safety through multi-faceted interventions aimed at all members of the home care team (Henriksen, Joseph, & Zayas-Caban, 2009; Tong, Sims-Gould, & Martin-Matthews, 2016). Ultimate goals include accurate, standardized, and regular assessment of the safety risks in the home care environment, comprehensive measurement of the impact of safety on each of the home care team members, and development of solutions to improve safety that caregivers can execute together.

However, research gaps prohibit these goals from fully being realized. For one, there is a lack of standardization in terminology for safety risks. Some research focuses on only one safety issue, such as environmental hazards or medication errors, overlooking the myriad sources and overlap of safety risks in a home. Terms such as “adverse event” are typically used to represent broader safety issues but can also be ambiguous, sometimes describing the incident itself, and sometimes explaining its outcome (Masotti, McColl, & Green, 2010). Further, much of the safety research considers only the home health workers’ perspectives. Even though the safety of care recipients, caregivers, and family are intrinsically linked (Lang, et al., 2009), others' views on safety are often absent.

Finally, the majority of research focuses on adult care recipients, especially older adults. While this population is a significant user of home care services, the needs of CYSHCN cannot be overlooked. CYSHCN are more likely to need personal care for very complex tasks (such as toilet use, personal hygiene, dressing, and bathing) due to their conditions. Unlike their older age counterparts, transfer, positioning, and bed mobility are less frequently requested (Phillips, et al., 2012). These differences in care need likely result in distinct safety concerns, but it is unknown in what ways.

Purpose of study

This study aims to examine the safety issues in the home care environment for CYSHCN based on the perceptions of different caregivers. The study examines what caregivers perceive to be the safety issues in the home and how they address them. Due to this subject's exploratory nature, I utilized qualitative research and chose a multiple case study approach. Case studies thoroughly examine a topic and are particularly useful in certain circumstances, such as when it's difficult to separate the subject under study from its context (Baxter & Jack, 2008; Tomaszewski, Zaretsky, & Gonzalez, 2020). Though the subject and context are intertwined, they represent a bound system that can be analyzed (Tomaszewski, Zaretsky, & Gonzalez, 2020). These conditions apply to the subject under study. Given the complexity of safety issues in the home care environment, it can be challenging to separate the context (the home, the care need, the individuals involved) from the issue of safety. Furthermore, in a multiple case study, different perspectives of the subject under investigation are used (Creswell, 2013). Given the variability of child/youth needs, living situations, and types of home care workers, including multiple cases allows for a deeper understanding of the broader issue of safety instead of narrowly focusing on a single case.

Methodology

Research questions

In this study, I investigated how caregivers of CYSHCN perceive safety in a home care environment. The research questions were:

1. How do caregivers of CYSHCN perceive safety in the home?
2. How do caregivers of CYSHCN address safety issues in the home?
3. What are the impediments to safety in the home care environment?

To answer these questions, I conducted semi-structured interviews with both formal and informal caregivers. I recruited caregivers to participate via convenience sampling based on their experiences providing care to a child/youth who receives home care services.

Each interview was audio-recorded, transcribed, and then coded. I analyzed the coded data using a constant comparative method. In this method, I used repeated comparisons to generate findings. As new data are gathered, I compared results to previously collected data. Each interview is compared to itself, then with other interviews in the same group, then across groups. Codes are created, delineated, and connected based on these comparisons (Boeije, 2002).

Scope and boundaries

The study explored various caregivers' perspectives and safety experiences when providing care for children/youth. Through semi-structured interviews, I asked caregivers what they think about safety in the home, when they feel most concerned with safety, if they have had any training or assistance to address safety issues, and what else they need to address safety issues in the home. I also collected additional data to provide demographic information on the caregiver and the child/youth.

Cases were confined to Texas caregivers who provided care to a child/youth who received home care or home health services at some point within the past three years. I defined a child or youth as under 26 years old. Twenty-six years was selected as the upper threshold to account for a youth's typical age cutoff to be on a parent or guardian's health insurance. I considered those paid to provide care to be formal caregivers, while informal caregivers were not paid and were typically the child/youth's parent. I did not collect data directly from the child/youth.

Significance

In this study, I analyze what caregivers perceive to be the safety issues in the home care environment and how they solve these issues. Defining safety for CYSHCN is the first step in determining how to measure safety. Informal caregivers, an often underutilized source in this safety research, are given a voice to share what is important to them. Relying on only formal caregivers' perceptions and assessment of safety is a deficit. Initial work suggests that informal caregivers conceptualize safety differently than formal caregivers (Lang, et al., 2009; Tong, Sims-Gould, & Martin-Matthews, 2016). Understanding this distinction is critical to defining and addressing safety in home care.

Ideally, this study leads to the expansion of informal caregivers in other parts of the safety process. There is currently a lack of comprehensive or standardized assessment of safety in home care. Tools exist for specific populations such as care recipients with dementia (Czaja, et al., 2009), but a broader tool does not exist. Such an assessment should gather the viewpoints of all members of the home care team. Informal caregivers and care recipients can articulate safety risk areas that may elude formal caregivers, such as the effects of interpersonal relationships between formal caregivers, informal caregivers, and care recipients (Tong, Sims-Gould, & Martin-Matthews, 2016).

Additionally, comparisons between formal and informal caregiver perceptions articulate necessary differences in defining safety and safety interventions. Their presence in the house typically limits formal caregivers' perceptions of safety in the home. In contrast, informal caregivers and care recipients are often concerned with safety for an extended period, regardless of the formal caregiver's presence (Tong, Sims-Gould, & Martin-Matthews, 2016). Informal caregivers can prescribe solutions to safety concerns that align with these realities of care when the formal caregiver is absent. For example, technology and medical devices are a frequently cited strategy to improving safety in home care. However, these devices are often lacking in the home (Gershon, et al., 2007) or caregivers are not trained in their proper use (Henriksen, Joseph, & Zayas-Caban, 2009).

Conversely, formal caregivers can use their experience and expertise to notice safety risks normalized to those in the home. Finding distinct differences in how caregivers perceive and solve safety issues would make a case for broadening safety definition and approaches to capture these distinctions. Whereas identifying similarities between the caregivers uncovers opportunities for teamwork in the home care environment.

This study sets the foundation for additional research closing the gaps identified above. Based on the data collected in this study, I make recommendations on how to further safety in home care in research and action.

Summary

This introductory chapter provides the background and context of the study and how it fits into the larger body of research. The research questions, data collection, and analysis strategies are introduced but will be fully articulated in chapter 3.

The second chapter further explores the literature on safety in home care. Additionally, I describe the conceptual model that organizes this chapter. Safety concerns, the factors that influence safety, interventions used to address safety, and the gaps are scrutinized. This discussion highlights the need for the current study and the methodology chosen.

Chapter 3 gives an in-depth description of the study design. I first present the rationale for the chosen methods and interpretive framework. I also address how I maintained rigor throughout the study, followed by a description of the recruitment process and the analysis plan.

Chapter 4 provides the results. The chapter starts with a description of the participants and how the data were collected and organized. I discuss the data analysis procedures step-by-step with evidence of the process. Then I present the findings organized by each research question. These results are the basis of the interpretation and recommendations in the final chapter

The final chapter provides the conclusions and recommendations derived from the study findings. The chapter starts with a summary of the study; then, each research question is interpreted. Next, I provide recommendations based on these interpretations. The chapter concludes with study limitations and concluding thoughts.

CHAPTER II

LITERATURE REVIEW[2]

This chapter describes the literature guiding this research project. The review focused on identifying the measures and interventions utilized to improve safety in home care environments. I conducted a scoping review with assistance from a research librarian to formalize my literature search on interventions in home care. Due to the paucity of research on safety and CYSHCN in home care, this review includes all populations in a home care environment. I begin this chapter with a summary of the challenges to defining safety in the literature; then, I present a conceptual model guiding the literature review. This conceptual model provided the framework for discussing safety issues in the home care environment.

The subsequent sections are organized into physical, interpersonal, and spatial safety. Throughout each of these sections, I describe the relevant safety issues and summarize key findings from the scoping review of interventions to address those safety issues. Together, this synthesis provides insight into how these safety issues are measured, targeted, and addressed. The chapter ends with a discussion on the gaps in this research and why this study is warranted.

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[2] Part of the data reported in this chapter is reprinted with permission from Tong, C. E., Sims-Gould, J., & Martin-Matthews, A. (2016). Types and patterns of safety concerns in home care: client and family caregiver perspectives. *International Journal for Quality in Health Care*, 214-220.
Part of the data reported in this chapter is reprinted with permission from Masotti, P., McColl, M., & Green, M. (2010). Adverse events experience by homecare patients: a scoping review of the literature. *International Journal for Quality in Health Care*, 115-125. Copyright 2010 by permission of Oxford University Press.

Assessing the research evidence

I utilized a scoping review process to identify and assess the field of safety research systematically. A research librarian facilitated the review and the database searches. To be included in the review, an article must:

- Be a peer-reviewed publication published after 1999 about home health, home care, safety, or adverse events in the United States.
    - 1999 was selected as the cutoff because it was the year of the Olmstead Decision, which signified an expansion of home care in the United States.
- Include measurement of safety as at least one outcome of the study. Research that focuses on other outcomes associated with safety (e.g., care recipient behavior or cognition, caregiver stress) but does not include an explicit measure on safety was excluded.
    - Safety is defined as a feeling of being safe or avoiding physical harm in the home care environment.
    - The safety measurement has a comparison group. This comparison could be a before/after comparison or comparison between groups.
- Include an intervention that addressed safety in a home care environment. I defined intervention as any formal strategy to improve safety and could include education, training, addressing the physical environment, providing supportive devices, policy changes, etc.

Based on these criteria, 28 articles were coded, reviewed, and synthesized. Figure 7 in the appendix illustrates the inclusion process and lists all articles included in the review. I coded all articles according to multiple a priori criteria of safety, including the unit of study (physical environment, care recipient, or caregiver), the type of intervention, including the target of intervention (care recipient, formal caregiver, informal caregiver, physical environment, organization level or some combination of the above). These scoping review results are supplemented with other research to provide a comprehensive picture of the current state of home care safety research.

Difficulties defining safety in home care

The concept of safety in home care is vague and ill-defined, leading to many operationalizations in the literature. Some research focused on only one safety issue, such as hazards in the home or medication errors, overlooking many other safety risks in a home. Related terms, such as an adverse event, are often used to define and discuss safety yet can be equally ambiguous. In some cases, an adverse event was an injury or safety incident, and in other cases, the term described an outcome of such an incident (Masotti, McColl, & Green, 2010).

What constitutes safety in the home also varies by individual. Formal caregivers think of safety in terms of institutional safety standards; older care recipients and informal caregivers consider home care safety in more holistic terms (Lang, et al., 2009). In recent decades, there has been a notable shift in favor in recognizing the individuals involved in home care as a team (Lang, et al., 2014; Masotti, McColl, & Green, 2010), with both care recipients and caregivers participating in planning and implementing care. Care recipients and caregivers are encouraged to play a role in their care and, subsequently, their safety. The nature of the home care environment asserts that safety concerns among caregivers and care recipients are interrelated, and risks that affect one individual can affect the other members of the home care team (Lang, et al., 2009).

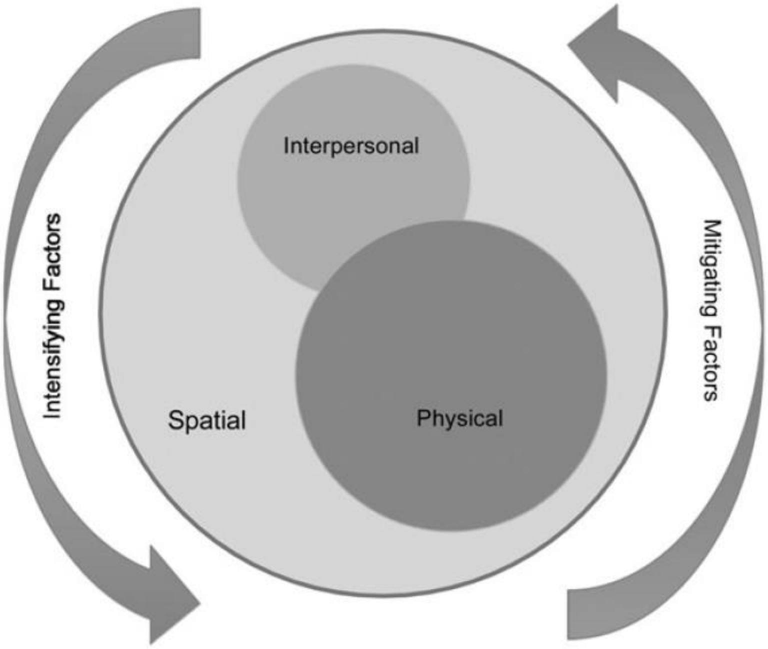
Throughout this study, I allow for such distinctions in defining safety. I define safety from the varying perspectives of both formal and informal caregivers of CYSHCN to uncover individual conceptualizations of safety. Their input will determine if caregivers of CYSHCN also think of safety differently, akin to the caregivers of older adults.

Conceptual model guiding review

A clear framework to study safety helps overcome the challenges of variable safety definitions. Previous research has generated multiple models of safety in home care (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Henriksen, Joseph, & Zayas-Caban, 2009; Lang & Edwards, 2006; Tong, Sims-Gould, & Martin-Matthews, 2016). For this review, I chose the conceptual model created by Tong, Sims-Gould, & Martin-Matthews (2016) because it was developed based on informal caregiver input similar to is study's aims. For simplicity, it will be known as the Tong model throughout.

In the Tong model, shown in Figure 1, three circles representing physical, interpersonal, and spatial safety illustrate safety in the home. Physical safety represents caregiver or care recipient concerns of a physical or medical nature. Interpersonal safety concerns the interactions between care recipients, caregivers, and others in the home. Lastly, spatial safety represents concerns related to the home itself, inside and outside of it. In the figure, the physical safety circle is larger than interpersonal safety to represent the participants' perspective that physical safety was a more significant concern. Spatial safety encircles the other forms of safety because of its dominant effect on physical and interpersonal safety. The authors stressed that safety types are interrelated and multidimensional, meaning specific concerns could cross domains and that safety in one area affects safety in another area. Two arrows surround the safety domains. These arrows represent intensifying factors (factors that exasperate safety concerns) and mitigating factors (elements that improve safety) (Tong, Sims-Gould, & Martin-Matthews, 2016).

Figure 1: Tong, Sims-Gould, & Martin-Matthews (2016) Conceptual Model as Framework for Review



The Tong model provides the framework for organizing the research found in the review. The following sections describe the body of literature categorized into spatial, physical, and interpersonal safety. Each section starts with a definition of safety and a description of what is known about the safety concerns. Many different safety concerns can fall into each category of safety; I focus on a few key ones to illustrate the research's key points. This is followed by a synthesis of the relevant intervention literature identified via the scoping review.

Spatial safety

Spatial safety includes concerns with the home's physical structure and the area around it (Tong, Sims-Gould, & Martin-Matthews, 2016). The home's built environment can be incompatible with home care, which in turn increases safety risks (Henriksen, Joseph, & Zayas-Caban, 2009). Physical barriers and inaccessible layouts may impede mobility, primarily when a care recipient utilizes a wheelchair or other device. Lack of safety equipment (such as grab bars in the bathroom) can lead to slips and falls. Furthermore, substandard housing conditions that pose safety risks to any inhabitants also increase the risks for home health care recipients and providers. Electrical, chemical, or fire hazards, poor lighting, uncontrollable temperatures, mold, peeling paint, and unsanitary conditions are just some of the potential hazards that both the home care recipient and caregivers may encounter (Henriksen, Joseph, & Zayas-Caban, 2009).

Unsanitary conditions (e.g., pests, excessive trash, mold, rotten food) are problematic, increasing the likelihood of spreading infections. A survey of over fifteen hundred home health workers in New York City found that one-third noted cockroaches in the homes. One quarter encountered mice/rats and 12% noted general unsanitary conditions (Gershon, et al., 2007). A similar survey found 43% of home health registered nurses (RNs) faced unsanitary conditions in the homes of individuals they cared for (Gershon, et al., 2008).

The scoping review identified three studies focused solely on the spatial safety aspect of home care (Samus, et al., 2014; Horvath, et al., 2013; Gershon, et al., 2012); and one additional study looked at spatial safety alongside other aspects of safety (Sylvester & Reisener, 2002). Of these studies, two relied on a formal caregiver's assessment of the environment (Gershon, et al., 2012; Sylvester & Reisener, 2002), while the other two studies relied on informal caregivers and adult care recipient input (Horvath, et al., 2013; Samus, et al., 2014). Table 1 provides additional information on each of the studies. Most studies used checklists or assessments of the physical environment to identify spatial safety issues. However, the number of items on these checklists varied from seven (Samus, et al., 2014) to sixty-four (Horvath, et al., 2013), suggesting varying levels of attention devoted to spatial safety.

Few items overlap on these assessments. Based on their inclusion in multiple assessments, relevant indicators of an unsafe physical environment are rugs as tripping hazards, inadequate lighting, excessive clutter, signs of roaches and vermin, spoiled food and drink, lack of carbon monoxide alarm/detector, and the presence of guns or other weapons.

Table 1: Interventions that Assessed Spatial Safety

	(Gershon, et al., 2012)	(Samus, et al., 2014)	(Sylvester & Reisener, 2002)	(Horvath, et al., 2013)
What	checklist	checklist	survey	checklist
Who completes assessment	FCG	CR; ICG	FCG	CR; ICG
Population under study	elderly	elderly with memory disorders	FCG	adults with Alzheimer’s disease
Total number of items	30	7	17	64*
The assessment has at least 1 item devoted to the following:				
Fall/trip hazards	x	x		
Clutter, trash, or dust	x			
Inadequate lighting	x		x	
Safety devices**	x			
Fire hazards	x	x		
Unsanitary food storage	x	x		
Rodents or bugs	x		x	
Weapons	x	x	x	
Pets	x		x	
Wander risks		x		
Crime			x	
Intervention Details				
Study Type	pre/post-test	randomized control trial	pre/post survey	randomized control trial
Sample Size	57	303	43	108 dyads
Intervention	1-hour education on hazards; assessment	education, assessment, care plans, referrals	tip sheet, safety agreement for care recipient, assessment	Educational booklet, safety devices (e.g., grab bar, smoke alarm)
Outcome(s) measured	FCG awareness of hazards	Change in safety score	FCG feels safe	Change in safety score
Results	Positive; statistical significance	Positive; statistical significance	Positive; not tested for statistical significance	Positive; statistical significance

* While the study noted an assessment, I was unable to retrieve it. I cannot determine the contents of the assessment

** Safety devices includes smoke alarms, fire extinguishers, carbon monoxide detectors, and grab bars in the bathroom

All four studies combined the use of the checklist with caregiver education on safety risks in the home. The intensity of education varied from a tip sheet to a booklet to more formal training. Two studies incorporated additional intervention activities, including care plans and referrals for therapies or other care (Samus, et al., 2014) and safety devices (Horvath, et al., 2013). Sylvester & Reisener (2002) incorporated an agreement that informed care recipients must maintain a safe environment or risk losing services from the agency. The findings suggest that these strategies do improve safety related to the physical environment.

One study found an unintended consequence of the intervention. A formal caregiver assessing the home for safety was associated with increased esteem between caregiver and care recipient. The formal caregivers reported that they felt more valued and essential to the care recipient when conducting the assessment (Gershon, et al., 2012). The assessment process identified spatial safety issues while also improving interpersonal relationships.

However, it’s difficult to ascertain how feasible and sustainable these interventions are. Identifying hazards only addresses one part of the issue; remediating them is also necessary. For assessment to be most effective, it would have to be updated regularly as new hazards arise in a home (Gershon, et al., 2012). Whether insurance companies or Medicaid/Medicare will cover such assessments and the subsequent remediation varies by payer, program, and state. A regular assessment may also tax a formal caregiver’s limited time in the home (Gershon, et al., 2012).

Moreover, adding appropriate safety devices is acceptable and effective when the item is provided and installed in the home for the care recipient (Horvath, et al., 2013). It can be prohibitive if the costs and installation fall to the care recipient. If a device makes a home look too “institutional” or causes inconvenience to other family members (e.g., difficult to open locks), it may be rejected, regardless of how well it aids safety (McKenzie, Bowen, Keys, & Bulat, 2013).

In contrast, implementing a care recipient safety contract such as the one suggested in Sylvester & Reisener (2002) is a low-cost solution to initiate. Yet, it can only be effective if supported by an appropriate formal caregiver and agency response. Some agencies may not value safety above client payment.

The scoping review results show that even though there is a lack of standardization of the home hazards, it is somewhat easy to identify them through checklists and surveys. Challenges still exist in routinizing the use of these checklists and finding more sustainable solutions to addressing them.

Physical safety

Physical safety concerns, according to the Tong model, are “[c]oncerns of a physical/medical nature, including musculoskeletal injuries, trips, falls and communicable diseases, related to both the experience of, and the potential risk for, physical harm” (Tong, Sims-Gould, & Martin-Matthews, 2016, p. 217). While this definition includes both caregiver and care recipient concerns simultaneously, most literature separates the groups. Therefore, the discussion of care recipient and caregiver physical safety is separated.

Physical safety for care recipients

Utilizing the term “adverse event,” Masotti, McColl, and Green (2010) produced one of the most comprehensive lists of study-level prevalence rates of home care recipient injuries and infections (Figure 2). Adverse drug events and line-related events are some of the most frequently studied adverse events in home care (Masotti, McColl, & Green, 2010). However, even with numerous studies, their review results cannot be construed as a population prevalence rate as the study designs varied and often relied on small homogenous samples. Instead, the list offers a starting point to understand what injuries and infections can occur in home care. A notable physical safety concern in home care not covered by the Masotti, McColl, and Green (2010) review is physical abuse, which is estimated to affect 5% of care recipients (Macdonald, et al., 2010).

Figure 2: Adverse Event Rates based on Masotti, McColl, and Green Review (2010)

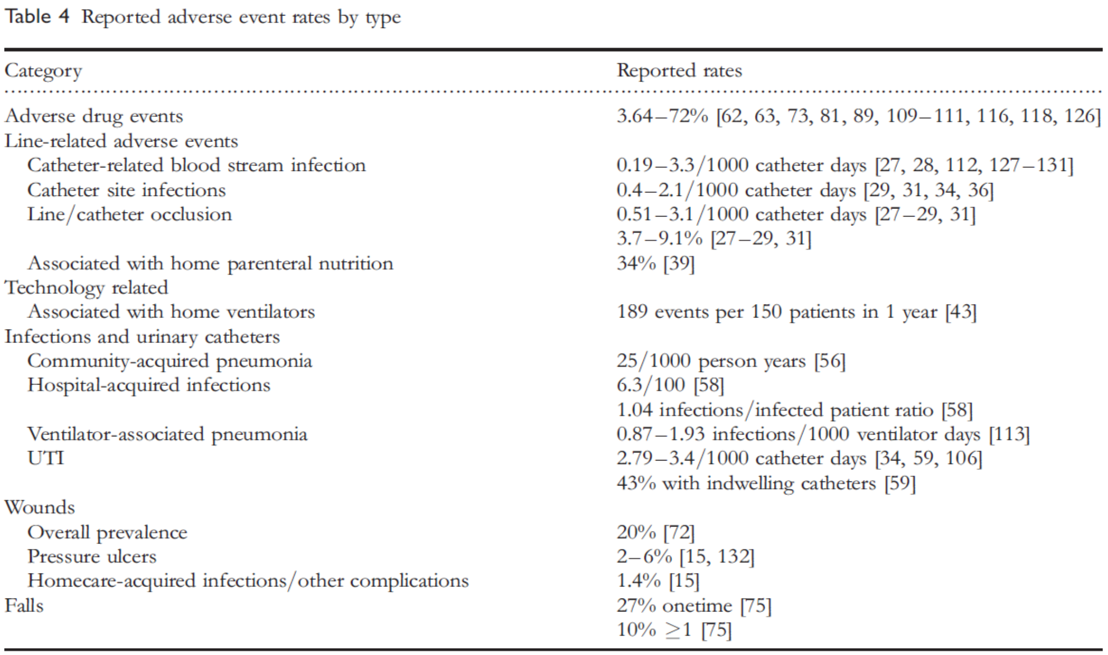


Table 4 Reported adverse event rates by type

Category	Reported rates
Adverse drug events	3.64–72% [62, 63, 73, 81, 89, 109–111, 116, 118, 126]
Line-related adverse events	
Catheter-related blood stream infection	0.19–3.3/1000 catheter days [27, 28, 112, 127–131]
Catheter site infections	0.4–2.1/1000 catheter days [29, 31, 34, 36]
Line/catheter occlusion	0.51–3.1/1000 catheter days [27–29, 31]
	3.7–9.1% [27–29, 31]
Associated with home parenteral nutrition	34% [39]
Technology related	
Associated with home ventilators	189 events per 150 patients in 1 year [43]
Infections and urinary catheters	
Community-acquired pneumonia	25/1000 person years [56]
Hospital-acquired infections	6.3/100 [58]
	1.04 infections/infected patient ratio [58]
Ventilator-associated pneumonia	0.87–1.93 infections/1000 ventilator days [113]
UTI	2.79–3.4/1000 catheter days [34, 59, 106]
	43% with indwelling catheters [59]
Wounds	
Overall prevalence	20% [72]
Pressure ulcers	2–6% [15, 132]
Homecare-acquired infections/other complications	1.4% [15]
Falls	27% onetime [75]
	10% ≥1 [75]

The scoping review of the literature found most safety studies with interventions focused on care recipient physical safety issues. Only two of the studies focused on care recipients under 18 (Bingler, et al., 2018; Walsh, et al., 2014). One other study did not distinguish adult care recipients from minor care recipients (Mamolen & Brenner, 2000). The rest (13 out of 16) of the studies focused solely on adults. Specific populations included individuals with cancer (Potter, Olsen, Marilee, Kubrik, & Huntley, 2012; Walsh, et al., 2014), dementia (Rowe, et al., 2009), and multiple sclerosis (Sosnoff, Finlayson, McAuley, Morrison, & Motl, 2014; Sosnoff, et al., 2015). In this review, I focus on two particular outcomes - falls and wounds - that frequently occur (Masotti, McColl, & Green, 2010) and appear prominently in the scoping review literature. These two injuries act as examples of other physical safety concerns in the home.

Falls

An extensive literature devoted to falls highlights how critical the issue is, especially for older adults. Multiple studies estimate that 30% of elderly adults fall each year (Bamgbade & Dearmon, 2016; Hall Ellenbecker, Samia, Crushman, & Alster, 2008; Masotti, McColl, & Green, 2010; Yount, 2016). Approximately 20% of these falls are severe enough to require medical attention (Hall Ellenbecker, Samia, Crushman, & Alster, 2008). Reducing the incidence and severity of falls has been a significant focus in home care research for the past few decades.

Table 2: Interventions Targeting Care Recipient Physical Safety - Fall Outcomes

	(Potter, Olsen, Marilee, Kubrik, & Huntley, 2012)	(Yount, 2016)	(Bamgbade & Dearmon, 2016)	(Schlismann, 2008)	(Sosnoff, Finlayson, McAuley, Morrison, & Motl, 2014)	(Moore Bucher, Szczerba, & Curtin, 2007)	(Duncan, et al., 2011)	(Sosnoff, et al., 2015)	(Gombar, Smith-Stoner, & Mitchell-Matters, 2011)
Study Type	Pre/post-test	Pre/post survey	Pre/post-study	Chart review	Randomized control trial pilot	Retrospective record review	Randomized control trial	Randomized control trial pilot	Pre/post-program
Outcome(s) measured	CR and ICG reported falls in a diary	CR report # falls before and after the program	CR's chart and incident logs: # falls or injuries	Emergent care for an injury caused by fall/ accident noted in OASIS record	CR report previous falls at baseline; check-ins during the program;	CR had a fall noted in OASIS record	CR reported falls in a diary and during research interviews	CR report previous falls at baseline; check-ins during the program; also kept fall diary	CR falls reported to the agency
Sample Size	38	183	30	n/s	27	n/s	408	34	n/s
Intervention	Educational video	Educational program	Risk assessment, education, exercise	Assessment, referrals, therapies	exercise	Risk assessment, education	exercise	Exercise and/or education	Check-ins
Source of information	CR; ICG	CR	Records	Records	CR	Records	CR	CR	CR; ICG
Results	Positive; No statistical significance	Positive; No statistical significance	Positive; not tested for significance	Positive; not tested for significance	Positive; not tested for significance	Positive; not tested for significance	Negative; No statistical significance	No effect; not tested for significance	Mixed; not tested for significance

*n/s = not stated in study

The scoping review identified nine studies that aimed to reduce falls. Table 2 summarizes these studies. There are numerous mechanisms to measuring falls, including tests and indices that can predict the risk or chances of a fall. I concentrated on the incidence of falls only instead of fall risk scores to align with other safety risks where only the outcome is measured.

All included studies focused on reducing the number of falls for adult care recipients, not children/youth. The majority relied on care recipients to report the number of falls within the study timeframe, either through a fall diary or questionnaire. Two of these studies asked an informal caregiver also to report the number of care recipient falls. The rest relied on agency records capturing falls.

The studies tested various interventions, including multiple education methods for care recipients, exercise, new tools to assess fall risk, additional physical or occupational therapy, and referrals for home care services or safety equipment. Despite this, there was no conclusive evidence the interventions worked in reducing the incidence of falls. Moderate positive effects were noted in some studies, but results were either not significantly different from the comparison group or were not tested for statistical significance. This result suggests that intervening on falls for adults in home care is difficult, and not all falls are preventable.

