Exploring care work system adaptation:

A study of family-generated strategies for caring for children with medical complexity

By

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Dedication

To Pop Jaques, who told everyone that I was going to be a doctor and swore I could "make

anything happen, even cooking, if I really wanted to."

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When I was accepted into the ISyE PhD program in 2019, my world—scratch that, the world—was profoundly different. It is hard to capture just how much my life has been transformed since then, though the pandemic may be an accurate metaphor. Like the pandemic, there were hard truths to face, uncertainties to navigate, and tough situations to make the best of. But also like the pandemic, there were profound opportunities to reassess values, redesign life, and forge new relationship(s) to community. I would not be completing this degree if not for the support of many people through my graduate education and the years leading up to it.

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Abstract

Families caring for children with medical complexity (CMC)—children with multiple chronic conditions requiring frequent hospitalizations, many care specialists, and complicated medication regimens and/or device use—face many challenges in providing the around-the-clock, in-home care their children need. These challenges often result from the mismatch between families' resources and the work required to provide high-quality care for their children. Families consistently report being under-trained and under-supported in performing necessary, yet complex care tasks, e.g., tracheostomy care. Thus, families are often forced to develop their own solutions to overcome the challenges they face in caring for their CMC in light of the limited resources. This dissertation uses a Human Factors Engineering approach to explore the strategies that families develop to care for their CMC, conceptualizing caregiving as *care work* that takes place in a *care work system,* which invariably shapes work processes and outcomes. Specifically, this dissertation expands our understanding of how family-generated strategies relate to the dynamic care work system. Building off previous analyses of a rich dataset of 30 in-home, contextual inquiry-style interviews with families caring for CMC, I conducted an analysis of the relationships between family-generated strategies and work system barriers and facilitators, i.e., factors that hinder or support care work. The results of this dissertation provide theoretical grounds for an expanded conceptual model of family-generated strategies that recognizes that work system facilitators are integrally related to strategies. Further, the study provides practical insight into the work systems of families caring for CMC that can be used to design interventions that support families' care work and their capacity to adapt, i.e., develop strategies, as needed to ensure the delivery of high-quality care to their child.

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Chapter 1: Introduction and Background

1.1 Problem statement

Children with medical complexity (CMC)—children with multiple chronic conditions and care specialists, frequent hospitalizations, and who often rely on medical devices to replace essential body functions—require around-the-clock care, the majority of which is delivered by family members in the home (Berry et al., 2011; Cohen et al., 2011; Simon et al., 2010). Caring for CMC often requires the performance of complex health care tasks, e.g., tracheostomy care and complex medication management, that families consistently report being under-trained and under-supported in providing (Abebe et al., 2020; Coller et al., 2016; Hodgkinson & Lester, 2002; Jennings, 1990; Nelson et al., 2016; Wang & Barnard, 2004). The mismatch in families' resources and the work required to provide high-quality care for their children negatively influences outcomes for children, caregivers, and families alike. For example, under-supported CMC are at an increased risk of otherwise avoidable hospitalization (Coller et al., 2014) and their family caregivers often experience isolation (Raina et al., 2005; Raina et al., 2004) and lost employment (Cohen et al., 2011) among other poor mental and physical outcomes (Coller et al., 2016; Kuo et al., 2011; Thyen et al., 1999). Further, the devices and technologies families must use are not typically designed for use in the home context, increasing caregiving burden and the likelihood of costly device-related complications, which have been associated with increased Emergency Department and hospital use (Barton et al., 2021; Berry et al., 2011; Nackers et al., 2019). Thus, families are often forced to develop their own solutions to overcome the challenges they face in delivering high-quality, in-home care with the resources they have (Barton et al., 2021; Barton et al., 2020).

The field of Human Factors and Ergonomics (HF/E), "the science of work," is uniquely equipped to support families caring for CMC through its aim to design human-system interactions that optimize workers' well-being *and* system performance (*What is Ergonomics?*). Researchers have begun to apply HF/E theories and methods to support caregiving by conceptualizing caregiving as a form of patient work, i.e., "the performance of effortful work activities by patients and informal caregivers in pursuit of health goals" (Holden et al., 2020; Holden et al., 2015). The patient work conceptualization situates patients and caregivers as performers of care work at the center of a *care work system*. This complex system is made up of interactions between work system elements—i.e., between *caregivers*, the care *tasks* they perform, the *tools and technologies* they utilize, and the *physical and organizational contexts* they perform care in—that shape work processes and outcomes (Holden, Carayon, et al., 2013; Holden et al., 2015).

Placing patients' and caregivers' work at the center of a care work system provides an opportunity to identify "barriers," i.e., aspects of the work system that impede an individual's ability to achieve their desired outcomes, and "facilitators," i.e., aspects of the work system that support an individual's ability to achieve their desired outcomes (Carayon et al., 2005; Carayon et al., 2019; Holden et al., 2015). Identified work system barriers can then be eliminated or counterbalanced by facilitators to achieve work system "balance," improving the system's processes and outcomes (Carayon, 2009). The re-balanced work system's processes and outcomes then can feed back to and re-shape the work system through system adaptation (Carayon et al., 2006; Carayon et al., 2014). To achieve desired outcomes—including the delivery of high quality, patient-centered care—the system adaptation feedback loop can be

leveraged to re-design the system (Carayon et al., 2014; Holden, Carayon, et al., 2013; Hollnagel et al., 2006).

Adaptation has been conceptualized in many ways, e.g., as working around barriers (Alter, 2014; Halbesleben et al., 2008), problem solving (Holden, Rivera-Rodriguez, et al., 2013), or developing strategies (Carayon et al., 2019; Durso et al., 2015; Mickelson & Holden, 2018). Literature on adaptation in formal healthcare delivery settings has mostly focused on workarounds to newly introduced technologies and procedures, such as problem-solving behaviors of nurses interacting with bar-coded medication administration (Holden, Rivera-Rodriguez, et al., 2013; Novak et al., 2013), the use of paper after implementation of the electronic health record (Saleem et al., 2009; Vogelsmeier et al., 2008), and the persistence of unsafe practices in the operating room (Espin et al., 2006). Morath and Turnbull (2005) call healthcare workers "masters at workarounds" given how frequently they must adapt their work, even in physical and organizational environments explicitly designed for care. In environments that support work less formally, such as the care work systems of patients and caregivers, workarounds may be even more pervasive as workers face more barriers (Barton et al., 2020).

Initial research studying adaptation in care work systems has used the concept of strategies, i.e. behavioral or cognitive activities aimed at dealing with work system barriers, to uncover how patients and caregivers perform or better fit care work to their lives and homes (Barton et al., 2021; Barton et al., 2020; Barton et al., 2022; Holden et al., 2019; Mickelson & Holden, 2018; Weiler, Lingg, Wilkins, et al., 2022). For example, Barton et al. (2020)'s exploratory study of CMC caregivers' care work systems identified four levels on which families were implementing strategies: (1) medical device, i.e., modifying a medical device or other tool required for caregiving, (2) direct care, i.e., modifying work done directly to the child, (3)

auxiliary care, i.e., modifying any other factor that supports direct care, and (4) integrate into life, i.e., modifying anything not directly related to care that is required to integrate caregiving into life in an effective way (Barton et al., 2020). These findings point to the range and scale of goals families aim to reach with the strategies they develop, yet there remains a gap in understanding how families generate strategies and how those strategies relate to the existing care work system.

A recent study of strategies employed by family caregivers of people with dementia provided a first step toward understanding the connection between the care work system and the strategies caregivers develop (Weiler, Lingg, Wilkins, et al., 2022). Weiler et al. did this by mapping work system barriers to common care events and the strategies families used to address those constraints (Weiler, Lingg, Wilkins, et al., 2022). While the resultant maps offer rich contextualized data of caregivers' strategy use, there remain gaps in our understanding of strategies' relationship(s) to work system barriers and facilitators. First, the study does not explicitly consider work system facilitators, which we know play an important role in system balance (Carayon et al., 2006; Carayon et al., 2014). Studying the relationship between work system facilitators and strategies may reveal how families leverage positive work system elements to achieve their care goals. Second, the study uses a linear conceptualization of strategies, i.e., in the context of an event, a caregiver uses a strategy to respond to a work system barrier. This linear approach does not fully capture the complexity of the work system in which caregivers are employing strategies. Work that aims to capture the broader work system context, i.e., related work system facilitators and barriers, around caregivers' strategies is warranted to explore strategies as an emergent property of a complex system.

The goal of my research is to explore the relationship between family-generated strategies and the care work system. First, I aim to identify the strategies that families have developed in caring for their CMC. Second, I aim to explore and describe the relationship(s) between work system barriers, facilitators, and family-generated strategies.

1.2 Structure of the dissertation

In Chapter 2, as the basis for my research, I review literature in patient ergonomics and work systems models, discuss a variety of conceptualizations of system adaptation, and present an integration of the adaptation literature. In Chapter 3, I present my conceptual framework of family-generated strategies and research questions. In Chapter 4, I describe the methods I used to answer my research questions, as well as discuss my research philosophy. In Chapter 5, I present the results of the study, including the family-generated strategies and work system barriers and facilitators identified as well as mechanisms that describe their relationship(s). In Chapter 6, I discuss my findings and their implications, the study's strengths and limitations, and potential future work. Finally, in Chapter 7, I summarize the key aspects and findings of the study to conclude the document.

Chapter 2: Literature Review

In Chapter 2 I provide an overview of the literature that informs this research. First, in section 2.1 I frame chronic illness management as work, define patient ergonomics, and identify a gap in our study of care work. Second, in section 2.2 I review the utility of a work systems approach, present a brief review of relevant work systems models, and describe the concept of system adaptation and resilience. Third, in section 2.3 I review a few key conceptualizations of adaptation, i.e., workarounds, problem solving, and strategies. Finally, in section 2.4 I present an integration of the adaptation literature.

2.1 Patient ergonomics and care work

For the hundreds of millions of people managing chronic illness(es) in the United States alone, interactions with formal healthcare represent a small proportion of their care when compared with daily self-care and illness management, e.g., taking medications, tracking health indicators, and performing daily care (Bodenheimer et al., 2002; Corbin & Strauss, 1985). The home- and community-based care that is done by patients or their caregivers themselves has been called "care between the care" (Figure 1) (Brennan & Casper, 2015). Recognizing the impact of "care between the care" on health outcomes, healthcare quality leaders have called for an integration of healthcare over time—between multiple healthcare delivery sites, home, etc.— through a focus on the "patient journey" (Carayon et al., 2020; Hignett et al., 2013). One key to integrating healthcare longitudinally is to recognize the role patients play in their own healthcare and designing patient-centered systems to support and empower them.
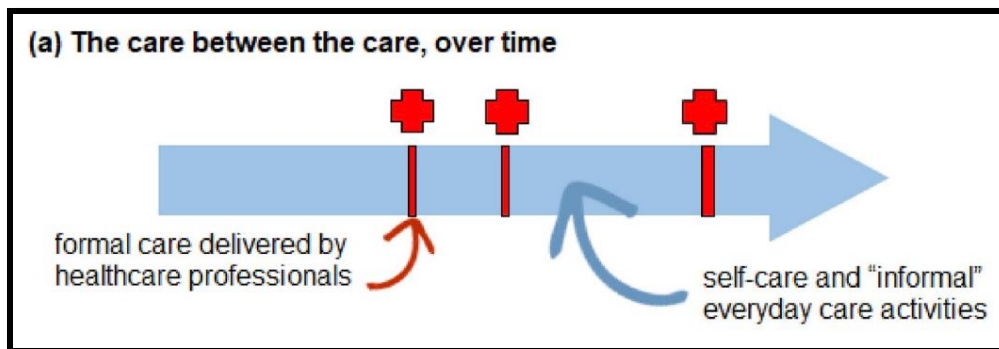
Figure 1. A graphical depiction, from Holden et al. (2020, p. 2)'s 10-year mapping review of patient ergonomics, of the "care between the care" over time.

The field of patient ergonomics addresses this need to study and design for the patient journey by conceptualizing the self-care that patients do as *patient work,* i.e., "the performance of effortful work activities by patients and informal caregivers in pursuit of health goals" (Holden et al., 2020; Holden et al., 2015) in order to apply Human Factors and Ergonomics (HF/E) tools to it. Holden and Valdez (2018, p. 466) define patient ergonomics as: "The application of HF/E or related discipline (e.g., human-computer interaction, usability engineering) to study or improve patients' and other non-professionals' performance of effortful work activities in pursuit of health goals" (Figure 2).

Patient ergonomics has been applied to a variety of activities integral to the self-management of chronic illness(es), often addressing care processes (e.g., communication, error management, self-care, decision making, etc.), tools and technology (e.g., medical devices, monitoring devices, health IT), or some combination thereof (Holden et al., 2020). Yet, there remains a gap in our understanding of the work that caregivers do to support patients who may otherwise be unable to engage in their own care. In Holden et al. (2020)'s review of the past 10-years' worth of patient ergonomics literature, the authors suggest this to be a critical area of future work.
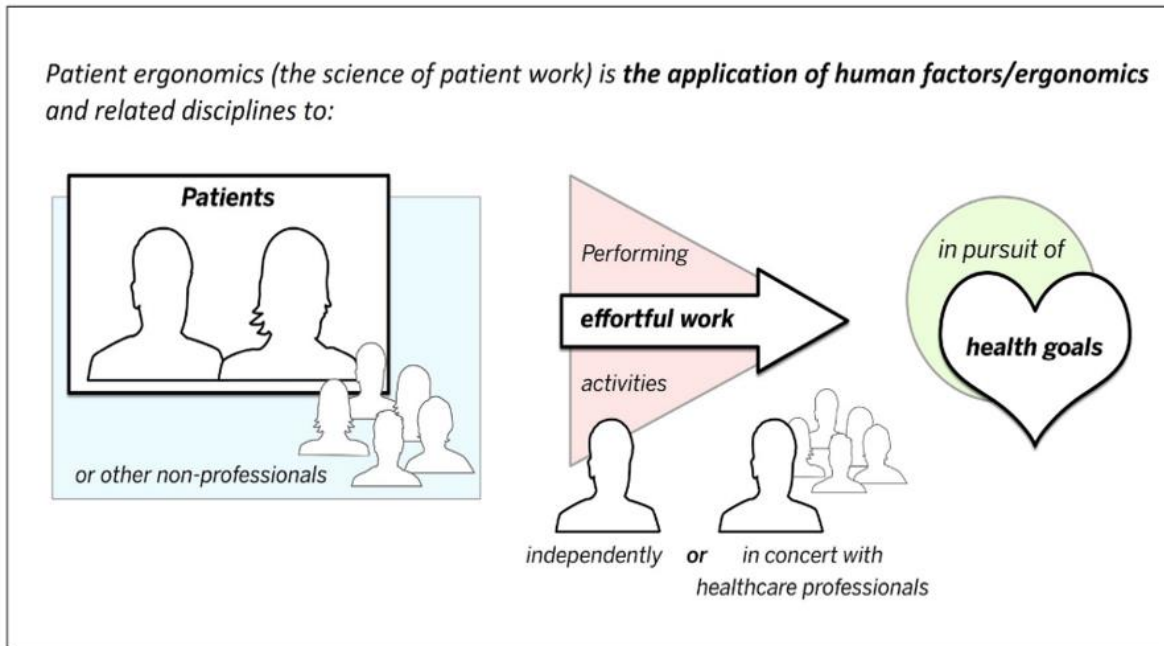
Figure 2. Depiction of the definition of patient ergonomics (Holden et al., 2020, p. 4).

Studying the work of caregivers, i.e., care work, is critical because caregiving is known to be quite burdensome (Adelman et al., 2014; Liu et al., 2020; Rigby et al., 2009; Thyen et al., 1999). While caregiving can be a meaningful experience that brings family-members closer, saves on resources, and gives the caregiver peace of mind that the patient is receiving high-quality care (Beach et al., 2000; Tarlow et al., 2004), under-supported care work is consistently associated with higher-rates of isolation and loneliness (Bonin-Guillaume et al., 2022; Raina et al., 2005), poorer mental and physical health outcomes (Adelman et al., 2014; Brodaty & Donkin, 2009; Kuo et al., 2011), and a greater mortality risk (Schulz & Beach, 1999). Further, the negative impact of overburdened caregivers often extends to the patient's outcomes, e.g., increased rates of hospitalization (Coller et al., 2014).

HF/E researchers have begun to fill in the gaps in our understanding of care work and care work systems so that we can better support caregivers (Werner, Rutkowski, et al., 2022).

For example, Ponnala et al. (2020)'s work defined caregiving roles, mapped how roles related in a care network, and proposed a comprehensive taxonomy of care work tasks the caregivers performed. Rutkowski et al. (2019) and Ponnala and Werner (2020) explored caregiver workload, adapting an HF/E workload measurement tool to study care work and providing a conceptual model of caregiving capacity, respectively. Further, HF/E research has described care work system elements individually, e.g., by studying barriers caregivers face with respect to the tools and technologies they use (Block et al., 2020; Parks et al., 2021) and the physical environment they provide care in (Doutcheva et al., 2019), and in complex interactions that shape processes, e.g., information management (Rutkowski et al., 2021; Weiler, Lingg, Eagan, et al., 2022). Finally, initial research has begun to describe the strategies that caregivers develop and implement to perform or better fit care work to their lives and homes (Barton et al., 2021; Barton et al., 2020; Barton et al., 2022; Weiler, Lingg, Wilkins, et al., 2022).

2.1.1 Caring for children with medical complexity

Families caring for children with medical complexity (CMC) are an exemplary case for studying care work. An otherwise heterogenous population, CMC are identified by their multiple chronic conditions, high healthcare utilization, reliance on medical devices, and significant need for care, typically provided by family members (Berry et al., 2011; Cohen et al., 2011). For example, a caregiver's tasks for a day could include operating multiple medical devices, managing medications, preparing feeds that meet specific nutritional standards, tracking symptoms, coordinating appointments, working with insurance and durable medical equipment suppliers, and implementing therapies, *in addition to* the caregiver's own health self-management, household chores, employment, and parental obligations. Families consistently report being under-trained and under-supported in caring for their CMC (Coller et al., 2016;

Nelson et al., 2016; Wang & Barnard, 2004), which contributes to poorer CMC outcomes, e.g., increased risk of hospitalization (Coller et al., 2014). Being under-supported in performing care work also impacts caregivers. Many family caregivers lose employment (Cohen et al., 2011), experience isolation and depression (Raina et al., 2005; Raina et al., 2004), and have poorer mental and physical health (Coller et al., 2016; Kuo et al., 2011; Thyen et al., 1999). Yet, families must continue to provide care, often developing their own solutions to overcome challenges with the resources they have (Barton et al., 2021; Barton et al., 2020).

2.2 A work systems approach

One Human Factors and Ergonomics (HF/E) method used by patient ergonomics researchers is a work systems approach. A work systems approach applies a work systems model, e.g., the Systems Engineering Initiative for Patient Safety (SEIPS) discussed in 2.2.2, to study people's work to improve it (Carayon et al., 2014). For example, by identifying aspects of the work system that either impede or support workers, e.g., caregivers, in achieving their goals. as a method for re-designing the system for better patient and caregiver outcomes. In section 2.2 I will discuss foundational work systems models and the conceptualizations of system adaptation as a basis for applying HF/E to support caregiving for CMC.