Wounds

A large proportion of home health care recipients have at least one wound that needs treatment. Three in five wounds were related to surgery, while vascular leg ulcers and pressure ulcers made up the rest. One-third of home health recipients are at risk for developing another pressure ulcer. A wound may not be a safety concern itself but can lead to infection if not properly treated. One study determined that only 27% of those with pressure ulcers received proper pressure-reducing treatment (Hall Ellenbecker, Samia, Crushman, & Alster, 2008). This lack of care can lead to further pressure ulcer development and associated infections.

There is more research on adult wounds than pediatric wounds. Adult standards and strategies are modified to generate care recommendations for children/youth. Yet children/youth have different wound needs. Pediatric wounds are likely related to medical devices as opposed to surgery. Children/youth also have different body compositions compared to adults that can affect care provision. Special considerations are needed to address their specific wound care needs (Freundlich, 2017).

The review identified four studies devoted to wound outcomes of care recipients. Table 3 provides a synthesis of the articles. Two of the articles were part of the same study, with one focusing on individual-level safety outcomes (Bliss, Westra, Savik, & Hou, 2013) and the other on agency-level outcomes (Westra, Bliss, Savik, Hou, & Borchert, 2013). Three–quarters of the studies utilized additional assessment by a wound care expert for adult care recipients as their intervention (Benton, et al., 2007; Bliss, Westra, Savik, & Hou, 2013; Westra, Bliss, Savik, Hou, & Borchert, 2013). The fourth study provided education and a new tool for formal caregivers to use with adult and child care recipients with burn wounds (Mamolen & Brenner, 2000). These studies had positive results, though not all of them used statistical testing, suggesting the interventions are promising.

Table 3: Interventions Targeting Care Recipient Physical Safety - Wound Outcomes

	(Benton, et al., 2007)	(Bliss, Westra, Savik, & Hou, 2013)	(Westra, Bliss, Savik, Hou, & Borchert, 2013)	(Mamolen & Brenner, 2000)
Study Type	Quality improvement	Retrospective record review	Retrospective record review	Prospective record review
Outcome(s) measured	Wound reduction in veterans	Change in pressure ulcer or UTI for adults in home care	Change in pressure ulcer or UTI for adults in home care	Wound infection in children or adults
Sample Size	15	785 agencies	785 agencies	66
Intervention	Wound care specialist review	Agency has a wound nurse	Agency has a wound nurse	Education, communication tool
Source of information	FCG assessment	Records	Records	Records
Results	Positive; not tested for significance	Positive; statistical significance	Positive; statistical significance	Positive; not tested for significance

Wound interventions incur challenges distinct from other injury concerns in home care. Wound assessment relies heavily on formal caregiver visual evaluation. Assessments must be reliable and consistent across different raters to effectively score wounds (Benton, et al., 2007). Interventions in this area often require specialized knowledge to ensure reliable assessment. As such, wound care interventions will likely always rely heavily on formal caregiver direct involvement, an important consideration when designing home care interventions.

Physical safety for caregivers

There is more research devoted to formal caregiver safety than informal caregiver safety. The formal caregiver experience provides insight into the risks that all caregivers face, but it’s difficult to know where the differences between caregivers lie. Home health workers face an increased risk of injury compared to workers in other health care sectors (Gershon, et al., 2007). In 2016, the Bureau of Labor Statistics (BLS) reported 11,340 cases of occupational injury or illness that led to days away from work in home health services. Table 4 presents the common reasons for injury (BLS, 2016). Other potential risks include physical abuse, pet injuries, and injuries related to car accidents on the way to and from a care recipient’s home (Butler, 2018; Schoenfisch, Lipscomb, & Phillips, 2017).

Table 4: Common Sources of Home Health Worker injury according to (BLS 2016)

	Occupational incidents involving days away from work (%)
Sprains, strains, and tears	48.1
Soreness, pain	22.7
Bruises, contusions	7.4
Fractures	4.9
Cuts, lacerations, and punctures	3.0
Tendonitis	0.4
Heat burns	0.2
Multiple causes	1.8
All other causes	11.6

This review focuses on two injuries, muscle injury and needlesticks, because of their frequent occurrence and appearance in the scoping review. An additional study aimed to improve caregiver injury and spatial safety hazards is also discussed here. Table 5 summarizes these interventions.

Table 5: Interventions Targeting Caregiver Physical Safety

	(Kraus, Schaffer, Rice, Maroosis, & Harper, 2002)	(Olson, et al., 2016)	(Amuwo, Lipscomb, Kathleen, & Sokas, 2013)
Study Type	Clustered randomized trial	Randomized control trial	Pre/post survey
Outcome(s) measured	FCG low back injury	Safety behavior, injury, removal of hazards	FCG Needlestick injury
Sample Size	12772	149	~800
Intervention	Provided back belts	Monthly training for FCG on safety, wellness, and personal development	Education and communication tool
Source of information	Workers compensation claims	FCG survey	FCG survey
Results	Positive, statistical significance (compared to control)	Mixed	Positive, no statistical significance

Muscle injury

Caregivers commonly injure themselves due to overexertion (from moving care recipients, moving heavy objects, or housework). The consequences of such injuries can be substantial. Formal caregivers in home care are more likely to miss work because of these types of injuries compared to providers in other health care sectors. Frequent heaving lifting, lifting in awkward positions, and lifting without assistance are significantly associated with a formal caregiver having a permanent work disability

(NIOSH, 2010). These circumstances are more likely to occur in a home care setting where caregivers work in isolation and equipment (such as lifts or transfers) is often missing in the home or difficult to operate (Henriksen, Joseph, & Zayas-Caban, 2009).

It is suspected that informal caregivers face many of the same safety issues as formal caregivers. However, fewer studies have assessed informal caregiver safety, so less is known about such injuries' prevalence and severity. Informal caregivers most frequently assist with transfers in and out of bed (AARP, 2015), putting them at risk for muscle injury. One study confirmed that muscle strain or injury due to improperly lifting the care recipient was a common injury for informal caregivers, even when the caregiver receives frequent assistance from formal caregivers (Brown & Mulley, 1997). Additional study needs to be done to understand the extent of this type of injury and others for informal caregivers.

The scoping review identified two interventions aimed at ameliorating muscle injury. In the first, formal caregivers were given back belts and compared to a control to see if using the belt reduced the rate of a back injury during multiple years of follow-up. The findings were mixed, while the use of a back belt reduced the rate of injury compared to the control, there were no significant differences between the use of a belt and merely reminding formal caregivers of safe lifting and transferring techniques (Kraus, Schaffer, Rice, Maroosis, & Harper, 2002). It's important to note that while the article was within the scoping review's time constraints, the research was conducted over twenty years ago. The utility of back belts has since been questioned, with the National Institute of Occupational Safety and Health (NIOSH) claiming there is no conclusive evidence that back belts are effective. Some speculate back belts may increase injury as the user becomes complacent and lifts more than they usually would (Neslon, Fragala, & Menzel, 2003). The applicability of this study in current home care situations is limited.

The second study was a randomized control trial evaluating the effects of a peer-led 12-month intervention for formal caregivers that included monthly education on safety and health, personal development, and social support[3]. The researchers measured safety through a variety of mechanisms, including safety behaviors and incidence of injury. Even though the educational program was well-received, they found mixed results in the outcome analysis, with some positive change at 6-month follow-up that was not present at the 12-month following or vice-versa. The authors speculated they might not have fully considered the limits of affecting behavior change when designing the intervention. The authors speculate that the formal caregivers' ability to change was taxed, leading to diminished returns (Olson, et al., 2016). This is a valuable lesson for other interventions on home care safety.

Needlestick injuries

Needlestick injuries are an additional hazard, often due to disposal issues. In one study, 14% of home health nurses suffered a percutaneous injury within the past three years (Gershon, et al., 2009). Many needlestick injuries go unreported, indicating the

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[3] The scoping review also identified the pilot study for this randomized control trial. The pilot study was excluded from discussion here to not give the one intervention undue influence on the overall research assessment.

frequency of such incidents might be higher. Some formal caregivers did not report incidents out of fear of punishment and as an attempt to avoid arduous reporting procedures (NIOSH, 2010).

The only study identified in the scoping review related to needlesticks was an educational intervention for formal caregivers. The researchers saw a reduction in injuries but faced methodological difficulties (such as difficulty matching pre- and post-intervention surveys) (Amuwo, Lipscomb, Kathleen, & Sokas, 2013). While formal caregivers are more likely to be using the needles, a growing number of informal caregivers (57%) are performing medical and nursing tasks (such as injections) in the home. Yet, they are often untrained to do so (AARP, 2015). This places them at increased risk for needlestick injury but lack training on safety that formal caregivers receive.

Interpersonal safety

Interpersonal safety includes “concerns arising from interactions between clients and their family members and/or their home care workers, impacting the client psychologically, socially or emotionally” (Tong, Sims-Gould, & Martin-Matthews, 2016, p. 217). Unlike physical safety, where injuries, infections, and incidents are more tangible signs of safety issues, interpersonal safety is often described as “feeling” safe in the presence of the other individuals in the household. Caregivers and care recipients use terms like “trust,” “fear,” “security,” and “threatening” when describing interpersonal safety (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Tong, Sims-Gould, & Martin-Matthews, 2016). Few studies have objectively measured feelings of interpersonal safety in the home. However, one survey estimated that 31% of formal caregivers felt threatened by care recipients and 38% felt threatened by a care recipient's family members (Gershon, et al., 2007).

More studies have measured tangible manifestations of interpersonal safety issues such as verbal abuse, physical abuse threats, sexual harassment, and psychological abuse[4]. However, similar to the disparity seen in other safety risks, home care research focuses predominantly on formal caregivers as the victims and situating concerns as an occupational safety matter, overlooking the other individuals in the home care team. Rates of verbal abuse directed at formal caregivers range from 28-59%, according to multiple surveys (Canton, et al., 2009; Gershon, et al., 2007; Sylvester & Reisener, 2002). Approximately 8-16% of formal caregivers faced threats of physical harm (Canton, et al., 2009; Gershon, et al., 2007). Furthermore, 41% of home health workers have faced sexual harassment, according to Nakaishi, et al. (2013). These previous estimates are based on surveys of formal caregivers in similar geographic areas, so results may not be generalizable to other populations. Nevertheless, the rates demonstrate the potential interpersonal risks formal caregivers face when entering a home.

Little research measures these threats directed at care recipients and informal caregivers. Estimates place verbal and emotional abuse directed at care recipients to be 5-12% (Kohn & Verhoek, 2011; Page, Conner, Prokhorov, Fang, & Post, 2009). One

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[4] Physical abuse, sexual abuse, and other violence would be included as concerns related to physical safety, according to this typology.

literature review estimated that psychological abuse occurs in 25% of caregiver-care recipient relationships (Macdonald, et al., 2010).

I was only able to identify one study that calculated rates of verbal abuse directed at informal caregivers. The study found that 46% of informal caregivers had been “yelled at or insulted,” and 13% were threatened with physical harm. These threats were most often from the care recipient; threats from other care providers were rare (Erosa, Elliott, Berry, & Grant, 2010). These rates were similar to formal caregiver estimates.

Through the scoping review, I found only one study that measured and intervened on interpersonal safety. This measure was part of a larger assessment of safety that included physical and spatial safety measures as well (Sylvester & Reisener, 2002). The authors surveyed 43 home care workers on how safe they feel when making visits before and after the agency’s safety initiative. The safety initiative included a tip sheet and training on being safe in the home. The initiative also updated the care recipient contract to notify clients that a safe environment was requisite to receive services and that the recipient risks losing services if they do not adhere to the standard outlined in the contract. The agency saw an increase in the number of formal caregivers who agreed they felt safe when making visits (68% before the initiative to 88% after the initiative) (Sylvester & Reisener, 2002). While the initiative shows promise in helping formal caregivers feel safer compared to be before, the study did not measure the effect of other safety outcomes. For example, if a home care provider identified safety risks in the care recipient’s home, were there attempts to mollify the risks, or were care recipients merely released from the agency? The intervention could be improving formal caregivers' feelings of safety while not improving the care recipient's safety.

The duality of intensifying and mitigating factors

In the home care environment, safety issues, factors, and solutions are not uniform across the population. What is safe for one individual may not be safe for another; a solution that works for one individual may not work for another. The individual's conditions, support, home, role, and situation all can influence the safety of any person in the home.

Numerous factors impact the safety concerns described above by either intensifying the concern or mitigating it. The same factor may act in either capacity depending on the situation or context (Tong, Sims-Gould, & Martin-Matthews, 2016). For example, from a formal caregiver perspective, other family members in the home can help as additional hands and support when needed or cause further issues by creating hazards to navigate around (Muramatsu, Sokas, Chakraborty, Zanoni, & Lipscomb, 2018). Informal caregivers and care recipients see the same duality in regards to formal caregivers. Formal caregivers can play a crucial role in providing support to care recipients and informal caregivers. However, if the formal caregiver is difficult to work with or ill-prepared, the care recipient or informal caregiver may see their presence as more of a challenge than an asset (Tong, Sims-Gould, & Martin-Matthews, 2016).

Adding equipment into the home is also met with mixed support. As previously described, devices are potential solutions to fix safety issues, but when the device is difficult or cumbersome to use, it may lead to a less safe environment (Henriksen, Joseph, & Zayas-Caban, 2009; McKenzie, Bowen, Keys, & Bulat, 2013; Tong, Sims-Gould, & Martin-Matthews, 2016). Other intensifying and mitigating factors include the household composition, the limitations of the care recipient, the experience and skills of the formal caregiver (Masotti, McColl, & Green, 2010), administrator support of formal caregivers, organizational policies and procedures, and enforcement of safety procedures (Fazzone, Funk Barloon, McConnell, & Chitty, 2000).

Impact of safety on care

It is essential to understand the safety issues in home care because safety issues can affect care for individuals with disabilities. A lack of safety can impact an individual's ability to receive care in two significant ways.

Safety concerns can lead to gaps in care

A formal caregiver feeling unsafe can directly affect whether an individual can receive care in the home. Numerous studies have shown that home health workers report shortening the visit ("leaving as soon as possible") or refusing a care assignment when they felt unsafe (Galinsky, et al., 2010; Gershon, et al., 2007; Kendra, Weiker, Simon, Grant, & Shullick, 1996; Sylvester & Reisener, 2002). It is unclear how this affects the quality of the care provided but the consensus is that greater security is associated with higher quality care (Fazzone, Funk Barloon, McConnell, & Chitty, 2000; Kendra, Weiker, Simon, Grant, & Shullick, 1996). If a care recipient cannot find another formal caregiver quickly, their ability to receive care in the home may be affected.

Safety concerns can lead to hospitalizations

When injuries and illnesses sustained in the home are too severe, the care recipient may be admitted to a hospital or other facility to receive treatment. Evidence suggests that a proportion of adverse events and associated outcomes are avoidable. One study reviewing records of home care recipients found that 27% of the recipients' adverse events were preventable; 43% were not preventable but could have potentially been reduced (Johnson, 2006). Another study showed approximately 20-25% of unplanned admissions were preventable (Hall Ellenbecker, Samia, Crushman, & Alster, 2008). While not all of these admissions may be due to safety directly, it's very likely the spatial, physical, and interpersonal concerns identified above played at least some role.

Summary assessment of the research evidence

There are myriad safety issues that can arise in the home care environment. Some are easier to define than others. For example, numerous checklists define hazards in the physical space, but few studies assess how safe individuals feel in the home unless it manifests into verbal or physical violence.

Identifying concerns is just the first step in ameliorating safety; a concern must also be remediated. As the Tong model argues, safety is complex and interconnected (Tong, Sims-Gould, & Martin-Matthews, 2016). Yet, the articles in the scoping review often had a narrow focus. Most interventions only attempted to remedy one type of safety issue or focused on only the formal caregiver or the care recipient in isolation.

It becomes clear that intervening on safety is challenging. Numerous safety solutions were identified through the scoping review and help understand what solutions work best for what concerns. Education and checklists can remediate spatial safety issues. Additional assessment by specialists also improves wound conditions. On the other hand, there are still challenges. Various interventions have tried to reduce the incidence of falls with little success. Many of the studies could not rigorously assess their outcomes given measurement or sample size issues. Any intervention design should consider the challenges identified above, such as the limitations of behavior change, the need for formal caregiver involvement, and the mixed reactions to the addition of devices in the home.

Gaps in the literature

Much of the literature studies safety from the elderly adult and formal caregiver perspective. Two significant populations – informal caregivers and children/youth care recipients – are understudied. Clarification is needed on how the inclusion of these populations shift home care safety definitions, how they approach safety issues in the home, and their role in safety in the future.

Lack of research on safety for children in the home care environment

The majority of research on safety in home care focused on adult care recipients. For example, in the aforementioned scoping review, only 10% of included articles focused on children/youth as the study population. One focused on children with cancer and reducing potential medication errors (Walsh, et al., 2014), another focused on infants with heart conditions (Bingler, et al., 2018), and the final did not distinguish between adults and children but assessed both for wound infection (Mamolen & Brenner, 2000). Even when research includes children/youth, the focus is often narrow on either a specific population or specific safety risk. No studies analyzed CYSHCN as a population or along multidimensional measures of safety.

Yet children/youth who receive home care have distinct conditions and needs compared to adults in home care. Previous research for CYSHCN in Texas's program highlights some of the characteristics of this group. Approximately two-thirds have both a qualifying medical and qualifying psychiatric/developmental/behavioral health condition to receive. Common diagnoses include intellectual disability (48%), epilepsy/chronic seizure disorder, asthma/respiratory disorder, cerebral palsy, and ADHD (24-28% each). These children can and typically do receive home care services. This population is more likely to need personal care for very complex tasks (such as toilet use, personal hygiene, dressing, and bathing) due to their conditions. Unlike their adult counterparts, transfer, positioning, and bed mobility are less frequently requested (Phillips, et al., 2012).

Together this emphasizes the need to assess CYSHCN safety concerns as a population distinct from adults. These differences likely manifest into divergent safety concerns as well. For example, falling is often a more significant concern for adults than children/youth. Additionally, children/youth are typically smaller in stature, so caregiver injuries due to transfers may be less of a concern. It's likely that other safety concerns not identified here become important to this population, but until there is further study analyzing CYSHCN's specific needs, these differences are unknown.

Sources of safety information in research

The majority of information on the home care environment comes from studies of formal caregivers. While formal caregivers can help identify safety risks that go unnoticed (i.e., normalized) to those who live in the home (Taylor & Donnelly, 2006), informal caregivers' perspectives are largely ignored. This exclusion is a deficit in the research, as informal caregivers' perspectives are necessary to paint a complete picture of the home care landscape. Assessments of the informal caregiver perspective recognize their value as a care provider (Czaja, et al., 2009) and acknowledge the autonomy and choice a caregiver faces in home care that does not exist in other care situations (Lang, et al., 2009).

Further, evaluating safety from only one perspective underscores the risks that can simultaneously affect the care recipient and care providers. Physical environment hazards, abuse, and infections are all safety issues affecting one or all individuals involved in home care. The safety of caregivers and care recipients is interconnected yet is often treated separately (Lang, et al., 2009). Measurement and assessment of safety risks from multiple perspectives, including the recipients themselves when possible, can fully illuminate the safety issues in a home care environment.

Summary

This chapter describes this study's foundation; it illustrates the complex relationship between variables that compose safety in a home care environment. Various influences shape safety - from the individuals in the home to the home itself to more downstream causes such as care systems. This chapter summarizes previous studies aimed at intervening and improving safety in the home. Interventions typically geared at the physical and spatial safety needs of formal caregivers and the older adults they served. In contrast, the amount of research and interventions aimed at understanding the needs of CYSHCN and their informal caregivers still has many gaps that warrant additional study. Exploring the specific needs of this population is the first step in reducing the gaps.

CHAPTER III

METHODOLOGY[5]

This chapter describes how I conducted a multiple case study approach using a constant comparison analysis method to examine home care safety issues. Details of the sample, data collection methods, and data analysis are explained as they relate to answering the following questions:

1. How do caregivers of CYSHCN perceive safety in the home?
2. How do caregivers of CYSHCN address safety issues in the home?
3. What are the impediments to safety in the home care environment?

Research design and approach

Qualitative research methods offer numerous gains compared to other methods. Qualitative methods are practical to provide a complex understanding of issues, explain mechanisms, and develop theories where quantitative research may not fit the problem under study (Creswell, 2013). They are particularly well-suited for issues that need further exploration "because of a need to study a group or population, identify variables that cannot be easily measured or hear silenced voices" (Creswell, 2013, p. 48). Due to the exploratory nature of this study's research questions, the lack of systematic measures and sufficient data on home care safety, and the lack of representation in research from those most involved in home care, a qualitative research study was necessary.

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[5] Part of the data reported in in this chapter is reprinted with permission from Boeije, H. (2002). A purposeful approach to the constant comparitive methods in the analysis of qualitative interviews. *Quality & Quantity*, 391-409.Copyright 2002 by permission of Springer Nature

Specifically, I selected a multiple case study approach for the following reasons. Case studies are practical when particular objectives are intended. One, the focus is to answer “how” and “why” questions. Two, a researcher cannot manipulate the behavior of those involved in the case. Three, the contextual conditions are relevant to the subject under study or the boundaries are not clear between the subject and context (Baxter & Jack, 2008). Yet, the subject and context are bound in a system (Tomaszewski, Zaretsky, & Gonzalez, 2020). These conditions are easily applied to the topic under study. The purpose was to identify how individuals perceive safety and approach safety issues in the home care environment. Additionally, because of the complexity of safety influences in home care (as illustrated in the literature review and conceptual model), it would have been challenging to separate the context (the home, the care needed, the individuals involved) from the issue of safety.

Multiple cases allow the researcher to show different perspectives of the subject under study (Creswell, 2013). Given the variability of child/youth needs, living situations, types of home care workers, and more in a home care environment, including multiple cases allows for a deeper exploration of the broader issues instead of narrowly focusing on a single case.

Interpretative framework

A case study approach generally relies on a constructivism (also known as interpretivism) view (Baxter & Jack, 2008). In this view, each individual constructs their reality, dependent on their perspectives and experiences. Research conducted through this approach relies heavily on the participant’s view of the situation - calling for open-ended questions, allowing for broad responses, and allowing the participant to construct their own meaning of their experience. A researcher then interprets the participant's meaning, recognizing that the researcher's own background shapes the interpretation of the participant's story (Creswell, 2013).

Setting and sample

Cases were confined to Texas caregivers who provided care to a child/youth who received home care or home health services. A child or youth was defined as under 26 years old, as children/youth who receive home health often remain on their parent or guardian's health insurance until that age. The caregiver had to have provided care for a child/youth sometime within the past three years. Formal caregivers were considered those who were paid to provide care, while informal caregivers were not paid and were typically the parent of the child/youth.

I utilized convenience sampling to recruit participants for the research. In convenience sampling, the researcher promotes the study to easily accessible individuals who may meet specific criteria (Robinson, 2014). Individuals see the study promotion then choose to participate. The researcher continues to accept these volunteers as they come until they achieve the desired sample size. While the participants are willing and eager to participate, the downside to convenience sampling is that generalizability can be hindered because participants select into the study, and established criteria limit the demographic representation (Robinson, 2014). I recruited participants until data saturation, that is until I obtained no new information from additional participants. Typically, 8-15 participants are appropriate (Green & Thorgood, 2014).

Recruitment

I identified potential participants through multiple avenues. With the convenient sampling strategy in mind, I began with personal and professional contacts where I knew the participant fit the eligibility criteria. After those connections were exhausted, I emailed nurses who participated in a previous study and had varying levels of pediatric home health experience. With these first two strategies, I directly asked the known contact to participate. A final recruitment strategy was to reach out to organizations and parent support groups via email and Facebook pages. When recruiting participants through these mechanisms, the process was different. Instead of asking each individual directly to participate, I sought permission to share information about the study with organizational and network members. Any interested participants would then reach out to me.

Direct recruitment strategies

Seven participants – two informal caregivers (ICGs) and five formal caregivers (FCGs) - came from direct recruitment methods. Six potential participants were known to me or committee members, and two interviews were completed (33.3% participation rate). One ICG and one FCG participated after being referred by professional colleagues (100% participation rate). I contacted 45 nurses who participated in a previous study, and from this list, I obtained 3 three interviews (6.7% participation rate).

Other recruitment strategies

To supplement the direct recruitment strategies, I sought participants through groups that might have eligible and interested members. I compiled a list of relevant organizations and support groups for FCGs and ICGs identified through the Navigate Life Texas website[6], Facebook, and Google searches. Instead of directly asking individuals to participate, this recruitment strategy necessitated a different approach. I first reached out to the organizational email, group contact, or group administrator to seek permission to post about the study. Once this contact granted permission, I posted information on the study, including how an interested participant could contact me to participate. Frequently I joined the Facebook group and posted the information myself, but occasionally a group administrator would post the information in a Facebook group, Yahoo group, or newsletter for me. Unlike the direct methods described above, an interested individual had to reach out to me first. Because of these additional steps, I had to contact many organizations and groups to gather a handful of interviews. This approach yielded seven additional interviews (five ICGs and two FCGs). Table 6 shows the success rate of these efforts.

Table 6 details the two moments of success that had to occur to have a completed interview. First, the organization or group administrator had to respond and agree to share the study's information. Few organizations or groups said no to the posting; the majority simply did not respond. Overall only 37% of contacts resulted in the administrator or organization agreeing to post. Facebook groups aimed at informal

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[6] Navigate Life Texas (www.navigatelifetexas.org) is a website dedicated to educate and support parents and caregivers of CYSHCN. The website includes a searchable list of organizations and support group by child/youth condition and/or geography.

caregivers were the most responsive, followed by Facebook groups aimed at formal caregivers.

Table 6: Interview Participation Rate based on Facebook and Website recruitment

	ICG		FCG		Total
	Organizations	Facebook Groups	Organizations	Facebook Groups	
Contacted via form/email	16	--	1	--	17
Contacted via Facebook	13	38	1	12	64
Admin agreed and I posted	2	16	0	3	21
Admin agreed and they posted for me	5	3	0	1	9
Post resulted in an interview	0	6	0	1	7
Percent contacts that resulted in post	24.1%	50.0%	0.0%	33.3%	37.0%
Percent of posts that resulted in participant	0.0%	31.6%	0.0%	25.0%	23.3%

After attempts to reach 16 organizations via website or email with only two organizations responding (12.5%), I shifted strategies. Whenever possible, instead of using the website or email, I found a Facebook page for the same organization and sent a message through Facebook’s direct messaging system. This strategy yielded a higher response rate as 5 out of 13 organizations responded and agreed to a posting (38.1% response rate).

The second point of success was that sharing the study information (typically through post or newsletter) had to yield a completed interview. One-quarter of posts produced a completed interview. Overall, I reached out to 81 organizations and groups to find the 7 additional participants.

An additional recruitment challenge should be noted here. I began recruiting for the study a few weeks before the Coronavirus (COVID-19) pandemic spread in Texas. Initially, I planned to conduct the study observations and interviews in-person. After discussion with the dissertation committee chair, we decided it would be best to pause recruitment. There was significant chaos around the state and requests for in-person research would not be well-received. Recruitment resumed two months later when it became clear that the interviews would be conducted only over the phone and that in-person activities would be discontinued.

After completing the interview, I asked participants if they could recommend others to participate (known as snowball sampling). However, this did not lead to any additional participants. Neither did contacting home health agencies to see if they would promote the study amongst their employees or those they serve.

Ethical protection of participants

I sought approval from the Texas A&M University Institutional Review Board (IRB) prior to data collection. I received initial approval in August 2019 and interviews with participants began that fall. Initially, interviews took place in-person in a location of convenience for the participant. However, due to the COVID-19 pandemic, I amended data collection procedures to allow for phone interviews, reducing the chance to transmit disease.

As qualitative research inherently connects researchers to participants, it’s crucial to build trust and a sense of reciprocity to ensure ethical participation during the entire research process (Creswell, 2013). I did so in multiple ways. First, I conveyed the study's purpose to participants in the initial recruitment material and at the start of each interview (see Appendix for recruitment materials (Figures 9 and 10) and interview facilitation guides). Before each interview, I reiterated that the participant could stop at any time, that their services or healthcare would not be affected by participating and that their responses would remain anonymous throughout the process. Each participant consented to participate through written or verbal consent. Finally, I used study ID numbers and de-identified abbreviations (e.g., CG to represent caregiver; CYSHCN to represent a child/youth) in note-taking and transcriptions to protect participants' identities.

Ensuring rigor in study

Houghton, Casey, Shaw, and Murphy (2013) suggest numerous strategies to ensure rigor in case study research based on four criteria previously established by Lincoln and Guba (1985). These criteria are:

- Credibility – the believability of the data, showcased in both how the research is conducted and “proving” credibility.
- Dependability – similar to reliability in quantitative research; data are consistent and stable
- Confirmability – degree of neutrality of research;

- Transferability – whether findings can be applied to other contexts while still maintaining meaning.