2.2.1   Balance theory

Balance Theory, first published by Smith & Carayon-Sainfort in 1989, was a pioneering conceptualization of the relationship between robust literatures in job stress and job design (Smith & Carayon-Sainfort, 1989). The Balance Theory model describes a work system as the interaction between five elements, i.e., the *person/worker*, the *tools and technology* they use, the *tasks* they complete, the *physical environment* they are in, and their *organizational environment*

(Figure 3) (Carayon, 2009; Smith & Carayon-Sainfort, 1989). Conceptualizing the work system as a collection of interactions introduces the notion of work system elements compensating each other, i.e., 'balancing' the work system to reduce job stress. This theory is the basis for many analyses that identify work system facilitators—aspects of the work system that support the system in achieving its desired goal—and barriers—aspects of the work system that hinder the system in achieving its desired goal (Carayon et al., 2005).
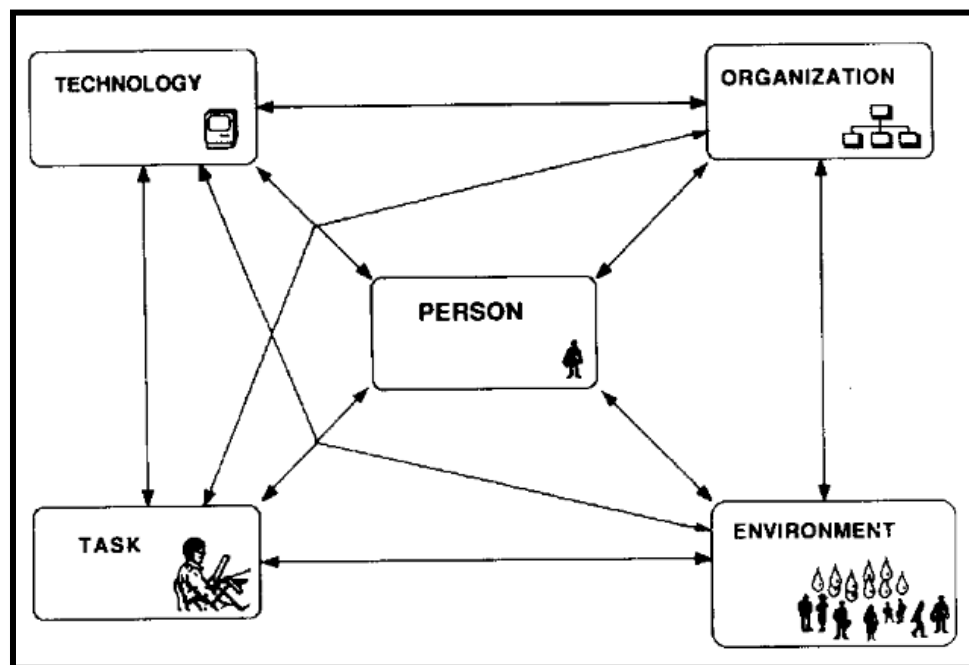
Figure 3. Balance Theory Model (Smith & Carayon-Sainfort, 1989, p. 75).

2.2.2   Systems engineering initiative for patient safety (SEIPS) model

The Systems Engineering Initiative for Patient Safety (SEIPS) model extends Balance Theory by situating it within popular healthcare quality framework, Donabedian's Structure-Process-Outcome (SPO) model (Figure 4) (Carayon et al., 2006; Donabedian, 1988). Thus, the interactions and compensations of work system elements can be thought of as producing the processes and outcomes of work. Processes can include the process of providing care or they can

be any other processes that support care, e.g., maintenance and housekeeping. Outcomes can include patient-oriented outcomes such as the quality of care they receive and patient safety measures as well as employee and organizational outcomes (Carayon et al., 2006). The SEIPS model includes feedback loops, depicted by arrows, from processes and outcomes back to the work system. These feedback loops show how data collected on care processes and/or patient and organizational outcomes can feed back to and trigger modification of the work system (Carayon et al., 2006; Carayon et al., 2014).
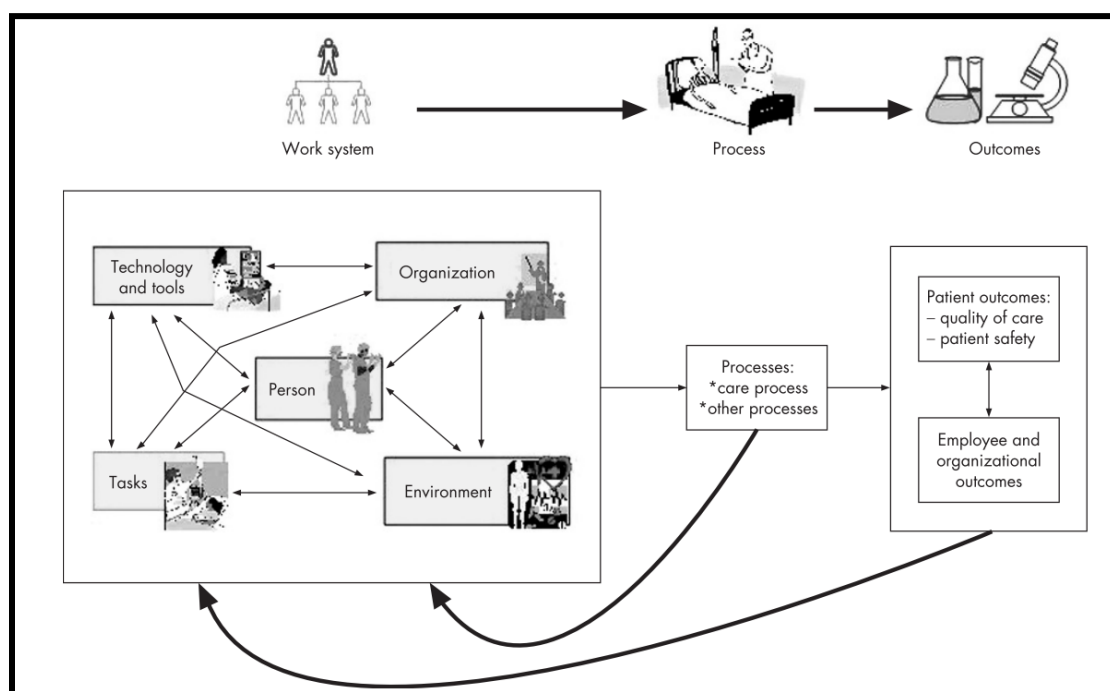
Figure 4. Systems Engineering Initiative for Patient Safety (SEIPS) model (Carayon et al., 2006).

2.2.3   SEIPS 2.0

A later iteration of SEIPS published in 2013, SEIPS 2.0, expanded on the initial model aiming to provide concepts that could address the emerging needs of healthcare systems (Figure 5). First, the authors expanded the person element to 'person(s),' acknowledging the importance of situating both patients and healthcare professionals in the work system to understand the

collaborative work they do together. The concept of *engagement* provides a framework for considering the degree to which an 'agent,' i.e., patient/caregiver or healthcare professional, is engaged in the resultant work processes. Holden et al. provide a continuum of work including (1) professional work, i.e., where the primary agent is a healthcare professional with little active input from patients or their caregivers, (2) patient work, i.e., where the primary agent is a patient or family caregiver, and (3) collaborative work, i.e., where professional and non-professional agents are actively engaged.
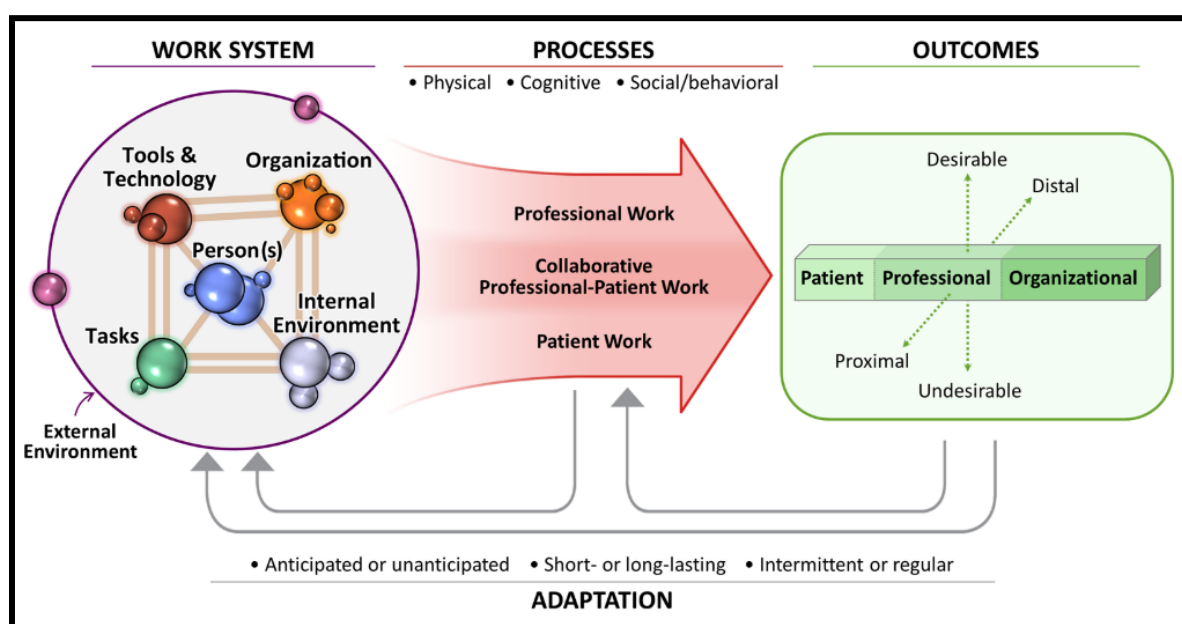
Figure 5. SEIPS 2.0 model (Holden, Carayon, et al., 2013).

Additionally, SEIPS 2.0 introduced the concept of *configuration,* stating that while "any number of work system components can interact simultaneously…to shape performance processes and outcomes," there is a discrete set of element interactions that are relevant in shaping processes and outcomes at any specific time (Holden, Carayon, et al., 2013, p. 6). Other interactions may still exist, but only shape the process and outcomes weakly in this situation.

Thus, a given work system configures differently, i.e., has different relevant interactions, in different circumstances.

Finally, SEIPS 2.0 expanded on the feedback loops presented in SEIPS to represent system *adaptation*. Holden et al. describe *adaptations* as responses "made in an attempt to decrease the gap between actual versus ideal performance" (Holden, Carayon, et al., 2013, p. 9). Adaptations may be planned modifications to the work system intended to improve processes or outcomes, e.g., implementation of a new technology (Holden, 2011) or through planned re-design efforts (Karsh et al., 2006); or adaptations may be first-order problem-solving behaviors reacting to an immediate barrier in a worker's work system (Tucker & Spear, 2006). In systems that are poorly designed, i.e., ones with many barriers, adaptations can be seen as workers' method for "balancing" their work system (Carayon et al., 2014).

2.2.4 System adaptation and resilience

As has been alluded to thus far in section 2.2, adaptation is inevitable in complex work systems (Holden, Carayon, et al., 2013; Wilson, 2014). In foundational sociotechnical systems literature, on which the presented work systems models were built, adaptation has been considered a key role of the social/personnel subsystem (Cherns, 1976; Hendrick, 1991; Pasmore, 1988). Sociotechnical systems theorists conceptualize two interdependent subsystems—social/personnel and technical—which operate inside of an external environment (Cherns, 1976; Hendrick, 1991; Pasmore, 1988; Trist, 1981). Once the technical subsystem has been designed and implemented it remains fairly fixed, leaving the duty of adapting to fit changing external environments to the socio/personnel subsystem (Hendrick, 1991). Further, included in Cherns' 1976 "Principles of Sociotechnical Design" is the principle of

"incompleteness," i.e., system design is never complete—implying that systems are constantly being re-designed, and thus, adapted (Cherns, 1976).

In the modern work systems models I have reviewed, system adaptation is conceptualized simply as the feedback loop between the work system's processes and outcomes and the work system itself (Holden, Carayon, et al., 2013). Feedback may be anticipated or not, short- or long-lasting, intermittent or regular, or even made into a routine (Holden, Carayon, et al., 2013). The system adaptation feedback loop offers a path for re-designing the care work system.

Studying system adaptation is essential for identifying aspects of the work system that need to be redesigned to improve patient and organizational outcomes (Carayon et al., 2014; Vicente, 1999). Beyond identifying work system barriers and facilitators (B&F), exploring system adaptation provides direct insight into the goals of workers and their perception of their ability to achieve them (Carayon et al., 2005; Holden, Carayon, et al., 2013; Holden, Rivera-Rodriguez, et al., 2013). Further, with the expertise that frontline workers develop in doing their work, solutions they develop can be identified, assessed for their impact on outcomes, and modified and/or implemented to improve system processes and outcomes (Al-Masslawi et al., 2017; Reason, 2013).

Ultimately, developing an understanding of how workers identify barriers and overcome them contributes to a broader literature on how systems build system resilience, sometimes termed adaptive capacity (Fairbanks et al., 2014). Hollnagel et al. (2006) define resilience as "the ability of an organization to recover quickly to a stable state after a major mishap" (Hollnagel et al., 2006, p. 275). Resilience, put simply, is a worker's ability to monitor the boundary conditions of acceptable risk, e.g., the risk of providing poor quality care, and respond when

necessary (Hollnagel et al., 2006). To offer insight into how to design care work systems resilient to mishaps, it is important to study the way the system adapts over time.

2.3 Conceptualizing adaptation

Adaptation has been conceptualized in a variety of ways. In this review, I will distinguish workarounds, problem solving, and strategies as prominent conceptualizations of adaptation. In the following section, 2.4, I will integrate the adaptation literature.

2.3.1 Workarounds

One practical conceptualization of adaptation, coming primarily from the information technology and computer science literature, is *workarounds.* Despite widespread recognition of the term, workarounds remained understudied and undertheorized for many years (Pollock, 2005). Kobayashi et al. (2005) was one of the first papers to define workarounds, aiming to describe them and the factors that influence their success. The authors define workarounds as "informal temporary practices for handling exceptions to normal work flow" (Kobayashi et al., 2005, p. 1561). Alternatively, Morath and Turnbull (2005, p. 52) define workarounds as: "work patterns an individual or a group of individuals create to accomplish a crucial work goal within a system of dysfunctional work processes that prohibit the accomplishment of that goal or makes it difficult."

In his *Theory of Workarounds,* Alter (2014, p. 1044) offers an expansive definition of workarounds:

> "A goal-driven adaptation, improvisation, or other change to one or more aspects of an existing work system in order to overcome, bypass, or minimize the impact of obstacles, exceptions, anomalies, mishaps, established practices, management expectations, or structural constraints that are perceived as preventing that work system or its participants from achieving a desired level of efficiency, effectiveness, or other organizational or personal goals."

A simpler way to parse this definition is by the four 'preconditions' to the occurrence of a workaround Alter (2014, p. 1044) specifies:

(1) "A specific process, policy, or set of practices within an existing work system"
(2) "Organizational and/or personal goals related to that situation"
(3) "An obstacle, exception, anomaly…or structural constraint…perceived as something to bypass or overcome"
(4) "An ability to imagine and execute a workaround"

Each definition emphasizes a worker's deviation from a standard work process in response to a challenge faced in pursuing work-related goals.

Consequently, studying workarounds is particularly useful for evaluating the implementation of a new work process or technology since how workers bypass the new process or technology directly identifies where it fails to fit the existing work system (Halbesleben et al., 2008). In healthcare, for example, several studies have focused on workarounds to implementation of medication administration technology (Holden, Rivera-Rodriguez, et al., 2013; Koppel et al., 2008; Novak et al., 2013) and the electronic health record (Saleem et al., 2009; Vogelsmeier et al., 2008). As more technology is implemented to support the delivery of high-quality healthcare, there's an increasing need to understand and design that technology to fit the work system and processes of healthcare workers (Morath & Turnbull, 2005). With an emphasis on processes and how they are bypassed, workarounds highlight the tension between the lived experience of healthcare workers and how their work is expected to happen; the field of HF/E has conceptualized this difference between prescribed work, i.e., one's job description, and how people *actually* do their work as "work as imagined" versus "work as done" (Carayon & Salwei, 2021; Leplat, 1989). Workarounds are the ultimate example of a deviation from "work as imagined."

Finally, workarounds in healthcare have important implications for patient safety. While the workarounds that healthcare workers employ often play an integral role in maintaining patient safety, some workarounds pose significant risk (Cook et al., 2000; Morath & Turnbull, 2005); for example, when a worker works around a process set in place by the organization to ensure patient safety, e.g., a safety checklist (Halbesleben et al., 2008). In practice, most workarounds that pose patient safety risk emerge when healthcare workers are under extreme organizational pressures to deliver more care and deliver it faster (Morath & Turnbull, 2005; Reason, 1990). For caregivers whom we know are under-supported in delivering necessary care (Coller et al., 2016; Nelson et al., 2016; Wang & Barnard, 2008), workarounds may pose significant, yet unidentified risk.
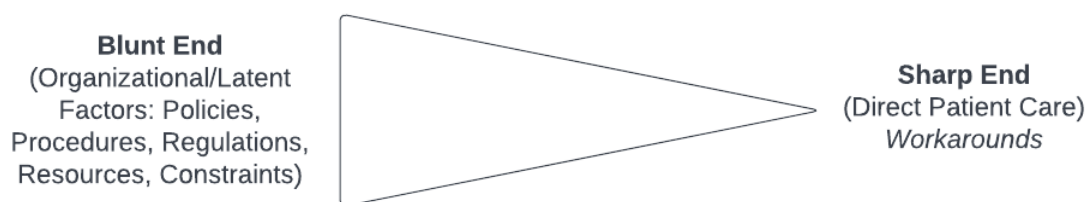
Figure 6. The blunt and sharp ends of healthcare delivery, adapted from Cook et al. (1998, p. 14).

Patient safety literature conceptualizes time-pressure and high workload, i.e., negative organizational factors, as being located at the 'blunt end' of healthcare delivery, opposite direct patient care at the 'sharp end' (Figure 6) (Cook et al., 1998; Morath & Turnbull, 2005). While the 'sharp end' is where healthcare workers—or in this case caregivers—encounter barriers, create workarounds, and where error occurs, organizational pressures, i.e., latent factors, are often key in creating a 'perfect storm' for harmful errors to happen (Morath & Turnbull, 2005; Reason, 1990, 1997). Thus, when studying workarounds to improve patient care and safety, it

may also be necessary to explore underlying latent factors that increase either the need for or risk of workarounds (Morath & Turnbull, 2005; Reason, 1997).

2.3.2 Problem solving

Another conceptualization of adaptation is as workers *solving problems* they encounter in their work. Holden, Rivera-Rodriguez, et al. (2013) define problem solving as "any response to (perceived) problems in which a process or system is manipulated, in order to accomplish some pre-established goal relative to standards for timely and effective performance" (Figure 7) (Holden, Rivera-Rodriguez, et al., 2013, p. 285). The image on the left of Figure 7 depicts unimpeded goal achievement, i.e., reaching the goal (green ball) via a direct path within the permissible zone of risk. The image on the right of Figure 7 depicts problem solving by circumventing the problem (crack in the original pathway) and reaching the goal (green ball). In the problem solving example in Figure 7, the new behavior falls within the permissible zone of risk; however, there may also be cases, although not shown, where problem-solving behaviors fall outside of the permissible zone of risk (Holden, Rivera-Rodriguez, et al., 2013).
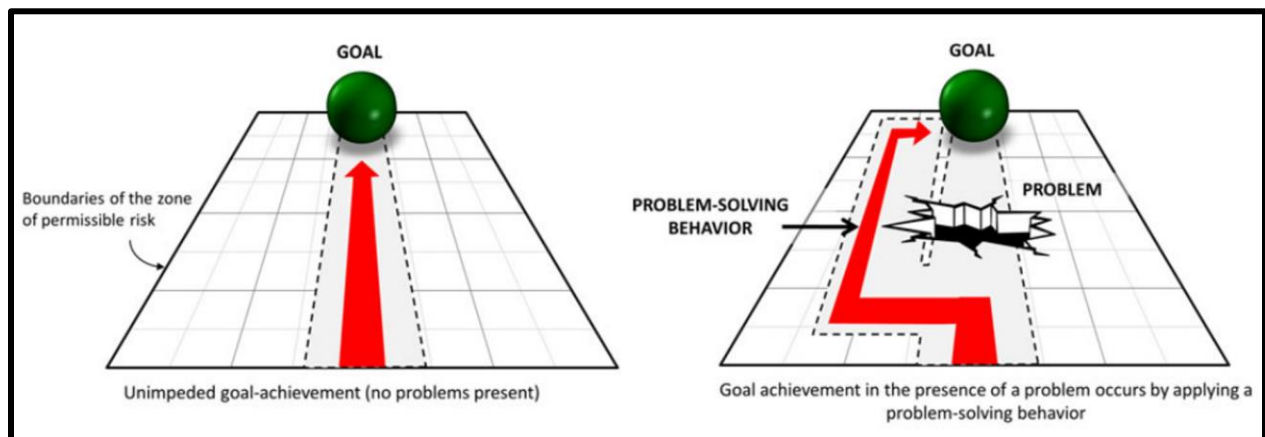
Figure 7. Problem solving (Holden, Rivera-Rodriguez, et al., 2013, p. 286).

Notable in Holden, Rivera-Rodriguez, et al. (2013)'s definition of problem solving, is the emphasis on the *worker's perception* of problems. First, the focus on the worker's perception points to the idiosyncratic nature of problem-solving, i.e., individuals solve problems in unique ways (Tucker & Edmondson, 2002). Second, in the context of a work systems model, this emphasis implies a need to focus on work-related outcomes, e.g., efficiency and usability, versus endpoint outcomes, e.g., patient safety metrics. This is because, mostly, workers are solving problems that arise in their work, not necessarily projecting the impact of their actions into downstream outcomes (Holden, Rivera-Rodriguez, et al., 2013).

Another useful aspect of the problem solving conceptualization is its ability to distinguish between first- and second-order problem solving (Holden, Rivera-Rodriguez, et al., 2013). First-order problem solving includes those solutions that are short-term that aim to solve or patch an immediate problem. Problem solving may be considered a kind of first-order problem solving. In contrast, second-order problem solving involves catching and correcting underlying causes of problems, contributing to organizational learning (Crossan et al., 1999; Hundt, 1988; Yang et al., 2021). A challenge of complex work systems is balancing first- and second-order problem solving, as a high rate of first-order problem solving can mask the existence of problems and the increased risk that is being assumed (Tucker et al., 2002).

2.3.3   Strategies

The final conceptualization of adaptation I will discuss is workers' *strategies* for overcoming barriers. Durso et al. (2015, p. 339) define a strategy as "a plan or method to achieve a goal" while also distinguishing them from obligatory work procedures. Strategies can be 'cued' and implemented quickly or deliberately to address a specific 'threat' happening in the context of a specific 'task' (Durso et al., 2015). Given cues can be hard for workers to identify, Durso et al.

(2015) introduce the Threat-Strategy Interviewing (TSI) framework to support strategy elicitation. The TSI method proceeds by selecting the task in question and then:

(1) asking the participant to identify threats, e.g., "what might happen that would threaten your effective management of the situation?"

(2) asking the participant to identify cues to threats, e.g., "how do you become aware of the threat?"

(3) asking the participant to identify strategies they use to "keep the threat from interfering with [the] task" and,

(4) asking the participant to identify cues to strategies, e.g., "when would you choose to use that strategy?" (Durso et al., 2015, p. 338).

Cues provide context as to how the person recognizes a threat (cues-to-threat) or when to employ certain strategies (cues-to-strategies) (Durso et al., 2015).

Another model for conceptualizing strategies that takes a cognitive approach is the Coping Model of User Adaptation (CMUA) (Beaudry & Pinsonneault, 2005, p. 496). Beaudry and Pinsonneault (2005) define what they refer to as *adaptation strategies* as "cognitive and behavioral efforts exerted by users to manage specific consequences associated with a significant IT event that occurs in their work environment." Figure 8 depicts the CMUA model, which involves a worker's initial appraisal of an IT event with potential consequences relevant to them, i.e., a threat (negative consequences) or an opportunity (positive consequences) (Beaudry & Pinsonneault, 2005). Like problem solving's emphasis on worker perception, discussed in section 2.3.2, an implication of the first appraisal of the CMUA is that strategies are triggered at different times depending on the information the worker has, how they synthesize it, and other individual factors (Agarwal & Prasad, 1998; Fiske, 1991; Griffith, 1999). In secondary appraisal, the worker assesses the level of control they have over the IT event, which together with their initial appraisal shapes the adaptation strategies they can use in response (Lazarus & Folkman,

1984). The four adaptation strategies that (Beaudry & Pinsonneault, 2005) introduce are (1) benefits maximizing, i.e., high control over an opportunity, (2) benefits satisficing, i.e., low control over an opportunity, (3) disturbance handling, i.e., high control over a threat, and (4) self-preservation, i.e., low control over a threat. A unique aspect of the CMUA is the distinction between emotion- and problem-focused strategies, given one of the outcomes of interest is the model is "restoring personal emotional stability" (Beaudry & Pinsonneault, 2005).
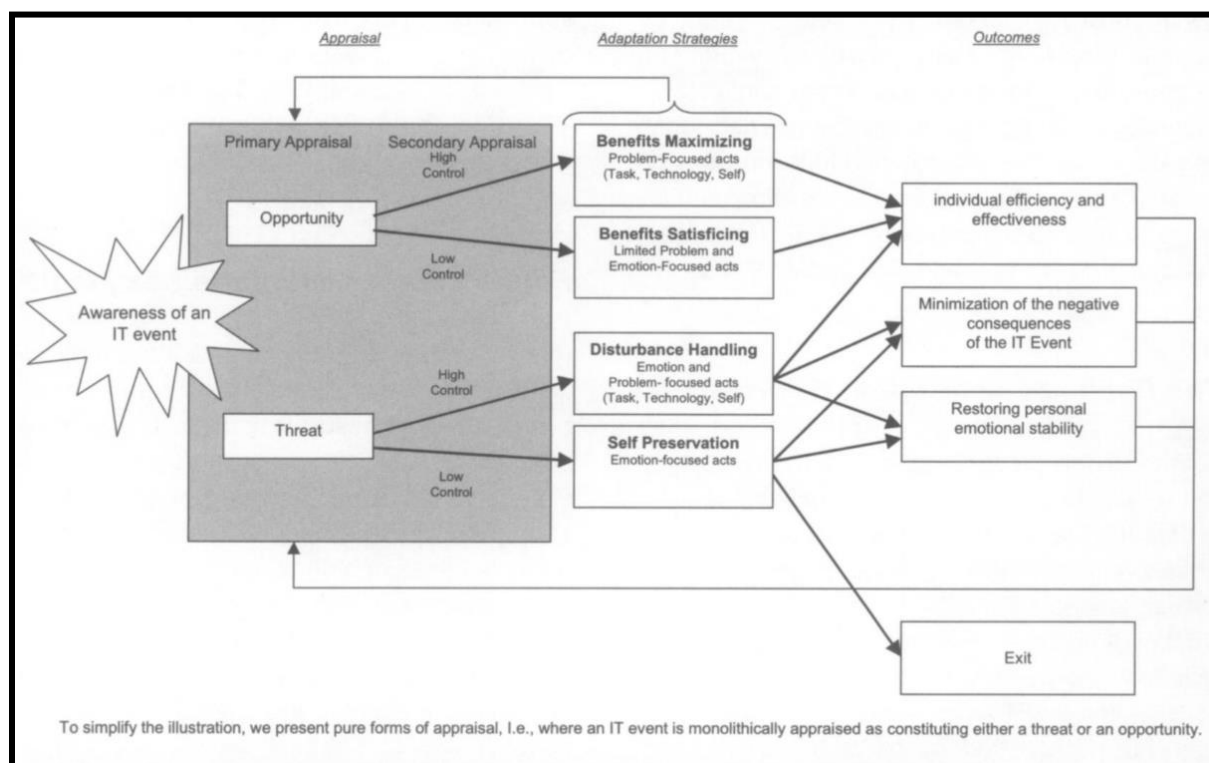
Figure 8. Coping model of user adaptation (Beaudry & Pinsonneault, 2005, p. 499).

While TSI and CMUA offer useful conceptualizations of strategies, e.g., how they are cued and what influences their selection, neither offers insight into strategies' relationship(s) with the work system. Understanding how strategies are developed from and continue to shape the work system can contribute to better overall *system* re-design. Carayon et al. (2019) proposed

a conceptual model of strategies that filled exactly this gap (Figure 9). The authors define strategies as "a behavioral or cognitive activity aimed at dealing with a work system barrier" (Carayon et al., 2019, p. 241). In essence, strategies are the worker's response to an imbalanced work system. I will build off this conceptualization in my conceptual framework, section 3.2.
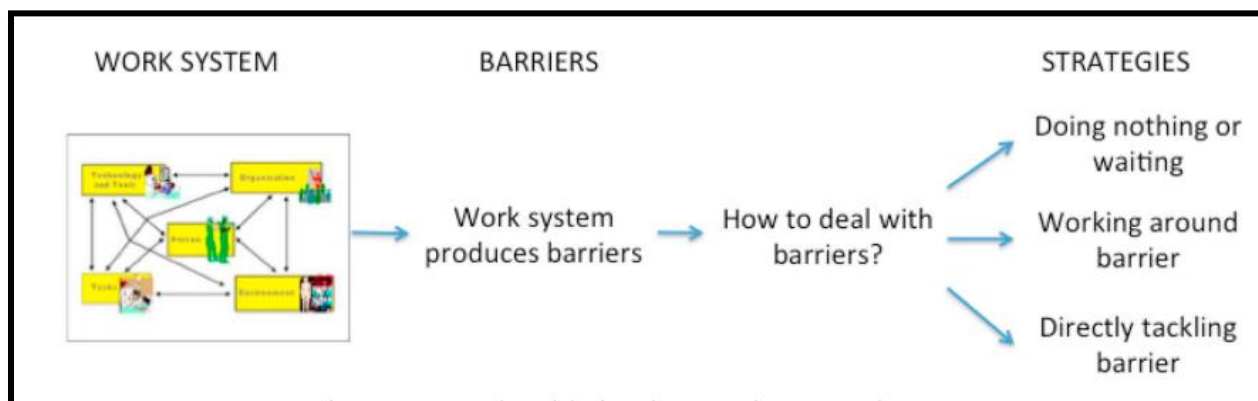
Figure 9. Work system barriers and strategies from Carayon et al. (2019, p. 241)'s study of technology-related barriers.

2.4 An integrated model of system adaptation

While in section 2.3 I distinguished the concepts of workarounds, problem solving, and strategies, they undoubtedly overlap and cross-reference each other. A few of these overlaps are worth noting and integrating before introducing my conceptual framework in Chapter 3.

First, there is an important temporality to these conceptualizations since system adaptation happens over time. Workarounds have typically been conceptualized as temporary, short-term behaviors or actions, as have first-order problem-solving behaviors (Halbesleben et al., 2008; Holden, Rivera-Rodriguez, et al., 2013; Kobayashi et al., 2005). Strategies fall broader on the timescale, ranging from short-term to deliberate implementation (Durso et al., 2015). Second-order problem solving explicitly involves a deeper look at the latent factors underlying the problem, aiming to fix those and consequently have a larger scope of impact (Tucker et al.,

2002). In Figure 10, I map the relationship between the concepts of workarounds, problem solving, and strategies, the time scale they occur on, and their scope of impact.

The basis of Figure 10 is a figure from Alter (2014, p. 1058)'s *Theory of Workarounds*, which originally depicted a series of processes moving up and to the left, i.e., longer in time and increasing in scope. The processes moved from: "temporary workaround or adaptation" to an "initial learning" to a "routinized workaround or adaptation" to "experience leading to rationale for planned improvements" to "formal improvement projects," and finally to a "workaround transformed into systemized methods" (Alter, 2014, p. 1058). In my depiction, I leave out these process steps, but retain the x- and y-axes time and scope, respectively.
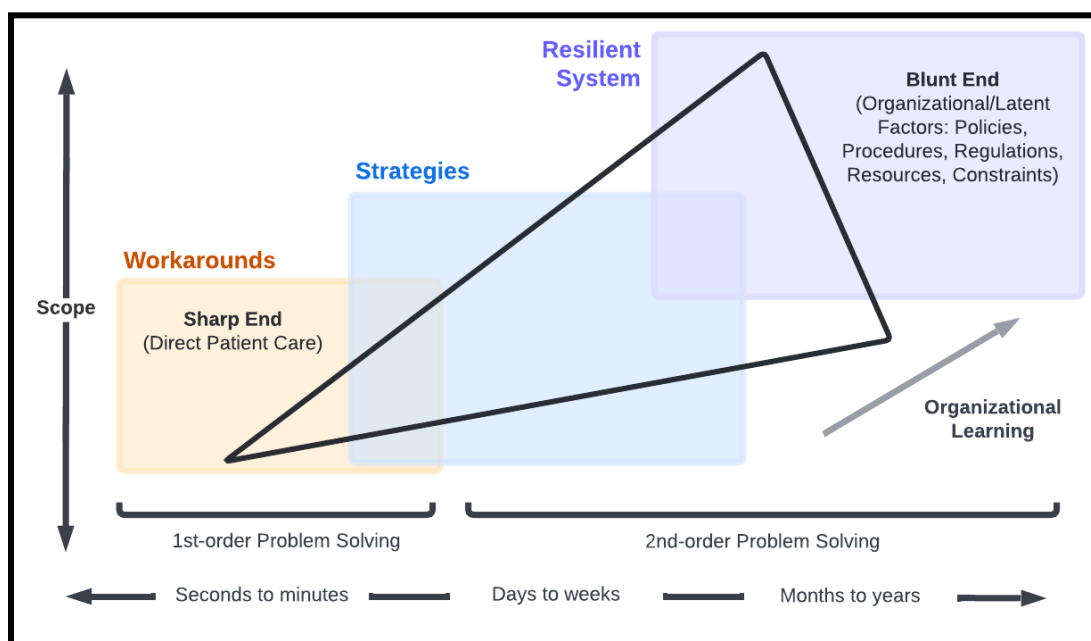
Figure 10. Integration of system adaptation literature, adapted from Alter (2014, p. 1058).

Further, I have incorporated additional concepts from the adaptation and patient safety literature into Figure 10. First, I incorporate a patient safety framework, distinguishing the 'sharp' and 'blunt' end of healthcare delivery, to contextualize the scope of impact and,

potentially, harm of adaptation (Morath & Turnbull, 2005; Reason, 1990). Second, I map, using orange and blue rectangles, the rough locations of workarounds and strategies respectively. Third, I note that traveling from bottom-left to top-right, i.e., longer in time and greater in scope, represents organizational learning (Crossan et al., 1999; Hundt, 1988). In the top right using a purple rectangle, I call out where *the potential for* system resilience or adaptive capacity lives, in the utilization of learnings from the sharp end to transform the latent organizational factors that have the broadest scope and persistence over time (Hollnagel et al., 2006). As discussed in section 2.3.2, a central challenge of having workers adept at employing workarounds or first-order problem solving at the sharp end is the potential for problems that could identify problematic latent factors to remain hidden (Tucker et al., 2002). Thus, Figure 10 depicts a pathway translating front-line workers challenges and insights into organizational change that must be kept open to improve the outcomes of the system.

Another notable connection between the reviewed literature is the aspect of perception. In the problem solving and workaround literature, it is emphasized that a problem or obstacle must be perceived by the worker, and not only perceived but perceived as in conflict with the worker's goals (Alter, 2014; Holden, Rivera-Rodriguez, et al., 2013). However, in the CMUA model, strategies can also be prompted by the perception of an opportunity (Beaudry & Pinsonneault, 2005). This suggests that workers perceiving work system facilitators may be able to develop strategies and then leverage them; though it may also be essential that a worker is able "to imagine and execute a workaround" to perceive an opportunity, or work system facilitator, to begin with (Alter, 2014, p. 1044). For those workers who are unable to imagine and execute workarounds, similar to the CMUA's concept of "low control," the strategies they develop may be exclusively emotion-focused (Beaudry & Pinsonneault, 2005). Morath and Turnbull (2005, p.

53) describe resignation as this kind of strategy: "individuals and teams defend against working in unmitigated risk by losing situational awareness and normalizing deviance. In other words, they become resigned to their environment and increase the probability of risk."

Chapter 3: Research Questions

In Chapter 3 I first, in section 3.1, briefly review aspects of the literature covered in Chapter 2 that inform my research questions. In section 3.2 I describe the conceptual framework that guided my dissertation. Finally, in section 3.3, I present my research questions.

3.1 Overview

As discussed in Chapter 2, Human Factors and Ergonomics (HF/E) can be used to support caregiving by conceptualizing it as a form of *patient work* that happens at the center of a *care work system* (Holden et al., 2020). This complex system is made up of interactions between work system elements—i.e., between *caregivers*, the care *tasks* they perform, the *tools and technologies* they utilize, and the *physical and organizational contexts* they perform care in— that shape work processes and outcomes (Holden, Carayon, et al., 2013; Holden et al., 2015). Conceptualizing caregiving as work is especially valuable because caregivers frequently report being under-trained and under-supported, providing care in work systems that do not meet their needs (Coller et al., 2016; Hodgkinson & Lester, 2002; Jennings, 1990; Nelson et al., 2016). An HF/E work systems approach provides a framework for assessing these care work systems, e.g., by identifying work system barriers and facilitators (B&F), and using that insight to inform their re-design (Carayon et al., 2014; Holden, Carayon, et al., 2013; Hollnagel et al., 2006).

One pathway for system redesign is to study system adaptation. While adaptation has been conceptualized in many ways, e.g., as workarounds, problem solving, and strategies, there remains a gap in our understanding of how adaptation happens in complex work systems. HF/E researchers have begun to study system adaptation, conceptualizing strategies as responses to work system barriers (Carayon et al., 2019; Weiler, Lingg, Wilkins, et al., 2022). Yet, we have yet to explore the relationship(s) between work system facilitators and strategies. Further, so far

conceptualizations of strategies have been linear, i.e., conceptualizing a strategy as a response to a single barrier, which fails to capture the complexity of the work system in which strategies are used.

My research explores these gaps: (1) how work system facilitators, in addition to barriers, interact with family-generated strategies and (2) how strategies interact with the work system at large, i.e., work system B&F. The goal of this study is to contribute to our understanding of how caregivers play an active role in shaping the care work system, by developing strategies to achieve their care goals.