Table 7: Strategies to Address Rigor in Case Study Research (adapted from (Houghton, Casey, Shaw, & Murphy, 2013))

Approaches to Rigor	Strategies	Description	In this study
Credibility	Prolonged engagement	Ensuring appropriate time is spent in data collection to understand the subject under study. Typically evidenced by the achievement of data saturation.	Tracked interview time and achievement of data saturation
	Triangulation	Multiple methods to study one subject	Utilized interviews with different types of caregivers to explain safety in home care
	Peer debriefing	An external researcher checks the research process	The external researcher reviewed transcripts, evaluated coding schemes, and discussed discrepancies.
	Member checking	Allowing participants to ensure data have been accurately recorded	Asked participants to review transcriptions
Dependability and Confirmability	Audit trail	Transparent documentation of data collection and analysis process	Maintained detailed notes about recruitment, reflection after interviews, and how coding categories developed. The external researcher was asked to review this during peer debrief
	Reflexivity	Reflecting on how personal history biases can affect the research process and decisions made during analysis	Throughout the study, I journaled on the rationale for decisions, instincts, and personal challenges.
Transferability	Thick descriptions	Detailed descriptions of participants and settings of data collection to allow for comparisons to other settings and participants	Included detailed descriptions of the context of the data collection process to allow the reader to make judgments on transferability

Table 7 describes the strategies Houghton, et al. (2013) recommend to address these criteria and how I applied them specifically in this study. In this framework, dependability and confirmability are linked and achieved through similar processes (Houghton, Casey, Shaw, & Murphy, 2013).

Beyond the strategies highlighted in the table, I have incorporated various other “best practices” into the analysis, including:

- Using counts and context as needed to support analysis,
- Attempting to identify deviant cases and explain, and
- Comparing results to previous studies (Green & Thorgood, 2014).

Role of researcher

Qualitative research is distinct from quantitative research as the role of the researcher cannot be overlooked. Regardless of the qualitative approach, the researcher becomes the conduit for data, spending countless hours analyzing participants’ experiences related to the subject (Creswell, 2013). It can become difficult to separate the researcher from the study. To address this, qualitative researchers need to be aware of their influences and consider their effect on the study (Creswell, 2013). Throughout this study, I maintained a journal of thoughts, decisions, and other influences when collecting and interpreting the data to increase the findings’ dependability and confirmability (Houghton, Casey, Shaw, & Murphy, 2013). I then revisited these notes as the analysis proceeded and evaluated for their effect on the findings. Creswell (2013) then describes a two-part process of incorporating this reflexivity in the final reporting.

The researcher relays their experiences with the subject under study, followed by a description of how these experiences shape their interpretation.

Researcher’s reflection

I note my biases as they pertain to the study at hand. I have spent a decade researching various topics related to CYSHCN, including as part of the research team that developed assessments for the state Medicaid program to determine what services and care a child/youth would receive. I was present during discussions of what items to include in the assessment. Any items related to safety were ultimately quashed in favor of being outside of the program's purview. Yet, it was this experience that first brought to my attention the safety concerns that could arise in the home care environment, encouraged me to delve into the previously conducted research to find little information, and currently drives me to investigate better what the safety issues are.

While these experiences spurred my interest in the subject, they are also better prepared me to complete this study. Through the previous research, I worked with formal caregivers and saw firsthand how the health care system functioned in terms of the complexities of home care and home health. Additionally, I collected stories and experiences from informal caregivers during this time. I have experience listening to the stories that can sometimes be emotionally charged (as discussions of challenging health care situations can be). This previous experience allows me a broad lens to analyze the safety concerns at hand.

I expected to hear about the frustrations with attempting to receive services or working with particular home health agencies and providers as these types of challenges had been brought to my attention before. I also expected to find a lack of data related to safety, a greater focus on adult care, and few opportunities for informal caregivers to participate given the literature review on the topic.

I attempted to minimize these perceived biases through member checking, peer debriefing, and triangulating findings through multiple caregivers.

Data collection methods

Interviews with caregivers

Interviews allow for a more in-depth discussion of the issues under study than other data collection methods. I used semi-structured interviewing to capture caregivers' voices because the structure provides flexibility for discussion while still ensuring the research topics are addressed (Rabionet, 2011). For these interviews, I asked both caregivers (formal and informal) broad questions on their perceptions, feelings, and actions towards safety in the home care environment, with room to explore the topic as it specifically related to them and their experiences.

I developed an interview protocol for both groups of caregivers (see Appendix). The interviews focused on seven critical questions supported by additional discussion prompts, as needed. While I allotted an hour for interviews, the actual length was dependent on the depth of caregiver responses. Specific details on interview time by caregiver type are provided in the results section. I provided multiple opportunities for caregivers to elaborate on their answers and perspectives. A short questionnaire supplemented the interviews. For informal caregivers, this captured information on the household and the child/youth. For formal caregivers, the survey focused on their background in home care and the services they provide. Both questionnaires can be found in the interview facilitation guides in the Appendix.

Other data collection strategies

I intended to conduct observations of informal caregivers' homes as part of the data collection process and provide additional data points. However, due to the COVID-19 pandemic, in-person research was temporarily banned by Texas A&M University. With support from my dissertation chair, I decided to permanently halt in-person data collection as CYSHCN is a particularly vulnerable population. The opportunity to spread infection between me, the caregiver, and CYSHCN was deemed too great of a risk. I only conducted one observation prior to this ban.

At the end of the interview, I asked participants if they used any other references, materials, or documents when addressing safety concerns. This questioning intended to identify additional materials for document analysis. Document analysis can serve many purposes, such as validating information already received or gathering additional information on an issue (Bowen, 2009). Analyzing the pieces was to proceed through the same level of coding as the semi-structured interviews. However, the majority of the participants were unable to cite a specific reference. In one case, I obtained examples of two assessments as they pertain to safety used by a home health agency. With the few pieces of additional data, the interviews ultimately became the primary data source.

Data analysis

Interviews were audio-recorded. I personally transcribed all audio files, increasing my familiarity with the data and forming the initial step in analyzing the responses (Green & Thorgood, 2014).

The transcripts were reviewed and coded several times before organized into categories. Coded excerpts, notes, and transcripts were re-read to code up and generate overarching categories and a taxonomy (as is common in health policy and management research) (Bradley, Curry, & Davers, 2007). Data were further distilled based on emerging similarities and differences found in the links and relationships between categories (Green & Thorgood, 2014).

Because an integral portion of this work compares the various caregivers' responses, I applied the constant comparative method to the multiple case study. The constant comparison method relies on repeated comparisons to generate findings. Each new piece of data is compared to previously collected data to find commonalities, connections, and differences (Boeije, 2002). The interpretation of the findings answers the study’s research questions. Boeije (2002) suggests five levels of comparison with distinct approaches and results (Figure 3). Whenever possible, I emulated these steps. First, I compared each completed interview to itself. I coded the next, noted contradictions, and memoed overall impressions. Then, I compared interviews among participants in the same group (formal and informal caregivers). In this step, I expanded on the codes, developed descriptions of more significant concepts, and began to form connections between codes. Finally, in step 3, I compared interviews across the caregiver groups to understand both similarities and differences.

Steps 4 (comparing interviews among couples) and 5 (comparing interviews with several couples) were conceptually possible if two caregivers to the same child/youth participated in the study, but this was not actualized. While I attempted to recruit such couples, none participated.

Figure 3: Constant Comparative Framework from Boeije (2002)

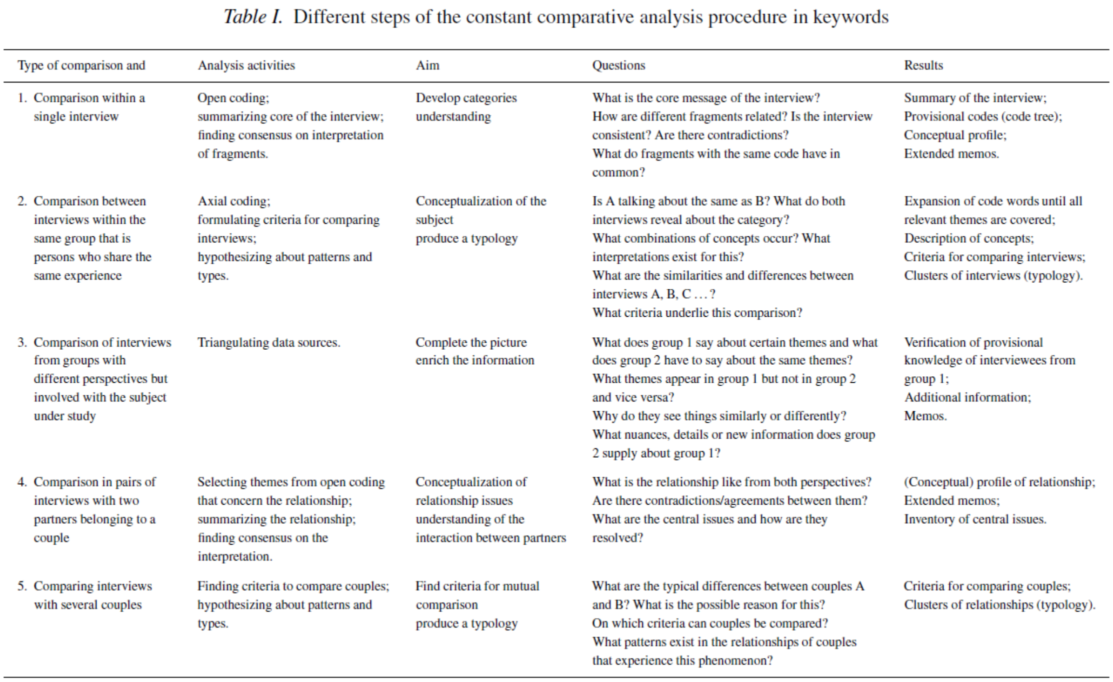


Table I. Different steps of the constant comparative analysis procedure in keywords

Type of comparison and	Analysis activities	Aim	Questions	Results
1. Comparison within a single interview	Open coding; summarizing core of the interview; finding consensus on interpretation of fragments.	Develop categories understanding	What is the core message of the interview? How are different fragments related? Is the interview consistent? Are there contradictions? What do fragments with the same code have in common?	Summary of the interview; Provisional codes (code tree); Conceptual profile; Extended memos.
2. Comparison between interviews within the same group that is persons who share the same experience	Axial coding; formulating criteria for comparing interviews; hypothesizing about patterns and types.	Conceptualization of the subject produce a typology	Is A talking about the same as B? What do both interviews reveal about the category? What combinations of concepts occur? What interpretations exist for this? What are the similarities and differences between interviews A, B, C . . . ? What criteria underlie this comparison?	Expansion of code words until all relevant themes are covered; Description of concepts; Criteria for comparing interviews; Clusters of interviews (typology).
3. Comparison of interviews from groups with different perspectives but involved with the subject under study	Triangulating data sources.	Complete the picture enrich the information	What does group 1 say about certain themes and what does group 2 have to say about the same themes? What themes appear in group 1 but not in group 2 and vice versa? Why do they see things similarly or differently? What nuances, details or new information does group 2 supply about group 1?	Verification of provisional knowledge of interviewees from group 1; Additional information; Memos.
4. Comparison in pairs of interviews with two partners belonging to a couple	Selecting themes from open coding that concern the relationship; summarizing the relationship; finding consensus on the interpretation.	Conceptualization of relationship issues understanding of the interaction between partners	What is the relationship like from both perspectives? Are there contradictions/agreements between them? What are the central issues and how are they resolved?	(Conceptual) profile of relationship; Extended memos; Inventory of central issues.
5. Comparing interviews with several couples	Finding criteria to compare couples; hypothesizing about patterns and types.	Find criteria for mutual comparison produce a typology	What are the typical differences between couples A and B? What is the possible reason for this? On which criteria can couples be compared? What patterns exist in the relationships of couples that experience this phenomenon?	Criteria for comparing couples; Clusters of relationships (typology).

Summary

This chapter describes the rationale for the chosen study approach and explains decisions made during the study design process. It documents the data collection procedures, including the challenges I faced implementing the study. It also describes the mechanisms used to ensure the rigor of the study. The next chapter details the results derived from these methods.

CHAPTER IV

RESULTS

This chapter describes the findings from a multiple case study. I conducted semi-structured interviews with 14 caregivers. I conducted two interviews in-person, while the remaining were conducted over the phone or through video conferencing to ensure safety during the COVID-19 pandemic.

The study explores the ways caregivers perceive safety and address safety issues in a home care environment. The following research questions were investigated and analyzed through a constant comparative method.

1. How do caregivers of CYSHCN perceive safety in the home?
2. How do caregivers of CYSHCN address safety issues in the home?
3. What are the impediments to safety in the home care environment?

Initially, the analysis was focused on two groups – formal caregivers (FCG; home care workers, nurses, therapists, etc. who are paid to provide care to a CYSHCN in the home) and informal caregivers (ICG; parents or other caregivers who provide unpaid care) of a CYSHCN who receives home care services. During the discussion with two formal caregivers, I learned both participants also functioned as informal caregivers to siblings with special health care needs. I then established a third category, the dual-role caregiver, meaning a caregiver who has acted both as a formal provider of care and as an informal provider. This additional category allows for greater triangulation of the findings, yielding a more comprehensive view of the subject under study.

Chapter 4 has three sections. First is a description of the participants, including demographics for the group, followed by a synopsis of their backgrounds and roles in home care. This section also explains how the strategies to maintain rigor were executed through the data collection and analysis phases. The next section highlights the categories created during the analysis of each caregiver, each group of caregivers, and across groups of caregivers. Finally, the chapter ends with a synthesis of findings as they relate to the research questions.

Participants

Fourteen individuals agreed to participate in the interviews. Seven were parents of children who received home care services; five had experiences as home health nurses. I initially recruited two participants for the study based on their role as home care aides. However, after discussion, I discovered that they also assisted siblings that received home care services. These two participants provided a unique perspective that helps triangulate findings from the groups. Of the 14 participants overall (Table 8), a majority (92.8%) were female and between the ages of 35-44 (64.2%), not Hispanic (85.7%), and White (78.6%). All had at least some college education. Tables 9 through 11 include a brief description of each participant and the CYSHCN they care for grouped by caregiver type.

Formal caregivers

All formal caregivers had a background in nursing, either currently acting as a nurse or as a home health agency administrator, with 7-12 years of experience in home care, and typically only caring for 1-2 children/youth at any given time (Table 9). Even though nursing was their predominant focus when providing care, all participants responded that they assisted with ADLs and IADLs when needed.

Table 8: Demographics of Participants

	FCG* (n = 5)	ICG (n = 7)	Dual (n = 2)	Total
	%	%	%	N (%)
Gender				
Female	100%	85.7%	100%	13 (92.8%)
Male	--	14.3%	--	1 (7.1%)
Age				
18-24	--	--	50%	1 (7.1%)
25-34	--	--	50%	1 (7.1%)
35-44	80%	71.4%	--	9 (64.2%)
45-54	--	--	--	--
55-64	20%	28.6%	--	3 (21.4%)
Hispanic				
Yes	--	--	50%	1 (7.1%)
No	80%	100%	50%	12 (85.7%)
Missing	20%	--	--	1 (7.1%)
Race				
White	40%	100%	100%	11 (78.6%)
Black	60%	--	--	3 (21.4%)
Education Completed				
Some College	--	28.6%	--	2 (14.3%)
College Graduate	80.0%	42.90%	50%	8 (57.1%)
Post-Bachelor’s Degree	20.0%	28.6%	50%	4 (28.6%)

[*] Additional Age, Race, and Education categories (such as over 65 years old, Asian, etc.) were included in the background questionnaire but were not selected by any participants. They have been removed from the table for brevity. The facilitation guide in the appendix includes a copy of the questionnaire provided to each caregiver.

Table 9: Characteristics of Formal Caregivers

	FCG02	FCG03	FCG04	FCG05	FCG06
Role	Nurse	Nurse and administrator	Nurse	Nurse	Nurse
Years in Home Health	12	11	8	12	7
Number of clients under 26 years old	1	18	1	2	10
Assists with ADLs	Yes	Yes	Yes	Yes	Yes
Assists with IADLs	Yes	Yes	Yes	Yes	Yes
Provides Nursing Services	Yes	Yes	Yes	Yes	Yes
Provides Other Services	No	No	No	No	Yes

Table 10: Characteristics of Informal Caregivers

	ICG01	ICG02	ICG03	ICG04	ICG05	ICG06	ICG07
Role of Caregiver	Mother	Mother	Mother	Mother	Mother	Father	Mother
Age of CYSHCN	15	9	19	22	19	6	2
Gender of CYSHCN	male	male	female	female	male (twins)	male	male
Number of other adults in house	0	3	0	0	0	0	1
Number of other children in house	0	2	1	0	0	0	2
CYSHCN receives ADL assistance	No	Yes	No	No	Yes	No	Yes
CYSHCN receives IADL assistance	Yes	Yes	No	Yes	Yes	Yes	Yes
CYSHCN receives nursing services	No	Yes	Yes	Yes	No	No	Yes
CYSHCN receives therapies	Yes	Yes	No	No	No	Yes	Yes
CYSHCN receives other services	Yes	No	No	Yes	Yes	No	No
Hours/week paid assistance	15	100	81	13	35	1	5

Informal caregivers

Over 70% of the informal caregivers interviewed are the only adult (over the age of 26) in the house; 42% care for another child or other children besides the child/youth at the center of our interview. The children/youth's ages ranged from 2 years to 22 years and are predominantly male (71%). The demographic representation is similar to other studies that show male and older children compose a larger proportion of the CYSHCN population than their female or younger counterparts (Bethell, Read, Blumberg, & Newachek, 2008). On the other hand, the caregivers themselves are predominantly female (86%). The children/youth need varying levels of formal assistance – ranging from 1 to 100 hours per week across various services. Table 10 summarizes the demographics of these caregivers.

Table 11: Characteristics of Dual-Role Caregivers

	FCG01	FCG07
Formal Caregiver Role	Home care	Home care and administrator
Years in Home Care	2	7
Number of clients under 26 years old	2	1
Assists with ADLs	Yes	Yes
Assists with IADLs	Yes	Yes
Provides Nursing Services	No	Yes
Provides Other Services	No	No
Role as Informal Caregiver	Sister	Sister
Gender of sibling CYSHCN	Male	Female

Dual-role caregivers

Two caregivers have acted in both a formal and informal caregiver capacity for CYSHCN. See Table 11 for a summary of their demographics. Initially, these caregivers decided to participate because of their roles as paid home care providers. However, during the interview, both provided insight into caring for their siblings in an informal caregiving role and their experiences in that capacity. Given the difficulty of separating how their informal caregiving experiences might be influencing their formal caregiving experiences (and vice-versa), I decided to analyze their data as a separate group. Both participants provide ADL and IADL support in their role as home care providers and informal caregivers. FCG07 has been a formal caregiver for longer, even taking on administrative duties in a home care organization.

Data organization and coding

Even though caregivers represented various roles in the home care environment, each was asked similar questions based on the interview facilitation guide (see Appendix). The questions were written in a semi-structured interview format, a mix of closed- and open-ended questions that encourage follow-up with why or how questions. This format lets the participant and interviewer move between topics comfortably instead of maintaining a rigid script allowing the participant to guide the interview to the most important topics (Adams, 2015). The level of discussion varied by role. Formal caregiver interviews lasted approximately 20 minutes, with one extending to 60 minutes. Informal caregiver interviews varied from 20 to 90 minutes, averaging 47 minutes. For the two caregivers that have acted in dual roles, the interviews were 25 and 45 minutes long. Every participant was encouraged to provide examples and describe any context and background in detail while answering the questions, yet this typically occurred more often with informal caregivers. Informal caregivers frequently used details of the child/youth’s conditions or previous experiences with programs or services outside of home care to elaborate on earlier responses.

Before each interview began, I announced the plan to audio record the interview for transcription and note-taking purposes while also noting the intent to keep individuals anonymous. All caregivers agreed. A transcript of the interview was given to the participant to review as a form of member checking. Member checking is another step in maintaining rigor intended to show credibility. It allows the participant to review the data and correct inaccuracies that may lead to misinterpretation (Houghton, Casey, Shaw, & Murphy, 2013). Only one caregiver suggested a change – correcting the abbreviation of a program referenced. During the interview, the participant often used the name of the child or youth under study. However, I removed these names from the transcription to demonstrate to the participants how anonymity would be maintained.

Once I transcribed the interview, I uploaded it into qualitative data management software, Dedoose 8.4 (2020), where each interview was divided into pieces and coded based on the content. I utilized some codes derived from the research questions and the conceptual model as a starting point, but most codes developed organically.

Throughout the process, I documented reflexive thinking multiple times. By doing so, a researcher can consider their own biases and perceptions that may influence the study and allow for transparency in reporting. Transparent reporting of biases increases the dependability and confirmability of the findings. While a reader may not have the same interpretation as the researcher, a reader should be able to understand how the researcher came to that interpretation. Documenting reflexive processes is the first step (Houghton, Casey, Shaw, & Murphy, 2013). After each interview, I completed a debriefing questionnaire for the interview (see facilitation guide in the appendix for a copy of the debriefing questionnaire). I noted general impressions of the interview and the interviewee and reflected on what needed to be changed before the next interview. The debrief also acted as the first step in identifying data saturation, as I reviewed each interview to consider what stood out from the previous interview. When no new information can be identified, data saturation is achieved. Journaling within the Dedoose software was used to keep notes and reflected on during analysis. I documented the decision behind certain codes, the perceptions of what the participants were saying, and how codes may connect in future analysis stages. I found journaling to be most helpful to note confusing ideas and unclear findings that could be revisited as I collected and analyzed new data.

A final method to ensure rigor was peer debriefing. Peer debriefing assists with the credibility of the findings. Peer debriefing intends to ensure other researchers can follow the analysis process and logic (Houghton, Casey, Shaw, & Murphy, 2013). I periodically shared my analysis process with an external researcher knowledgeable in qualitative research methods. The external researcher reviewed transcripts, definitions and applications of codes, and the relationship of codes to each other. We discussed any discrepancies in thinking, resulting in further elaboration or reframing.

Data analysis

As prescribed by the Boeije framework (2002), I utilized a constant comparative method to analyze the qualitative data. First, I made comparisons within a single interview. At this stage, I used open coding to code the content of the interview. I noted any consistencies or contradictions in memo format. This step resulted in a code list and codebook. I built relationships between the codes, resulting in the development of subcategories and categories. Then, interviews were compared within the same group of caregivers. I also analyzed what categories and subcategories were used together by the same participants. Finally, I compared the responses across groups, focusing on triangulating the findings and scrutinizing similarities and differences (Boeije, 2002).

Analysis within each interview

The first step on the path to answering the research questions is to analyze each interview's content. Codes were assigned to pieces of each interview and then grouped based on similarities in ideas. These codes form the basis of the subcategories, categories, and themes and are explained in greater detail in future sections. A complete codebook is in the Appendix.

Analysis within each group

I then compared the responses across all interviews within a group to ascertain which categories and subcategories appear together. This process helps determine patterns and typologies that can demonstrate how data are connected (Boeije, 2002). I include some initial findings here described by the caregiver group to illustrate this process; a complete interpretation is in later sections.

The most frequently cited concerns for informal caregivers were concerns with the child/youth injury, wandering, and interpersonal relationships. Building relationships and utilizing devices (like cameras) were the most frequently described solutions to these safety concerns. I identified one specific pattern here. The caregivers who had concerns with the child/youth hurting themselves or wandering were the same caregivers who utilized devices as part of their safety solutions.

Formal caregivers' main safety concerns were responding to emergencies because of the child/youth's condition and interpersonal relationships. To address these issues, formal caregivers typically relied on building relationships and being aware of their surroundings.

For the caregivers that served as both formal and informal caregivers, the predominant safety concerns are the child/youth hurting the caregiver or themselves. Both caregivers mentioned relationships and devices as strategies to overcome these safety issues.

Analysis across groups

Comparing categories and subcategories across groups validates and deepens the understanding of the central subject (Boeije, 2002). Table 12 shows which caregiver group(s) provided a response that fit a particular subcategory or category. From here, I derived what concepts overlap each group and what is specific to a particular group.

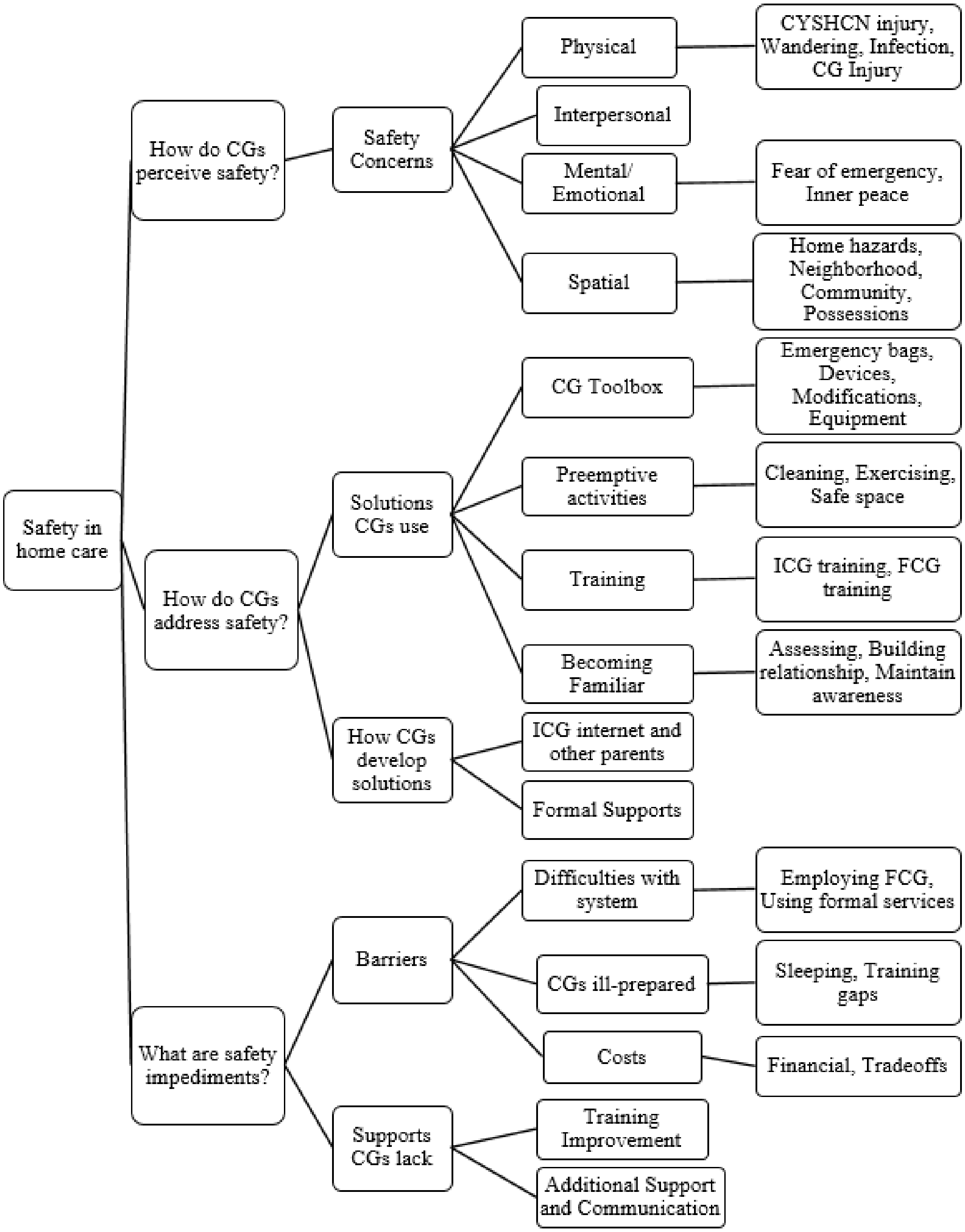
For example, the following observations were noted. All groups of caregivers responded that child/youth injury and interpersonal safety are salient safety issues. Other safety concerns, solutions, and impediments are unique to each group. Formal caregivers were the only group to mention the fear of responding to an emergency, whereas informal caregivers were the only group to mention cleaning and sanitizing. I elaborate on other comparisons and contrasts in the reporting of each research question.

Table 12: Category and Sub-category Use by Caregiver Group

Research Question	Theme	Category	Subcategory	ICG*	FCG	Dual
How do CGs perceive safety?	Safety Concerns	Physical	CYSHCN injury	x	x	x
			Wandering	x		x
			Infection	x	x	
			CG Injury	x	x	x
		Interpersonal	--	x	x	x
		Mental/emotional	Fear of emergency		x	
			Inner peace	x		x
		Spatial	Hazards in the home		x	x
			Neighborhood		x	
			Community	x		x
			Possessions	x		x
How do CGs address safety?	Solutions CGs use	CG Toolbox	Emergency bags	x		
			Devices	x		
			Modifications	x	x	
			Equipment	x	x	x
		Preemptive activities	Cleaning	x		
			Exercising	x		
			Safe space	x		x
		Training	ICG training	x		
			FCG training		x	x
		Becoming Familiar	Assessing	x	x	x
			Building relationship	x	x	x
			Awareness		x	x
	How CGs develop solutions	ICG internet and other parents	--	x		x
		Formal Supports	--		x	x
What safety impediments?	Barriers	Difficulties with system	Employing FCG	x	x	
			Formal services	x		
		CGs ill-prepared	Sleeping	x	x	
			Training gaps	x	x	
		Costs	Financial	x		x
			Tradeoffs	x		
	Supports CGs lack	Training Improvement	--	x	x	x
		Additional Support and Communication	--		x	x

* x denotes at least one participant in the caregiver group spoke on this topic.