3.2 Conceptual framework

While there are many conceptualizations of adaptation, a few of which I have reviewed in Chapter 2, there remains a gap in our understanding of how adaptation happens in, shapes, and is shaped by the work system. Carayon et al. (2019) conceptualize strategies as responses to work system barriers (Figure 9), which is a first step towards understanding system adaptation in the context of the complex work system. To study system adaptation in the care work systems of families caring for CMC, I propose the study of *family-generated strategies*:

> **Family-generated strategy:** "Any dynamic response to (perceived) work system barriers or facilitators to timely and effective performance of effortful work activities in pursuit of the patient's health goals."

The conceptual framework of family-generated strategies I used to guide this study builds on the work of Carayon et al. (2019) in a few key ways. First, family-generated strategies may be responses to either work system barriers or facilitators or some interaction therein. Second, strategies can either "directly address a work system barrier" or "leverage a work system

facilitator." My inclusion of work system facilitators in the proposed conceptualization builds off the CMUA model which explicitly conceptualizes opportunities as triggers to strategies (Beaudry & Pinsonneault, 2005; Carayon, 2009; Carayon et al., 2005), and the concept of balance, in which work system facilitators play an integral role (Carayon et al., 2006; Carayon et al., 2014). Further, the conceptualization of a family-generated strategy necessarily frames strategies as actions that *families* take based on their perception of their care work system, privileging the goals and perspective of the worker, i.e., caregiver.

3.3 Research questions

To explore the overarching question of how the care work system and family-generated strategies interact, I have two research questions:

RQ1: What are the family-generated strategies that families develop to provide care for their CMC?

RQ2: What is/are the relationship(s) between work system barriers, facilitators, and family-generated strategies?

Chapter 4: Methods

In Chapter 4 I describe the methods I used to answer my research questions. To begin, in section 4.1, I discuss my worldview. In section 4.2 I provide an overview of the parent study in which this dissertation is situated. In section 4.3 I describe my study design. Finally, in sections 4.4 and 4.5 I describe, in detail, the data analysis for RQ1 and RQ2, respectively.

4.1 Researcher's worldview

Any research proposal is indisputably shaped by the researcher's worldview and epistemological orientation (Creswell & Creswell, 2018; Devers, 1999). Thus, it is important for researchers to disclose their beliefs about research and the nature of truth/reality that shape their research design and methods (Creswell & Creswell, 2018; Emerson, 2011). I hold transformative and pragmatic worldviews and apply a feminist, queer, anti-capitalist lens to my research. I believe there is no one, generalizable truth 'out there' that can be identified through research; rather, research can uncover *situated knowledge* that is relevant to a specific context (Haraway, 1991; Mohanty, 1988). The way we get closest to articulating the 'truth' about our social realities is by weaving together specific, detailed description into a dynamic and invariably incomplete patchwork of knowledge (Geertz, 2001; Haraway, 1991). Donna Haraway, a foundational feminist theorist, calls for "a practice of objectivity that privileges contestation, deconstruction, passionate construction, webbed connections, and hope for transformation of systems of knowledge and ways of seeing" (Haraway, 1991, pp. 191-192).

A transformative worldview situates research as a tool for creating real-world change by addressing power differentials that maintain oppressive systems (Mertens, 2009). As someone who holds this worldview, I place an emphasis "on the study of lives and experiences of diverse groups that have traditionally been marginalized" (Creswell & Creswell, 2018, p. 10). I believe

that research should be used to improve the world and that to do so requires critiquing its current form. In this respect, marginalized peoples' perspectives provide insight into hegemonic structures and their impact (Hesse-Biber, 2012). Thus, my research aims to explore and codify caregivers' knowledge that is typically overcast by the *authoritative knowledge*—that which is considered "legitimate, consequential, official, worthy of discussion, and appropriate for justifying particular actions"–of medical professionals (Jordan, 1997, p. 58; Wenger & Kibler, 1990). Further, under the capitalistic division of public and private spheres, the work of caregiving is typically undervalued and relegated to unpaid women, despite its necessity (Bhattacharya, 2017). My focus on supporting the care work of families caring for CMC subverts production pressures placed on us by capitalism and instead places value on improving the experiences and health outcomes of CMC and their families for their own sake.

A pragmatic worldview is one that places emphasis on the research problem, and the methods best suited to study it, over any one philosophical orientation (Creswell & Creswell, 2018). Typically, pragmatists employ mixed methods justified by the practical contribution of the research—contending that several fundamental values between quantitative and qualitative researchers are the same, e.g., that reality is complex and stratified and that any data are explicable by more than one single theory (Creswell & Creswell, 2018; Robson, 2016). I am, in part, influenced by my training as an engineer, oriented towards identifying and solving design problems. It is also the case that a pragmatic approach fits neatly with a transformative one, as a transformative worldview simply adds another objective in which to apply my pragmatism, e.g., selecting a method that is both appropriate for my research question and likely to yield knowledge that can be returned to community to improve their lives.

Finally, I'd like to note my positionality in relation to the people I 'study' and the research problem presented herein. Particularly with respect to utilizing qualitative methods, I regard myself as a key research instrument (Creswell & Creswell, 2018; Emerson, 2011; Geertz, 2001). I shape and am shaped by the data I collect, analyze, and report (Emerson, 2011). Thus, a reflexive approach that adequately discloses, while not absolving me of, my biases is warranted (Hesse-Bibber & Piatelli, 2012; Pillow, 2003). I am a white, non-binary, highly educated, queer person who was raised in a middle to upper class household with a disabled mother. I saw firsthand how her care was distributed between physicians with differing expertise, but also where she supplemented it in seeking nutritional and homeopathic solutions. In my late teens I experienced several sports injuries and surgeries that opened my eyes to both the complexities of healthcare and the day-to-day impact of an environment that is poorly designed for disability, even if temporary. While I am incredibly privileged to have had primarily consistent access to high-quality healthcare, I have also dealt with my own challenges in obtaining the care that I have needed in managing my chronic pain and illnesses. I carry the complexity of these identities and experiences to my research work.

4.2 Overview of @HOME study

This dissertation falls under the purview of a large parent study, "Advancing the home care of medically complex children through human factors engineering" or @HOME. The study is a collaboration between Dr. Nicole Werner and Dr. Ryan Coller at the American Family Children's Center's Pediatric Complex Care Program (PCCP) aimed at studying and designing ways to improve the in-home care of children with medical complexity (CMC).

The @HOME study involved conducting 30 in-home interviews with families caring for children with medical complexity. These interviews have been the basis for work system

analyses (Doutcheva et al., 2019; Parks et al., 2021) as well as collaborative mHealth application design (Cheng et al., 2020; Werner, Fleischman, et al., 2022). Thus, I will start by describing the methods of the primary study, @HOME.

4.2.1 Data collection

In-home family interviews lasting up to 2 hours were conducted by two researchers, one to lead the interview and another to assist with taking photos and notes. Using a contextual inquiry approach (Holtzblatt & Beyer, 2016), participants were asked to walk the interviewers through a "day in the life" providing care for their child: demonstrating tasks and pointing out tools and technologies they used in the different spaces of their home. The interview guide was developed using SEIPS 2.0 by two senior researchers with expertise in qualitative research, complex care, and human factors, see Appendix B (Holden, Carayon, et al., 2013). Researchers used probes to ensure all elements of the work system were addressed during the interview. Interviews were audio-recorded and transcribed for analysis. Data collection took place from October 2017 to January 2019.

4.2.2 Study setting and sample

Families caring for CMC (n=30) were enrolled in and recruited from the PCCP. PCCP enrollment criteria include age <18 years, ≥ 3 organ systems affected by chronic conditions, ≥ 3 medical or surgical specialists, and either ≥ 10 outpatient clinic visits or ≥ 5 hospital days in the previous year. All participants spoke English and were located within a 1.5-hour drive of the Children's hospital. Purposive recruitment was used to ensure diversity of education level, urbanicity, and duration of caregiving experience. Participant characteristics are described in more detail in Appendix A.

4.2.3   Data analysis

We used a team-based, deductive content analysis to conduct a work system analysis

based on the SEIPS 2.0 model (Elo & Kyngäs, 2008; Holden, Carayon, et al., 2013; Hsieh &

Shannon, 2005). Transcripts were first uploaded to NVIVO 12, a qualitative analysis software

(QSR International, Doncaster, Australia). Then two researchers independently coded each

transcript for SEIPS 2.0 work system elements, process, and outcomes, codebook in Appendix C.

In addition to the work system codes, each excerpt was coded as either a barrier or facilitator in

providing care.

Additionally, as a first step in the line of research that my dissertation continues, I

conducted a combined inductive and deductive content analysis to identify strategies that

families developed (Hsieh & Shannon, 2005). To guide the deductive aspect of the analysis, I

developed a broad definition of *strategies* that incorporated relevant literature, including the

SEIPS 2.0 definition of adaptation and Alter's *Theory of Workarounds* (Alter, 2014; Carayon et

al., 2019; Debono et al., 2010; Halbesleben et al., 2008; Holden, Carayon, et al., 2013).

> **A strategy is:** "a goal-driven adaptation, improvisation, or other change to one or more
> aspects of an existing work system (Patient Work System) in order to overcome, bypass,
> or minimize the impact of obstacles, mishaps, established practices, or structural
> constraints that are perceived as preventing that work system or its participants from
> achieving a desired level of efficiency, effectiveness, wellness, or other personal goals."

Two researchers began the analysis by coding two transcripts independently for

strategies, meeting to compare notes, and bringing their initial findings to discussion with a

senior researcher (NW). Inductively, we derived codes which described the "levels" at which

families used strategies, the results of which have been published previously (Barton et al.,

2020). To continue to refine our inductive codes and our application of the strategy code, the

research team met regularly while dual coding the remaining transcripts. Any disagreements in coding were resolved through discussion among the research team.

4.3 Study design

I conducted a secondary analysis of the @HOME interview transcripts to answer my research questions. With an interest in developing a thick description of the care work systems within which families caring for CMC generate strategies, I am taking a qualitative descriptive approach (Kim et al., 2017; Sandelowski, 2000). To address my research questions, I used the methods described in sections 4.4 and 4.5, described briefly in Table 1.

Table 1. Brief view of my research methods.

Research Question	Methods
RQ1: What are the family-generated strategies that families develop to provide care for their CMC?	- **Summarized strategies** from excerpts co-incidentally coded as work system B&F and strategies. - Conducted an inductive content analysis of the resulting list of strategies to **identify categories of strategies**. - Consolidated the list of strategies into a list of **unique strategies**. - Abstracted strategies to identify **strategy types.**
RQ2: What is/are the relationship(s) between work system barriers, facilitators, and family-generated strategies?	- Conducted a content analysis to identify **categories of work system B&F.** - Explored, using descriptive statistics, **relationships between strategies, B&F, and work system elements**. - Conducted a deductive, inductive analysis of strategies to identify **strategy mechanisms** and categorize strategies by strategy mechanism.

4.4 Methods for RQ1

RQ1: What are the family-generated strategies that families develop to provide care for their CMC?

To answer RQ1, I conducted a secondary analysis using the data from the preliminary analyses described in section 4.2.3—the work system barriers and facilitators (B&F) analysis and the strategy analysis—to explore and describe the strategies that families develop to care for their child.

4.4.1   Data Analysis – collecting co-incidentally coded excerpts

NVIVO 12 files containing the coded data from the preliminary analyses described in section 4.2.3 were obtained and reviewed for initial impressions (QSR International, Doncaster, Australia). Using NVIVO 12 qualitative analysis software's matrix feature, I identified excerpts in the transcripts that were co-incidentally coded as a strategy AND as either a work system barrier OR facilitator. Table 2 shows the number of excerpts that were coded at each intersection, for a total of 1,009 excerpts. Excerpts that met these criteria were exported from NVIVO 12 into Excel®. Table 3 is included to exemplify the Excel® sheet. Each excerpt was assigned a unique ID, labeled with the transcript number it came from, and summarized as a strategy and its associated work system element B&F, described in detail in section 4.4.2. Any excerpts that had no quote, i.e., there was an overlap of coding on blank space, were not added to the Excel® sheet. Finally, to support my coding, I added the definitions for a family-generated strategy (top-left of Table 3) and each work system element, as defined by Carayon et al. (2006), to the header of the database.

Table 2. Number of excerpts exported from NVIVO 12 that were coded as a strategy and a work system barrier or facilitator.

Excerpts coded as:	Excerpts coded as a strategy
Organization Barrier	53
Organization Facilitator	182
Person Barrier	80
Person Facilitator	86
Task Barrier	68
Task Facilitator	112
Tools & Tech Barrier	83
Tools & Tech Facilitator	345
Total:	1,009

Table 3. Excel® sheet database example demonstrating how co-incidentally coded excerpts were summarized as strategies and work system barriers or facilitators. The database's headers contain the code definitions to help guide strategy summarization and work system element coding.

Family-generated strategy: "any dynamic response to perceived work system barriers to, or facilitators of, timely and effective performance of effortful work activities in pursuit of the patient's health goals"				Tools & Tech e.g., various technologies, medical devices, characteristics of tools, e.g., usability		Organization e.g., teamwork, coordination, collaboration, organizational culture, work schedules, social relationships		Person e.g., education, skills, knowledge, motivation, needs, physical and psychological characteristics		Task e.g., variety of tasks, challenge and utilization of skills, autonomy, participation, workload, time pressure, cognitive load, need for attention		Phys Environ e.g., layout, noise, lighting, temperature, humidity, air quality, work station design	
ID #	Transcript Number	Excerpt	Strategy Summary	Tools & Tech Barrier	Tools & Tech Facilitator	Organization Barrier	Organization Facilitator	Person Barrier	Person Facilitator	Task Barrier	Task Facilitator	Phys. Environ. Barrier	Phys. Environ. Facilitator
2	#	Yeah, for the week, yeah. So when we order stuff from the pharmacy, we make sure that they send us either extra labels or extra bottles with labels on. You know, some of the medicines we draw up into a syringe and we cap it, and we put a label on it. Because the school, of course, can't just give something that's not labeled, you know.	Ask pharmacy to send extra labels (or labeled bottles) for sending medications to school.		Labeled medication bottles.	School cannot give medication that is unlabeled.							

During the initial work system coding described in section 4.2.3, physical environment B&F were coded in an Excel® sheet, and as such were not exported from NVIVO 12. To add them to my database of co-incidentally coded excerpts, I first obtained the Excel® sheet that contained the physical environment B&F excerpts (n=320). To identify co-incidental strategy and B&F codes, I coded each line as either a *family-generated strategy,* definition included in Table 3, or not and summarized the strategy if it was one. In total, this process resulted in 113 excerpts being coded as strategies and added to the Excel® sheet database. To assess the application of the *family-generated strategy* code to the physical environment B&F, I reviewed 10% of the 320 excerpts with a senior researcher (NW). Of the 32 excerpts randomly selected to review, we had a 96.9% agreement on the coding, i.e., if it was coded as a strategy, agreeing that it was, or if it was not coded as a strategy, agreeing that it was not.

Further, two transcripts in the NVIVO file did not contain the previous coding data, i.e., one transcript was missing strategy coding and the other was missing work system B&F coding. To address this issue, I recovered coding for one transcript from an old data file. For the other, I independently coded work system B&F. Through this process another 56 excerpts were added, bringing the total number of excerpts contained in the database to 1178.

4.4.2   Data Analysis – summarizing strategies and work system B&F

As a first step in both cleaning the compiled data set and analyzing the data, I identified duplicate excerpts by reviewing the Excel® sheet, line by line, using the search function. When identical excerpts were identified, I "merged" them by writing the strategy ID # in the associated column (e.g., person barrier) of the original excerpt's row and struck through the duplicate's row. This process (1) eliminated duplicates caused by exporting excerpts from NVIVO 12, i.e., the software does not consolidate excerpts if they are coded at different lengths, and (2) identified

co-incidental coding. Through this consolidation process 496 (42.1%) excerpts were eliminated and combined into the 682 remaining excerpts.

Next, line by line, I summarized each strategy and its associated work system barrier(s) and/or facilitator(s). If the excerpt did not describe a strategy, it was coded as "not a strategy" and eliminated. Work system B&F codes were also reviewed critically and removed if they were not relevant to the summarized strategy. Additionally, I coded any work system element B&F that were missed in the initial analysis. For any excerpts that I had questions about, I made note to review them with either a senior researcher (NW) or a clinician (RC). All flagged excerpts were later resolved through discussion with their respective expert. Throughout this process, I data analysis activities, insights, and questions using Birks et al.'s mnemonic for the purpose of analytic memos as a prompt (Table 4) (Birks et al., 2008).

Table 4. Birks et al. (2008)'s mnemonic MEMO for remembering the purpose of analytic memos (Saldaña, 2009, p. 53).

M	Mapping research activities (documentation of the decision-making processes of research design and implementation as an audit trail)
E	Extracting meaning from the data (analysis and interpretation, concepts, assertions, theories)
M	Maintaining momentum (researcher perspectives and reflexivity throughout the evolutionary journey of the study)
O	Opening communication (for research team member exchanges)

In applying my family-generated strategy code—which is more narrowly defined than the initial strategy analysis—280 excerpts were eliminated from the Excel® sheet. A quarter of the eliminated excerpts were reviewed by a senior researcher (NW) to assess consistent application of the family-generated strategy code. This review resulted in 8 excerpts (10.9% of those initially eliminated) being coded as a strategy and prompted me to review the remaining excerpts line-by-line. In that review, 35 excerpts (16.9%) were coded as a strategy. Thus, each excerpt that was

eliminated, i.e., coded as "not a strategy," was reviewed twice by either a combination of me and a senior researcher (NW), a clinician (RC), or myself again.

4.4.3   Data Analysis – analysis of strategies

To better describe the breadth of strategies that families developed, I conducted an inductive content analysis on the family-generated strategies in my Excel® sheet database (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Reviewing the strategies line by line, I generated a code to describe the strategy. As patterns emerged, I refined the wording of the codes and iteratively re-applied them to the previously coded strategies. The first round of coding resulted in an initial codebook (Table 5, Col 1), which was organized into a second codebook (Table 5, Col 2). I then applied the second codebook to the strategy database and iteratively refined codes again, i.e., when a new code or phrasing for a code emerged, the codebook was updated and re-applied to the strategies. After the second round of coding, I met with a senior researcher (NW) to discuss and refine the codebook to reflect our insight that the codes were categories of care work. The resulting codebook was applied in a third round of coding, discussed again with a senior researcher (NW), and refined into the final codebook (Table 5, Col 3).

Next, I generated a list of *unique strategies* from the complete list of strategies in the strategy database. The aim of this process was to combine strategies that were used by multiple families, e.g., multiple families described monitoring their child with a camera, so those strategies were combined into one unique strategy. Strategies were sorted by their codes and then line by line, I reviewed and assigned a "unique strategy ID" to each unique strategy, i.e., when I came across a strategy that was previously mentioned, I assigned it the previous strategy's "unique strategy ID." On a second pass, I combined strategies that shared a unique strategy ID and revised the unique strategy to ensure it represented each of the original strategies.

Finally, I developed strategy types by abstracting the unique strategies that were used to address each category of care work. To do this, within each sub-category of care work, I reviewed the strategies and grouped them by similarity. I then abstracted the groups of similar strategies, i.e., I removed specific details to create a strategy type that jointly described each of the original strategies (Hollnagel et al., 1981; Xiao & Vicente, 2000).

Table 5. Inductively derived strategy codes.

1. First round of coding	2. Second round of coding	3. Final codebook
environment	Environment	Direct care
designated environment	Environment/Van	Direct care/moving the child
house	Environment/House	Direct care/positioning the child
Ramp	Environment/Layout	Direct care/monitoring
van	Environment/Prevention	Direct care/communicating and working with the child
medication	Medication	Direct care/delivering care via device
medication mgmt	Medication/Delivery	Direct care/delivering direct physical care
medication storage	Medication/Storage	Direct care/safe and healthy
monitoring	Medication/Management	Direct care/inclusion and independence
supplies	Monitoring	Meds & Food
supplies mgmt	Supplies	Meds/preparing
supplies/insurance	Supplies/Cleaning	Meds/administering
supplies/obtaining	Supplies/Insurance	Food/preparing
supplies/future needs	Supplies/ergonomics	Food/administering
supplies/ergonomics	Supplies/Future needs	Supplies
supplies/travel	Supplies/Redundancy	Supplies/navigating insurance
supplies/storage	Supplies/Storage	Supplies/obtaining
supplies/redundancy	Supplies/obtaining	Supplies/storing
medical device	Supplies/Management	Supplies/cleaning
direct care	Direct care	Supplies/preparing for insufficient or broken
direct care/transfer	Direct care/moving the child	Caregivers
direct care/workload	Direct care/workload	Caregivers/hiring
direct care/medication	Direct care/Prevention	Caregivers/training and supporting
new tool	Direct care/Distraction	Caregivers/well-being
new tool, environment	Direct care/Location	Caregivers/workload
new tool, van	New tool	Care coordination
new tool?	New tool/Ergonomics	Care coordination/sharing information
new tool/ergonomics	School	Care coordination/scheduling caregivers
school	Emergency	Care coordination/scheduling appts
emergency	Emergency/Prevention	Care coordination/school
food prep	Emergency/Planning	Environment
task efficiency	Emergency/Response	Environment/safety
other caregivers	Food Preparation	Environment/clean
other caregivers/hiring	Food Preparation/Efficiency	Environment/inclusion and independence
other caregivers/respite	Caregivers	Environment/navigable
caregiver wellbeing	Caregivers/Hiring	Leaving home
caregivers coordination	Caregivers/Training&Support	Leaving home/transporting the child
info sharing	Caregivers/Well-being	Leaving home/transporting devices and supplies
info sharing/reminding	Routine	Leaving home/caring for the child outside of the home
info mgmt	Routine/Learning	Leaving home/preparing supplies and food
practice/procedure	Routine/Prevention	Leaving home/inclusion
Practice/Procedure,	Travel	Emergency
Medication	Travel/supplies	Emergency/planning
practice/procedure,	Travel/food	Emergency/responding
learning	Travel/preparation	Info Management
practice/procedure,	Care Coordination	Info Management/contacts and care team
prevention	Care	Info Management/changing care plan
practice/procedure, info	Coordination/Information	Info Management/tracking symptoms
sharing	Sharing	Info Management/learning
	Care Coordination/Scheduling	
	Information Management	
	Information	
	Management/Tracking	

4.5 Methods for RQ2

RQ2: What is/are the relationship(s) between work system barriers, facilitators, and family-generated strategies?

To answer RQ2, I used the data set I built to answer RQ1 to explore the relationships between work system B&F and strategies.

4.5.1   Data Analysis

To explore relationships between work system B&F and family-generated strategies, I conducted an inductive content analysis to identify categories of work system B&F (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). I began by acquainting myself with the breadth of work system B&F in my strategy database. I worked through the database (Table 3) by filtering one work system element barrier or facilitator column at a time, e.g., filtering for all organization barriers. First, I familiarized myself with the filtered data, e.g., organization barriers. Then, I generated a table of categories to capture the breadth of the data, e.g., categories of organization barriers. On a second review of the data, I refined the themes and selected demonstrative examples to add to the table. The resultant data table was discussed with a senior researcher (NW) and categories were refined for clarity and consistency.

Next, I used descriptive statistics to look at how work system B&F and family-generated strategies were related. I started by calculating how many work system B&F were associated with each strategy. I also calculated how many strategies were associated only with a work system facilitator(s) and how many strategies were associated with only a work system barrier(s). Finally, I was interested in how strategy associations were distributed across the five work system elements, i.e., person, tools and technology, task, organization, and physical environment. As such, I calculated the number of strategies that were coded as either a barrier OR facilitator

OR both of each work system element, e.g., any strategy coded as a person barrier OR a person facilitator OR both a person barrier and facilitator.

Finally, I conducted an inductive, deductive analysis to identify different strategy mechanisms, i.e., specific relationships between work system B&F and strategies. I began my analysis using two codes, "leverage a facilitator" and "directly address a barrier," definitions included in Table 6. Upon initial application of the codes, I found that they poorly described a portion of the strategies and, as such, added "avoid or work around a barrier" to the codebook (Table 6). The codebook was applied for all 447 strategies, i.e., I coded all strategies not just unique strategies. In applying the codebook, strategies were only coded as "leverage a facilitator" if they were associated with a previously coded work system facilitator. Similarly, "avoid or work around a barrier" and "directly address a barrier" were only coded if the strategy was associated with a previously coded work system barrier. The codes "avoid or work around a barrier" and "directly address a barrier" were mutually exclusive and were not coded together on a single strategy. After coding every strategy, 45 randomly selected strategies (10% of the total number) were reviewed by a senior researcher (NW). We had 97.8% agreement. Basic descriptive statistics were used to describe the data.

Table 6. Codebook for strategy mechanism analysis.

Code	Definition: The primary mechanism of the strategy is…	Notes on applying codes
Leverage a facilitator	Utilizing a positive aspect of the existing work system to achieve their goals.	Must have a previously coded work system facilitator.
Avoid or work around a barrier	Finding a way to achieve their objective without interacting with the barrier.	Must have a previously coded work system barrier and NOT be concurrently coded as "directly address a barrier."
Directly address a barrier	Confronting or dealing with the barrier.	Must have a previously coded work system barrier and NOT be concurrently coded as "avoid or work around a barrier."

Chapter 5: Results

In Chapter 5, I present the results of my study. First, in section 5.1, to answer RQ1, I list the family-generated strategies that I summarized from excerpts coded as strategies and work system B&F and categorize the strategies by the care work they address. In section 5.2, I present the work system barriers and facilitators that were associated with the family-generated strategies. Finally, in 5.3, to answer RQ2, I present data that describes the frequency with which strategies were associated with barriers and/or facilitators of different work system elements. I further describe those associations by presenting my findings about strategy mechanisms, i.e., leveraging facilitators, avoiding/working around, or directly addressing barriers.

5.1 Family-generated strategies

Of the 682 excerpts that were coded as both a strategy and a work system barrier or facilitator, 447 (65.5%) were summarized as strategies. Those 447 strategies were condensed into 319 unique strategies by combining the strategies that multiple families used into one unique strategy. The unique strategies were then abstracted into 108 strategy types that addressed nine categories of care work, each with additional sub-categories, discussed in more detail in the following sections. The complete table with all 319 unique strategies is included in Appendix D.

I identified nine categories of care work that strategies addressed: (1) providing direct care, (2) ordering, organizing, and maintaining medications, medical devices, and supplies, (3) preparing and administering medications and feedings/food, (4) hiring, training, and supporting caregivers, (5) coordinating care, (6) managing information, (7) managing the physical environment of the home, (8) leaving the home care environment, and (9) planning for and responding to emergencies. Table 7 summarizes the care work categories and sub-categories and lists the strategy types that addressed each sub-category of care work.

Table 8. Strategy table

Care work categories	# of strategies (%)	Sub-categories of care work (# of strategies)	Strategy types
1. Providing direct care	101 (31.7)	Providing direct physical care to the child (25)	• Provide care in a location that makes it physically easier. • Store devices and supplies in the places(s) care is done. • Move or modify the child's bed to make care more ergonomic. • Develop routines for simplifying direct physical care. • Buy/implement tools that support direct physical care.
		Keeping the child clean, safe, and healthy (23)	• Keep the child home to avoid getting the child sick. • Use devices or supplies to prevent messes. • Use devices or supplies to keep the child safe. • Develop routines to prevent negative outcomes.
		Delivering care using medical devices (12)	• Modify devices or supplies to fit the child. • Modify devices or supplies to fit the home environment. • Develop methods for using or modifying device use to fit the home environment.
		Communicating and working with or around the child (12)	• Develop methods for communicating with the child. • Develop methods for modifying the child's behavior. • Develop routines that avoid experiences that upset the child.
		Monitoring the child (10)	• Use a tool to monitor the child. • Modify routines to stay near the child or keep the child nearby to monitor them. • Organize the physical environment to support monitoring the child. • Develop personal methods for monitoring the child.
		Supporting the child's inclusion and independence (8)	• Develop methods for including the child. • Buy/implement tools that support the child's independence.
		Positioning the child (6)	• Buy/implement tools that support positioning the child. • Develop methods for positioning the child.
		Moving the child (5)	• Develop methods for moving the child.
2. Ordering, organizing, and maintaining medications, medical devices, and supplies	44 (13.8)	Storing medications, devices, and supplies (18)	• Organize medications to support the cognitive work of preparing and administering them. • Organize medications and supplies to make them easy to store, access, and inventory. • Implement/use tools to organize medications, devices, and supplies.
		Navigating insurance, DME vendor, pharmacy (8)	• Develop methods for communicating with insurance, DME vendor, or pharmacy to get what they need. • Work with clinicians to get flexibility from the DME vendor or pharmacy. • Take on the work of the DME vendor to avoid interacting with them. • Schedule medication or supply delivery.

		Obtaining necessary equipment and supplies (9)	• Use social media to find necessary equipment and supplies. • Buy necessary equipment and supplies. • Make or modify supplies themselves. • Obtain equipment and supplies before they are needed.
		Preparing for insufficient supplies or broken devices (5)	• Wash and reuse supplies. • Stockpile devices and supplies.
		Cleaning devices and supplies (4)	• Implement/use tools to clean supplies. • Develop routines for maintaining device and supply cleanliness.
3. Preparing and administering medications and feedings/food	23 (7.2)	Preparing medications (5)	• Develop methods for preparing medications that support their cognitive work. • Prepare medications ahead of time to simplify medication administration.
		Administering medications (6)	• Develop methods for ensuring safe medication administration. • Develop methods for remembering to administer the medication. • Modify medication administration routine to improve the child's symptoms.
		Preparing food/feedings/formula (8)	• Develop methods for preparing food/feedings/formula efficiently. • Buy/implement tools to support preparation of food/feedings/formula.
		Administering feedings/feeding the child (4)	• Modify tools to support feeding/administering feeds. • Modify feeding administration to improve the child's symptoms.
4. Hiring, training, and supporting caregivers	29 (9.1)	Hiring new caregivers (9)	• Recruit caregivers with particular expertise and/or motivation. • Hire their own caregivers to avoid working with agencies. • Hire respite because finding qualified caregivers is challenging. • Develop methods for interviewing and hiring caregivers.
		Training and supporting caregivers in providing high-quality care (7)	• Create tools for supporting daily care delivery by any/all caregivers. • Develop methods for training caregivers in care tasks.
		Ensuring caregiver well-being (7)	• Use social media to connect with people who understand them. • Develop routines that support the caregivers in taking care of themselves. • Make decisions about how to conceptualize time and/or space.
		Addressing workload (6)	• Modify employment status to be able to care for the child themselves. • Modify standards to be able to accept help from another caregiver. • Develop methods for reducing workload.
5. Coordinating care	22 (6.9)	Scheduling caregivers (4)	• Use digital tools to communicate schedules to caregivers. • Have one person manage the caregiving schedule.
		Coordinating care delivery among caregivers (7)	• Create/use shared tools to track the delivery of the child's care. • Use physical notes to leave timely messages for other caregivers.
		Scheduling and managing appointments (6)	• Use/implement tools to store and keep track of the child's appointments. • Work around another caregiver's method for tracking the child's appointments. • Develop methods for avoiding challenges at appointments.

		Supporting the care delivered at school (5)	• Coordinate with school staff to fit schooling to the child. • Use/implement tools to communicate about the child's care. • Work with the pharmacy to ensure the school can administer the child's medications.
6. Managing information	23 (7.2)	Understanding the child's conditions and treatments and accessing resources (9)	• Use digital tools to ask questions, research the child's conditions and therapies, get advice about care, and find resources. • Develop methods for working with clinicians. • Seek out resources from experienced people. • Develop methods for learning from experience.
		Managing the child's changing care plan (6)	• Develop methods for storing/recording decisions around the child's care. • Develop methods for updating other caregiver(s) with a recent care plan change.
		Managing important contacts and care team/clinic information (5)	• Use digital tools to save, organize, and share important contacts and care team/clinic information. • Use physical tools to record and organize clinic information. • Use physical tools to display important contacts and care team/clinic information.
		Tracking the child's symptoms (3)	• Develop methods for determining when to track the child's symptoms. • Use/implement tools to track the child's symptoms.
7. Managing the physical environment of the home	32 (10.0)	Ensuring the home environment is safe (10)	• Organize the home so it is safe for the child. • Buy/use/implement tools to make the homes safer.
		Supporting the child's inclusion and independence (10)	• Design/outfit the child's environment to make it feel like home. • Design/outfit the home to make spaces and experiences accessible to the child.
		Ensuring the home environment is navigable (10)	• Move to a new home or modify the current one to improve navigability. • Use/implement tools to make the home more navigable. • Organize the home to make it more navigable.
		Cleaning and maintaining the home (2)	• Modify the home to make it easier to clean and maintain.
8. Leaving the home care environment	34 (10.7)	Caring for the child outside of the home (10)	• Care for the child in a specific location. • Buy/use/implement tools to support caring for the child outside of the home. • Develop routines for avoiding accidents.
		Preparing supplies and food for use outside of the home (8)	• Create tools to make preparing to leave home with the necessary supplies easy. • Develop routines for leaving home that ensures all supplies are packed. • Develop routines for ensuring the child has food they can eat outside of the home.
		Transporting the child (6)	• Buy/use/make tools to make transporting the child easier.
		Transporting the child's wheelchair, devices, and supplies (5)	• Keep devices/supplies in the vehicle. • Keep devices/supplies ready for leaving the home. • Use alternate wheelchair that is more portable.
		Including the child in activities outside of the home (5)	• Buy/use tools to include the child in activities outside of the home. • Modify tools to include the child in activities outside of the home.

			Work with a clinician to support the child's travel.		
9. Planning for and responding to emergencies	11 (3.4)	Responding to emergencies (9)	• Conceptualize oneself as an emergency care provider. • Develop methods for responding to emergencies while also caring for the family. • Modify methods of responding to emergencies if not at home. • Keep emergency supplies nearby. • Buy/implement backup systems to ensure the family has power.		
		Planning for emergencies (2)	• Develop packing list for use during emergencies. • Work with clinician to develop an emergency plan.		
Total:	319 (100)				

5.1.1   Providing direct care

The largest category of care work for which families generated strategies was providing

direct care. The 101 strategies (31.7% of all unique strategies) for providing direct care fall into

eight sub-categories, including: (1) providing direct physical care to the child, (2) keeping the

child clean, safe, and healthy, (3) delivering care using medical devices, (4) communicating and

working with or around the child, (5) monitoring the child, (6) supporting the child's inclusion

and independence, (7) positioning the child, and (8) moving the child.

Families described a variety of strategies for providing the direct physical care their child

needs including providing care in a location that makes it physically easier, e.g., on the floor,

storing devices and supplies in the place(s) where care is done, and buying/implementing tools

that support care. Three families raised the child's bed using bed risers to reduce the strain

placed on the caregivers' backs. One caregiver went so far as to build boxes with which to raise

the child's bed themself, saying:

> "So our nurses are older, and so it was hard for them to like bend over and even just like
> get [the child] dressed and stuff. And it is hard on your back. So then one day, I built
> these boxes. And like I should probably have like a professional do them, but it's been
> nice because then [the child is] like at waist level. So you don't have to bend over
> constantly. And [child] can't roll, so it's not like [the child is] going to fall out anyways."
> – Participant 6

To keep the child clean, safe, and healthy, families employed strategies such as keeping

the child home, e.g., from school, to avoid getting the child sick, using devices or supplies to

keep the child safe or prevent messes, and developing routines to prevent negative outcomes.

Three families described using extra supplies such as diaper liners or chux pads to prevent

leaking, e.g., through the child's diaper. To deliver care to the child using medical devices,

families described having to modify devices and supplies to fit the child and their home

environment. Three families described creating a portable cart to hold the child's medical

devices to make it easier to move the child around their home and optimize outlet usage, since typically moving the child would require identifying as many outlets as there are devices to move with the child.

To communicate or work with or around the child, families developed their own methods for communicating with their child, modifying their behavior, and avoiding upsetting them. For example, one family taught their child to hit the audio monitor to get the caregivers' attention since the child was primarily non-verbal. Another family took their child's blood pressure after they had fallen asleep to avoid upsetting them. Families also used multiple different strategies to monitor the child. The strategies included using tools, e.g., video cameras or audio monitors, modifying routines to keep the child near them, organizing the physical environment to make it easier to monitor the child, and developing their own methods for monitoring what the child is experiencing. Ten families described using video monitoring, the most prevalent strategy throughout the data. Caregivers also described personal methods for monitoring the child such as always listening for the sound of the child de-cannulating and holding their breath while changing the child's trach to personally feel how long the child has been without air:

> "So that's how easy it for me to tell like if I'm taking too long, because I hold my breath, and I'll change [the child's] trach. And once I get to where I'm panicking, where I need air, I'm like, I'm moving too slow." – Participant 19

To include the child and support their independence, families described buying and implementing tools that support the child's independence as well as developing specific methods for including the child in their care, such as writing a checklist of the tasks the caregiver will do with the child on a whiteboard so they can cross them off together. Similarly, to address the work positioning and moving the child, families developed specific methods and, in the case of positioning the child, implemented tools, too. Examples of tools that families used to support

positioning the child were a small bathtub that helps the child stay sitting up at an angle and a specially designed tool for helping to orient the child to sleep on their side. Methods for positioning and moving the child included rolling up blankets to create cushions to support the child's head and having the child sit down on the stairs and scoot down them, respectively.

5.1.2   Ordering, organizing, and maintaining medications, medical devices, and supplies

The next largest category of care work for which families generated strategies was ordering, organizing, and maintaining medications, medical devices, and supplies (44 strategies, 13.8%). Strategies in this category are further divided into five sub-categories: (1) storing medications, devices, and supplies, (2) navigating insurance, DME vendor, pharmacy, etc., (3) obtaining necessary supplies, (4) preparing for insufficient supplies or broken devices, and (5) cleaning devices and supplies.

To address the work of storing medications, devices, and supplies, families used multiple strategies. For medications, they organized medications to support the cognitive work of medication preparation and administration, e.g., one family organized medications by route of administration. The other strategies families employed were systems for organizing medications and supplies to make them easy to store, access, and inventory and implementing tools to help store supplies efficiently. Multiple families described storing supplies in one central location, developing a labeling system, and storing items based on the frequency of their use.