Figure 4: Code Tree



Code trees are visualizations in qualitative research that present the relationships between data in a hierarchical manner (Hsieh & Shannon, 2005). The code tree in Figure 4 illustrates the research questions, themes, categories, and subcategories explained in upcoming sections. I combined the subcategories to save space in the figure, but I explain each individually in the findings sections. Additionally, the text of some items was shortened to fit in the figure.

Findings

This section presents the data based on the analysis steps above. First, each research question is divided into themes, categories, and subcategories. I present data directly from the caregiver interviews to explain each. The findings below emphasize not only what was said but also takes into account other observations such as how many caregivers said it and when. I end each with a summary that includes my synthesis of all the data related to the research question.

Research question 1

How do caregivers of CYSHCN who receive home care perceive safety in the home? During interviews, I asked caregivers what first comes to mind when thinking about safety in home care. As the interview proceeded, participants had multiple opportunities to clarify with more specific questions about when and how they were most concerned with safety. Even when the interview moved on to other questions, caregivers often interjected additional safety concerns as they thought of them. Their responses captured diverse definitions of safety that had just as many similarities as distinctions.

Theme: defining safety concerns

The foundation of how caregivers perceive safety in a home care environment lies in what they see as the safety issues affecting the child/youth they care for and themselves. This group of caregivers described over a dozen different concerns. I grouped these concerns into four categories based on similarities: physical safety, interpersonal safety, mental/emotional safety, and spatial safety.

Category: physical safety

Physical safety encompassed safety issues that affect the body. Caregivers almost immediately mentioned the physical safety of their child/youth first. Additional probing was needed to understand the risks to the caregiver too. The discussion of this category starts with a description of the potential injuries to child/youth, followed by concerns of the child/youth wandering and potential infections. It ends with the description of the injuries the caregivers themselves face.

<u>Injury to child/youth</u>

First and foremost, caregivers framed their safety concerns around avoiding injury to child/youth. Twelve out of the fourteen caregivers described some concern with a child/youth injury in the home during the interview; for six caregivers, concerns over injuries were the first thing that came to mind when thinking of safety. One informal caregiver (ICG01) summarized safety as “making sure the child has what they need and that they can do it in a manner that doesn’t harm themselves or others.”

Another caregiver noted avoiding injury as the immediate concern when thinking about the safety of her twin 19-year old sons with special health care needs (SHCN):

> *"My first thought on safety is how to keep them from injuring themselves when they are in their rooms. they each have their own rooms, and they jump around, they have behaviors, and my biggest worry is that one of them will hurt themselves while they are in their room." – ICG05*

One formal caregiver highlighted the extra considerations that arise to prevent injury to CYSHCN without hindering their development:

> *"Although [there is] a child [in our agency] who is very on-development verbal and loud, and rambunctious, and just a three-year-old boy - who is running around jumping off the back of the couch while attached to a trach and a vent. That's a safety concern…But you don't want to hinder their development, or their exploration, or their normalcy for the sake of having a vent attached. That causes a huge safety concern. Because now you are not just a nurse, but you are also a toddler monitor. And our parents don't always hang around when the nurse is there. So you don't have an extra set of hands. You have to be multi-talented." – FCG03*

Concerns were not limited to running and jumping. As ICG05 described, she is careful what she leaves accessible to her sons after an everyday object used incorrectly caused a trip to the emergency room (ER):

> *"I don't take a chance on - even though they don't go looking for it - everything I have. I have to look at it and say, well, this has to be put away because what if he, for whatever reason we never know, got into it. In the bathroom, one time, [YSHCN] took a Q-tip and shoved it in his ear causing him to bleed, and that was unexpected. And that happened, the aide was standing right there, and she turned her back right after they got him out of the shower. And he did it. and that was a trip to the ER" – ICG05*

I asked caregivers when they are most concerned – either time of day or during an activity – with the child/youth's safety. Five caregivers noted cooking as being a particularly worrying time. The caregivers repeatedly cited knives and the oven as potential sources for an injury that children/youth had to be monitored around.

Another caregiver noted that when the child/youth was tired, they were more likely to injure themselves:

> *"…if you are doing a transfer and they are tired, they might not be as strong. Or might not be as capable to help you as normal. So maybe [the child/youth] are used to bearing more weight, but the longer the day is, the less weight they can bear. Or also just like the long day, the being tired, or being overheated or whatever, that can trigger more behavior issues, and trigger a client to do more harm or self-harm or just those kinds of things." – FCG07*

In a similar vein, the child/youth becoming upset is an injury concern for FCG01:

> *"Sometimes, and this is not anybody's fault, when [CYSHCN] throws tantrums, she'll drop to the floor and shell flail her arms everywhere. And I always get concerned if she drops in like the middle of a hallway because then she is hitting the walls of the hallway. So then it's important for me to get over there quickly. And like restrain her or move her into a different area, so she doesn't hurt herself. "- FCG01*

Informal caregivers were likely to describe injuries rooted in the child/youth hurting themselves. In contrast, formal caregivers also discussed the issues that arise from eating or when caregivers may unintentionally cause injury to the child/youth.

Safety concerns while eating included swallowing and choking. Swallowing or choking issues themselves are not unusual. Yet, in these situations, the children have a diagnosis of pica or have dietary restraints due to their conditions that intensify the concern.

A rarer but still noted concern in terms of injury to the child/youth is when a caregiver causes the injury as described by FCG07 discussing her sister's caregiver:

> *"[My sister and her nurse] went out for a walk and it started raining…so she started running with my sister's wheelchair…the front wheel dropped due to the concrete was uneven between the sidewalk and someone's driveway, so she face-planted in her wheelchair. Like, face forward. So that's an obvious safety problem." – FCG07.*

Wandering

For four parents and one dual-role caregiver, some significant concerns arose when the child/youth wanders or runs away. FCG01 described her concerns when caring for one child/youth:

> *"Sometimes, whenever we go out, [CYSHCN] gets very antsy. She'll get right out the car and just go walking through the parking lot; I always have to make sure I get out of the car before her. So when she gets out of the car, I can immediately grab her hand and arm to make sure that she does not go running anywhere…But if I don't, then in public situations, she will tend to run sometimes and just kind of get away from me. If she feels upset or like…not threatened…but she gets a little bit anxious in loud or crowded spaces. She'll tend to throw a tantrum so she can leave. And I have to keep a close eye on her to make sure she doesn't go running off. I do get a little bit anxious in those times." – FCG01*

These concerns are not limited to younger children. Of the parents who describe wandering as a concern, their children/youth are ages 19, 16, 9, and 6 years old. Typically, caregivers of older children/youth would not be concerned with wandering; instead, wandering becomes a concern due to the health conditions or diagnoses of the CYSHCN inhibiting their development. For example, ICG01 illustrates how her 16-year-old son's condition affects his safety:

> *"If he's like overwhelmed or overburdened or asked for too many things, rather than do those tasks, he'll just take off. And he'll run out of the house…Other times, he will just be so intent on some thought that he will leave to go do whatever he has thought of. He won't get permission; he will just leave the house." – ICG01*

Avoid infection

Two caregivers – one formal and one informal – cited avoiding infection as a safety concern. For ICG07, this was her first and primary concern for her two-year-old immune-compromised son, who receives home health services. She illustrated the various thoughts that contextualize her concern and feelings about the unknown risk her family faces. Underlying her concern is the trust and relationship between her family and the home health providers.

> *"My first thing is hygiene and cleanliness…of the providers…making sure they are washing their hands before touching the kids. That they are taking their shoes off at the door like we request, that they cover their mouth if they sneeze or something…And then more broadly, communicating with us if they have a fever or if someone in their family is sick. Because we worry about them bringing diseases to [CSHCN]. He still is but at that time, extremely immune suppressed and compromised. And that time, he was getting ready for his surgeries, and he already had two surgeries postponed. It was a risk to even have people in the home, but we knew he needed the support too. So it was a gamble. I would say safety-wise, that is the first thing I think of, is contagious…They're going into all these other homes and bringing stuff from them to us potentially. So even though their homes might be clean and great, their patients might not be. It was kind of scary to think that they might be bringing with them, even if they were well."- ICG07*

For the formal caregiver (FCG02), the discussion of infection was more straightforward. She considered it her professional responsibility to avoid an infection spreading through her client's feeding tube.

Injury to caregiver

Eight of the fourteen caregivers also discussed caregiver injuries during the interview. Informal and dual-role caregivers discussed the child/youth hurting the caregiver, whereas formal caregivers and dual-role caregivers described back injuries and injuries from pets.

In some instances, when the child/youth hurts the caregiver, the caregiver describes it as an unintentional consequence of being near the child when upset or stressed. As ICG01 said when discussing her son, "when he's overwhelmed, or he's been asked to do tasks he doesn’t want to do, in the past, he would do head butting or scratching of himself or other people to get out of that task."

In other cases, the injury is directly related to the child/youth's behaviors, but the child/youth’s conditions likely influence the behavior. As ICG05 illustrates, “I’ve been bit and pinched and slapped and hit and punched- because of the behaviors. Physically they are 19-year-old young men who don’t understand that if I pinch mom, I am going to hurt her.”

The three caregivers that mentioned back injuries attributed the injury to transferring, repositioning, or lifting the child/youth. They would describe using proper protocols for these activities to avoid these injuries. The nurse who mentioned the potential injury from pets was concerned with meeting a dog at a new client’s house.

Category: interpersonal safety

In home care, formal caregivers and informal caregivers must interact and rely on each other to provide care to the child/youth in the home. The concerns related to this relationship were the second most frequently cited safety concern; 11 out of 14 caregivers noted the connection between safety and caregiver relationships.

One of the dual-role caregivers defined safety early on in the interview in terms of hiring other caregivers for her sibling:

> *"Safety as far as trusting who you have in your home. You don’t know anybody that comes in. If you are going through the [Consumer Directed Services]*[7]

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[7] Consumer Directed Services, or CDS, is an option available for many formal care programs in Texas for those who receive Medicaid or Medicare. The main distinction is that the individual with disabilities (or in this case their parent of the individual) is responsible for employing their care provider directly as opposed

> *option, then you get to choose and hire who comes to work. but if you are doing the agency option, you don't necessarily have a say in who the agency sends." – FCG07*

Other informal caregivers confirmed that they often have little input into who is assigned to their home, and that can cause apprehension. Informal caregivers' concerns revolve around two mains ideas. For one, there was concern over having someone in their physical space:

> *"You never know when someone is going to be in a desperate situation and decide 'ok well you know what, I have to do what I need to do, so I'm just going to stick you up with a gun and take everything you got' or who knows." – ICG05*

Additionally, informal caregivers face concerns about trusting another person to care for their child/youth. As ICG02 said, "there is a certain level of trust the nurses have to earn with us before they take [CSHCN] anywhere before they're alone with him...it's a weird world." She elaborated further:

> *"I have a ton of people that come in and out of my home, so I'm always worried about the body protection of him… just keeping him safe from predators keeping him safe from neglect, abuse, those types of things." – ICG02*

Even though formal caregivers are paid to provide care, they face similar apprehensions entering a family's home. As one nurse explained:

> *"I have had patients where family is fighting while I was there. Or having a party that got out of control. So I think about my safety and the patient's safety because you never know what to expect because anybody, any family member, or friend or anybody could come and they could have a problem, and you are like right there." – FCG04*

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to using an agency. The individual becomes responsible for seeking, hiring, and disciplining the provider. A 3rd-party agency is responsible for handling the payroll processes for the provider and the individual.

The nurse elaborated on how this is a situation distinct to home care; one you would not see in an institutional setting;

> *"I work overnights, so anybody can come over for anything. I luckily haven't had that problem. But yeah, you're concerned about safety because you just never know what to expect. They don't have it where you have to be paged or where you have to identify yourself like at the hospital. If the parent or somebody else in the house decides they can come in, they let that person in. You in the room in the back, and you don't really know what's going on." – FCG04*

Category: mental/emotional safety

The mental/emotional safety category covers additional feelings of safety not tied to the issues above. Multiple caregivers describe one specific fear – the anxiety of tending to emergencies. A second more general category of anxieties is covered when discussing the safety of inner peace.

Anxiety of tending to emergencies

Half of the caregivers described safety as avoiding emergency or urgent care situations. This concern was predominantly a formal caregiver concern; all five home health nurses, alongside two parents, noted these concerns.

For some nurses, those who tend to care for children/youth dependent on machines, the concern manifests itself in fear. The fear intensifies by the isolation of being the only healthcare provider in the home. FCG03, a long-time home health nurse who also acts as an agency administrator, explains:

> *"Probably the biggest thing that one of our nurses will think of as a risk to safety, our bedside nurses will tell you, that they might feel alone in the world when it comes to a trach- and vent-dependent patient and they're the code team. You know, they are trained, but nobody ever wants to deal with a situation where they are the code team, and 911 is going to take ten minutes to*

> *get to the home… And our nurses always have that fear in the back of their mind."- FCG03*

FCG04 echoes these concerns from her own experience:

> *"When I first started working with the patient before him, he was on oxygen, continuous feedings, he had coded a few times. I was kind of on eggshells because you don't know what to expect at work. You don't have the doctor or anything, I mean, you have the equipment there, but you are responsible for everything."-FCG04*

Other home health nurses describe this desire to avoid emergencies in terms of preparation, as exemplified by FCG06:

> *"If I am dealing with a child, who has seizures, that is dealing with a lot of safety around the home…like the layout of the home…you always have to look at where the patient slept, where are they living, what kind of protective features or protective things do they have for the child."-FCG06*

Safety of inner peace

For four caregivers, it was impossible to discuss safety without mentioning mental health or feeling secure. ICG02 called this "safety of inner peace." Inner peace could be the mental health of the child/youth or the caregivers' security. The feeling is rooted in many various reasons. As such, the concepts overlap many of the other safety issues described, such as trust of people coming into the home, or concerns taking child/youth into the community, or safety of possessions. Some caregivers overcame these feelings; for others, the feelings are unresolved.

For FCG07, it was feeling secure in how she was caring for those in her charge. She says, "Leaving her by herself, it's fine. I can see her through the window, but what if something happened?" For ICG02, security means sharing with others about the struggles she encounters from her son's conditions and feeling comfortable exposing these vulnerabilities to others.

For ICG04, this feeling of inner peace encompassed multiple concerns. It included ensuring her daughter's mental health and feeling comfortable that the people providing her daughter services were helping her, as she elaborated here:

> *"You can tell that the particular [provider]that she was assigned to was not comfortable with my daughter, my daughter's sense of humor, beliefs, and practices. And she was constantly trying to inflict her beliefs and values on my daughter. And that was not good for [YSHCN's] self-esteem. So we ended up not working with them anymore." – ICG04*

Inner peace was also about the struggle between helping her daughter become independent without overwhelming her:

> *"She has never taken the bus; she is not independent at all. And there was a time when I was not comfortable with her being independent because she is just so naïve and kind and sweet and saw the goodness in everybody. And I didn't want to break that spirit. But I also needed her to develop skills understanding that there are bad people out there – a lot of them. So now she is very wise to the world; I am not concerned about her being taken advantage of. But if she were at the mall and a shooting took place, I don't know that she would know what to do. If she were driving by herself and it was raining, and the car started spinning out of control, I don't know she would know what to do. Because she has a diagnosis of major anxiety disorder and major depression, and so all of that comes into play with the autism. She's very sensitive and I feel like a lot of times people just don't get that." – ICG04*

ICG05 described her anxiety with home care workers in her home due to experience and inability to choose her provider.

> *"…because I do what's called the CDS option where I am actually the employer even though I am the parent. I had an agency back in 2008 that I was with, and the girl robbed me, robbed my home, not only my debit cards out of my purse but my jewelry. And after that, I said, 'I can't do this anymore.' Because one thing we were told was that if we're with the agency and they*

> *send someone to fill the hours, you should let them work. But I am not screening these people."*-ICG05

Category: spatial safety

The final category relates to the safety of the space around the caregiver or the child/youth. The most prominent piece of spatial safety in home care is the home itself. However, participants expanded on the definition of the home as they discussed the neighborhood and moving around the community. This category encompasses hazards in the home, feeling safe in the neighborhood, feeling safe in the community, and possessions in the space.

Hazards in the home

The hazards in the home were distinct from the people in the settings. For example, if a participant was concerned with the family members in the household, that was considered interpersonal safety. If the participant was concerned with physical features in the house, such as a rug or the layout of a room, that was considered a physical environment concern.

FCG01 best described the potential roots of the concerns in a home:

> *"One of my clients, I have a safety concern at their house…And I think there is issue with the person I take care of, tripping over things at times because things aren't super clean. Or there seems to be an easier spread of germs because the house isn't cleaned super regularly. And I would consider that a safety concern just for the health of the client. Then she'll trip over things sometimes whenever she is walking in the living room. Like a rug or a blanket that she'll trip over sometimes and I think things like that can just be a bit more picked up so it's less of a risk."* – FCG01

Other hazards in the home may be less noticeable. As FCG03 alluded, nurses in the home have to consider potential hazards they usually would not think about in a hospital:

> *"…how to dispose of sharps, what to do in the event of a fire, how to shut off a water meter - crazy stuff you don't have to think about in the hospital. But when you are at home, and the house is flooding, and you're caring for the patient, you need to know how to shut off the water meter."-FCG03*

Feeling safe in the neighborhood

When asked what she first thinks of in terms of safety in the home care environment, FCG05 immediately responded, "The location of the home. Some homes are not in good neighborhoods." The general description of neighborhoods that concerned caregivers was summarized as where illegal activity was evidenced or presumed to be happening. FCG03 noted that if a home is in a neighborhood with a bad reputation, it can be challenging to find nurses willing to take on the family as a client.

Moving around the community

One caregiver described safety concerns that arise from taking CYSHCN into the community. When I asked FCG07 when she was most concerned with safety, she responded:

> *"Probably for outings; anything not in the home. Which is such a challenge. The whole thing is being out of the home and being able to work and be with people in the community - it's the only way to normalize disability. But when you are a person who takes care of someone with disabilities, you don't just plan for an outing; you have to plan for all the contingencies. You have to make sure wherever you're going is accessible. You have to make sure that the doorways are wide enough. Because ADA is a thing, but if there are buildings that are grandfathered in, then they don't have the same capacity. So when I was working with my friend [YSHCN], who also passed away last year, she and I went to go get ice cream, but it was in a building that was 100 years old*

> *or something, and she couldn't get in with her wheelchair. So I had to go in and get it and come back out to her. Leaving her by herself, it's fine. I can see her through the window, but what if something happened." – FCG07.*

Furthermore, it's difficult for most informal caregivers to talk about home care without talking about child/youth's school. The school becomes an extension of the home and can influence the home environment in numerous ways. As ICG05 described, the school was where her sons picked up certain behaviors that can cause injury to others in the home:

> *"[My sons] are in a self-contained classroom with nine other students that have a variety of behaviors. And they pick up things. And we never know what they are going to come home with. So [YSHCN] picked up slapping; [other YSHCN] picked up kicking. And there is not much you can do about that, when the other child is in a meltdown, they try to keep them safe." – ICG05*

For some caregivers, the school was an additional source of stress, one that they must balance with the desire to do what's best for their child/youth. "You want to give her the school experience, but you also want to protect her," said ICG03.

Often precautions are needed to support the child/youth at school. ICG03 described additional restrictions placed into her daughter's education plan when she was allowed or not allowed to go to school depending on her health in previous days. ICG04 described connecting to her daughter's college counselors and trying to find a space on campus where her daughter felt safe if she became anxious or overwhelmed. In some cases, those precautions tie directly into services received at home, as ICG02 explained concerning her son:

> *"if his nurse wasn't there, he would not be in school. [The school staff] do not have the same level of safety concern that I do. He's actually gotten lost at school; yeah, it's rough there. We transferred to [New School], which is an*

> *ABA like intensive one-on-one therapy school. So we have had a lot less concern during the day when he's over there. But it also raises new concerns, so he's riding over there on medical transport. So it's not me taking him. Which adds in another person, adds in somebody else driving, which is scary. you know there's a whole bunch of you give a little bit… give and take to make it happen" – ICG02*

As ICG02 relayed, sending her son to school is important to her, but she must rely on her formal caregivers to transport him, which generates apprehension about his safety.

Safety of possessions

ICG02 introduced a new concept of safety, "We worry about the safety of our objects, our things that we don't want [CSHCN] to destroy. That's a way I think of safety; I keep my stuff safe from him." The caregiver went on to add the ways her family secures their possessions, placing them in a room where her son does not have access.

A dual-role caregiver reiterated this idea:

> *"When I would drive [CYSHCN] places, I had to double, triple check that the child safety locks were on and the windows were locked because he would throw all my stuff out the window. Or try to open the door while we were driving"-FCG07*

The final informal caregiver (ICG04) who noted concerns in this area described possessions differently. She was worried about her personal information in the hands of a non-responsive service provider. To receive services, caregivers often have to provide personal and sensitive information like diagnoses or income. Her concern arose when she felt like the information was not being kept secure.

Summary of conclusions for research question 1

Fourteen caregivers defined various safety concerns across four different categories. The large number of concerns shows the breadth of what safety can look like in home care and how it means different things to different caregivers. Their concerns varied depending on numerous factors such as the caregiver experience and expertise, the lifestyle of the family, the child/youth's age, and the care needs of the child/youth.

Physical safety is the most immediate source of concern for most caregivers, with child/youth injuries and infection at the forefront. Cooking, nighttime, when in new places, and when child/youth was tired or agitated were are all times when caregivers were most concerned with safety. Many of the safety concerns described above are typical for all children/youth. What sets them apart for a child/youth in home care is that their condition or diagnosis exasperates the safety issue. Caregivers described this idea in multiple ways, such as older youth lacking the awareness not to wander away, feeding tubes leading to aspiration concerns, and infection affecting an immune-compromised child.

ICG02 highlights the additional stressors this places on the caregiver and the intensity of the precautions she has put in place to ensure safety when caring for her son

> *"I would say the biggest concern in the biggest impact that we have in our life is just him not being able to be left alone… so again, it encompasses all of our safety concerns with him...the eating things, the jumping off things, the eloping[8]. Any of that is corrected by always having someone with him. Like I don't shower if there is not someone here to sit with him because it could be a*

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[8] Eloping in this context describes when a child/youth has the urge to leave safe surroundings without notifying anyone.

> *seizure, he could run away, he could find the tiniest fleck of whatever and eat it and choke on it. So he is always monitored. Always." – ICG02*

Caregiver injuries were a lesser concern but still present. For some caregivers, the child/youth caused these injuries (such as biting and hitting). For others, the injuries come about when providing care (such as back injury while transferring).

Interactions between formal and informal caregivers or between formal caregivers and children/youth were a common safety concern for all groups. Trust must go both ways in home care and is paramount for caregivers to feel safe in a home care setting. For informal caregivers, they have to feel comfortable with an unknown person coming into their home and their ability to care for their child/youth. Formal caregivers are equally concerned about who else might be in the home when providing care.

One of the critical concerns specifically for formal caregivers was the fear of having to respond to emergencies. The formal caregivers describe often being on edge with something going wrong and being solely responsible for responding.

Finally, the participants described safety concerns that fall under the umbrella of spatial safety – safety issues in the space around them. The home was not just a building, and not even just the neighborhood surrounding the building. Instead, it consisted of their possessions, the home, the neighborhood, and the community. Caregivers described their feelings of discomfort based on these issues in the physical environment.

To sum, when defining the safety issues in the home care environment, one must consider the myriad issues and how they relate to each other. Formal and informal caregivers define safety differently, in a way that takes their specific needs and situation into account. To address safety for the whole home care population requires a broad definition of safety that captures all of these individual needs.

Research question 2

Once a safety concern is identified, it becomes difficult to ignore. The second research question under study is how do caregivers address safety issues in the home. When answering this research question, two themes arose – the solutions caregivers use and how they determined these solutions.

Theme: caregiver solutions

The participants identified 13 different solutions to their safety concerns. Most of the solutions are unique to one group of caregivers, but a few solutions – training, assessing, and building relationships - were used by all three caregiver groups. This section describes the solutions according to the following categories– the caregiver toolbox, preemptive activities to improve physical safety, training caregivers, and becoming familiar with the caregiver and the home.

Category: the caregiver "tool chest"

"My job is to give [others] the tools they need to keep [YSHCN] alive. I just have to build my tool chest so that they know the correct things to do," ICG03 said. For ICG03, the "tool chest" included her daughter's emergency bag. I defined tools as things the caregiver used (as opposed to activities) to address safety. In addition to emergency bags, other tools cited by caregivers included adding devices, investing in medical equipment, and modifying the home. Each one of these tools is described below. As

ICG03 alluded, the informal caregiver is primarily responsible for finding these tools and implementing them.

Emergency bags

Emergency bags, also known as go-bags, typically include medications or devices to mitigate emergencies due to the child/youth's conditions, such as seizures or respiratory issues. ICG02 described her protocol for both formal and informal caregivers in terms of the emergency bag:

> *"We always make sure that a phone is left wherever [CSHCN] is. Always has his seizure bag...whoever has him has the bag…It actually causes anxiety for my nurses...they're like, 'where's the bag? where's the bag?' so they keep it in their pocket, and you know, lesson learned. We had it in his bag on the school bus, and so she had to pull over and get the bag as opposed to having it right next to them. But now they carry it on them all the time." – ICG02*

ICG03 recommended an emergency bag for all caregivers of CYSHCN that is tailored to the specific child/youth. "A to-go bag is really key, and it looks different for everybody, obviously. A person who has a trach's to-go bag is going to be different than my to-go bag. Someone with a g-button - obviously the same thing," said ICG03.

Devices

Caregivers utilized devices to reduce physical, mental/emotional, interpersonal, and spatial safety concerns. In this case, a device is anything added into the home for a particular purpose. Devices are different from equipment for being less medically necessary. Furthermore, these devices typically can be removed or altered easier than more intensive home modifications. The informal caregivers who had concerns with the child/youth hurting themselves or wandering were the same caregivers who utilized devices as part of their safety solutions.

Two parents relied on video cameras in the home. For ICG02, the camera offered security if she is ever concerned about who is in her home. For ICG05, the camera provided reassurance to her and independence to her sons:

> *"I have installed cameras, and I have a TV out in my living room that is dedicated just to the camera system that we can give [sons] some independence to be in their room but also watched. And since they also have seizures, it's really helped a lot of my anxiety, like going back and forth. It's been a godsend to me. They really like being in their own room, but they have to be monitored because they don't understand that it's not safe for them to like stand up on the beds and jump off. We can keep an eye on them, but we don't have to be in the room with them all the time." – ICG05*

These same two caregivers also described babyproofing their homes – adding outlet covers and stove knobs to prevent injuries to their children.

Three caregivers talked about the addition of more difficult locks in their home - both as a way to protect their things and prevent their child/youth from wandering. ICG05 stated an unintended consequence of her sons' therapies made them more adept at conquering locks, leading her to resort to more complicated ones.

> *"I have key deadbolts that I take the key out of. [Sons] have not learned how to do that yet, but they do know how to remove chain locks, flip locks, knobs, locks on the doors, things like that. You can thank the [Occupational Therapist] for that. I can take the key out of the deadbolt, and I have a little special place I can hang it by the door, and they don't mess with it." – ICG05*

Three caregivers added sensors, chimes, or alarms to their doors to be alerted to when their child/youth is trying to leave the house. Caregivers of children/youth who wander use multiple devices, as ICG06 demonstrates when talking about his son:

> *"He's an escape artist. I have a childproof lock; it's almost adult proof too. It's pretty complex, and it keeps the door locked, and on top of that, I have a little sensor where if the door opens, there is an alarm. So if he does somehow manage to get the lock open, I will know if he opens the door. Because he's*

> *gotten out of the house like three times over the past four years, but that's been a pretty long time now." – ICG06*

Medical equipment

Medical equipment ameliorates the child/youth's conditions or illnesses in the home. It is distinct from the devices as the equipment is designed specifically for a medical purpose. Given the specialized nature of medical equipment, it may be paid for by healthcare services if certain requirements (such as a doctor's prescription) are met.

Medical equipment had the additional benefit of helping caregivers feel safer in the home. The caregivers listed various medical equipment they use to protect the child/youth and the caregiver from potential injury. ICG02 noted a seizure monitor, suction machine, pulse oximeter, and a safety bed, all to mitigate the effects of her son's seizures. In the past, her son also relied on a helmet to prevent injury while seizing. The child FCG02 cares for also utilizes a safety bed. As FCG07 noted, a mobility lift reduces the likelihood of back injury when moving the child/youth.

Formal caregivers assisted in obtaining medical equipment. Both FCG06 and FCG07 provided suggestions to informal caregivers during initial home visits. Their role in assisting with equipment was to make referrals to other services. For example, FCG06 would tell her clients, "Human health services will come to the home and give you monies and say we will install a ramp for you. Or installation of some things in your bathroom – like bars in the tub."

Home modifications

To protect the possessions in their home (and sometimes the home itself), informal caregivers made modifications to the home. Two caregivers, ICG02 and ICG05, elaborated on such modifications. ICG05 had few modifications:

> *"their rooms are pretty basic, they have heavy-duty desk and a bed, and that's pretty much it. Their computers are mounted on the wall behind plexiglass, and now that they are older, I have to think about trying to thicken the plexiglass"-ICG05*

In contrast, ICG02 noted extensive modifications. As she said, "we've actually remodeled our … whole home to accommodate [our son]." She drew attention to numerous modifications, including:

- Rearranging the furniture to block the windows so her son could not break them,
- Covering the walls in tin so her son could not punch a hole in them,
- Building custom heavier furniture that he cannot pick up and break when upset, and
- Adding a tall countertop and gates to the kitchen to prevent him from reaching over and touching dangerous things.