Families also had to develop strategies to address the work of navigating their insurance, DME vendor, and pharmacy. Strategies included developing methods for effectively communicating with insurance/DME vendor/pharmacy to get what they needed, working with clinicians to get flexibility from the vendor or pharmacy, taking on the work of the DME vendor to avoid interacting with them at all, and scheduling medications to be delivered monthly to limit

the work of managing them. The strategies that families developed to communicate with their insurance/DME vendor/pharmacy ranged from "pulling on someone's heart strings" to complaining until they got what their child needed.

The strategies that families developed to obtain the necessary equipment and supplies their child needs included using social media to search for, buy, and exchange equipment or supplies. Three families described swapping supplies with other families caring for CMC found on a social media group. One parent described the collegiality of families on these groups:

> "We can trade things, like supplies. (Exchange supplies with other parents?) Yeah… Like if people are like, hey, we just got switched from this feeding pump to this feeding pump but we have all these bags for that feeding pump that we're no longer, or a family loses a child and they're like, I have all these supplies. Does anyone need this, this, or this? They're like, I'll send the tube for you for shipping." – Participant 10

The other strategies families employed included buying, making, or modifying equipment and supplies themselves and proactively obtaining equipment they expected to need in the future. Three families sewed, or had another caregiver sew, their own bibs out of towels. Two families had caregivers who were proactive in obtaining equipment they expected their child to need in the future, e.g., a bath chair or hospital bed.

Families also described strategies they developed to prepare for insufficient supplies or broken devices. To avoid an emergency if/when supplies ran out or devices broke, families washed and reused some supplies and stockpiled others. One caregiver described how they order the maximum number of supplies that they can:

> "Always, always order trach, because you can never have too many of those, because you're supposed to change them weekly, and they only give you one a month." – Participant 27

Finally, to clean and maintain the devices and supplies, families used tools and routines. One family implemented the use of a baby bottle sterilizer that they used to clean ventilator

circuits and trach supplies. Other families described routines for cleaning supplies after they

were used, e.g., wash the nebulizer immediately after use and put it back in its designated place.

5.1.3   Preparing and administering medications and feedings/food

Another important category of care work for which families generated strategies was the

preparation and administration of the child's medications and feedings/food. The four sub-

categories in this category include: (1) preparing medications, (2) administering medications, (3)

preparing food/feedings/formula, and (4) administering feedings/feeding the child.

Families developed methods that supported the cognitive work of medication preparation

and prepared medications ahead of time to simplify medication administration. One parent

described a method for preparing medications that helped them remember to do everything, and

therefore eased their mind:

> "I get nervous, I'm going to forget something. Even though I've, it's been the same
> routine now for a while, but, yeah, so I do usually set it all out on the counter, and I put
> stuff away as I'm done with it just to remind myself, so I don't go crazy." – Participant 6

To accomplish the work of administering medications, families developed a few

strategies, including developing methods for ensuring safe and timely administration and

modifying medication administration to improve the child's symptoms. For safety purposes,

some families only had one caregiver administer medications or had a practice of always double

checking the medications that came out of the pillbox before administering them.

Families' strategies for preparing the child's food/feedings/formula focused on preparing

the food more efficiently, such as by marking a pitcher at a pre-measured place for quicker

measuring or pre-cooking food to be added to the blenderized food that is prepared daily. Tools

that families utilized to support food/feeding preparation included a metal blender ball for

mixing up the child's formula and one-cup containers for storing pre-prepared feeds.

Families modified tools to support the work of administering feedings/feeding the child and modified the feeding administration itself when it improved the child's symptoms. Two families described modifying a lunchbox to hold the child's feeding bag to keep it cool. One family removed a component of the feeding machine which regulates the flow of the formula/feed through the machine to pass the thicker, blenderized food through the machine more easily.

5.1.4   Hiring, training, and supporting caregivers

Families also generated strategies for the care work of hiring, training, and supporting caregivers. This category of care work was divided into four sub-categories: (1) hiring new caregivers, (2) training and supporting caregivers in providing high-quality care, (3) ensuring caregiver well-being, and (4) addressing workload.

To hire caregivers, families described a variety of strategies. These included recruiting caregivers with specific expertise or motivation, e.g., a pre-med student who needs caregiving experience, hiring caregivers themselves to avoid working with a caregiving agency, hiring respite caregivers because finding qualified caregivers is challenging, and developing methods for interviewing and hiring caregivers. For example, one family described the importance of assessing how well the caregiver will fit in with the family's culture and values. As such, this family created an interview guide that discusses their culture and values:

> "You know, we have, we've developed, you know, a caregiver interview form that we use. And it talks about things about how comfortable are you with this, and how do you handle different types of behaviors, and, you know, all that kind of stuff just, it's not just like, so tell me about yourself, you know. You know, it talks about like the atmosphere of our home, you know, that we have a dog. That, you know, our son is kind of really free-spirited, and one day he might come down in a princess dress, and, you know, those kinds of things, just because, you know, we don't want there to be any problems that way." – Participant 8

Families developed methods for training caregivers and created a variety of tools to support the delivery of care by all caregivers. Five families created care schedules for caregivers to reference which listed the child's daily care needs. Other tools that families used to support caregivers were photos to show other caregivers how to set up a device, e.g., the feeding machine, and a whiteboard for reminding the caregivers when the child was due for their scopolamine patch to be replaced.

Caregivers described multiple strategies for ensuring their own well-being. Three caregivers described using social media to connect with other parents of CMC who get what it is like to be parent to a medically complex kid. Some caregivers developed routines that supported their well-being, including hiring respite care workers so that they could spend a night away from home to get some rest and working out regularly to stay fit and have alone time. Families also described decisions they made around their time and space, such as designating one floor of the home as private space.

To address the workload of providing care for their CMC, families developed multiple strategies. Some families modified their employment status to be able to care for their child themselves, i.e., some caregivers quit their jobs, one coordinated their work shifts so they could provide weekday care to their child, and another took a leave of absence from work. The other strategies families used were modifying their standard to accept help from another caregiver and developing other methods of reducing workload, e.g., switching the child's care off between caregivers daily.

5.1.5   Coordinating care

For this care work category, strategies were divided into four sub-categories, including: (1) scheduling caregivers, (2) coordinating care delivery among caregivers, (3) scheduling and managing appointments, and (4) supporting the care delivered at school.

To support the work of scheduling caregivers, families developed two strategies: using digital tools to communicate schedules with caregivers and assigning one person the task of managing the care schedule. Families used a variety of methods for communicating caregivers' schedules with them, including sending them via email, text, and even taking a screenshot of a digital calendar to send to them. Families also used strategies to address the work of coordinating care delivery among caregivers. The strategies included creating and using shared tools for tracking the care delivered to the child, e.g., a paper medication log, mobile application, or excel sheet, and using verbal communication or physical notes to deliver timely messages for other caregivers.

To address the work of scheduling and managing appointments, families developed strategies that included using tools to store and keep track of the child's appointments, working around another caregiver's method of tracking appointments, and developing methods for avoiding challenges at appointments. One caregiver described how they have learned to cancel appointments if they are having a bad day and the appointment is not essential:

> "I've also learned where if it's a non-essential appointment, I hate canceling things, but like if we're going through a day and we're having just a day and everything is hitting a wall and it's not essential, then I'm like we're not going to do this today. We're going to take a step back." – Participant 30

Families' strategies for supporting the care delivered at school included coordinating with school staff to fit schooling to the child, using or implementing tools to communicate about the child's care, and working with their pharmacy to ensure the school can administer the child's

medications. Families described meeting with school staff ahead of the school year to discuss the child's care needs and working with school staff to arrange for a later start to their day. Four families described some version of a record, e.g., binder or journal, for tracking and communicating about the child's care between the home and the school.

5.1.6   Managing information

The four sub-categories of managing information are (1) understanding the child's conditions and treatments and accessing resources, (2) managing the child's changing care plan, (3) managing important contacts and care team/clinic information, and (4) tracking the child's symptoms.

Families developed a variety of strategies for understanding the child's conditions and treatments and accessing resources, including using social media and the internet to research and ask questions, developing methods for working with clinicians, seeking out resources from people with experience, and developing methods for learning from experience. Nine of the families described using social media groups to connect with other families caring for CMC to ask questions and get advice.

To manage the child's care plan, families developed methods for storing and recording decisions around the child's care and methods for updating other caregivers on a recent care change. Families stored notes from past appointments in binders and digital documents. Notes from more recent appointments were often given a more prominent location, such as how this family stores the child's most recent after visit summary on the fridge for other caregivers to reference:

> "I mean, sometimes I'll also post up like if something has changed and I just took [child] to [child's] neurologist or whatever or [child] just got out of the hospital or whatever, then we'll take that, I don't know what you call them, release papers from the hospital or after-visit summaries, and put them on the fridge just because it's like, oh, okay, what

was that again, and it changed. And yeah, so I'm sorry, there is something that we do just kind of until we get the hang of it, right, yeah." – Participant 12

Families developed multiple strategies to support the work of managing important contacts for the child's care team and clinics. For one, families used digital tools to save, organize, and share contacts, e.g., using their phone contacts, notes app, or google document. Other families used physical tools to organize clinic information, e.g., a planner for recording all the child's care clinic information or a whiteboard for displaying important contact information.

Finally, families developed methods for determining when to track the child's symptoms and used or implemented tools for tracking those symptoms. One family described their process of deciding to track the child's symptoms when they seemed to be occurring more frequently.

5.1.7   Managing the physical environment of the home

The four sub-categories of managing the physical environment of the home are (1) ensuring the home environment is safe, (2) supporting the child's inclusion and independence, (3) ensuring the home environment is navigable, and (4) cleaning and maintaining the home.

To ensure the home environment is safe, families described two strategies. These strategies were organizing the home so that it is safe for the child and buying, using, or implementing tools to make the home safer. Examples of organizing the home so that it is safe include keeping the home clear of clutter and items that the child can get into and keeping the child's bed on the floor to eliminate the risk of the child falling out of bed. Tools that families implemented to make the home safer included play mats and foam to make the home physically safer for the child and a humidifier to make the home's air safer for the child.

Families developed strategies for supporting the child's inclusion and independence, including designing/outfitting the child's environment to make it feel like home and to make

spaces and experience accessible to the child. Families described attempting to make the hospital feel like home and using tools to make the environment of the child's room less medical. To support the child's independence, families described building an accessible playset and using a futon in the living room because it is more comfortable for the child to be on. One family described how the open space in their home was an intentional choice to support the child's ability to navigate the home on their own:

> "We kind of have the house set up so [child] can, because [child] drives, and because [child is] very low vision, we try to set it so there's open space for [child] to drive around." – Participant 3

Strategies for ensuring the home was navigable included moving to a new home or modifying the current one, using or implementing tools, or organizing the home to improve navigability. Five families described moving to a home that had features that made navigation easier, e.g., open floorplan, ranch-style. Families who did not move into a new home made modifications to bathrooms to make them more accessible and installed ramps. Families that could not afford to modify the home permanently used tools to make it more accessible, e.g., ramp that is not to code. Finally, to address the work of cleaning and maintaining the home, a few families described modifying the home to make it easier to clean, e.g., installing a dishwasher or removing carpet.

5.1.8   Leaving the home care environment

For this care work category, strategies were divided into five sub-categories, including: (1) caring for the child outside of the home, (2) preparing supplies and food for use outside of the home, (3) transporting the child, (4) transporting the child's wheelchair, devices, and supplies, and (5) including the child in activities outside of the home.

To provide care for the child outside of the home, families described caring for the child in a specific location, e.g., lying the child down in the back of the van, buying, using, or implementing tools to support caregiving, and developing routines for avoiding accidents. For example, one caregiver describes how they always chance the child before long car rides to prevent accidents:

> "And what we do, because when [child] has to go to the doctor, we use Madison for everything, is that it's about an hour [away], so [the child] always gets changed just before we go. But then whenever we're there, it is the rule that we have to change [the child] there just because if something would happen, you know. So this is always what we do. I bought this setup. It has [the child's] diapers and her wipes. And then on, oh, then there's wipes there. And then this is our little pouch that carries all of [the child's] little necessities, [the child's] catheters and then the gel that we have to use and our rubber gloves, [the child's] diaper wipes." – Participant 14

Families developed strategies to ensure the child has the food and supplies they need outside the home, including creating tools to make preparing to leave the home easier, developing routines for leaving the home that ensure all necessary supplies and foods are packed. For example, two families kept a tote-sized box full of the child's supplies that could simply be put in the car and taken with them. Three families described preparing supplies the night ahead of leaving the home, and a few families described preparing meals that fit their child's diet for them to eat when at school or another caregiver's home.

To support transporting the child, families bought, used, or made tools. Two families described fundraising for and purchasing a wheelchair accessible van and three others described buying and modifying one. One family made their own portable ramp, and another described utilizing a mirror in the car to monitor the child. Families kept devices/supplies in the vehicle or ready for leaving the home and used alternate wheelchairs to successfully transport the child's wheelchair, devices, and supplies. For example, two families kept medical devices in bags to make them easy to grab and go.

Finally, families developed strategies to include the child in activities outside of the home. These strategies included buying or using tools and modifying tools to include the child in activities outside of the home and working with a clinician to support the child's travel. Examples of these strategies included buying an electric bike that can help the caregiver pull the child in their bike trailer. One family described how, in preparing to fly with the child, they worked with their clinician to have them write a note to allow the child's special food through security with them.

5.1.9   Planning for and responding to emergencies

The final category of care work for which families developed strategies is planning for, preventing, and responding to emergencies. The two sub-categories of this care work category are (1) responding to emergencies, and (2) planning for emergencies.

Families developed a variety of strategies for responding to emergencies. These strategies included conceptualizing oneself as an emergency care provider, developing methods for responding to emergencies while also caring for the family, modifying methods of responding to emergencies when not at home, keeping emergency supplies nearby, and buying and implementing backup systems to ensure the family has power. Ten families described having a bag packed with all of the child's care supplies, including emergency medications, extra tubes, etc. One family described how they have a backup generator for ensuring that they do not lose power in case of an outage:

> "We have generators in the garage for, if we have a power outage, we have to have two generators. We had one at our old house but it wasn't enough. So those are like built in, so the electrician had to wire for the generators so that if we go out of power, I pull the generators out, and I flip a switch in the basement that pulls things off the regular power grid and onto the generator grid, and then I can start the generators up." – Participant 29

To plan for emergencies, families developed two strategies, developing packing list to be used in an emergency and working with a clinician to develop an emergency plan.

5.2 Care work system barriers and facilitators

We identified 19 types of barriers and 18 types of facilitators that were associated with family-generated strategies. Table 8 describes the barriers and facilitators for each work system element, i.e., person, tools and technology, task, organization, and physical environment, with examples.

5.2.1   Person barriers and facilitators

For the person element, there were 88 instances of barriers and 47 instances of facilitators associated with the complete list of 447 strategies. I identified two types of person barriers: the child's dynamic care needs and caregivers' preferences and capabilities. Examples of the child's dynamic care needs being a barrier include that the child is growing (and thus their care is changing, and they are growing out of devices and supplies), they have allergies, and they have a hard time regulating their temperature. Examples of caregivers' preferences and capabilities being barriers are when caregivers are uncomfortable with and do not want to use digital technologies or caregivers who are older and have a poor memory.

I identified four types of person facilitators: the child's capabilities, caregiver's awareness, caregiver's willingness, and caregiver's capabilities. One example of a child's capability that facilitates care is that they are expressive and responsive. Examples of caregiver's awareness are awareness of potential risks, future needs, and their own capacity. Examples of caregiver's willingness facilitating care include the caregiver being willing to ask questions, complain, or try something new. Finally, examples of caregiver's capabilities being facilitators

are that the caregiver has training as a certified nursing assistant or nurse or has been caring for their child for several years.

5.2.2   Tools and technology barriers and facilitators

For the tools and technology element, there were 73 instances of barriers and 268 instances of facilitators associated with the 447 strategies. I identified seven types of barriers, including having too few supplies, supplies being expensive, poorly fitting the child, poorly fitting the home environment, being of poor quality, and barriers that are inherent to the medication or medical device. Families frequently described receiving too few supplies, e.g., suction catheters, syringes, trach or BiPAP supplies, due to Medicaid or DME vendor limits. Families also described some tools being expensive, including accessible vans and an advanced machine for warming the child, e.g., "Bair Hugger." Examples of tools and technologies not fitting the child include diapers that do not fit young adults, i.e., diapers that are scaled-up versions of diapers designed for babies, and nebulizer masks that are too large for the child. Examples of tools and technologies being poorly fit to the home environment include IV poles with large bases that make it challenging to move them around the home and oxygen concentrators that are noisy and disruptive. Families also described certain supplies as being poor quality, such as the diapers provided by the DME vendor being weak. The final two tool and technology barriers pertain to the nature of the medication or medical device, i.e., the barrier is inherent to the tool or technology. Examples of medication barriers include that certain medications require refrigeration to maintain their therapeutic benefit and that other medications increase the child's risk of being sunburnt. Examples of medical device barriers include that, to be on a continuous feed, the child must always remain connected to the feeding pump, that alarms are not always accurate, and that certain medical devices have poor battery life.

Table 9. Types of work system barriers and facilitators that were associated with family-generated strategies.

Work system element	Types of Barriers	Types of Facilitators
Person	• **Child's dynamic care needs**, e.g., they need to be monitored constantly, they cannot orient themselves. • **Caregiver's preferences and capabilities**, e.g., they are uncomfortable with digital technologies, they are short, they cannot lift the child.	• **Child's capabilities**, e.g., child is expressive and responsive, child is getting stronger. • **Caregiver's awareness**, e.g., of potential risks, the child's experience, potential future needs, their own capacity. • **Caregiver's willingness**, e.g., to ask questions, complain, modify routines, try something new, collaborate with clinicians. • **Caregiver's capabilities**, e.g., they have experience welding and building, they can sew, they are physically fit and/or strong, they can quit their job to provide care.
Tools & Technology	• **Too few supplies**, e.g., DME vendor and/or insurance limits the number of syringes or suction catheters delivered per month. • **Tools are expensive**, e.g., accessible van, Bair Hugger machine for warming the child. • **Poor fit to the child**, e.g., diapers do not fit the child, nebulizer mask does not fit the child. • **Poor fit to the home environment**, e.g., devices take up too much space or are challenging to move around the home, devices are too loud. • **Poor quality**, e.g., diapers provided by DME vendor are weak, replacement feeding pump from the DME vendor works poorly. • **Nature of the medications**, e.g., child is more likely to be sunburnt on certain medications, some medications require refrigeration. • **Nature of the medical devices**, e.g., canister of suction machine gets smelly, eye gaze machine is cumbersome, alarms are not always accurate, battery on device does not last very long.	• **Redundant devices and extra supplies**, e.g., multiple feeding pumps, additional syringes, generator for use if the power goes out. • **Proper fit to the child and/or caregiver**, e.g., bed risers that make caregiving ergonomic, modified nebulizer mask that fits the child. • **Proper fit to the home environment**, e.g., pole for feeding bag that can easily be hung up in multiple locations, cart for devices that can follow the child around the home. • **Tools support caregivers to meet their care goals**, e.g., increase efficiency/reduce workload, simplify direct care, organize medications and supplies, etc.