In fact, ICG02 noted that these modifications turned the kitchen into its own zone:

> *"Then it became our safety zone. He can't get in, so we left stuff that didn't need to be out. You'll notice [the living space] is all pretty clean and safe for him, but that kitchen is a disaster. Because that's where we go 'blah.' That helped us a lot - being able to keep him out of it" – ICG02*

These modifications required the caregivers to get creative. Both caregivers had to build something custom to their space. When asked if she had ever reached out to formal services to help with home modifications, ICG02 replied:

> *"it is so many hoops you have to jump through. It is just so much easier [to build it ourselves], it's more costly, of course…To get the gates, for example, I would have had to get three quotes from certified builders, and it would have to be ADA compliant. I don't care about ADA compliance to keep him out of my kitchen. So it's stuff like that. Where anytime that I reached out for help I found it to be harder or being told that is something you shouldn't do or that type of thing." – ICG02*

Category: preemptive activities to improve physical safety

Alongside the tool chest, informal caregivers described preemptive measures – cleaning, exercising, providing the child/youth a safe space – that maximize the physical safety of their children/youth or others in the home.

Cleaning

Two caregivers (ICG02 and ICG07) described cleaning and sanitization that was more intensive than typical households. As ICG02 stated, "I sanitize my house all the time because I have a kid that licks the walls. Literally. No, really, there are lick marks." Both of these parents have immune-compromised children who rely on this cleaning and sanitization to avoid additional illness.

When asked what her safety issues were, ICG07 immediately responded with personal hygiene; therefore, it is unsurprising that cleaning was a critical activity in her household. She asks providers to wash hands, take off shoes, and other hygienic activities when in her home. ICG07 elaborated the concern is more significant than her immediate household's cleanliness.

> *"[The providers are] going into all these other homes and bringing stuff from them to us potentially. So even though their homes might be clean and great, their patients might not be. It was kind of scary to think that they might be bringing with them, even if they were well." – ICG07*

Further, according to ICG07, a parent has to be attentive to who is in the home and what they do:

> *"I know that some parents have found it helpful to have those signs like 'a heart warrior lives here' or 'please wash your hands.' I mean, maybe if I wasn't as upfront with people, I might need that sign…But no, I felt like everyone respected my requests. And even his feeding therapist was in chemo, and even she herself was very vigilant, so I never had to worry about her not washing her hands."-ICG07*

Exercising

Informal caregivers mentioned two more physical strategies to avoid injury to the child/youth themselves or others. As ICG02 explained:

> *"We also do things to try to make [CSHCN] stronger, which in turn should make a safer. Like you'll see the trampoline in the corner, that's to jump and build strength, we try to do those things to try to prevent falls, prevent stumbling, prevent those types of things."-ICG02*

ICG06 described taking his son to run, play, walk, and even pretend-fight for two hours every day to burn off excess energy. According to ICG06, by doing so, the child is unlikely to injure others as he feels more in control and calmer.

Providing the child/youth a safe space

Three caregivers described seeking out a safe space for their child/youth. ICG02 saw her son constantly jumping and climbing on things, so she carved out space in her home with a trampoline and climbing wall for him to do it without injury. FCG01 moves her client to a safe space to prevent her from hurting herself or others during meltdowns.

ICG04 seeks out space for her daughter to compose and calm herself when in stressful situations.

Category: training

The term training encompasses any form of teaching or education provided to caregivers. All seven formal caregivers and five of the informal caregivers talked about what training looked like for them. Training was a common strategy to solve safety issues in the home, but the intensity, type, and content of training varied significantly by type of caregiver.

Training formal caregivers

Formal caregiver training was more structured than informal caregivers. Five of the seven formal caregivers were nurses who, at minimum, had medical expertise to rely on when in the home. One nurse described additional material from the home health agency she worked for:

> *"they just give you safety tips like to always be on guard, not to have your back to the door, escape route, make sure you have a way for you and the patient get out safely if there was a fight. Make sure there is nothing blocking the path."- FCG04*

Other nurses described having training related to gastronomy tubes, tracheostomies, transferring, and what to do if you have an issue in the home.

FCG01 described the training she receives as a home care worker:

> *"[My organization] has a whole training protocol that I have to go through annually. And they've got a unit in there about sexual assault and things like that. And then also about violent and aggressive behaviors. And about restraining and then they also have things about if I ever have to do physical lifting for my clients – ways to keep myself safe in those situations… it's part of a video series. The whole video series, which is the complete training for the*

> *job which includes just talking about disabilities and mental illnesses and things like that…encompasses the whole job… that's about four hours of different online videos. It's a series. I would say maybe ½ hour to an hour was devoted to safety. Whether it be sexual assault, making sure you feel comfortable in the home, making sure you're in a safe environment, restraining, de-escalation techniques." – FCG01*

FCG07 described her experiences training other home care workers. She promoted hands-on techniques when she led training, asking home care workers to show how to transfer an individual or change a diaper safely.

Formal caregivers were more likely than the informal caregivers to say they have training annually or have refresher training. Half the formal caregivers felt their training was sufficient, but one formal caregiver added a caveat:

> *"I think I feel prepared because I have been doing it for so long. But if I just started, I don't know. When I first started, I probably didn't feel that way. I felt like that they could do more training. But you kind of have to train yourself, once you are doing it for so long, and then you have to adjust it for you." – FCG04*

Training informal caregivers

In contrast, informal caregiver training revolved around how to manage the child/youth's condition at home. Caregivers received the training in response to a change in condition or a change in care (such as new symptoms or new equipment). As ICG02 highlighted:

> *"We've had little things like the seizure safety. That didn't come in until he started having seizures, then we were trained on it. [And] g-tube safety, that didn't come in until we had a g-tube, and then we were trained on it. And I will say probably the biggest thing we've ever been trained on was the g-tube." – ICG02*

General education often supplemented the condition-specific training, as ICG05 illustrated.

> *"When I was with [a home health] agency, they would send out things like it's the flu season, look out for this, every now and then we would get a newsletter if they had that. I had several agencies over the years, and they would send out little flyers about flu season, or this is going around, what to do if someone has a toothache, I mean it was pretty basic care." – ICG05*

Three of the informal caregivers received Applied Behavior Analysis (ABA) therapy that they applied to help ensure their children's safety in the home, like redirection, calming, restraining, and managing wandering. All three were satisfied with this training and felt it was successful in improving safety.

Beyond the ABA training, which was well-received, informal caregivers had varied opinions on the value of the other training and education. Some agreed they would like additional training, while others asserted that training was not particularly useful, so they were not open to additional training. Still, others were unsure what training could cover that would be relevant to them. As ICG03 affirmed, "I don't even know what [training] would look like…The thing is nobody ever said, 'let's give you some safety measures while providing care.' That's just not a thing."

Category: becoming familiar with caregivers and the home

Many of the solutions caregivers use can be categorized as mechanisms to foster increase comfort within the home environment. These solutions overlapped and addressed the home and the people in it, often at the same time. This category includes assessing the environment and the caregiver's skills, building relationships between caregivers, and being aware of the surroundings.

Assess the environment and the caregivers' skills

Formal caregivers rely on assessments in two ways. In one, formal caregivers who have administrative duties used skill assessments during the hiring process to understand who they are employing. Additionally, formal caregivers often have checklists to assess a home. These assessments provide an initial picture of what safety concerns may be present.

The two formal caregivers with administrative experience explained their hiring processes. They utilize assessments to ensure the staff they hire can provide care safely in the home. In both capacities, the administrator used these processes to identify skills requiring additional training rather than a disqualifier for hiring.

> *"We do exams as part of our interview process [that bring us awareness of the potential risks of where a nurse might not be able to care for the child/youth]. One of them is a pediatric medication administration exam, which requires them to do dosage calculations. And 95% of our nurses that interview have to re-test. And that is a teaching tool for us. In the hospital, dosage calculations are not really required as much because they have a lot of safety measures in the equipment to prevent them from making a medication error… Then we also do a home health exam…We ask pertinent questions so that we need to know that their perception and assessment skills are in place for the conditions they will be treating… it helps us to understand where the risks are. And we always tell them 'don't feel bad if you fail the test… We will educate you, we will send you home with the study materials, and you can come back and take it again. But we need to know you could care for your patient while you are out there.'" – FCG03*

FCG07 described a similar process for the home care workers she hired:

> *"I had a list I made based on all of the ADLs I could think of. And it was like three pages. But it was just you sign off; I sign off. So if it was a skill like 'ok, I have done XYZ,' they either had to show me or be able to verbally explain it. Like I've given someone a bed bath. I am not going to make you give me a bed bath right now, but I am going to make you like walk through what you do. So I make sure you have the competency." –FCG07*

Four formal caregivers mentioned assessing the home that included safety issues. For some, the assessment was more informal; for others, there was a checklist of things to identify.

FCG07 describes one of the more comprehensive assessments:

> *"when we get new clients, I would do a home assessment. So I would go through and get them to tell me… 'ok what are your needs, what do you want, what are your preferences? How do you do certain things?' If they were a challenging transfer or they did something a little different, some people have specifics on the way they do things. I would have the family train me so that whenever I could bring a caregiver, I want them to have a picture of what it could look like in their mind, so they could have a preliminary training. So that they at least know what to expect. And then assess the homes, like if someone has challenges with walking do they have loose rugs all over the place. Do they need grab bars in the bathroom? Being able to make referrals and say, 'hey, this might be a good place to help install the grab bars, or this sit and stand recliner might be a little better than the one your loved one is trying to crawl out of.' And then just like different baby stuff, if the kiddo is crawling around on the floor, is there stuff that they can eat, like that." – FCG07*

Assessments typically covered the child/youth's medical history, care preferences, the physical environment, what protective measures were present, what medical equipment was needed, and medications. Occasionally, the assessments also included potential issues for the caregiver (such as transfers) or emergency plans.

Informal caregivers have a different perspective on home assessments. Only one informal caregiver mentioned completing an assessment before her child received services, noting that it did not address her particular safety concerns. "They focused on aggression and violence. I don't remember any of them saying anything about [wandering]. I always had to write that in or tell them 'hey, he will run away,'" ICG01 said.

Build relationships

As participants described how they overcome their safety concerns, feeling comfortable with their caregiving counterparts was repeatedly mentioned. Informal caregivers have to feel comfortable with who is coming into their home and formal caregivers have to feel comfortable going into the home. Assessing the home and the caregivers is an initial step but not sufficient on its own to fully address the caregivers' concerns. The next step is to build relationships between these caregivers. Twelve of the fourteen caregivers described the importance of building a cooperative relationship and gave examples of how they have done so.

ICG02 suggested one reason a good relationship is necessary:

> *"If you had told me nine years ago, I would be spending more time with my nurses instead of my husband; I would have laughed at you. It's weird, right? If I'm not friends with them, it's not good because I have to spend a lot of time with them. And not that has stopped me from having a good nurse. If they are good for [CSHCN] they are good for me, but I would have never envisioned that." – ICG02*

Three caregivers noted that losing a formal caregiver they have a good relationship with can be more devastating than just losing the care assistance. When asked how CYSHCN would be affected if she could not provide care, FCG05 responded:

> *"it would impact them greatly. My one patient, I've been with them for 12 years. She loves me; I love her. If I'm not there for a few days, she's looking for me, asking where I am at. So it would impact her greatly because you build a relationship with the patient and the families. You become like an extended family member, especially when you have been there for a long time. If something were to happen like I was out last year for a whole month, and they were just stressed out with different nurses coming in. it impacts them greatly" – FCG05*

As ICG03 said:

> *"It's very imperative to have a good relationship with your nurse because how you treat your employees is how long they are going to stay. If you feel heard and feel like you're part of the team and feel like an active member and that what you say is important. Then you are more likely to stay and do a good job… But it's also a partnership. It's definitely not 'I'm your boss,' and she does what I say. We work together." –ICG03*

A dual-role caregiver, FCG07 echoed the same thought:

> *"… one of the biggest priorities for families when they are looking for a caregiver is consistency. They want someone that is going to be there long-term because the change can really mess with the mood of the client. It can cause them to have different types of behavior or act out. Consistency is key in caregiving in any age group." -FCG07*

Strong relationships also benefit formal caregivers, as FCG06 described:

> *"But just being able to have that parent trust that you are giving good care to the child. Having that parent trust you, you are able to get more information out of the parent. When they trust that you are there for them and speak up for them, that's what they are looking for." - FCG06*

Good relationships between caregivers lead to caregivers feeling more comfortable in interactions and feeling safer in the home. The caregivers had multiple comments on building these relationships, but complementary personalities and skills were at the forefront.

> *"You have to make sure the personality with the person meshes with the family, you have to make sure the skill level matches the need. And if it doesn't, are they capable of coming up to the skill level. Or do we need to find someone that is a better fit" -FCG07*

Multiple informal and formal caregivers agreed, emphasizing getting to know their counterparts during the initial meeting and screening processes. For informal caregivers, the screening process involved background checks, referrals, or recommendations from other caregivers and introducing them to others so they can best get a feel for the potential formal caregiver. Formal caregivers often go to the home to meet the child/youth and the family to learn their needs.

Both formal caregivers with administrative backgrounds discussed getting this process off on the right foot by matching the children/youth to the right caregiver. FCG07 quipped, "I am like a dating service for caregivers." She elaborated that this process can be quite tricky, though:

> *"it was something that I have been told I have a knack for. But I know it is very challenging…personally I would get a gut feeling, and I feel like I am a seasoned judge of character when it comes to caregiving. I have occasionally felt it's not going to work out pretty quickly. But that's why I like to do the assessments and the caregiving side of it because I feel like you're not going to get a good picture unless you meet the client. You need to be able to see the full puzzle." – FCG07*

When FCG03 matched caregivers to care recipients, she also considers the caregiver's level of comfort:

> *"There are some situations where one nurse feels like their safety is at risk, but another nurse, who was raised a different way, might not have any concerns at all. We had a patient one time who lived in an apartment that was in a sketch part of town, and we couldn't get nurses to go out there; it was really hard to find just one. And [the care recipient] had 24-hour care, but we were having a hard time trying to find one nurse who would go out there. And we did. And one day, we show up to a supervisory visit, and there are cop cars and caution tape all over the parking lot, and when we get in, we ask, 'what's going on?' And they said, 'oh, they found a head in the dumpster.' 'there is a head in the dumpster five feet away from where our nurses park their cars, aren't you scared?' She's like, 'no, please, I grew up like this, that's not even a concern.' …But if the nurse doesn't feel like their safety is at risk, I can't really argue with that. But we had already asked the family to consider other housing options, and if they needed us to connect them to some resources, we would. So we addressed it. But we found a nurse who didn't seem to have a problem with it. Take it day by day." – FCG03*

Informal caregivers also consider how the formal caregiver interacts with the child/youth.

> *"The other thing [my husband and I] do is we generally gauge how [CSHCN] interacts with them too. If he is not wanting to go with them, if he's not wanting to hang out with them, because he bonds with those nurses pretty darn quick. So it is definitely a gauge if he doesn't want to be with them."* -ICG02

In her role as home care aide, FCG01 felt easing into the process of caring for the child was a critical first step.

> *"I kind of eased in to being there by myself with her. And I would work shorter shifts with the parents home so they could jump in if there was a problem. And I could kind of see their methods of de-escalation with her, and I could kind of see what words they used with her. And I was able to adapt that into my own methods and my own ways." – FCG01*

For best relationships, communication is a two-way street, as ICG01 and FCG05 demonstrated:

> *"And then communication, if they tell me what's going on, that's good. One time [YSHCN] got stung by a bee, and he had never been stung before, and flying things really bother. And rather than come and tell me, they waited until the end of the session and were like, 'oh yeah, he got stung.' Come on communicate with me."* - ICG01

> *"I meet the parents, get a feel for them and how they like things to be done. Some parents, aside from the medical [stuff] they may want you to hold the child a certain way or position a certain way, little things like that. So I just listen to what they say and go from there".* -FCG05

Also, seeing how a formal caregiver will handle a particular situation can put informal caregivers at ease, as ICG01 explained:

> *"Time and getting to know them are definitely two big parts. But if there is a situation that happens and they handle it in a good way, then that quickens that...I mean, the biggest thing I can think of is how they would handle it if [YSHCN] did run off."* -ICG01

Finally, the caregivers suggested showing appreciation helps. ICG02 cited that the long-term successful relationships with her son's caregivers were in part due to the fact she and her family "work really hard at Christmas and go crazy during nurses' week to show them how they are appreciated."

Good relationships were associated with consistency, communication, appreciation, and respect. Together these built trust, which in turn led to overcoming safety concerns. Once the caregivers build a good relationship, they feel more comfortable interacting and, therefore, safer in the home.

These strategies can foster relationships with other providers as well. ICG03 stressed the importance of building a relationship with another entity to feel safe in the home:

> *"the thing is we have a lot of resources that a lot of us don't use. And the fire department is a great resource… they can at least stabilize [CYSHCN] enough to get them to a hospital. And it's very important to talk to your local fire department. And then if you don't share the same fire department that your school does, make sure you talk to the fire department for the school as well."*
> *– ICG03*

She introduced her daughter to the fire department staff, so they were aware of her conditions if there was ever an emergency at school or her house.

Maintain awareness of surroundings

Six out of the seven formal caregivers emphasized that they try to stay aware of their surroundings when providing care. Sometimes nurses drive around a neighborhood or meet the family to get a feel of working with them before they even agree to provide care. FCG04 offered a caveat. Even if a caregiver has been working with a family for a while, a provider must still be aware.

> *"The main thing is just to be aware of your surroundings because even though I have worked with the patient for 4-5 years, something personal could be going on with the parent and could come while I am there. So I just try to always be aware. If I hear her arguing with someone on the phone and things like that because you never know. People nowadays are crazy, even though I'm comfortable with them. But she's good; if she has something going on, she lets me know." – FCG04*

Theme: determining the right solution

During the interviews, caregivers often discussed how they came up with their safety solutions. The seven techniques mentioned are shown in Table 13 by type of caregiver.

Category: informal caregivers rely on other parents and the internet

The main strategies for informal caregivers were asking other parents and seeking out answers on the internet, often in conjunction with figuring things out independently (coded as doing their own research). Typically, informal caregivers sought advice on what devices/equipment to use and how to do specific care tasks. Support groups (in-person and online), YouTube videos, and google searches were the most mentioned mechanisms to finding solutions for informal caregivers.

Category: Using formal supports to determine a solution

In contrast, formal caregivers were more likely to cite policy manuals or handbooks when needed and occasionally ask other home care providers.

Table 13: How Caregivers Determine Solutions by Type of Caregiver

	# ICG	# FCG	# Dual	Total #	Example Quote
Ask other parents	4	0	0	4	"We have a Facebook group. The seizure monitor came from 'hey who's using what,' and that was the resounding choice from a couple on the market. Then someone said, 'hey, the Danny Did Foundation helps [pay for] stuff like this.' So that's what led us to it." - ICG02
Do own research	6	1	1	8	"I've learned a few things here and there from the nurses, but most of what I know is self-taught. Either by learning that is not the way you do it"- ICG02
Utilize formal services	4	3	0	7	"With disability services…if [YSHCN] had problems, they would be there to either assist her or contact me." - ICG04
Use internet	4	2	1	7	"For example, I had a client with some serious behavioral stuff – autism, bipolar, explosive stuff – I go to YouTube and check out training videos on different things. I have done that for pretty much everything – most heavily on Alzheimer's and dementia – but with younger people, I have looked up and googling videos and sometimes Pinterest just to check and see what are some ideas on how to deescalate. Like with kiddos, a lot of times, the behaviors come because they are bored. And idle hands. So being able to keep the mind active and be creative is important." - FCG07
Discuss/work as a team to come up with a solution	2	1	1	4	"I typically go straight to the parents… It's their home, and I want to respect that and respect their authority over their home. And if there is ever a safety concern in regards to their child, I try to make them the main person involved in that. in a respectful way, 'hey I think this a concern, what can we do about it' we usually talk about it and brainstorm ideas." - FCG01
Assess and anticipate	3	4	2	9	"Like I said [YSHCN] don't mess with a lot of things in the house, I don't have that worry. But I always look at things, and say 'ok, what is this going to; I try to think ahead.'" - ICG05
Discuss with colleagues	0	1	0	1	"I would talk to the parents, talk to my work, and look up on the internet" - FCG02
Cites policy or rulebook	0	5	1	6	"My client, her dad, is very good and on top of keeping the CDS handbook in front of him. Anytime we have concerns about anything, we usually go straight to that. I would think that would be the document we would go to if we had any safety concerns to address. We haven't at this point in time. But that would probably be what we do – the CDS handbook." - FCG01

Assessing the situation and anticipating what safety issues might arise is a frequent activity for all groups. This anticipation went hand-in-hand with the assessment solutions described earlier in the section. The assessment was often informal – a quick scan of the environment to understand what or who is around. For formal caregivers, the assessment could be more structured, involving checklists and worksheets to complete.

Caregivers described utilizing formal services to get medical equipment installed, access to immunizations or other healthcare, and other disability service support. Occasionally utilizing formal services also means involving emergency services, the police, or other social service agencies (like child protective services) to protect the child/youth.

Finally, under the category "working as a team," two formal caregivers mentioned working with the child/youth parents to develop a solution when there is a concern. Other caregivers mention working with medical professionals and therapists to come up with solutions.

Summary of conclusions for research question 2

Caregivers' solutions to safety issues were as numerous and diverse as how they defined safety. Often, the solution is a measured response to the caregiver's specific concern. For example, when wandering is the concern, caregivers added devices that alert a caregiver to the wandering or prevent wandering. When children/youth have conditions that make them immune-compromised, sanitizing and cleaning to prevent infection is critical. Some solutions, such as training and assessment, are more broadly focused on identifying and mitigating multiple safety issues at once.

Relationships between the formal and informal caregivers were once again a significant point of discussion. Both groups recognized how a good relationship could improve the safety of the home care environment; building a relationship with their caregiver counterpart generated trust, which diminished feeling unsafe. Communication, mutual appreciation and respect, connecting with the child/youth, and time to get to know each other were all cited as fostering the relationship. Formal caregivers also had to become familiar with the environment in and around the home. Even when a formal caregiver works with a family for years, they will still diligently appraise their environment.

While formal and informal caregivers agreed on the importance of building relationships, there were dissimilarities between the caregiver groups on how to address safety and how they developed that solution. The differences seem to be rooted in the distinctions between the caregivers’ roles and places in the home care team. Formal caregivers are more likely to rely on formal supports such as handbooks, assessment tools, and training compared to informal caregivers. Their solutions focused on the tasks they were most responsible for. More often, informal caregivers did their own research to figure out what worked for their home and family. Their solutions focused on preventing the child/youth’s injury or illness.

The tool chest is a good illustration of the differences between caregivers. Formal caregivers described connecting the family to medical equipment, a natural extension from their medical care expertise. Other adaptations to the home, such as adding devices or modifying the home, fell entirely under the informal caregiver's purview. The informal caregivers determined how to implement these solutions independently, with help from the internet, or by talking to other informal caregivers. Formal caregivers were rarely involved.

There was no consistent experience in terms of training. Informal caregiver training focused more on emergent conditions (e.g., caring for a new g-tube or addressing a recent diagnosis of autism) with little attention given to other safety concerns in the home. Formal caregivers were more trained in the day-to-day interactions of being in the home – whether it be what to look out for in the home or neighborhood, how to avoid injury, or whom to call in an emergency.

Maintaining safety in the home for CYSHCN relies on significant effort from multiple people – not just the ones in the home at any given time. Safeguards are in place from the onset of hiring home care providers. Other entities like physicians and emergency personnel also have a role to play. However, the crux of safety solutions is contingent on the caregivers. Services and supports exist to assist the caregiver, but the caregiver must first be aware it exists. For the most part, formal and informal caregivers each have a specific role in these solutions. Both groups try to build relationships to feel more comfortable around each other. Yet, there were few examples of addressing safety issues together; too few for this to be considered a routine in home care. The following research question further explores what is missing.

Research question 3

The final research question under study is: What are the impediments to safety in the home care environment? During the interviews, participants expressed frustration or uncertainty about aspects of these safety experiences. Additionally, participants explained what else did they need to be safer or feel safer in the home. Their responses in these areas comprise this study's final piece, stressing where additional efforts to address safety are still needed. This section is divided into two themes – the barriers to safety in the home and the support caregivers lack.

Theme: barriers to safety in the home

Caregivers cited numerous barriers to safety in the home. I grouped their responses into the categories of difficulties with the home care system, caregivers being ill-prepared, and safety costs.

Category: difficulties with the home care system

Eight caregivers described system-level problems in home care. Six of these caregivers were parents, one was a formal caregiver, and one was a dual-role caregiver, highlighting that this is primarily a barrier from the informal caregiving perspective. Informal caregivers likely have the most interaction with the system as they seek assistance for their child/youth. The caregivers communicated issues in the formal caregiver employment process and navigating the complex system of formal programs.

Frustrations with the formal caregiver employment process

Multiple informal caregivers expressed frustrations on how formal caregivers are assigned to families with little input from them. ICG05 expressed her struggles when she still worked with an agency

> *"Because one thing we were told was that if we're with the agency and they send someone to fill the hours, you should let them work… They would send me people, like an older lady that was 50 years old and my sons are very*

> *active. And she had a bad back and all this other stuff, and I was like 'I am sorry, I can't,' and the agency knew this. So you kind of roll the bones on what you're going to end up with."*- ICG05

FCG07 mentioned that personnel standards can vary from agency to agency and how this uncertainty affects informal caregivers' feelings of safety:

> *"You have to follow the state [regulations], you can't hire them, but some agencies hire people with other things on the record. Or there are a lot of agencies in the state who do not drug test people. It's a company policy. I have seen companies that do drug tests and other companies that don't. So you just don't know who's coming into your home."*-FCG07

Complicating the matter is that the care needed is often critical, time-sensitive, or specialized that caregivers feel they have to accept whoever is assigned. ICG07 told the story of her son, who was assigned a particular home health nurse, the only one adequately experienced in addressing his specific needs according to hospital medical staff. When the nurse was suddenly unavailable on a day that a critical care task needed to be done, the agency sent a replacement nurse. The original nurse was also supposed to bring new equipment when she did the task as the family initially received adult-sized equipment instead of child-sized.

> *"So I called the nurse we were supposed to have to ask 'what happened, why are we getting this different nurse.' And she said, 'oh, my schedule changed and I can't come, so I sent her instead. It'll be fine'. 'But we were told it should only be you. And I want to make sure what's changed'. 'well, I can't be there, and this has to be done today.' Because it was very time-sensitive, and she was like, 'this is the best I can do.' We really had no choice because it did have to be done that day. – ICG07*

The replacement nurse was not only a novice; she also did not have the right-sized equipment. She tried to make do with the original equipment but made a mistake that ultimately landed the boy in a hospital. The medical staff thought it would be better for the boy to stay in the hospital for weeks instead of continuing home care.

Not only is it difficult to get a caregiver, removing problematic caregivers is sometimes challenging. FCG07 had familiarity with both CDS and home care agencies. She described why informal caregivers might hesitate to remove caregivers, even when ineffective. When asked what happens when you want to remove a provider from the home, she said:

> *"I think it depends on the program you are in. If it's CDS, then the patient or the patient's guardian is the employer, so they can do what an employer would do – they can write up, they can fire, they can do those things. But there is often retaliation and 'we're going to file for unemployment against you.' and sometimes things get lost in the system, and they win, and you didn't even get a letter. So your tax rates go up and you have less money in your budget to take care of your loved ones…If it's through the agency, then you call the agency and let them know. And it depends on the agency policies on what they do. Often times they just move them to a new client and send someone else – if you're lucky. But I have seen so many families…[where] the family is like if we do this, we don't have anybody [to provide care]. And then 'I can't work' and 'who can provide for my family?'"-FCG07*

When discussing replacing nurses, ICG03 responded that it is not a simple request:

> *"To get [the home health agency] to do it, you have to call them and throw a humongous fit. It's not like, 'hey, I need a nurse; can you help me find one.' It's like you have to get very angry and very mean to get them to get you a nurse."- ICG03*

Not having a formal caregiver can have significant consequences for the family. FCG07 mentioned families unable to work because they have to care for their child/youth when the formal caregiver is unavailable. ICG03 articulated another concern. When her daughter did not have a nurse for a few days, it was up to the caregiver herself to cover the time, giving up sleep in the process:

> *"If you have no nurse and have been [awake] for three days in a row, [the agency doesn't] find that a safety issue. And the reason they don't feel like that is a safety issue is because if something were to happen to [YSHCN] while she is on my watch, then they are not liable. All they care about is what is happening when the nurse is there. And usually, they don't really care that the nurse is sleeping, honestly. They just really want a warm body in the house because they can charge that." – ICG03*

The informal caregivers' general feeling was that they have little say in who is coming into the home to provide care and that they must take whoever comes, or otherwise be left without care. However, this stresses the caregiver to the point of being concerned with the safety of themselves or their child/youth.

Complexity of obtaining and using formal services

Informal caregivers were eager to utilize formal services and programs to address their child/youth's concerns but encountered barriers. As ICG04 described, support was not available to her daughter until there was a mental health crisis:

> *"I asked for help; I begged for services. Because I couldn't do it by myself, and I didn't know what to do, but even as a social worker, I could not get what I needed. It was awful. That is where all the services come into play. She qualifies for a lot of them because she has Asperger's syndrome or a diagnosis of Asperger's syndrome, but it was the suicide attempts that finally got these agencies to open their eyes and realized I needed help. And so that is when she started getting the services." – ICG04*

Other caregivers described not qualifying for services because their household income was too high or because their youth were just above the age threshold. In another instance, the waiting list for services was so long that by the time the youth reached the top of the list, they would be too old to be eligible.