Tasks	• **Onerous physical requirements of the care task**, e.g., carrying the child and their equipment up and down stairs, providing care that puts strain on the caregiver. • **Higher care task complexity**, e.g., storing and finding supplies, preparing and administering complex medication regimens. • **Care task timing and requirements**, e.g., monitoring the child while performing other task, irregular or inopportune timing/frequency of care tasks.	• **Physical requirements of the care task**, e.g., having the child sit and scoot down the stairs, getting water from a device that the child can operate. • **Lower care task complexity**, e.g., administering pre-prepared medications, suctioning the child's trach instead of replacing it in an emergency when they are not at home. • **Care task supports cognition**, e.g., medication preparation routine, pairing medication administration with feeding the child.
Organization	• **Process of recruiting, hiring, and onboarding new caregivers**, e.g., challenging to find qualified care attendants or people to work overnight. • **Quantity/frequency of information to be shared**, e.g., challenging to update every caregiver when something changes in the child's care plan. • **Organizational boundaries**, e.g., school cannot administer medication unless it is labeled. • **Defining one's role in the care work system**, e.g., EMT cannot provide emergency care for a child with a trach.	• **Coordinated care network**, e.g., having phone and family nearby. • **Information sharing infrastructure**, e.g., care schedules and medication checklists, open communication among caregivers. • **Predictable organizational environment,** e.g., device, and supply organization systems, pre-packed emergency supplies.
Physical Environment	• **Layout of the home**, e.g., hard to hear or see the child, multi-level home, narrow halls and doorways, inconvenient bathroom placement. • **Lack of space**, e.g., limited storage space, cannot store supplies accessibly. • **Inaccessible spaces**, e.g., entries to the home or other homes, shower/toilet.	• **Layout of the home**, e.g., easy to hear or see the child, ranch-style home, open spaces to navigate a wheelchair, wide halls and doorways. • **Sufficient/Extra space**, e.g., in refrigerator, at the school, to leave devices and supplies set up for care. • **Accessible/comfortable spaces for the child**, e.g., furniture they can sit on, open floor space. • **Shared mental models of the space**, e.g., shared space, designating spaces for specific uses.

I identified four types of tools and technology facilitators: redundant devices and extra supplies, the tool or technology fits the child and/or caregiver properly, the tool or technology fits the home environment properly, and the tool or technology helps caregivers meet their care goals. Families described redundant and extra supplies as a facilitator. Examples of this include having multiple devices, e.g., feeding pumps and suction machines, etc., and having a stock of extra supplies, e.g., syringes and suction catheters. An example of tools and technologies being properly fit to the child and/or caregiver is a nebulizer mask that has been modified to have the proper length of elastic to be effectively secured on the child. Tools and technologies properly fit to the home environment include carts for containing the child's devices that both optimize outlet usage and make the process of moving the child to another location in the home much simpler. The last tools and technology facilitator is tools that are fit for caregivers use in meeting their care goals, e.g., increasing efficiency/reducing workload, managing information, communicating with their child, finding resources to support care, etc. Examples include a shower chair that supports the work of transferring the child into the shower or tub, bins for storing medications, and an emergency checklist for quickly packing the child's supplies in an emergency.

5.2.3   Task barriers and facilitators

For the task element, there were 50 instances of barriers and 51 instances of facilitators associated with the 447 total strategies. I identified three types of task barriers: the physical requirements of the care task, care task complexity, and care task timing and requirements. Families described the physical requirements of certain tasks as a task barrier. Examples of this include the need to carry the child up and down stairs, transfer the child into and out of the bed, van, or shower, position the child effectively, and carry heavy devices and supplies. Examples of the care task complexity barrier are the need to manage and track multiple order statuses, e.g.,

from the DME vendor, pharmacy, etc., and prepare and administer complex medication regimens. The last task barrier is the timing and requirements of care tasks. Examples include the need to constantly monitor the child, including overnight, and perform certain care tasks that have irregular use schedules, e.g., a scopolamine patch that must be changed every three days.

I identified three types of task facilitators: the physical requirements of the care task, care task complexity, and care task supports cognition. Families described the physical requirements of certain tasks as facilitating care, such as having the child sit themselves down on the stairs and scoot down them, versus standing and requiring the caregiver to ensure they do not fall. Examples of care task complexity facilitators are administering pre-prepared medications and preparing feedings using pre-cooked and pre-portioned ingredients. The last task facilitator is when tasks support cognition. For example, when medication administration has been paired with another task to ensure it gets done.

5.2.4   Organization barriers and facilitators

For the organization element, there were 28 instances of barriers and 111 instances of facilitators associated with the complete list of 447 strategies. I identified four types of organizational barriers, including the process of recruiting, hiring, and onboarding new caregivers, the quantity/frequency of information to be shared, organizational boundaries, and defining one's role in the care work system. Families described the process of recruiting, hiring, and onboarding new caregivers as an organizational barrier, for example, because finding qualified caregivers can be challenging. The quantity and frequency of information to be shared about the child was also an organizational barrier since after any change to the care plan, every caregiver must be updated. Organizational boundaries posed barriers such as that the child's school is not able to administer medication unless it is labeled. The last organization barrier is

defining one's role in the care work system. For families who care for children with tracheostomies, an example of an organization barrier is that EMTs are not trained or able to provide emergency care for their child.

I identified three organization facilitators: coordinated care network, information sharing infrastructure, and predictable organizational environment. Examples of a coordinated care network are having access to respite care and other family caregiving resources. Information sharing infrastructure is an organization facilitator which includes care schedules, medication checklists, and open communication among caregivers. The last organization facilitator is having a predictable organizational environment, including having clear systems for storing and finding supplies.

5.2.5   Physical environment barriers and facilitators

Finally, for the physical environment element, there were 50 instances of barriers and 71 instances of facilitators associated with the 447 strategies. I identified three types of barriers and four types of facilitators. The three types of barriers were the layout of the home, a lack of space, and inaccessible space. Examples of the layout of the home being a barrier include the hallways being narrow and hard to navigate and having the bathroom placed in an inconvenient place, e.g., on the second floor. Examples of the lack of space barrier include having limited storage space and needing to store supplies far from the site of care. Lastly, examples of the barrier of inaccessible spaces are having stairs at the entrance to the home or bathrooms that make it quite challenging to get the child into the shower/tub.

The four types of physical environment facilitators were the layout of the home, having sufficient or extra space, accessible and comfortable space, and shared mental models of the space. Families described the layout of the home as a facilitator when it has open spaces and

wide hallways and doorways that allowed for easy navigation of a wheelchair. Having sufficient or extra space was also frequently described as a facilitator to care, e.g., there is room to store supplies near where care is delivered or to keep the child's supplies and devices laid out. Examples of the physical environment facilitator of accessible and comfortable spaces for the child include having open space for the child to be on the floor and furniture that is comfortable for them to sit on. The final physical environment facilitator is shared mental models of the space, including thinking of certain spaces as shared and designating certain spaces for specific tasks, e.g., schooling.

5.3 Family-generated strategies' relationship to the work system

In exploring the relationships between family-generated strategies and work system B&F, we found that most strategies (63.6%) were associated with two or more work system barriers or facilitators. There were 116 (36.4%) strategies that were associated with only one work system barrier or facilitator. Further, 153 (47.6%) strategies were not associated with a work system barrier. Whereas 38 (11.6%) of strategies were not associated with a work system facilitator.

Each work system element was well represented, at least 1 in 5 strategies were associated with each work system element. The work system element that was most frequently associated with family-generated strategies was tools and technology (63.3%), next were person (32.6%), organization (30.1%), physical environment (23.8%), and task (20.4%) (Table 9).

Table 9. Number of strategies associated with each work system element, i.e., were coded as either a work system barrier, facilitator, or both. *Percentage of all strategies (n=319). Percentages do not add up to 100% because strategies could be associated with more than one work system element.

Work system element	Number of strategies associated with each work system element, # (%*)
Person	104 (32.6)
Tools & Technology	203 (63.6)
Task	65 (20.1)
Organization	96 (30.1)
Physical Environment	76 (23.8)

5.3.1   Leveraging facilitators

The most frequent strategy mechanism was leveraging a facilitator. Strategies that

leveraged a facilitator often leveraged a tools and technology facilitator (151, 66.2%), although

all work system element facilitators were leveraged with some frequency, i.e., organization

facilitator (92, 40.4%), person facilitator (29, 12.7%), task facilitator (26, 11.4%), and physical

environment facilitator (33, 14.5%). An example of a strategy where families leveraged a tools

and technology facilitator is buying a recliner in which the child can sit comfortably. In this case,

the facilitator being leveraged is the recliner. One strategy that leveraged an organization

facilitator was labeling all the child's supplies so that any caregiver can re-stock and order

supplies, where the organization facilitator is that the task is designed to be done by multiple

people in a way that is easy to pick up in the caregivers' downtime. A strategy that leveraged a

person facilitator was that of hiring caregivers who are interested in pursuing health degrees, e.g.,

physician assistant program, who are looking for care experiences. In this example, the person

facilitator is the caregiver's motivation to provide high quality, and likely a high quantity, of

care. Families' strategies for pre-preparing medications or feedings were examples of leveraging task facilitators since they simplify the later administration of the medication or feeding. Finally, an example of a strategy that leverages a physical environment facilitator was when caregivers leave notes on the kitchen table to share timely information about the child's care, where the facilitator is that the sense that the kitchen table is a "shared space" facilitates communication.
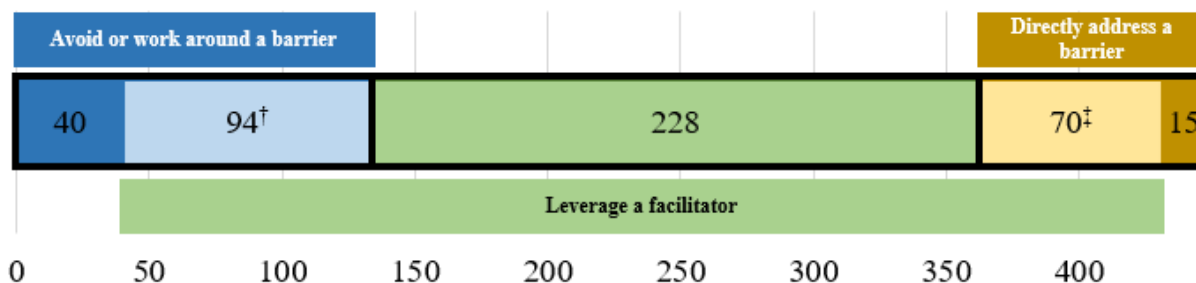
Figure 11. Number of strategies per strategy mechanism, i.e., avoid or work around a barrier, leverage a facilitator, and directly address a barrier. Some strategies had two mechanisms, depicted by an overlap between the mechanisms, i.e., [†]strategies that avoid or work around a barrier by leveraging a facilitator and [‡]strategies that directly address a barrier by leveraging a facilitator.

5.3.2 Avoiding or working around barriers

Strategies that avoided or worked around barriers, without leveraging a facilitator, most frequently addressed the work of providing direct care (21, 52.5%). Families described, for example, carrying their child rather than using the wheelchair which poorly navigates their home, choosing to only provide care to the child on the ground floor of the home, and keeping the child home from school to avoid them catching a cold. Strategies that leveraged a facilitator to avoid or work around a barrier most frequently addressed the work of providing direct care (44, 46.8%) and organizing, obtaining, and managing medications, medical devices, and supplies (20, 21.3%). A large proportion of strategies that leveraged a facilitator to avoid or work around a barrier were associated with person barriers (43, 45.7%). Examples of these strategies include narrating to the child what they are doing in providing care because the child is blind and using

foam and play mats to make the home safer for the child whose gait is poor. Tool and technology facilitators were leveraged in 58 (61.7%) of the strategies.

5.3.3   Directly addressing barriers

Strategies that directly addressed barriers, without leveraging a facilitator, most frequently addressed the work of ensuring the home environment is navigable (9, 60%). For example, families described moving to a single-level or larger home, re-designing a bathroom, and building a ramp. Strategies that leveraged a facilitator to address a barrier most frequently addressed the work of providing direct care (24, 28.5%) and leaving the home environment (17, 24.3%). Most of the strategies that leveraged a facilitator to address a barrier leveraged a tool or technology facilitator (55, 78.5%). Examples of these strategies include buying specialized tools, e.g., accessible van or portable ramp, modifying or creating tools, e.g., a cart to hold and more easily move around the child's medical devices around the home, and using tools in specific ways, e.g., using a mirror in the car to monitor the child in the back seat or using a baby bottle sterilizer to sterilize supplies.

Chapter 6: Discussion

In Chapter 6 I discuss the findings and implications of my research. First, in section 6.1 I summarize my results. In section 6.2 I discuss the key findings of my work and in 6.3 describe an expanded conceptualization of strategies. I then, in section 6.4, discuss the practical implications of this work for families caring for CMC, clinicians, and designers of any tools, environments, or interventions meant to support family caregivers. I conclude this chapter by discussing the strengths and limitations of my work, section 6.5, and areas of future research, section 6.6.

6.1 Summary of results

The results of this study address two research questions: (**RQ1**) What are the family-generated strategies that families develop to provide care for their CMC? (**RQ2**) What is/are the relationship(s) between work system barriers, facilitators, and family-generated strategies?

6.1.1 Addressing RQ1

To address RQ1, I conducted a secondary analysis of 30 in-home, contextual inquiry-based interviews of families caring for CMC. I identified excerpts of the interview transcripts where families described strategies and either a work system barrier or facilitator using two previous analyses' coding. I then individually reviewed each excerpt to summarize the strategy and identify the coded work system barrier(s) and/or facilitator(s). In total, after applying my family-generated strategy code and eliminating excerpts that did not contain a strategy, I found 447 strategies. Upon combining strategies that multiple families used, I consolidated the 447 strategies into 319 unique strategies, included in Appendix D. I then abstracted the unique strategies into 108 strategy types that addressed nine inductively-generated categories of care

work: (1) providing direct care, (2) preparing and administering medications and feedings/food, (3) ordering, organizing, and maintaining medications, medical devices, and supplies, (4) hiring, training, and supporting caregivers, (5) coordinating care, (6) managing the physical environment of the home, (7) leaving the home care environment, (8) planning, preventing, and responding to emergencies, and (9) managing information (Table 7).

6.1.2   Addressing RQ2

To address RQ2, I began by reviewing the work system B&F associated with the family-generated strategies that were identified in RQ1. I identified 19 types of barriers and 18 types of facilitators, described with examples in Table 8. Further, using basic descriptive statistics, I found that 63.6% of strategies were associated with two or more work system barriers and facilitators and 47.6% of strategies were not associated with a work system barrier. Strategies were most likely to be associated with the tools and technology (63.6%) element, although every work system element was well represented (>20%) across the strategies. Finally, to further explore the relationships between family-generated strategies and their associated work system B&F, I conducted a combined deductive, inductive analysis of strategy mechanisms, i.e., leveraging a facilitator or avoiding/working around or directly addressing a barrier. I found that 87.7% of strategies leveraged a facilitator—a portion of which were used to either avoid or work around a barrier (21%) or directly address a barrier (15.7%). Only a few strategies (12.4%) avoided, worked around, or directly addressed a barrier without leveraging a facilitator.

6.2 Discussion of key findings

In this dissertation, I have presented a comprehensive list of the strategies that families develop to provide care to their CMC and categories of care work that those strategies address. The

family-generated strategies I have identified provide a window into the work of family

caregivers—uncovering aspects of care work that are often 'invisible' (Gorman et al., 2018).

Describing the work that caregivers do that often goes unnoticed and, by virtue, undervalued is an

essential step towards supporting caregivers' work. Further, the categories that emerged from my

inductive analysis are intriguing because they are categories of care work itself. The fact that my

inductive analysis of family-generated strategies identified care work categories underscores the

importance of understanding what people are trying to accomplish in using strategies, not just what

they are responding to. While this insight may seem obvious, discerning the goals of family

caregivers is likely more challenging than in the other contexts in which strategies have been

studied, e.g., studying nurses' workarounds after the implementation of BCMA where the nurses'

primary goal is to administer medication. Thus, despite Alter (2014)'s *workaround* (section 2.3.1),

Holden, Rivera-Rodriguez, et al. (2013)'s *problem solving* (section 2.3.2), and Durso et al. (2015)'s

strategy (section 2.3.3) conceptualizations explicitly mentioning worker's goals in their definitions,

this aspect of strategies has been underdeveloped. My results suggest that, if we are going to extend

these conceptualizations of strategies to the work of caregivers, we must better understand the

goals and care tasks of family caregivers.

Further, my findings suggest that work system facilitators are integrally related to family-

generated strategies, given half of the strategies I identified were not associated with any work

system barriers, i.e., they were only associated with work system facilitators, and 90% leveraged a

facilitator. Consequently, studying only work system barriers, as most current conceptualizations

would suggest doing, would have failed to capture a large proportion of the strategies that families

developed. While one could potentially infer work system barriers that were associated with these

family-generated strategies, it remains important to consider that—at least from the view of the

family caregiver—exact work system barriers may be challenging to articulate or may not be perceived at all. Another explanation for this could be that some strategies are proactive and as such are not associated with a lived experience of a work system barrier, but rather barriers are anticipated given caregivers' knowledge or explicit communication from other parents of CMC or clinicians. Anticipating is an aspect of system resilience, i.e., "the ability to produce success despite conditions that could easily lead to failure"—among monitoring, responding, and learning (Fairbanks et al., 2014). The strategies that were associated only with facilitators may best describe where families have developed this aspect of resiliency in their care work system.

6.3 Toward an expanded conceptual model of strategies

A major contribution of my research is that it lays the groundwork for expanding our conceptualization of strategies. My findings suggest that, in addition to responding to a work system barrier, a strategy can be a proactive action prompted by caregivers' perception of a work system facilitator that can be leveraged to achieve their care goals—much like the CMUA model's concept of "opportunity" (Beaudry & Pinsonneault, 2005). In this expanded conceptual model, strategies may be best thought of as a response to, or motivated by, the caregiver's goals in performing care work. As such, a refined definition of a family-generated strategy could be:

> **Family-generated strategy:** "Any dynamic response to a perceived work system barrier to, or facilitator of, achieving the caregiver's goals in performing care work."

This conceptualization of strategies fits well within a recently published, HFE-based model of the care work of family caregivers of people with dementia. Werner, Rutkowski, et al. (2022)'s model conceptualizes caregivers' goals as the driving force behind their performance and prioritization of care work tasks, which influences the strategies that caregivers engage to accomplish that care

work. Given my findings suggest that some strategies are not associated with work system barriers—which is surprising given the ways we have typically conceptualized strategies—this model may explain why families are developing strategies that are not a response to a barrier. Further, my findings may suggest that a goal-directed model of strategies may more accurately capture the strategies family caregivers develop. My conceptualization of strategy mechanisms, i.e., leveraging a facilitator, avoiding or working around a barrier, and addressing a barrier, offers a first step in this direction.

In expanding the definition of a strategy to consider both work system barriers and facilitators, we can conceptualize strategies themselves as a method for balancing the work system: a form of system adaptation. Using this conceptualization of family-generated strategies, we situate families as the designers of their own care work system. At the "sharp end" of providing care for CMC, families develop strategies to achieve a variety of goals which shape how care work is done (Werner, Rutkowski, et al., 2022). In turn, those strategies re-configure the care work system and produce new outcomes and so on. Thus, caregivers' continuous interpretation of their care work system and development and implementation of strategies is an aspect of the care work system's adaptive capacity (Woods, 2018). The expanded model of family-generated strategies presented here elucidates potential avenues for increasing adaptive capacity by increasing families' ability to perceive and leverage work system facilitators and anticipate and address future work system barriers.