Even when the child/youth received services, complications arose on what is covered or not covered – things that may affect care and safety:

> *"Like gloves, they won't allow me to purchase gloves and be reimbursed for that; they won't allow me to purchase masks and be reimbursed for that. But I can purchase ink and paper. And envelopes and things like that. Which I never really understood. So it takes a whole thing with the doctor then, like with this whole COVID [-19] thing. I have had to take the expense on myself. When the doctor did write the orders, we got denied saying, 'Oh, you didn't need that.' I have two boys who are pretty much incontinent at times, and I would say they only allow us two packs of wipes a month. And they are like 'you will never get any more' and I'm like 'my boys poop on themselves, they are messy, they are men.' Two packs of wipes will be gone." – ICG05*

Category: caregivers ill-prepared to provide safe care

Participants highlighted instances when caregivers were not fully prepared to provide safe care. Caregivers may be sleeping or lack appropriate training. This lack of preparation, in particular, affects caregivers' abilities to respond to urgent situations that may arise or protect the child/youth.

<u>Caregivers sleeping</u>

Caregivers sleeping – even when it is their job to be awake – was cited by some participants as the root of their safety concern:

> *"[YSHCN] is on life support; she's on a ventilator. She doesn't breathe at all. And when the nurses are here at night. Sometimes they try to work during the day and then try to take a shift at night. I'll go in because [YSHCN] alarms are going off, and nobody is attending to them. So I will go into check on them and see that the nurse is asleep. And that's common. That's not just me in general; that's across the board. It's one of the biggest problems in home health."- ICG03*

FCG03 agreed and provided additional context to such situations:

> *"I think our patient is more at risk during sleeping hours because there is a higher chance, our patient doesn't have a nurse, harder to staff them. And the*

> *parents are a little more relaxed with their concerns. Like when you are a nurse, you have a responsibility to be awake and alert and monitoring the patient. When you're a parent, you're snoozing with your hand on the patient, and you have the alarm turned on so you can wake up and suction when you need to. So there is a little bit more risk if they are asleep when the family is asleep. And also, if we do have a nurse staffed at night, some of them are not able to be that alert. And when you are in the home environment, you don't have the busy-ness and the lights of the hospital and the other coworkers keeping you alert all night long. You just have a quiet, dimly lit room, and so there is a higher chance you may doze off. It's against the law, but it happens."- FCG03*

The caregivers agreed that the comfort of the home (in contrast to the hospital) means formal caregivers may fall asleep on the job, hindering their ability to respond to emergencies.

<u>Gaps in caregiver training</u>

Caregivers may also lack sufficient training to care for the child/youth's needs. ICG03 described how she often trains the formal providers who come to care for her daughter, instead of them having the requisite knowledge before coming into the home:

> *"So [nurse] came to my house, and it took me six months to train her because she just wasn't qualified to take care of [YSHCN]. They never send a nurse who knows how to work a ventilator, the life support machine. So [YSHCN] is only supposed to have an RN, but they will place in an LVN or LPN. And they usually don't know at all the diagnosis, or how to work the machine or anything like that. And so they put them in my house, and if I feel like I can get along with them and they are trainable, I train them on the ventilator. This particular nurse had a hard time getting it. Usually, it takes about three months, that's usually the pinnacle." – ICG03*

Formal caregivers rely heavily on their medical training to prepare them for being in the home. Yet, as FCG03 noted, there are significant differences between the home health care processes for adults and children/youth. FCG03 has sought out training materials for her home health agency, and in her experience, the differences between the adult and child/youth needs lead to gaps in their training protocols. FCG03 has struggled to find resources specific to the child/youth population. As she explained:

> *"I want to be on top of the most recent and the latest studies and the evidence-based materials. And you can't even find an organization for pediatric home health nurses. You've got your American nurses association; you've got your pediatric nurses association. But you go and look at their [continuing education units]and the stuff they have to support you and your organization, and it doesn't address these children. It talks about immunization records and well-child visits, and health steps. Things that are talking about your typical children with common health problems but not your complex genetically, premature…these complex children in the home receiving care…So there is just no organization that helps to guide these nurses. Our home health agency has developed our own materials so we can train our nurses. But is it the latest information? Is it evidence-based?" – FCG03*

She focused on three common care procedures that differ operationally between adult and child/youth care - "changing the trach[eostomy], operating the…ventilators, and how to care for a g-button versus a g-jay button in a pediatric patient." Her description of changing the pediatric tracheostomy is illustrative of the issues in training for all of the procedures:

> *"And it's an invasive procedure that is done bedside, and you don't learn that information anywhere but a pediatric home health agency. They don't teach it in nursing school; there is not a special program out there for it. We have education packets that we train from. But we have to say this is not an adult trach, this is a pediatric trach, so this is different. We have the written materials, but we have developed our own way of teaching trach care and trach changes of that nature. But it is the stuff that we don't have in written material – we have written material that is not truly applicable, but we train from it." – FCG03*

The training materials and resources available to the home health agency are for adult patients. While her agency has adapted, the administration would feel more prepared with specific resources for children/youth.

Informal caregivers also lack training but have differing opinions on whether it is needed. The majority of informal caregivers only received training in response to the child/youth's condition. ICG02's response was typical when asking informal caregivers if they received training:

> *"Definitely not in totality. I feel like for each little thing, like having the orthotics guy come in and talk about the safety of taking them off when I'm supposed to. That stuff we listened to and followed, but I can't think of someone coming in and being like, 'hey, you should do this to keep him safe.'"*
> *- ICG02*

At the same time, ICG02 was skeptical of such training. Three informal caregivers were unsure what training would look like or how it could be relevant to their child/youth. Another informal caregiver (ICG04) felt training would have been helpful when her daughter was younger but was not useful now that her daughter was in her 20s.

Category: costs of Safety

There are two types of costs associated with safety. The first is the direct financial costs of implementing the safety measures. The second is the tradeoffs caregivers make to maintain or improve safety in the home.

Financial costs

Informal caregivers highlighted the costs of the equipment and devices they use to keep their children/youth safe in the home. Multiple caregivers expressed that the device/equipment costs were a deciding factor in which piece to choose. As ICG02 noted, the costs are often considered essential to the CYSHCN, "Like his seizure monitor, that thing was like $650 and it just a little pad. But it's priceless." Even when insurance might cover the costs of equipment, there are barriers. FCG07 described picking out a lift for her sister: “my parents had to purchase [the lift] out of pocket because insurance said we only needed the hydraulic version of the lift. Whereas the electric version is easier and safer to use when you are doing one person [lifts].”

The caregivers pay out of pocket, utilize charities, or build something themselves to find a way to close the gap.

> *“It is just so much easier [to pay out of pocket], it's more costly of course, but I mean to get like the gates, for example, I would have had to get three quotes, from certified Builders and it would have to be ADA compliant.”-ICG02*

Some costs are not one-time costs but require maintenance and replacement:

> *“Like right now, my camera system is probably ten years old. So a lot of the infrared, you’re supposed to be able to see at night, some of the cameras are burning out. So they need to be replaced. And it’s expensive.” – ICG05*

In the CDS option, informal caregivers are responsible for selecting and hiring providers instead of relying on an agency. The informal caregiver is also given a budget for care and allowed to choose how much and what types of care their child/youth receives. ICG05 illustrated how selecting the CDS option has different costs to consider. ICG05 noted paying more than the minimum wage to recruit and retain higher-quality home care staff, yet this decision comes at the expense of having less money for other care (such as therapists). She also pays for additional insurance to protect providers who come into her house. She noted that CDS offers a workman’s compensation program but utilizing it is taken out of the overall budget. Instead, she pays for additional home insurance out-of-pocket:

> *“I have had caregivers that get bitten, which I carry an extra policy on my house for this. Because I don’t subscribe to the workman’s comp program…which gets taken out of your budget, they hit the budget, just like if*

> *someone files an unemployment claim. So I have an enhanced policy for personal people, so anyone who comes on my property I have more coverage than you usually do. It's usually like $300,000; I have like $500,000. Only because if something happens, the workers also have to be protected". -ICG05*

Tradeoffs

Caregivers also made concessions in the quest to keep children/youth safe. Two informal caregivers, ICG03 and ICG05, traded the quality of their sleep. When ICG03 cannot trust a home health nurse to respond to her daughter, she cannot sleep. She feels she needs to be ready to respond to her daughter's warning alarm because the formal caregiver would not. In ICG05's experience, the devices she installs prevent sleep, but she believes the tradeoff is worthwhile:

> *"So having that camera close by where I can hear and see them - yeah, it's annoying, don't get me wrong - but I sleep so much better knowing that if something does happen, I will hear. It turns you into a very light sleeper." – ICG05*

The caregiver may sacrifice where they live or how they live. ICG03 builds relationships with her fire department to ensure their staff are aware of her daughters' conditions and described how this strategy influenced where she lived. "I picked this particular house because it was next to the school. So they would share the same fire department. So I didn't have to go to two different fire departments to talk about it," ICG03 said.

ICG02 noted that the modifications they have made to their home (extra high counters, climbing equipment in the living area, tin on the wall) would likely make it difficult to sell in the future. If they had to move, they would need to build a custom house to add the protective features they require.

For ICG02, another tradeoff was accepting that others may judge her family's decisions:

> *"It looked like we were putting him in a cage, but we just had to get over that stigma and understand that we're doing it for his safety. If he falls out of bed and…has a seizure, the monitor won't alarm, and I won't know...We have to look past what people think about what we are doing and just do what we have to do to keep them safe." – ICG02*

ICG05 took on the additional work of recruiting and hiring her sons' home health workers to feel more comfortable with who is in her home. As she explained, "I said 'ok. I'll take on the burden of doing the CDS option' where I take on the recruiting, offer a little more money, which most parents cannot do that from what I understand." She further elaborated on the care decisions she makes, trying to find a balance in addressing her sons' needs:

> *"it's hard when the program says this much is how much you are allocated in hours per week and per year and part of that money can be split across several different areas- OT, PT, whatever the individual needs but when say for instance I wanted an OT in here, they would charge the program $30 an hour. So when you have such a limited amount [of money], what is it that is your utmost need. Yes, they need therapy, but in order for them to maintain life and quality of life, based on their need, you have to say, 'ok, I am not going to have an OT, I am going to go teach myself to OT.' The state doesn't allow you to pay yourself. In this program, I am not paid, even though they are now 18 years old. So you have to be able to know how to juggle it all." – ICG05*

Occasionally the caregivers decide to forgo the solution altogether because of the constraints. While equipment and devices were valuable safety additions to a home, one challenge caregivers encountered is that these additions might now always fit in the realities of their home. As ICG02 considered a medical bed for her son's needs, she came across an issue:

> *"And they are ginormous; they are huge. We don't have the room for that. We have two kids in that tiny room. There are actually panels that flip up… I don't have room for that. It's a medical size bed. Its medical equipment. You're buying it for medical equipment, which someday down the road, may have to happen." – ICG02*

For ICG01, certain devices did not work within a rental home's constraints, such as being unable to affix alarms and sensors in the home.

Theme: supports caregivers lack

In this section, the caregivers expanded on the challenges and barriers described above to discuss what supports they wish they had to address safety in the home care environment. They described the training and other supports that they would like to be safer or feel safer in the home.

Category: training improvements

Many suggestions were related to training the formal caregivers wished they received or how to improve the training they did receive. FCG03 reiterated her desire for training and materials targeted explicitly toward children/youth instead of adults:

> *"It's been pretty easy for me to find vent trainings because there are like DME companies, I think smith medical is one, that have developed a video training on how to operate the trilogy ventilator, and that video is probably one I've used multiple times just to get people a video of it…But there is not an official information packet that you might see through a continuing education type thing. It's a…company having one of their respiratory therapists videotaping themselves on how to operate the ventilator. And it was really meant for their patient population to educate the families; it wasn't meant for nurses."- FCG03*

ICG03 recommended every caregiver with a CYSHCN learn CPR. ICG05 articulated a similar suggestion but added that it could be difficult to go to an all-day CPR or first aid training and instead recommended someone come in the home to train caregivers. FCG07 felt every professional caregiver needs nonviolent crisis intervention training to deescalate hostile or aggressive behaviors.

Some caregivers were less specific on the content and instead had thoughts on how the training should be done. As ICG01 voiced:

> *"I think the most useful thing… [would be] two steps. One would be like just going through a checklist; these are things to keep in mind. Then after going through that, asking questions about how it could be tailored to [the CYSHCN's] specific situation."- ICG01*

Other informal caregivers repeated this idea - starting with general information and then focusing on topics specific to their child/youth's needs. ICG04 layered in peer support:

> *"instead of just saying [training is] available, talking to people like one-on-one. Like 'I realize your child is profound, and because your child is profound, this will be some things you need to look at and some plans you have in place.' Or 'I realize that your child is very high functioning, but just because they are high functioning, they aren't going to be in the clear. And so we want to train you on what to look for and how to do it.' so it would be individualized. And very one-on-one oriented but yet in a group, so there would be support systems. And maybe just maybe, as kids got older the parents of the older children could mentor the [parents of the] younger children."-ICG04*

FCG03 emphasized she needs a variety of training formats to train her nursing staff properly:

> *"For me personally, I would like to see it on video. But as a case manager and a part of distributing that information to the nurses, all formats are necessary. Because we have different learning styles. And we also have different settings in which we have to teach it. Sometimes we might not have access to a video, but we need to instruct from a pamphlet or a binder. All formats work…and we have some patients that are rural, and don't have access to the internet" – FCG03*

FCG07 encouraged incorporating hands-on training whenever possible because, as she noted, “you can only do so much training on paper. It really takes that hands-on training and being with the client and learning that person.”

Category: additional support and communication

Caregivers cited some innovative solutions to increase comfort between caregivers, reduce injury, and feel more prepared in an emergency. These supports are related to bringing in additional personnel or expanding the activity and communication between current providers. FCG04 wished for a special 911 line where CYSHCN could be flagged in the system and some of the pertinent questions related to their conditions were already answered:

> *“if they had like a special line for us to call instead of 911 during emergencies. Because sometimes they have to ask a lot of questions that take up time when you could be providing care or something else if there wasn’t so many questions.” – FCG04*

FCG06 requested another provider to accompany the formal caregiver to a home, especially at an initial visit:

> *“I don’t know if this would be financially able for people to do, but it’s so much better if, let’s say you know it’s an area or a home where you don’t really need to be by yourself, it would be nice for two people to go. Yes, if at all possible. Nowadays it would be best if you had two people”*-FCG06

FCG07 described a system with greater communication between medical providers, home care staff, and caregivers.

> *“I would want competent providers – medical providers – because I have seen a lot on clients, not on the right meds. So like better documentation as well. Because if the caregivers are documenting things like the family, the people paid to caregive, all of these people – basically coordination of care. Better coordination of care would make a lot of things easier because if we have the*

> *right psych meds or have the right whatever then the person could be more balanced, and I think that could help with safety as well…If their medicine is off, everything is off which can pose stressors and problems. Also, just awareness of the family…I have seen families that are in denial about what their loved one does when they are not around… then, when mom leaves, he beat the [heck] out of me. And I was like, 'why didn't you tell me he had violent tendencies,' no one warned me…it will not change how I feel about a person, but I could have been more prepared. Or I could have known the triggers better and known what to avoid. So communication is super important as well for safety."*- FCG07

FCG03 wished for someone to call when there was a concerning issue that is important but does not necessarily warrant additional medical care. She elaborates on how the current protocols lead to an emergency room visit that puts the child/youth at a greater risk. She used the example of a child/youth who is ventilator dependent and having issues with the ventilator.

> *"if it's an alarm on the vent and the patient is stable, but there is an alarm going off on the vent. And the nurse has been unable to resolve the issue that's causing the alarm… they can't figure out; they have gone through all the training they may have had to try to discover what might be causing the alarm to go off. The patient is stable, so it's not necessitating a 911 call, but the alarms are going off. The case manager is not going to be able to do more for them than what [the nurse] already [has] been trained to do by the case manager. And you call the DME company, and they monitor the vent, not the patient. Having that resource. Who is it that I call for this patient? Because you call the [primary care physician] and they are just going to tell you to take them to the ER. And bringing them to the ER is a way to solve the immediate problem, but it's a way to expose them to disease…and we shouldn't have to take them to the ER to troubleshoot a ventilator. Having someone that can come out and assist that patient with that current problem. But who is that on-call person…it would be really awesome if the pulmonologist who cares for these patients has an on-call person who does home visits. A lot of times, what we see in the home is not what the doctor sees in the office. That would be in the dreamy world."*-FCG03

Finally, ICG05 requested additional support in the form of an electronic personal assistant to help juggle all the things she must remember:

"I would like to get an Alexa, so I can say 'hey Alexa remind me to give [son] his medicine at this particular time, or 'hey Alexa remind me to check the wiring on [son's] TV or VCR or whatever after he goes to bed.' I literally need a mission impossible one." –ICG05

Summary of conclusions for research question 3

Caregivers cited numerous impediments to safety. Trust among formal caregivers and informal caregivers is the crux of safety for many caregivers. Yet, the caregivers describe a system that stunts trust. There are two main ways to receive a home care provider, according to the group of participants. The first is when a parent (or another informal caregiver) selects a home care agency that assigns them a provider. Often the informal caregiver has little say in who this provider is, and, as described above, the standards are variable across agencies. If an informal caregiver feels unsafe with the provider assigned to their child/youth, it's often difficult to replace them. When a child/youth's needs are severe, critical, or urgent, this can lead to the informal caregiver feeling like they have to "take what they can get" in terms of providing care, and in at least one case, this resulted in hospitalization for the child.

Alternatively, an informal caregiver can employ a provider themselves (referred to as the CDS option above) and has the responsibility to hire, discipline, and fire the provider. While the informal caregivers feel they have more say in who is coming into their house, there are still distinct barriers. Unlike an agency with a pool of providers, an informal caregiver often has to replace each provider individually and is likely to face care gaps as they go through the hiring process.

Even when caregivers found appropriate solutions for the child/youth, they encountered barriers to implementation. Complicated care systems and training that do not fulfill all needs were cited as hindering home care safety. Costs of safety can be prohibitive and often shouldered fully by informal caregivers. Informal caregivers make further concessions to address safety – whether it be giving up sleep, limiting where or how they live, or taking on more responsibility. These gaps most often affected their physical and spatial sense of safety.

Perceptions on home care training varied. Some felt satisfied; others had multiple suggestions on how to improve the training they receive. Still, others were not even open to the idea of training or were unsure what aspects of home care could improve with training. Formal caregivers wanted more specific training related to their tasks in the home and offered in various ways – written, video, and hands-on. For informal caregivers, training may not be the most effective way to affect safety. Some caregivers were not open to the idea of training. The informal caregivers felt there should be general education every caregiver knows, such as CPR or behavior modification techniques, followed by resources and support specific to the individual child/youth's needs and bolstered by connections to other caregivers.

Formal caregivers requested additional assistance in a variety of ways - special 911 lines for faster response in an emergency, additional providers to play a role in home care, and increased communication or coordination. Their solutions address their interpersonal and mental/emotional safety concerns, helping formal caregivers feel safer in the home, feel less isolated, and more prepared to address emergencies. Addressing these gaps can lead to further improvements in safety solutions.

Summary

The purpose of this multiple case study was to explore how caregivers of CYSHCN perceive and address safety issues in the home care environment. Fourteen caregivers with varying roles and relationships to CYSHCN participated in interviews describing their experiences.

The data show that caregivers define safety in myriad ways, often unique to their specific situation. Conceptually these definitions can be grouped into physical, mental/emotional, interpersonal, and spatial safety, affecting both the child/youth and the caregiver. Injury to the child/youth, trusting other people in the home, and responding to emergencies were the most frequently cited safety concerns.

Solutions to the issues vary as much as the definitions. Building relationships was a key strategy to improve interpersonal safety for both informal and formal caregivers. While the caregivers made other recommendations for successful relations, the crux of relationships seems to be matching caregivers to family and having time to build trust. Beyond building relationships, formal caregivers rely on their training and assessments to prepare themselves for going into a home. In contrast, informal caregivers depend more frequently on adding devices or equipment to their homes to best address their safety concerns.

Yet, barriers remain to safety in the home care environment. Caregivers lack the proper preparation and complex services are challenges to overcome. Moreover, there are high costs and tradeoffs to improve safety. Informal caregivers may pay out of pocket to avoid the complications of formal service requirements. They may also give up sleep, the ability to work or move, and free time to address safety in a way they feel is best. In an ideal world, caregivers would have training tailored to their specific needs, increased care coordination, and further support in the home.

The final chapter compares these findings to other studies and makes recommendations for future research and action.

CHAPTER V

CONCLUSIONS

Many children and youth with special health care needs in the United States receive home care and home health services to allow them greater participation in the community and avoid hospitalization or admission to long-term care institutions. This population has a variety of diagnoses, conditions, and care needs. Unlike institutional care settings, homes are not explicitly constructed for providing health care and other assistance (Henriksen, Joseph, & Zayas-Caban, 2009). This leads to many issues that can affect how care can be safely provided in the home, potentially preventing these children/youth from fully attaining the benefits of home care. While some research illuminates the safety issues for adults who receive home care or home health, there is less known about children/youth safety in home care environments.

The study explores the ways caregivers of CYSHCN define safety and address safety issues in a home care environment. Specifically, this research aimed to answer the following for children/youth who receive home care services:

1. How do caregivers of CYSHCN perceive safety in the home?
2. How do caregivers of CYSHCN address safety issues in the home?
3. What are the impediments to safety in the home care environment?

A multiple case study approach was selected for several reasons. Case studies are useful to answer “how” and “why” research questions and when behaviors cannot be manipulated. A case study approach is also valuable when it’s difficult to separate the topic of study (i.e., safety) from its context (i.e., home care environment) (Baxter &

Jack, 2008; Tomaszewski, Zaretsky, & Gonzalez, 2020). Finally, by exploring various perspectives through multiple cases, the research can better represent the diverse population of CYSHCN (Creswell, 2013).

Setting and sample

I recruited caregivers of children/youth who received home care services to participate in semi-structured interviews to describe their safety experiences in the home care environment. Fourteen caregivers (seven informal, five formal, and two dual-role caregivers) participated in semi-structured interviews. These participants brought various experiences to the research, each providing care to children/youth with different diagnoses or care needs, different ages and genders, and in different circumstances. Some participants were known, others had participated in a previous study, and others were referrals from colleagues. I recruited the rest through social media groups for caregivers.

Data collection methods

For the semi-structured interviews, I asked caregivers broad questions on their perceptions, feelings, and actions towards safety in the home care environment, with room to explore the topic as it specifically related to them and their experiences. Interviews across all caregivers averaged approximately 45 minutes. I encouraged every participant to give examples and describe any context and background in detail while answering the questions, yet this typically occurred more often with informal caregivers. Details of the child/youth’s conditions or previous experiences with programs or services outside of home care were frequently used to elaborate earlier responses.

Due to the COVID-19 pandemic, I had to make adjustments to the data collection strategies after completing two interviews. Originally interviews were to be conducted in person and supplemented by home tours (of informal caregivers) and document retrieval. The remaining 12 interviews were conducted over the phone to minimize exposure between myself, the caregiver, and the child/youth. I eliminated the home tours and document retrieval, as it was challenging to find virtual alternatives.

Data analysis

Each interview was audio-recorded, transcribed, and then coded. I utilized a constant comparative analysis to analyze the qualitative data. First, each interview is compared to itself, then to interviews within the same group. Finally, I compared interviews between groups (Boeije, 2002).

Interviews were initially coded based on the content of the statement. I analyzed the patterns of codes in each group to identify the most commonly cited points among caregivers within the same role. Categories were also compared across groups to understand the differences between groups. These strategies guided the final synthesis towards answering each research question.

Throughout the study, I incorporated multiple strategies to maximize the study's credibility, dependability, confirmability, and transferability. I addressed credibility in several ways. First, participants had unlimited time to discuss issues and an opportunity to review their interview transcripts to ensure I accurately and comprehensively recorded their perspectives. I triangulated the findings by including multiple types of caregivers in the data collection. Lastly, I used peer debriefing of the transcripts, coding, and interpretation as an external check on the logic and decisions made. Documentation in the form of an audit trail and reflexive notes increased the study's dependability and confirmability by making the collection and analysis processes transparent. Finally, incorporating detailed descriptions of data collection processes, settings, and participants into the final report allowed the reader to judge the transferability of the results to other settings and participants (Houghton, Casey, Shaw, & Murphy, 2013).

Summary and interpretation of results

This section provides my interpretation of the results described in Chapter 4. Each research question is interpreted based on the findings, the original conceptual model, and previously-conducted research. Because literature is absent on safety in home care for CYSHCN, much of the research I discuss focuses on older adults. I note the discrepant findings between these findings and previous research.

Research question 1

How do caregivers of CYSHCN perceive safety in the home?

Overall, the caregivers defined many physical, interpersonal, mental/emotional, and spatial safety concerns. Previous research has proposed similar categorizations concerning the safety of adults in home care[9]. Table 14 compares three previously conducted studies that included a conceptual model or typology on home care safety (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Lang & Edwards, 2006; Tong, Sims-Gould, & Martin-Matthews, 2016). All of the models include physical harm,

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[9] The Tong model was used to frame the findings of the literature review and is explained in Chapter 2.

interpersonal relationships (especially between caregiver and care recipient), and the physical environment as crucial safety elements, but there are notable differences. The Craven and Tong models do not define safety from a mental or emotional standpoint, and the Craven model included a temporal aspect that does not appear in the other categorizations.

The safety categories in this study’s model are distinct from the others for several reasons. For one, physical safety (specifically the concerns of injury of the child/youth and wandering) and interpersonal safety were the most emphasized safety concerns. While many caregivers in this study mentioned spatial safety, they focused more on the neighborhood's safety than potential hazards in the home or the layout of the home. Also, the definition of spatial safety in this study includes protecting possessions, which is not discussed in the Craven, Tong, and Lang models. This study’s findings also include the fear of responding to an emergency as a safety concern for formal caregivers. While the previous studies noted that caregivers face isolation or have distress related to caregiving, responding to emergencies was not discussed. Caregivers of CYSHCN noted similar concerns as previous studies but placed different emphasis on the relative importance of these concerns.

Table 14: Comparison of Safety Conceptual Models

	Current Study	Craven Model* (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012)	Tong Model** (Tong, Sims-Gould, & Martin-Matthews, 2016)	Lang Model*** (Lang & Edwards, 2006)
Home Care Population	CYSHCN	Adults	Adults	Adults
Data Collection Method(s)	Interviews with formal and informal caregivers	Interviews with formal caregivers (home care)	Interviews with adult care recipients and informal caregivers	Literature Review, key informant interviews, expert roundtable
Physical Safety	Injury to CYSHCN (hurt self, eating, injury from CG) Wandering; Infections; injury to CG (back injury, biting, hitting from CYSHCN)	Injury to Caregiver including musculoskeletal injuries, trips, falls, and communicable disease	Injury to Caregiver or Client including musculoskeletal injuries, trips, falls, and communicable disease	*called functional safety – how health condition, the aging process, and provision of care affects daily living
Interpersonal Safety	How caregivers interact with each other or with the CYSHCN	Concerns from interactions between workers' and families impacting psychologically, socially, or emotionally	Concerns from interactions between workers' and families impacting psychologically, socially, or emotionally	*called social safety – where a client lives in the community, who lives with the client, who visits home, social network
Mental/ Emotional Safety	Fear of tending to emergency, inner peace of CYSHCN or caregiver	n/a	n/a	*called emotional safety - the psychological impact of receiving/providing services
Spatial Safety	Including hazards in the house, unsafe neighborhoods, and being unable to move around the community; Safety of possessions –	Concerns arising from the layout of home, hazards, and neighborhood	Concerns arising from the layout of home, hazards, and neighborhood	*called physical safety – location of the home in the community, the layout of the home

*Also has temporal safety - Concerns related to the timing of the service and the worker's schedule, rushing with clients, and time pressures **This model was based on the Craven et al., 2012 model. Researchers found temporal safety was not a primary concern for clients and family caregivers. ***This model uses different terms noted here.

Looking at the specific concerns within the safety categories highlights other differences. Previous research indicates that some of the most pressing safety concerns in the home are adverse drug events, line-related incidents, infections, wounds, and falls (Hall Ellenbecker, Samia, Crushman, & Alster, 2008; Masotti, McColl, & Green, 2010). In contrast, in this study, these concerns received little attention. Only one or two caregivers mentioned these concerns briefly. There was more focus on other aspects of safety rather than these issues. For example, more participants discussed injuries due to behavior or cognitive abilities affected by child/youth conditions.

Another difference was how caregiver injury is operationalized. In this study, caregivers discussed their own injuries in the context of back injury from transferring the child/youth and injury from the child/youth when overwhelmed or upset. Previous studies showed needlestick injury to be a prevalent risk to caregivers, potentially affecting 14% of home health workers (Gershon, et al., 2009). Yet needlestick injuries were not mentioned by any of the caregivers in this study, even those who provide nursing care or whose child/youth receives nursing care. It seems this is not a significant concern for them.

Lastly, as elaborated in Chapter 2, much of the literature on the physical environment of the home identifies unsanitary conditions, unsafe home layouts, chemical or fire hazards, and lack of safety equipment (Henriksen, Joseph, & Zayas-Caban, 2009; Gershon, et al., 2007; Gershon, et al., 2008). In this study, only two formal caregivers discussed these concerns, and the discussion was brief. Instead, conversations around the physical environment focused more heavily on the neighborhood and the community and how safe caregivers feel. In particular, the school setting influences caregivers' safety concerns, a result not found in the adult care literature. The school acts as an additional stressor for informal caregivers because they must put safeguards in place or release control and trust others to care for their child/youth.

Research question 2

How do caregivers of CYSHCN address safety issues in the home?

The caregivers have implemented solutions targeting their safety concerns, affecting one or more of the safety categories. Table 15 summarizes the solutions introduced in Chapter 4, organized by which category of safety the solutions affect according to caregivers.

Formal caregivers have more structured supports than informal caregivers. They refer to assessments and rulebooks or training they receive more readily than informal caregivers. Their solutions address their specific role in the home. Informal caregivers were more likely to develop solutions on their own to identify what worked for their home and family. They were also more focused on physical safety issues. Informal caregivers rely heavily on adding devices, modifying the home, and strategies that reduce the chance of injury or disease (e.g., cleaning and exercising).

The interventions identified in the scoping review in Chapter 2 show a similar pattern. Formal caregivers were more likely to receive the intervention, being the target of interventions in approximately 40% of the scoping review studies. By contrast, informal caregivers were only the target of intervention strategies in 20% of the studies. Education or training was the most utilized intervention in the scoping review, followed by additional assessment or adding equipment and technology. This finding is perhaps, not surprising, as it mirrors a typical institutional care perspective on addressing safety – where paid care providers with mandatory training requirements are the norm.

Table 15: Summarized Caregiver Solutions by Safety Categories

	Solution	Physical*	Mental/ Emotional	Interpersonal	Spatial
Tool chest	Device	x	x	x	x
	Emergency bags		x		
	Home modifications				x
	Medical equipment	x			
Preemptive activity	Clean and sanitize	x			
	Exercise	x			
	Provide CYSHCN with a safe space	x			
Training	Train formal caregiver	x	x	x	
	Train informal caregiver	x	x	x	
Become familiar	Assess environment or caregiver	x	x	x	x
	Be aware of surroundings			x	x
	Build relationships			x	

* x denotes at least one participant in the caregiver group spoke on this topic.

However, there are benefits to the inclusion of informal caregivers in research and care. Doing so is often cited as a care ideal to strive for. In fact, the Institute of Medicine considers informal caregiver involvement critical as part of their quality and accountability standards (Varni, Burwinkle, Seid, & Skarr, 2003). Informal caregivers are reliable conduits for care recipient’s needs and barriers to care while also providing rich, lived input on the day-to-day experiences (Elliott, et al., 2011; Seid, Sobo, Gelhard, & Varni, 2004). As seen in this study, informal caregivers articulate areas of safety risk that elude formal caregivers, such as the potential for wandering, children/youth hurting themselves or others, and the mental safety of the caregivers and care recipient. The presence and role of formal caregivers in the home typically limit their perceptions of safety. In contrast, informal caregivers and care recipients are often concerned with safety for a longer period, regardless of a formal caregiver’s presence (Tong, Sims-Gould, & Martin-Matthews, 2016).

There are few instances in which formal and informal caregivers address safety together as a team. I found no examples of this through the scoping review. As seen in this study, occasionally, formal caregivers make referrals or teach informal caregivers, while informal caregivers explain their care preferences or provide their own teaching to the formal caregivers. Yet, for both groups, these exchanges seem to be unstructured, sporadic, and highly dependent on the individual caregiver. Involving informal caregivers in interventions such as training can lead to more effective care (Matson, Mahan, & Matson, 2009; McConachie & Diggle, 2006). Addressing informal and formal caregivers' needs in one safety intervention may be particularly salient in home care. Mutual acknowledgment of skills and consideration for their roles between informal caregivers and health care professionals can influence interventions' success (Pelchat & Lefebvre, 2004).

In this study, the caregivers use similar solutions identified in the scoping review: education/training, assessment, adding equipment or technology, modifying the home, exercising, and cleaning. However, they also incorporate safety strategies into their lives not found in the scoping review. Formal caregivers were the leading proponents of being aware of their surroundings. Informal caregivers suggest having an emergency bag tailored to their child/youth's needs and providing a safe space for the child/youth. Both groups felt building relationships was critical to feeling safe. These solutions could be formalized into interventions to determine the effectiveness of these strategies on safety for CYSHCN in home care.

Research question 3

What are the impediments to addressing safety in the home care environment?

This group of caregivers identified several challenges that hinder safety - including formal caregivers sleeping, lack of relevant caregiver training, and a home care or home health system that hinders trust between caregivers. Further, caregivers noted multiple ways home care settings might be less safe than the hospital; hospitals have multiple safeguards to address emergency situations, prevent medication errors, prevent caregivers from falling asleep while working, and keep unsafe individuals from entering the hospital. Additionally, at home, a child/youth can move around even when attached to medical equipment, unlike in a hospital where mobility can often be limited.

This final point echoes sentiments from Henriksen, Joseph, & Zayas-Caban, (2009) in that "a home is more than a physical structure" (p.232). In their proposed model focused on human factors affecting adverse events in home care, the authors review an extensive list of potential concerns in the home care environment that can affect safety, including many described here. Yet, the authors advise, one must balance the care needs of the home care recipient with the comforts of home while ensuring safety (Henriksen, Joseph, & Zayas-Caban, 2009).

Adding a device or piece of medical equipment that addresses the primary safety concern was a common solution. Challenges arise in finding the best device to fit in the home. For one, the most appropriate safety devices or equipment do not fit within a home or are too permanent to affix in certain situations, like rental housing. Costs also become a potential barrier here. Multiple caregivers cited considering the costs of the device when choosing one to put in their home. Other caregivers lamented the costs of the device, especially long-term costs of maintenance and upkeep. Caregivers describe circumventing the formal service system to pay for equipment or devices out of pocket; either because it would not be covered or having it covered required extra obstacles to overcome.

In one study, the Safe Home Program, researchers identified 21 possible devices and equipment to improve safety for individuals with dementia in the home (McKenzie, Bowen, Keys, & Bulat, 2013). Many of which the caregivers in this study also utilize (sensors, cameras, locks). The researchers used a home assessment and worked with caregivers to determine which devices or equipment addressed their needs. They installed the devices and provided hands-on training for the caregivers. They found caregivers felt safer given the new additions. Even when an individual needed the most expensive equipment (bed occupancy sensor that cost $500 in 2013 dollars), the device was cost-effective compared to the potential costs of a hospital visit from injury (McKenzie, Bowen, Keys, & Bulat, 2013). Such supports for CYSHCN may help overcome the challenges noted in this study. It is a comprehensive solution that considers both the broad and the specific needs of the family and the child/youth.

Training (or some form of education) is often the first choice of intervention when addressing safety. However, based on the caregivers' feedback in this study, training may only be effective in certain situations. For formal caregivers, it’s an expected part of their job. Still, formal caregivers felt improvements could be made to their training regarding what it covers and how. Informal caregivers cited lack of time, inability to leave for long periods, lack of interest, and skepticism that training could address their specific needs as barriers to completing the training.

In the adult safety literature, education aimed at informal caregivers was successful when combined with other supports. Horvath, et al. (2013) found that combining an educational booklet with low-cost safety devices in a randomized clinical trial of caregiver/patients with dementia dyads improved safety in the home. Samus et al. (2014) saw significant improvement in a home and personal safety score for elderly adults with memory disorders when they incorporated informal caregiver education alongside comprehensive care coordination.

When asked what else they would like to feel safe or be safe in the home, formal caregivers turned to strategies that would increase the personnel support. They suggested including two home care providers whenever possible, better connections to physicians or medical professionals, and increased care coordination. One example of additional personnel addressing safety that shows promise is the inclusion of non-clinical community workers (who could consult with an RN and geriatric psychiatrist when needed) as care coordinators. As care coordinators, the workers provided education and referrals, assessed needs to create individual care plans, and monitored care, among other activities (Samus, et al., 2014). Such a solution may address the concerns of the formal caregivers in this study.

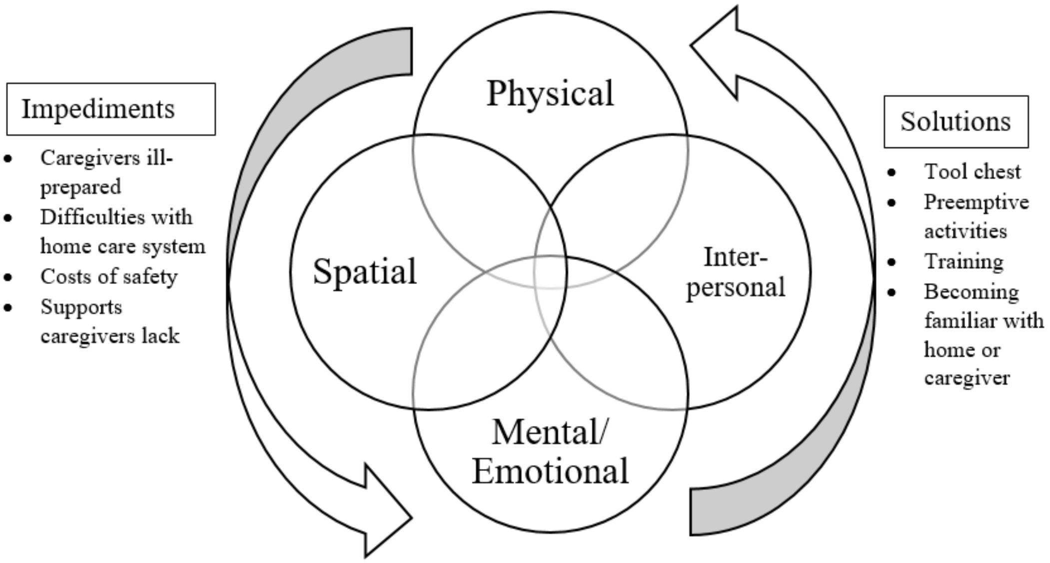
Finally, one informal caregiver wanted a voice-controlled device to help remind her when to complete certain tasks. Proponents of this technology suggest such a device would not only be useful as a reminder system but could increase care coordination by being a more user-friendly way to log symptoms, events, or care provided. Furthermore, integrating the information gathered in the device within the larger health care system will maximize its potential as a health care tool (Sezgin, et al., 2020).

Final interpretation

Creating a conceptual model for CYSHCN

Based on these findings, I propose a conceptual model for children/youth in home care, as shown in Figure 5. The four categories of safety – physical, interpersonal, mental/emotional, and spatial – described by the caregivers fill the center of the model. The safety categories are represented as overlapping circles to illustrate that some safety concerns may intersect.

Figure 5: Conceptual Model for CYSHCN



The arrows on each side of the safety circles represent the solutions caregivers use and the impediments they face regarding safety. These solutions and impediments influence safety. Solutions mitigate or prevent the negative consequences of safety and include the caregiver tool chest, preemptive activities, training caregivers, and becoming familiar. The impediments include the challenges caregivers face that make addressing safety more difficult. They include a lack of preparation, complex systems, and the costs of safety.

Comparison to other conceptual models

I constructed this model based on the Tong model (Tong, Sims-Gould, & Martin-Matthews, 2016) and the caregivers' responses in this study. The model distinguishes itself from its predecessors because it represents CYSHCN as the care recipients and considers formal caregivers and informal caregivers within the same model. The definitions of safety used in this model reflect how the caregivers defined safety and vary somewhat from the original model.

In previous studies, spatial safety plays a more prominent role in safety and is diagrammed accordingly by overlapping all other safety domains (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Tong, Sims-Gould, & Martin-Matthews, 2016). The caregivers in this study did not emphasize the role of spatial safety to the same degree, so this distinction is not made in the model I propose. Further, allowing all types of safety to have a similar size represents the need to consider all types of safety in the home in any further study.

This model’s solutions and impediments mirror the predecessor models’ mitigating and intensifying factors, respectively. However, the terms solutions and impediments reflect the research data better. I intended this conceptual model to form the base of further study on the safety in home care environments for CYSHCN.

Summary

These findings indicate that caregivers of CYSHCN consider many factors when determining what safety looks like in the home care environment. The safety challenges for children/youth in home care are similar to adults in many capacities but not all. Caregivers of CYSHCN prioritize various concerns and think about safety in somewhat different ways. Similarly, while the previously conducted research in adult home care settings can guide how to address safety, solutions still need to be tailored to children/youth's specific circumstances.

A fully comprehensive approach to safety in home care for CYSHCN should consider the following elements. The next section discusses how research and the health care system can incorporate these constructs.

- Using a multi-faceted definition or measure of safety that goes beyond assessing the physical environment and the risk of injury to also include emergency preparedness, interpersonal relationships, possessions, and feelings of safety for all caregivers and the care recipient.
- Include supports (whether it be training, assessment, referrals) that address general concerns for all CYSHCN and be tailored to each child/youth's specific needs individually.
- Training may be insufficient on its own but effective as part of comprehensive supports (e.g., additional assessment, referrals, and peer support),
- Incorporate formal and informal caregivers in identifying issues or implementing solutions. Addressing safety issues together has the added benefit of helping foster the relationship between caregivers needed to help them both feel safe in the home.
- Cost for any solutions measured in both financial costs and tradeoffs.

Recommendations

Based on the study's findings, I derive recommendations for the next steps in research and action. First, safety measures should be developed and tested that better reflect all of the physical, mental/emotional, interpersonal, and spatial concerns identified in this study. The measures should incorporate formal and informal caregiver input to assess all the concerns in a home fully. Additionally, the safety measures should include discussion of caregiver safety alongside child/youth safety.

Once developed, the collection of such data through assessment could be routinized and utilized alongside other assessments of the child/youth’s needs. Subsequent solutions could then be tailored to the home and the individuals' needs and guided by the findings above. Such assessment may result in additional safeguards when in the home, referrals for services or devices and equipment, education related to the concerns, or increased oversight for the home to ensure safety. In particular, informal caregivers noted preferences for assessments and solutions that start broadly and include common safety challenges for CYSHCN and then layering in items specific to their child/youth's needs or conditions.

A vital part of this process would be to encourage informal and formal caregivers to identify and create solutions for these safety issues together whenever possible. Such partnerships recognize both caregivers as essential players in the home care team and help facilitate the caregivers' relationship. Comprehensive solutions that address safety through multiple mechanisms will likely be more supported by informal caregivers. For example, addressing a concern with wandering could encompass training and devices. Additional research should study what solutions would be most realistic, feasible, and sustainable as supports for formal and informal caregivers.

Moreover, there is an absence of data for children/youth who receive home care services. Standardizing data elements across the state or nation and making them unidentifiable and publically available can answer a multitude of questions about safety.

One example of a home care dataset is the Centers for Medicare and Medicaid Services (CMS) Outcome and Assessment Information Set (OASIS) data. Medicare-certified home health agencies must complete OASIS records for their adult patients and submit them to CMS regularly. An OASIS record covers a wide range of data, including conditions, care needs, behavior, cognition, and living conditions for each care recipient. Safety underlies many of the items in the record. OASIS data at an individual record level is available for researchers who follow proper protocols to obtain it. Researchers could answer various questions related to outcomes, quality, and care for those in home health agencies. I did not find any comparable dataset for children/youth or those who need just home care (and not home health).

Additionally, CMS aggregates some of the OASIS data in conjunction with a client survey to create a quality rating for each home health agency, which is publically available. The rating is also available via a Medicare website called Care Compare, which allows any user to search for home health agencies near them and filter by various services and quality ratings.

A system like this replicated for CYSHCN would provide numerous benefits. Standardized data would be available for researchers to identify safety issues and outcomes, especially as they tie to care needs and gaps. A rating website for children/youth in home care would allow informal caregivers to evaluate the home care or home health agencies they are working with, giving them additional information to guide decisions when choosing an agency. If possible, aligning the child/youth data to match adults' data would allow researchers to look at what safety in home care looks like across a lifetime, comparing priorities, needs, and issues between the populations.

Study limitations

Some limitations to the study must be noted. Recruitment into the study was based on volunteers sourced via convenience sampling. Participants may have a more significant interest in safety in the home care environment or had more intensive experiences related to safety that motivated them to participate than the larger home care population. These experiences may hinder the transferability of the findings. Second, the formal caregivers in the study were limited to nurses and home care providers. I attempted to recruit other providers, such as therapists, but none participated. The results may not be transferable to other providers.

Qualitative research relies on the researcher's interpretation of the data collected (Creswell, 2013). Other researchers could organize and analyze the data differently and come to a different interpretation. To minimize this and increase the credibility and dependability of this study, I shared my process for others to offer judgments. The peer debriefing and review strategies ensured that decisions made during the analysis process were logical and clear. Moreover, incorporating reflexivity into the process helps make the process transparent to readers (Houghton, Casey, Shaw, & Murphy, 2013).

Finally, I made changes to the study design due to the COVID-19 pandemic. These changes included most of the interviews conducted over the phone instead of in-person, data collection taking part before and during the pandemic, and no in-house observations. These changes limited the study at hand to findings based on participants' verbal descriptions. I could not confirm findings through observational data. Future studies should consider including such data collection techniques to verify and support the data collected from interviews.

Concluding thoughts

Many children and youth with special health care needs rely on home care and home health to have integrated and healthy lives in the community. For home care to be effective, it must also be safe. Yet safety in a home is different from safety in institutions. It’s a complex issue that varies depending on the individuals in the home, the home itself, the healthcare system, and the community. It is a balance between implementing a multitude of solutions that can limit a child/youth and still allowing a house to feel like a home. There are many gaps in understanding safety, including the best ways to assess and measure safety, what outcomes are associated with safety, and how to create sustainable solutions that are most applicable to those in the home care environment day-to-day. However, by addressing these issues, some of the most vulnerable children and youth can avoid unnecessary gaps in care and hospitalizations.

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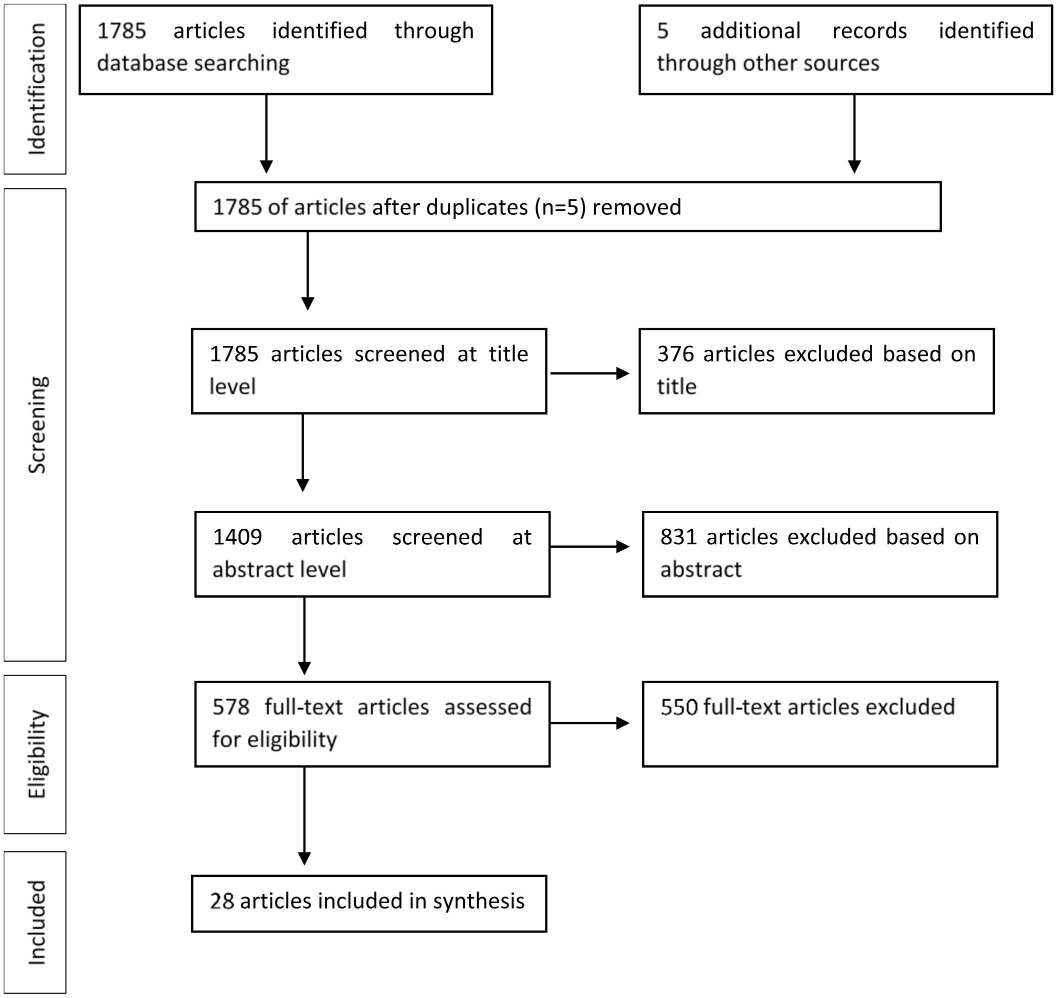
APPENDIX A

ARTICLE INCLUSION PROCESS AND REFERENCES INCLUDED IN SCOPING REVIEW ON SAFETY IN HOME CARE INTERVENTIONS

Figure 6: Article Inclusion Process for Scoping Review



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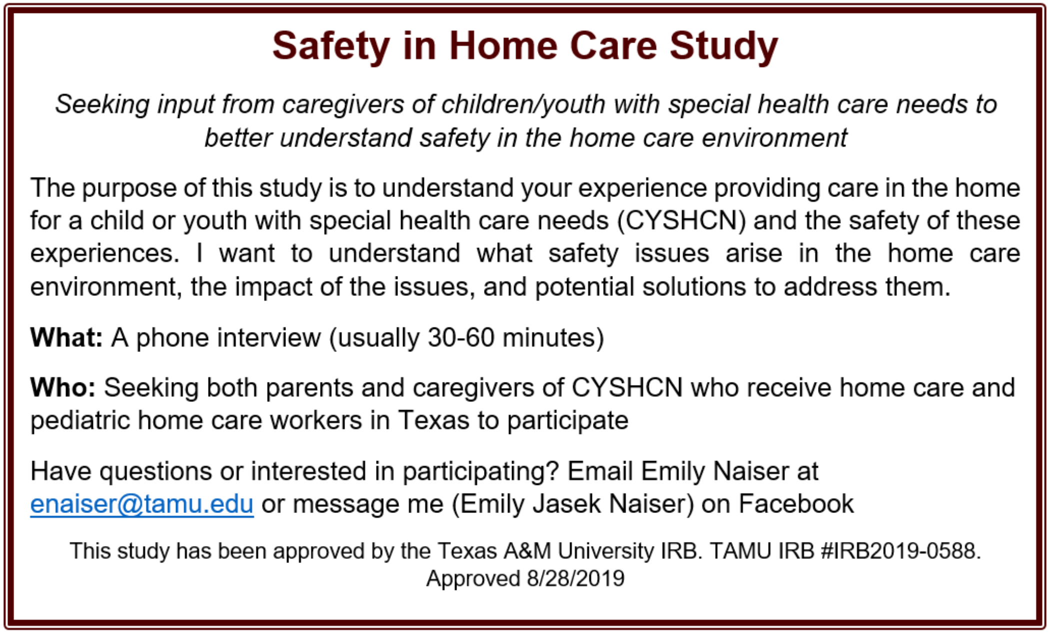
APPENDIX B

RECRUITMENT MATERIALS

Figure 7: Sample Facebook Recruitment Message



Safety in Home Care Study

Seeking input from caregivers of children/youth with special health care needs to better understand safety in the home care environment

The purpose of this study is to understand your experience providing care in the home for a child or youth with special health care needs (CYSHCN) and the safety of these experiences. I want to understand what safety issues arise in the home care environment, the impact of the issues, and potential solutions to address them.

What: A phone interview (usually 30-60 minutes)

Who: Seeking both parents and caregivers of CYSHCN who receive home care and pediatric home care workers in Texas to participate

Have questions or interested in participating? Email Emily Naiser at enaiser@tamu.edu or message me (Emily Jasek Naiser) on Facebook

This study has been approved by the Texas A&M University IRB. TAMU IRB #IRB2019-0588.
Approved 8/28/2019

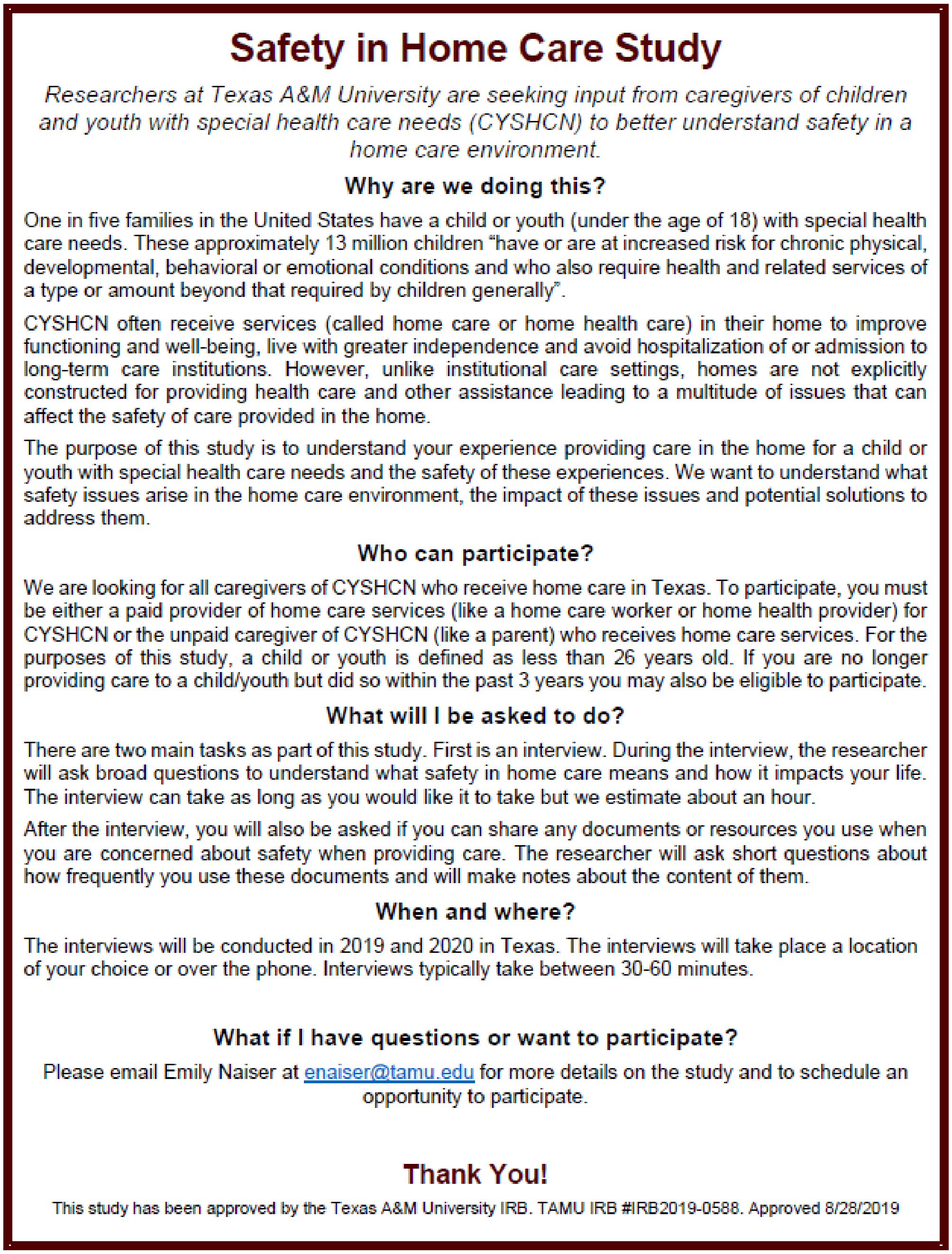
Text Accompanying Facebook Message

Hi all,

I am seeking participants to be interviewed about their perspectives on safety while providing care to children with disabilities in the home for a dissertation study. I want to know what issues you've experienced and how you address them. A little more information on the study is included in the photo. Feel free to reach out to me via email at enaiser@tamu.edu or through Facebook (Emily Jasek Naiser) with any questions or to participate.

Thank you!

Figure 8: Sample Recruitment Flyer



Safety in Home Care Study

Researchers at Texas A&M University are seeking input from caregivers of children and youth with special health care needs (CYSHCN) to better understand safety in a home care environment.

Why are we doing this?

One in five families in the United States have a child or youth (under the age of 18) with special health care needs. These approximately 13 million children "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally".

CYSHCN often receive services (called home care or home health care) in their home to improve functioning and well-being, live with greater independence and avoid hospitalization of or admission to long-term care institutions. However, unlike institutional care settings, homes are not explicitly constructed for providing health care and other assistance leading to a multitude of issues that can affect the safety of care provided in the home.

The purpose of this study is to understand your experience providing care in the home for a child or youth with special health care needs and the safety of these experiences. We want to understand what safety issues arise in the home care environment, the impact of these issues and potential solutions to address them.

Who can participate?

We are looking for all caregivers of CYSHCN who receive home care in Texas. To participate, you must be either a paid provider of home care services (like a home care worker or home health provider) for CYSHCN or the unpaid caregiver of CYSHCN (like a parent) who receives home care services. For the purposes of this study, a child or youth is defined as less than 26 years old. If you are no longer providing care to a child/youth but did so within the past 3 years you may also be eligible to participate.

What will I be asked to do?

There are two main tasks as part of this study. First is an interview. During the interview, the researcher will ask broad questions to understand what safety in home care means and how it impacts your life. The interview can take as long as you would like it to take but we estimate about an hour.

After the interview, you will also be asked if you can share any documents or resources you use when you are concerned about safety when providing care. The researcher will ask short questions about how frequently you use these documents and will make notes about the content of them.

When and where?

The interviews will be conducted in 2019 and 2020 in Texas. The interviews will take place a location of your choice or over the phone. Interviews typically take between 30-60 minutes.

What if I have questions or want to participate?

Please email Emily Naiser at enaiser@tamu.edu for more details on the study and to schedule an opportunity to participate.

Thank You!

This study has been approved by the Texas A&M University IRB. TAMU IRB #IRB2019-0588. Approved 8/28/2019

APPENDIX C

INTERVIEW FACILITATION GUIDE

Overview

The majority of research in home care safety relies on the formal caregiver perspective; there is a paucity of research on informal caregivers' perceptions (Lang & Edwards, 2006; Tong, Sims-Gould, & Martin-Matthews, 2016). Initial work suggests that informal caregivers conceptualize safety differently than home health workers (HHWs) (Lang, et al., 2009; Tong, Sims-Gould, & Martin-Matthews, 2016). Understanding this distinction is critical to defining and addressing safety in home care.

Even less is documented on the potential impact of safety incidents on caregivers' ability to provide care. One small study has shown that when informal caregivers were injured significantly enough to have stop providing care to care recipients, around 40% were able to find alternative caregivers while the remaining 60% of care recipients had to be admitted to a hospital (Brown & Mulley, Injuries sustained by caregivers of disabled elderly people, 1997). Formal caregivers report shortening the visit ("leaving as soon as possible") or refusing the assignment when they felt unsafe (Kendra, Weiker, Simon, Grant, & Shullick, 1996) (Gershon, et al., 2007) (Galinsky, et al., 2010).

This phase of the research plan has three main goals. The first is to understand how caregivers view safety in the home care environment. The second is to determine the potential impact of caregivers being unable to continue providing care due to safety risks. Finally, caregivers will be given an opportunity to identify potential solutions to home care safety issues. To improve safety in the home care environment and to perpetuate a team approach in home care, perceptions of and solutions to safety issues need to be derived from the perspectives of all members.

Additionally, operationalizations of safety, caregiving impacts of injury and incidents, and potential solutions will be compared between formal and informal caregivers. Finding distinct differences in how caregivers perceive and approach safety would make a case for broadening safety definitions and approaches to capture these distinctions. Whereas identifying similarities between the caregivers highlights natural points to utilize team-based strategies.

To gather these perspectives, I will conduct semi-structured interviews, document analysis, and observations with caregivers. I intend to analyze their responses with a case study methodology using constant comparative strategy.

Research Topics

Other themes will likely emerge during analysis but I will specifically answer:

- How do caregivers define safety in home care? What individuals do they focus on when discussing safety (themselves, care recipient, other caregivers, their family, etc.)?
- What sources of safety or injury risk concern caregivers? Is any cause more significant or more frequently mentioned than others?
- What is the potential impact on caregiving when the caregiver is injured?
- What are the training or knowledge needs of caregivers to reduce safety risk?
- Are there solutions to ameliorate safety concerns at home?

Participants

Participants from each group will be recruited until saturation, that is until no new information is being obtained from additional participants. Previous research suggests that between 8-15 participants in each group (informal caregivers and formal caregivers) will be appropriate (Green & Thorgood, 2014).

Materials

- Informed consent form (if in person)
- Consent script (if over phone)
- Protocol
- Background Questionnaire and Interview Guide
- Document Retrieval Form
- Audio recorders, tapes, batteries
- Paper and pens for participants to jot down thoughts (if in person)

- Business cards for participants in case of followup (if in person)

General Guidance

1. Prior to beginning of the meeting with participant, be sure to review the entire protocol.
2. Obtain Informed Consent. Ask each participant to read and sign the informed consent form. Give each person an unsigned copy of the form to keep.
    a. If telephone interview, read consent as part of introductory script
3. If participants agree to be audio recorded, begin both audio recorders (use iPhone as recorder should one or both audio recording devices fail).
4. Text to be read aloud to participant is noted with [SCRIPT], bolded and in purple
5. Conduct introduction (see Introductory Script).
6. Conduct interview (see Questions). Numbered questions are the main questions that should be asked or covered during the focus group. Bulleted questions and questions in parentheses are guidance for probing and ensuring rich responses to main questions**.**
    a. Record verbal consent and responses to demographic questions.
7. Request document retrieval (see Document Retrieval tasks)
8. Thank participant and close.
9. Complete the post-assessment facilitator questions found at the end of this protocol.

Introductory script

[SCRIPT] Welcome. Thank you for agreeing to be a part of this study. My name is Emily Naiser and I will be leading this interview. This is [Name] who will be taking notes.

There are two tasks I would like to do with you today. The first is an interview. The purpose of this interview is to understand your experiences providing care in the

home care and the safety of these experiences. I want to understand what safety issues arise in the home care environment, the impact of these issues and potential solutions to address them.

Your cooperation is totally voluntary. If you decide not to participate or do not want to answer a question, you may do so. You can, of course, decline to answer any question, as well as stop participating at any time. This will not affect any services you receive.

I will be recording this interview solely for note-taking purposes. Nothing you say will be linked to you. Any analysis or reporting of your responses will be anonymous.

After the interview, I would like to see any documents or materials you use when you have a safety concern about caregiving. I have a few short questions about each resource and will take notes about the content.

Your de-identified information may be used or shared with other researchers without your additional informed consent.

This is a consent form for the study. I will give you a few minutes to review and complete it.

Before we begin, do you have any questions?

Participant Information

Each interview will start with collecting contextual information on the caregiver. All participants will be asked initial demographic questions about themselves and their experience in home care. See Background Questionnaire at end of this document for exact questions.

[SCRIPT] To get started, I have some questions about you. This will provide me with a bit of background when I am analyzing the data.

Interview Questions

[SCRIPT]

1. ***Today, I am interested in understanding what you as a caregiver perceive to be the safety concerns of providing care in the home to a***

child or youth with special health care needs. What comes to your mind when you think of safety while providing care?

2. *What safety risks do you face?*
    a. *Are there any particular safety risks that are more concerning to you than others?*
    b. *Are there particular times or activities that have you more concerned with safety than others?*
3. *When are you most concerned with safety? Is there a certain time of day or when performing certain tasks?*
4. *If you were to have an injury or incident that prevented you from providing care, how would that impact the child/youth with special health care needs?*
5. *Have you received any training or information on being safe while providing care?*
    a. *If so, who provided the training/information, and what did it cover?*
    b. *If not, would you like to receive such training/information?*

6. *Do you feel you need additional training/information on safety while providing care?*
    a. *What do you think would be the most effective way for such education/training to be delivered?*
7. *What would help you be safer or feel safer when providing care in the home?*

Document Retrieval

[SCRIPT] I am also interested in any documents or resources you might use to address safety issues when providing care in the home.

1. *Can you share with me any training materials you have that are related to safety in home care?*

2. ***Can you share with me any documents that describe policy guidelines or guidance in regards to safety in home care environment?***
3. ***Are there any other particular websites, books, documents you look at when you are concerned about safety? Can you share them with me?***

For each document, I will note the following:

- Title
- Author/Organization
- ***General idea of content [Ask caregiver, if unsure]***
- ***What pieces do you refer to the most [Ask Caregiver]***
- ***How frequently do you refer to this [Ask Caregiver]***
- For each document/resource, I will take a picture of the relevant pieces or find it on the web and bookmark it.

[SCRIPT] Thank you, if you think of any other materials you would like to share with me, please email me.

Closing

[SCRIPT] Is there anything else about safety in the home care environment that you would like to talk about today that we have not already discussed?

That is all we have for today. Thank you so much for your time and your input. If you are interested, I can provide you with the transcript of our interview today to review. Here is my contact information if you have any other concerns.

Post-assessment

Within 24 hours of meeting with the participant, I will answer the following questions on each task of the meeting.

Interview

1. Where was this participant recruited from?
2. Where was the data collected? Telephone or in-person Interview
3. Was anyone else present besides the participant and interviewer?
4. How long was the interview?

5. General impression of interview.
6. What were key points?
7. What was surprising?
8. How did this interview differ from prior interviews?
9. Does anything need to be changed prior to the next interview?

Document Retrieval

1. Does CG need follow-up email to share documents? If yes, send email (see included)
2. Approximately, how long did it take CG to find document(s)?
3. How familiar did CG seem with document(s)?
4. Was I able to find the documents referenced?

ID# ___________

Background Questionnaire for Formal Caregivers

This is a short questionnaire to gather demographic information about yourself and your experience in home care with children/youth.

About Yourself:

Sex

☐ Male ☐ Female ☐ Prefer not to answer

Age

☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ Over 65

☐ Prefer not to answer

Are you Hispanic, Latino or Spanish origin

☐ Yes ☐ No ☐ Prefer not to answer

Race (select all that apply)

☐ White ☐ Black or African-American ☐ American-Indian or Alaskan Native

☐ Asian ☐ Other (specify)__________________________ ☐ Prefer not to answer

What is the highest level of education completed?

☐ Some high school ☐ High School Graduate/GED ☐ Some College

☐ College Graduate (Bachelor’s or Associate’s degree) ☐ Post-Bachelor’s Degree

☐ Prefer not to answer

What is your current position? ____

How long have you been working in home care? __________________________________

Approximately, how many clients do you provide care for each week? _________________

How many of these clients are children/youth (under 26 years old)? ________________

Think about the children/youth you care for. Typically, what tasks do you assist with? (Select all that apply)

ADLs

☐ Mobility ☐ Positioning ☐ Eating ☐ Transferring

☐ Toileting ☐ Dressing ☐ Personal Hygiene ☐ Bathing

IADLs

☐ Meal Preparation ☐ Medication Assistance ☐ Laundry

☐ Light Housework ☐ Escort/Transportation Services

☐ Telephone Use or other Communication ☐ Money Management

☐ Grocery or household shopping

Other

☐ Nursing Services ☐ Therapies (physical, occupational, speech, etc.)

☐ Other (specify)____

ID# ___________

Background Questionnaire for Informal Caregivers

This is a short questionnaire to gather demographic information about yourself and the child/youth with special health care needs you provide care for.

About Yourself:

Sex

☐ Male ☐ Female ☐ Prefer not to answer

Age

☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐Over 65

☐ Prefer not to answer

Are you Hispanic, Latino or Spanish origin

☐ Yes ☐ No ☐ Prefer not to answer

Race (select all that apply)

☐ White ☐ Black or African-American ☐ American-Indian or Alaskan Native

☐ Asian ☐Other (specify)__________________________ ☐ Prefer not to answer

What is the highest level of education completed?

☐ Some high school ☐ High School Graduate/GED ☐ Some College

☐ College Graduate (Bachelor’s or Associate’s degree) ☐ Post-Bachelor’s Degree

☐ Prefer not to answer

Annual Household income

☐ Less than $50,000 ☐$50,000 - $99,000 ☐$100,000 or more

☐ Prefer not to answer

How long have you lived in your current residence? ___________________

About the Child/Youth with Special Health Care Needs You Care for:

Sex of child/youth

☐ Male ☐ Female ☐ Prefer not to answer

Age of child/youth _________________

Relation of child/youth to you____

Does the child/youth live with you full-time?

☐ Yes ☐ No ☐ Prefer not to answer

Who else lives in the home with you and the child/youth?

Number of adults (18 years old or older) (not counting yourself) ______________

Number of children (under 18 years old) (not counting child/youth) ____________

What health insurance is the child/youth currently covered on? (Select all that apply)

☐ Insurance through employer ☐ Insurance purchased directly from insurance company

☐ Medicare ☐ Medicaid or CHIP ☐ TRICARE or other military health care

☐ Other (specify)______________________________ ☐ Prefer not to answer

☐ Do not know

Does the child/youth receive assistance/services in the home by individual(s) paid to provide care (e.g., home health worker, personal care aide, nurse, therapist, etc.)?

☐ Yes ☐ No ☐ Prefer not to answer

If yes, what kinds of tasks does the child/youth receive assistance in? (Select all that apply)

ADLs

☐ Mobility ☐ Positioning ☐ Eating ☐ Transferring

☐ Toileting ☐ Dressing ☐ Personal Hygiene ☐ Bathing

IADLs

☐ Meal Preparation ☐ Medication Assistance ☐ Laundry

☐ Light Housework ☐ Escort/Transportation Services

☐ Telephone Use or other Communication ☐ Money Management

☐ Grocery or household shopping

Other

☐ Nursing Services ☐ Therapies (physical, occupational, speech, etc.)

☐ Other (specify)____

Approximately, how many hours per week does the child/youth receive care from paid provider(s) in the home? __________

Verbal Consent script

Did you have a chance to read the information sheet I gave you? Did you have any questions?

{if participant indicates they read the sheet and have no question}

Great! Are you ready to proceed?

Welcome. Thank you for agreeing to be a part of this study. So just to re-iterate

There are two tasks I would like to do with you today. The first is an interview. The purpose of this interview is to understand your experiences providing care in the home care and the safety of these experiences. I want to understand what safety issues arise in the home care environment, the impact of these issues and potential solutions to address them.

Your cooperation is totally voluntary. If you decide not to participate or do not want to answer a question, you may do so. You can, of course, decline to answer any question, as well as stop participating at any time. This will not affect any services you receive.

I will be recording this interview solely for note-taking purposes. Nothing you say will be linked to you. Any analysis or reporting of your responses will be anonymous.

After the interview, I would like to see any documents or materials you use when you have a safety concern about caregiving. I have a few short questions about each resource and will take notes about the content.

{if participant indicates they did not read the sheet}

Before we begin, I need to read some important information about the study.

I am conducting a research study to understand the safety issues faced by those who care for a child/youth with special health care needs in their home as part of a dissertation. You are being asked to participate because you provide care in the home.

This research is supported by Texas A&M University.

There are a few things you should know about this study.

Whether or not you take part is up to you.
You can choose not to take part.
You can agree to take part and later change your mind.
Your decision will not be held against you.
You can ask all the questions you want before you decide.

The purpose of this study is to understand your experience providing care in the home for a child or youth with special health care needs and the safety of these experiences. We want to understand what safety issues arise in the home care environment, the impact of these issues and potential solutions to address them. We are asking for up to 50 people to participate in this study.

This study will take approximately 2 hours of your time over multiple days. First, there will be an interview, taking approximately 60-90 minutes. Then you will be asked if you would like to share any documents that you reference when you think about safety. This document retrieval will take about 15 minutes. After your interview response is transcribed, you will be given an opportunity to review your transcript via email. This will take up to 15 minutes.

If you say yes, you will be asked to take part in an interview. During the interview, I will ask broad questions to understand what safety in home care means and how it impacts your life. The interview can take as long as you would like it to take but we estimate about an hour. The interview will be audio-recorded for note-taking purposes. You will also be given an opportunity to review the transcription from the interview and provide comment at a later date. Prior to the interview, you will be given a short questionnaire to complete that asks you about yourself and the child/youth you care for.

After the interview, you will also be asked if you can share any documents or resources you use when you are concerned about safety when providing care. The researcher will ask short questions about how frequently you use these documents and will make notes about the content of them. You may be asked to send the documents electronically and will be instructed to remove identifying information. The only identifying information will be your email address.

There are no risks to being a part of this study beyond the discomfort you may feel when discussing health and safety issues.

Efforts will be made to limit the use and disclosure of your personal information, including research study and other records, to people who have a need to review this information. We cannot promise complete privacy. Organizations that may inspect and copy your information include the TAMU HRPP/IRB and other representatives of this institution. Confidentiality will be maintained to the extent of the law.

Identifiable data will be retained for up to 5 years after study completion. The data will be stored in a secured, locked cabinet and on an encrypted server only accessible to the research team.

I will send you the contact information for myself, the principal investigator on this study and the Texas A&M University Institutional Review Board. You can contact them at any time if you have any concerns or questions about this research.

Do you have any questions?

Would you like to participate in the study?

Good morning/afternoon,

I want to thank you again for participating in the interview with me to discuss safety in home care. During our conversation, you indicated that you would like me to follow-up in case you thought of more safety references or documents.

If the following information is included in the documents, please cover up before sending:

- Names of the care recipient
- Any ID numbers (such as Social security Number, beneficiary number, Medicaid number)
- Geographic information (address, zip codes)
- Telephone number

If you have any further questions, please do not hesitate to ask.

Thank you,

Emily Naiser

APPENDIX D

CODEBOOK

Table 16: Codebook in Alphabetical Order by Parent ID

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
1		Advocate	This is less about safety explicitly and more about how CG has to advocate to get certain care/treatment for CR.	n/a	excluded from final analysis	n/a	9.9.9
2		Always thinking about safety	CG is constantly thinking about what the next safety issue	n/a	excluded from final analysis	n/a	9.9.9
3		Assessing safety	Examples of how CGs assess the home or other CGs. For FCG, this is often talking about what types of assessments they do and the details about it. For ICG, there is an occasional comment about types of assessment done but most are talking about what they would like an assessment to look like and how it should be conducted	Address	Solution	Becoming Familiar	2.1.1
4		Barrier	Barriers to safety	Impediments	Barriers		3.1.0
5	4	Gap or problem in current "system"	CG noted struggle in the health care system or when working with specific organizations/services	Impediments	Barriers	Difficulties with system	3.1.1
6		CG unable to respond	CG concern is rooted in (other) CG being unable to respond to emergency or child/youth need	Impediments	Barriers	Ill-prepared to provide safe care	3.1.2

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
7	6	Asleep	Concern that (other) CG is unable to respond because sleeping	Impediments	Barriers	Ill-prepared to provide safe care	3.1.2
8	6	not trained	Concern that (other) CG is unable to respond to issue because they are not trained properly	Impediments	Barriers	Ill-prepared to provide safe care	3.1.2
9		Costs of safety	CG gives some indication of the costs of addressing safety issues.	Impediments	Barriers	Cost	3.1.3
10	9	Financial Costs	describes the $ costs of addressing a safety issue	Impediments	Barriers	Cost	3.1.3
11	9	Tradeoffs	describes the tradeoffs the CG/family makes to address a safety issue.	Impediments	Barriers	Cost	3.1.3
12		Decreasing safety issue	CG notes that something is less of a concern than it used to be.	n/a	excluded from final analysis	n/a	9.9.9
13	12	Outgrew issue	CG said child growing older/more mature was the reason for a decrease in safety concern	n/a	excluded from final analysis	n/a	9.9.9
14		Defining Safety	how safety is defined by CG or source	Perceive	Concerns		1.1.0
15	14	"safety" of possessions	CG defines safety as feeling protective of possessions - space, things, or information	Perceive	Concerns	Spatial	1.1.4
16	14	Avoid CG injury	CG defines safety as avoiding CG injury or incident; specifics often relate to these types of injuries that occur or that CG anticipates could occur.	Perceive	Concerns	Physical	1.1.1
17	16	Specifics	CG describes example/specific concern related to CG injury	Perceive	Concerns	Physical	1.1.1
18	14	Avoid CR injury	CG defines safety as avoiding CR injury or incident; specifics often relate to these types of injuries that occur or that CG anticipates could occur.	Perceive	Concerns	Physical	1.1.1
19	18	Specifics	CG describes example/specific concern to CR injury	Perceive	Concerns	Physical	1.1.1

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
20	14	Fear of having to tend to emergency	CG defines safety as fear of responding/dealing with emergency	Perceive	Concerns	Mental/Emotional	1.1.2
21	14	Physical environment	when the CG describes the safety concerns as being the house, the layout of the house or the neighborhood itself	Perceive	Concerns	Spatial	1.1.4
22	14	Relationships	when CG cites relationships with others as the point of concern It may include people in the neighborhood. When the CG defines safety concern as the people in the neighborhood, it ends up here; if its the neighborhood itself, it goes in PE	Perceive	Concerns	Interpersonal	1.1.3
23	22	Protect CR or CG from violence/abuse/neglect	this is similar to relationships - the root cause is relationships but a little more connected to physical harm instead of just "feeling" safe	Perceive	Concerns	Physical	1.1.1
25	14	Safety of inner peace	safety of mental health and "feeling safe"; this may overlap with relationships a bit	Perceive	Concerns	Mental/Emotional	1.1.2
26		Describes feeling generally safe	the CG used words describing feeling safe at this point, but these comments do not make sense in isolation. often they felt "safe" about a particular issue or after overcoming the challenges that make them feel unsafe - i.e., a previous home health worker gave them an issue, but now they had a different one - things like that	n/a	excluded from final analysis	n/a	9.9.9
27		Does not need additional training or support	CG responded they did not need anything else at this point to feel safe	Impediments	Supports Lack	Additional Support and Communication	3.3.2

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
28		emergency preparedness (not related to conditions)	CG talks about being prepared for an emergency that is not related to or affected by CR's conditions/diagnoses - just general emergency preparedness	n/a	excluded from final analysis	n/a	9.9.9
29		Future safety issues	when the CG indicates they are thinking about what safety issues will arise in the future	n/a	excluded from final analysis	n/a	9.9.9
30		Home health is not a hospital	CG indicates how care/concern would be different if it were a hospital setting	n/a	excluded from final analysis	n/a	9.9.9
31		ICG doing complex care	I coded this because it was an interesting observation I got from the literature. Not sure it will fit into my final code tree. CGs do not express concern overdoing these activities; they just state that they are done.	n/a	excluded from final analysis	n/a	9.9.9
32		Reactionary	this is when the CG stated the solution was in relation to an incident occurring.	n/a	excluded from final analysis	n/a	9.9.9
33		Reference	discusses safety reference (website, material, book) either use or do not use	Address	Determining Solution	Using formal supports	2.2.1
34	33	Cites policy/rulebook	CG describes a policy or handbook in regards to safety (but it seems like its more thought of in terms of care not specific to safety)	Address	Determining Solution	Using formal supports	2.2.1
35	33	Does not have specific references	CG does not use particular safety references.	Address	Determining Solution	Using formal supports	2.2.1
36		Safety Impact	what would happen if CG was unable to provide care	n/a	excluded from final analysis	n/a	9.9.9
37	36	Backup for Emergency	only has a backup for emergencies; not long-term	n/a	excluded from final analysis	n/a	9.9.9

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
38	36	Has backup	CG would have a backup if something were to happen to them while providing care	n/a	excluded from final analysis	n/a	9.9.9
39	36	Likely have a backup but not positive	CG may have a backup but isn't sure	n/a	excluded from final analysis	n/a	9.9.9
40	36	No backup	CG does not have backup	n/a	excluded from final analysis	n/a	9.9.9
41	36	Psychological	The FCG feels the CR would be impacted on an emotional level if FCG was to leave - not just care-wise.	Address	Solutions	Becoming Familiar	2.1.4
42		Safety Strategies - Approaches	This describes what strategies CG use to address safety in the home	Address	Solutions		2.1.0
43	42	Avoid chemicals	CG avoids chemicals	n/a	excluded from final analysis	n/a	9.9.9
44	42	Aware of surroundings	CG is aware of surroundings and minimizes the potential for incident/injury	Address	Solutions	Becoming Familiar	2.1.4
45	42	Baby proof	CG adds a baby-proof device or other babyproofing strategies to prevent incidents. This is similar to a device, so likely will combine later, but this is meant to be for things that are not really medical or related to conditions but instead are general for children/youth	Address	Solutions	Tool Chest	2.1.1
46	42	Challenge	CG noted challenge to implementing a safety strategy	Impediments	Barriers		3.1.0
47	42	Cleaning/sanitize	Cleaning/sanitize to avoid injury or illness	Address	Solutions	Preemptive Activities	2.1.2
48	42	Create something	The CG creates a device or a home modification or a tool to decrease safety risk typically because they	Address	Solutions	Tool Chest	2.1.1

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
			can't find what they want or they need something more tailored to their needs				
49	42	Device	CG describes device (camera, sensor, etc.) as support for safety issue	Address	Solutions	Tool Chest	2.1.1
50	42	Emergency bag	Always have an emergency bag/to-go bag to respond to emergencies	Address	Solutions	Tool Chest	2.1.1
51	42	Give CR safe space	Give CR safe space to reduce the likelihood of an incident	Address	Solutions	Preemptive Activities	2.1.2
52	42	Home modifications	modifications/add something to respond to safety concern	Address	Solutions	Tool Chest	2.1.1
53	42	Identified Gap	when discussing the solution, identified gap	Impediments	Barriers		3.1.0
54	42	Increase strength to reduce the likelihood of injury	Increase strength to reduce the likelihood of injury; recoded as an exercise in the final analysis	Address	Solutions	Preemptive Activities	2.1.2
55	42	Medications, vitamins, supplements	Medications, vitamins, supplements (including holistic) to prevent illness or injury	n/a	excluded from final analysis	n/a	9.9.9
56	42	Relationships	CG describes building a relationship with other CG as a critical element of safety	Address	Solutions	Becoming Familiar	2.1.4
57	42	Release energy to reduce injury to others	CG discusses how they avoid CR injuring others by wearing them out first; recoded as an exercise in the final analysis	Address	Solutions	Preemptive Activities	2.1.2
58	42	remove CG from situation	to get out of an unsafe situation, CG is removed	n/a	excluded from final analysis	n/a	9.9.9
59	42	Shelter in place	CG describes protecting themselves by locking themselves away	n/a	excluded from final analysis	n/a	9.9.9
60	42	train siblings	ICG has trained CR siblings to help with a safety issue	n/a	excluded from final analysis	n/a	9.9.9

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
61	42	Uses equipment	uses equipment/DME or other devices to avoid safety issue	Address	Solutions	Tool Chest	2.1.1
62	42	Working as a team	CG cites working together with providers, others, CGs as critical to safety	Address	Determining Solution	Using formal supports	2.2.1
63		Safety Strategies - How Developed	CG gives insight as to how came up with a solution/approach to the issue	Address	Determining Solution		2.2.0
64	63	Adjustment	changing up strategies to work with CR;	n/a	excluded from final analysis	n/a	9.9.9
65	63	Ask other parents	CG talks to other parents to get advice, recommendations, etc.	Address	Determining Solution	Using formal supports	2.2.1
66	63	Assess and anticipate	Cg is aware of surroundings/situation and trying to predict what could happen	Address	Determining Solution	Using formal supports	2.2.1
67	63	Discuss with colleagues	CG would talk to other FCGs about issues	Address	Determining Solution	Using formal supports	2.2.1
68	63	Discuss/work as a team to come up with a solution	when CG talks about working with parents, providers, etc. to develop a solution (not peers)	Address	Determining Solution	Using formal supports	2.2.1
69	63	Do own detective work	The CG seeks out answers on own	Address	Determining Solution	Informal Caregivers	2.2.1
70	63	Use internet	uses the internet to find the strategy	Address	Determining Solution	Informal Caregivers	2.2.1
71	63	utilize formal services/supports to help	utilize formal services/supports to help	Address	Determining Solution	Using formal supports	2.2.1

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
72		Tailoring	how the CG would like training/information, HHW, or other safety strategies tailored to their CR's specific needs	n/a	excluded from final analysis	n/a	9.9.9
73		The role of school in safety	When the CG described the influence of the school setting - sometimes it was where new habits were picked up; other times it was when incidents happened at school; still, others were how the school environment was a source of stress for CG as CR couldn't protect themselves	Perceive	Concerns	Spatial	1.1.4
74		Training	The CG describes training they received or wished to receive.	Address	Solutions	Training	2.1.3
75	74	Describes training wish to receive	CG discusses what training they or someone else would receive.	Impediments	Supports Lack	Training Improvement	3.3.1
76	74	Has not received training	when asked it received training on safety, CG states they have not	Impediments	Supports Lack	Training Improvement	3.3.1
77	74	Not open to training	CG is not open to the idea of training.	Impediments	Barriers	Ill-prepared to provide safe care	3.1.2
78	74	Received	Responded yes to the "have you received training related to safety" question	Address	Solutions	Training	2.1.3
79	74	Satisfied	CG said they were satisfied with the training received	Address	Solutions	Training	2.1.3
80	74	Specifics of Training Received	Describes what training look like	Address	Solutions	Training	2.1.3
81	80	Relies on non-HH training	CG talks about non-home health or non-healthcare training received that helps them now	Address	Solutions	Training	2.1.3
82	74	Unsure what it would look like	CG is unsure what such training would look like	Impediments	Barriers	Ill-prepared to	3.1.2

Id	Parent Id	Code	Description	RQ	Theme	Category	Tree Number Code
						provide safe care	
83	74	Would like training	Stated open/was open to receiving training; discussed what training would like	Impediments	Supports Lack	Training Improvement	3.3.1
84		Wants additional supports	when asked if they need anything to feel safer or be safer, these are the supports suggested. this does not include requests for training (as that is captured above)	Impediments	Supports Lack	Additional Support and Communication	3.3.2
85	84	Two people to assist	additional person to assist CG	Impediments	Supports Lack	Additional Support and Communication	3.3.2
86	84	an on-call specialist who makes house calls	a back-up to deal with specific issues related to a condition	Impediments	Supports Lack	Additional Support and Communication	3.3.2
87	84	special 911 line	a special emergency response where a lot of the information is already known.	Impediments	Supports Lack	Additional Support and Communication	3.3.2