In summary, my work contributes to the growing field of patient ergonomics with my focus on *family-generated* strategies, centering the caregiver's experience and knowledge (Holden et al., 2020). My conceptualization of family-generated strategies as system adaptation provides insight into how families participate in re-designing their work system. Further, my findings

expand on what we know about the relationship between work system barriers and facilitators and family-generated strategies and how those relationships balance the care work system of families through different strategy mechanisms. My work builds off other care work researchers' strategy mapping approaches to further describe the relationship between the complex care work system and the strategies families implement to care for their loved ones.

6.4 Implications for improving care work

Practically, the contribution of this dissertation is a comprehensive list of care work system barriers, facilitators, and family-generated strategies that can be used in a variety of ways to improve the care work of families caring for CMC. And while the list of strategies is long, I have categorized strategies by *care work category* and *strategy type* to make it accessible. My findings, grounded in the experiences of family caregivers, provide perspective on the goals of caregivers as they perceive and respond to their care work system. Given there is no "manual" for caring for a CMC, it is essentially the case that all families can do is develop strategies to get through their day—pointing to a marked failure by healthcare systems to deliver the support these families need. Thus, the resultant list of barriers, facilitators, and strategies can be used by researchers and designers to design and develop family-centered interventions, and by healthcare professionals as they aim to provide context-sensitive care plans and medical guidance. Each potential use of the data is a tangible step toward achieving the goal of developing and delivering safe, patient/caregiver-centered health care for all (Arnetz et al., 2020; Kohn et al., 2000).

Further, the *care work categories* I identified may serve as a useful framework for conceptualizing and communicating the work that families caring for CMC do. My work extends conceptualizations of care work that have primarily been developed in the context of caring for people with dementia (Ponnala et al., 2020; Werner, Rutkowski, et al., 2022). And while there

are similarities between the work of caring for people with dementia and CMC, one important

difference, salient in the findings presented here, is that the child's growth and development

often occur as a barrier in the care work system. As the child ages, their care needs may change,

they may outgrow the supplies or equipment that once fitted them, and the routines that once

worked well no longer do. Thus, supporting families in building the adaptive capacity they need

to care for a child as they grow may be an especially integral aspect of supporting the work of

caregivers of CMC. One of our participants who, at the time of their interview, was caring for a

child who would soon age out of the PCCP's services offered the following reflections, bolded

for emphasis:

> "I got authorization for personal care services, so we're thinking about the **things that we need to do to bridge that.** Going from daycare, pre-school, to school. Elementary, going from elementary to middle, going from middle to high school…. Every one of those has **required us to adapt our perspective.** We have to figure out how to resource it. So while we haven't, we made the first step, and it's a process. It doesn't happen quickly. None of it happens quickly. **It's a process**." – Participant 2

To support families in participating in the *process* of care work system adaptation we must be

willing to see the care work system from the perspective of the caregivers and design from there.

By developing clear understandings of how families perceive their care work system, we can

design interventions to support their perception of work system facilitators and even redesign

their care work system to facilitate families' resilient behavior.

Beyond supporting caregivers in adapting their care work system through strategy

development, it will also be important to support them in discerning what strategies are most

effective for their child and family in their specific context. However, evaluating strategies'

effectiveness may be challenging given the number of ways in which effectiveness could be

defined. For example, strategies could be considered effective if they address a work system

barrier efficiently or safely, if they effectively support a care task, if they reduce the burden of

caregiving, or if they improve the experience, e.g., peace of mind, of family caregivers. Outside of family-focused outcomes, strategies could also be considered effective if they improve the child's health or reduce healthcare utilization or cost. The strategies that are found to be effective will be greatly impacted by how we choose to define effectiveness; thus, it will be important to consider where these ways of conceptualizing strategy effectiveness conflict. Future research assessing how families and other key stakeholders, e.g., physicians, conceptualize strategy effectiveness could support the development of interventions that prioritize strategies accordingly.

Finally, families should be supported in assessing the risks of implementing strategies (Barton et al., 2021). Building systems for communicating about the work-as-done of in-home caring for CMC between clinicians and family caregivers will be essential to effectively assess the risk of certain strategies' use. Clinicians will need to defer to families' expertise about their home environment and the resources they have available to carry out the care that is prescribed. Families will need to be honest with clinicians about the strategies they have implemented that may be risky and their reasonings for doing so, so that their goals can be identified and then explicitly planned for. A practical aim of this dissertation is to give credence to the expertise that families have already developed that has until now remained invisible.

6.5 Strengths and limitations

A few strengths and limitations of this research should be considered. First, this was a secondary analysis—meaning that, while the study aimed to provide a rich data set for descriptive qualitative analysis, the interviews did not explicitly focus on strategies. Thus, we only captured strategies that families spontaneously described. It may be the case that families utilize more strategies but would not have thought to share about them unless explicitly asked. It

is also possible that families may not realize they utilize strategies at all. Future research that explicitly asks families to describe the strategies they employ could be conducted to compare the nature of the strategies identified spontaneously in this analysis with those identified through an explicit approach. I expect that using an explicit approach may yield more discussion of strategies that did not work and thus were not described spontaneously in this study. Identifying the strategies that families tried to use may be useful for understanding the process of strategy development and further clarifying families' goals.

Given my study's focus on the relationship between family-generated strategies and work system B&F, the way families described their work, i.e., the barriers and facilitators they face, invariably shaped the relationships and strategy mechanisms that were identified. One strength, however, of using data collected with a broad focus on how families provide care in the home is that the findings presented here are especially reflective of the perspectives of the families caring for CMC. Again, an alternative approach—such as asking families to explicitly identify work system barriers and facilitators—could yield interesting insight into the nature and type of B&F that families recognize and how those B&F relate to the strategies that I have presented here that may not have been explicitly linked to B&F.

Additional methodological limitations include the fact that participants were recruited from a Pediatric Complex Care Program (PCCP), which provides substantial support to families in communicating and coordinating care. It is likely that families who do not have access to such services face additional barriers and have potentially developed strategies to address the work that the PCCP has replaced and/or augmented for the families enrolled in our study. Further, participants were primarily white women and lived within a 1.5-hour drive radius of the PCCP. It is possible that families of different races, ethnicities, geographic locations, abilities, and/or

financial means have different goals in providing care and therefore develop and employ different strategies.

In terms of data analysis, an important limitation of this data is that it is qualitative and thus cannot be generalized, nor interpreted purely by its quantitative aspects. While some of the data I present here is quantified, it is not necessarily the case that the number of identified strategies would represent the prevalence of the strategy. Further, while some care work categories or strategy types may be scarcely represented here, that does not mean that those strategies are rare, unimportant, or ineffective in supporting caregivers in achieving their goals. A major strength of this study, as such, is its robust qualitative results, describing a broad range of family-generated strategies and work system barriers and facilitators.

Another important limitation of this study that should be considered is that, in setting the boundaries of my analysis, I excluded the external environment. From the work presented here, though, it is certainly the case that families generated strategies to respond to external environment barriers, e.g., supply limits set by Medicaid, by leveraging facilitators over which they had control. Future work could explicitly look at the ways in which the external environment shapes the strategies that families develop and potentially generate guidance for developing policies that are associated with a lighter workload and fewer strategies or higher quality strategies, etc.

6.6 Future research

There are a multitude of ways to meaningfully extend this work. For one, to translate these findings into personalized recommendations for families caring for CMC, it may be pertinent to understand what makes some families more "innovative," i.e., more likely to develop strategies, than others. The person facilitators I identified as being associated with family-

generated strategies that may promote innovation and creativity included caregivers' awareness, willingness, and capabilities. Further work could seek to enumerate and prioritize person facilitators, as well as other work system element facilitators, that promote families' creativity. This would extend existing models for supporting and preparing families by framing caregivers' adaptive capacity within a work system in which more than just person facilitators can be leveraged (Houts et al., 1996). A family-centered intervention, then, could take a systematic approach to building families' adaptive capacities based on the "current state" of their care work system with respect to personal attributes and resources.

Another way to carry my work forward could be to further explore the relationship between families' resources and the barriers they face and strategies they employ (and the effectiveness of those strategies). Woods (2018) defines adaptive capacity as: "the potential for modifying what worked in the past to meet challenges in the future; adaptive capacity is a relationship between changing demands and responsiveness to those demands, relative to goals (Woods, 2018, p. 438)." Considering how and to what degree resource availability influences the quality and quantity of strategies developed by families could lay the foundation for policy that re-distributes resources to address inequities. For example, families caring for CMC could be assigned to a PCCP at the closest qualified health system or, if living too far to benefit from a PCCP's services, be assigned a case manager by Medicaid to support the child's care coordination. Further elucidating the quantity and quality of strategies associated with various resources could direct the design of a staged intervention wherein strategies that were most effective with fewer resources could be implemented first, followed by strategies that are more niche, i.e., effective for some families but not others, or require more resources.

Finally, an important next step in this work is to explore how the strategies that families develop impact outcomes, e.g., for the child and the family, and how strategy effectiveness is best defined. It may not be that families who develop more strategies necessarily develop more effective or less risky ones. As such, assessing the effectiveness of different strategies and their potential risks will be important in ensuring that, as we develop interventions to support families, we are not introducing mitigatable risk (Barton et al., 2021).

Chapter 7: Conclusion

As a way of exploring work system adaptation, this dissertation aimed to identify the strategies families developed to provide care for their CMC and describe the relationships between those family-generated strategies and work system B&F. I conducted a comprehensive work system analysis and identified 447 family-generated strategies that were associated with work system B&F. Then, condensing any strategies that were implemented by multiple families, I identified 319 unique strategies. Unique strategies addressed nine care work categories and were associated with X types of barriers and Y types of facilitators. I further abstracted unique strategies into 108 strategy types. Finally, I described the relationships between work system B&F and family-generated strategies with statistics and strategy mechanisms, i.e., by conceptualizing strategies as either "leveraging a facilitator" and/or "avoiding or working around a barrier" or "directly addressing a barrier."

The findings of this study lay the groundwork for expanding our conceptualization of strategies to explicitly incorporate work system facilitators. Half of the identified family-generated strategies were not associated with a work system barrier and as such would not have been captured in a conceptualization that focuses solely on work system barriers. Further, nearly 9 out of 10 identified strategies leveraged a facilitator—most frequently a tools and technology facilitator. Supporting caregivers in identifying work system facilitators may be one way of building families' adaptive capacity. The study's resultant lists of family-generated strategies, care work categories, and work system B&F—explicitly situated in the experiences of family caregivers—may be used by researchers and designers to develop family-centered interventions and by healthcare professionals as they aim to provide personalized care plans and guidance.

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Appendix A: @HOME Study Participant Characteristics

Participant characteristic table published in Barton et al. (2021).

Caregiver		n=30
Age, mean (SD)	Years	38.3 (12.1)
Gender, n (%)	Female	24 (80)
Race/Ethnicity, n (%)		
	Non-Hispanic White	23 (77)
	Non-Hispanic Black	3 (10)
	Hispanic	1 (3)
	Asian	2 (7)
	Other	1 (3)
Education Level, n (%)		
	High School Degree or GED	8 (27)
	Some College or Apprenticeship/Technical College	6 (20)
	Associate's or College Degree	10 (33)
	Graduate Degree	6 (20)
Total Income, n (%)		
	<$20,000	4 (13)
	$20,000-$39,999	7 (23)
	$40,000-$79,999	8 (27)
	>$80,000	10 (33)
	Did not answer	1 (3)
Urban/Rural[*], n (%)	Rural	7 (23)
Child		
Age, mean (SD)	Years	7.0 (5.7)
Gender, n (%)	Female	13 (43)
Race/Ethnicity		
	Non-Hispanic White	17 (57)
	Non-Hispanic Black	5 (17)
	Hispanic	4 (13)
	Other	4 (13)
Complex Care Program Enrollment Duration, mean (SD)	Months	20.0 (9.9)
Organ systems involved at enrollment in PCCP, mean (range)	Count	5.2 (3-9)
Medications taking at enrollment, mean (range)	Count	10.1 (2-24)
Technologies used at enrollment in PCCP, mean (range)	Count	3 (0-8)
Technologies used upon enrollment in PCCP, n (%)		
	Enteral Tube (Gastostomy, Jejunostomy, and/or Naso-enteral)	26 (87)
	Suction Machine	14 (47)
	Nebulizer machine	13 (43)
	Home oxygen	8 (27)
	Tracheostomy	7 (23)

	Cough-assist	5 (17)
	Ventilator	5 (17)
	Vest	5 (17)
	Baclofen pump	3 (10)
	BiPAP/CPAP	3 (10)
	Ileostomy/Colostomy	1 (3)
Affected organ systems, n (%)		
	Gastroenterologic	26 (87)
	Neurologic	26 (87)
	Respiratory/Airway	26 (87)
	Orthopedic	16 (53)
	Renal/Genitourinary	14 (46)
	Endocrine	12 (40)
	Genetic/Metabolic/Mitochondrial	12 (40)
	Cardiovascular	11 (36)
	Allergic/Immunologic/Rheumatologic	8 (27)
	Hematologic/Oncologic	3 (10)
	Dermatologic	2 (6)
	Psychiatric	1 (3)

*Urban/Rural category determined from zip code.

PCCP: Pediatric Complex Care Program

BiPAP: Biphasic Positive Airway Pressure

CPAP: Continuous Positive Airway Pressure

Appendix B: @HOME Semi-Structured Interview Guide

Administrative notes prior to turning audio recorder on:

Thank you for agreeing to participate in this interview. The purpose of today's interview is to find out more about:
- What your experience is like providing care to your [child's relationship]
- Strategies and resources you use for providing care to [child's name] and how these are working well for you as well as ways they could be improved
  What you feel are your greatest areas of need in caring for [child's name]

(If you would like to establish child's communication abilities, use the following):

Does your child communicate with you, and if so, how?

Explain purpose of recording, remind participant that no names should be mentioned and no should be mentioned and no identifiable info etc. is ever used in the future

Is it okay for me to turn on the audio recorder now?
Turn on recorder and start interview

The audio recorder is now recording and for the purposes of the recording, this is interviewer [INTERVIEWER INITIALS], [DATE], [TIME] and I am interviewing [PARTICIPANT ID].

Note: Use contextual inquiry approach: <u>ask questions as they describe</u> to clarify or to gain a more in-depth understanding of what you observe/what they talk about – ask 'why-type' questions to dig deeper into a concept

1. Can you start out by telling me who else lives here with you (without using any names)?
   - Children? – ask about ages
   - Pets?
2. We would like to learn about the types of activities you have to perform daily to provide care for your [child's relationship]. Can you talk me through and show me what you do on a typical day to provide care to your [child's relationship] in your home and where you do it?
   - Are there different routines on different days or of different people? (e.g., mom vs dad days?)
     - *NOTE: Use the prompts below for spaces, tools/tech, and communication.*
   - In what spaces in the home do you perform care activities for your [child's relationship]?
     - Can you show me those areas? (if not already showing)
     - What objects, items, technologies, supplies, devices are helpful to you here?
       - Are there other things [such as medical devices, technologies, supplies, tools – *will refer to collectively as 'X' thing(s) moving forward in the guide*] that I haven't seen already that you use to help you provide care or organize care to your [child's relationship]?
       - Have you created anything to help you provide or manage care to your [child's relationship]? (e.g., calendar, note pad, bulletin board)

3. Who else helps care for your [child's relationship]?
   - What kinds of things do they do?

- What kinds of things don't they do and why (e.g., don't feed because never received training)?
- How are daily schedules decided and who plans them?
- How do you coordinate with them?

4. What support do you get from outside services and resources such as nursing, social work, and respite?
   - Do you use any community resources/support?
   - Does anyone help you coordinate care or services?

5. In what ways do you use the internet in caring for your child?
   - Are there any blogs/message boards/websites you use or find useful?
   - Are you in any support groups (i.e., Facebook or other virtual?)

6. How do you communicate/share information with others that help you provide care to your [child's relationship]?

7. Where else does your child spend a lot of time (i.e., at school, at grandma's)?
   - What do you do to make sure they are successful at these places?

8. Have you had to care for your [child's relationship] in a place other than your home?
   - What were the situations which led to spending time away from home? (e.g., Travel? Appointments?)
   - How did you replicate your home environment? How did you manage differences to the layout of the environment?
   - What was it like after time away from home?
   - How did you manage changes to your routine? What went well? What was more challenging?

9. Closing Questions
   - What would an ideal day be for you and your family?
   - What does a good/bad day look like?
   - If you could have anything to help you, what's the one thing that would make your life easier?
     - What would 'X' thing(s) be helpful for?
   - How could you have been better prepared to care for your child?
   - What's something you've learned that you wish you knew earlier, in caring for your child?
   - How would you complete the following sentence? A healthy life for my child includes _____.
   - If you could have three wishes, what would you wish for?
   - Is there anything else you want to show me?
   - Is there anything I forgot to ask about?

Thank you for answering all of my questions. I am going to turn off the recorder now.

Survey questions to follow

Space prompts

- Why is the space arranged in this way?
- Have you had to make any changes to the space?
- Is there anything you find challenging about the space?
- Is there anything about the space that makes providing care easier?
- Are there certain things about the layout, space, or physical environment of your home that makes providing care easier or more challenging? (e.g., stairs; divided spaces rather than open layout)

Tools/tech prompts: (dig in to find out about adaptations/self-design/workarounds/ emergency use/breakdowns):

- How do you use 'X thing'?
- Has 'X thing' been modified at all?
- How often do you use 'X thing'?
- How do you know when to use 'X thing'?
- What kinds of challenges do you experience using 'X thing'?
- How do 'X things' make life easier?
- How did you learn to use the 'X thing'? Did someone teach you?
- How did you find out about "X thing" ?
- What do you do if something goes wrong with 'X thing'? How do you get help when needed?
- Do others use 'X thing'?
- What about 'X thing' do you find challenging? Easy?

Communicating/info sharing prompts

- How do you get information from one caregiver to the next? How is the [process/thing] useful? How could it be improved?
- What information needs to be passed on?
- How do you know or communicate with one another that a task is completed or not? (e.g. a medication is given, a feed is completed, bath is done, supplies are ordered, etc)
- Do you use anything to help you organize or plan? Why did you choose that? Have you adapted it in any way? How has it been useful? How could it be improved?
- How do you remember what to do when?
- If you could have any feature you want in a technology, what would you ask for?
- Do you use any technologies (e.g., pc, phone, apps) to help plan, organize, communicate, share information or assist with caring for your [child's relationship]?

Appendix C: @HOME Work System Analysis Codebook

Code	Definition	Example
Person	Individuals who carry out or assist patients in health-related activities, and their physical, cognitive, psychosocial characteristics.	Parent of the CMC;
Task	The activities performed while caring for the CMC, characteristics of the task.	Preparing food for the CMC; Bathing the CMC;
Tools and Technology	Medical devices, technology, or information source used to assist in providing care and characteristics of the tools; both cognitive and non-cognitive.	tool access/usability; design characteristics; "nozzle breaks off" "google calendar for appointments"
Physical Environment	The space and layout of the home and how it affects care for the CMC, structural properties.	distance and spaces, surfaces (terrain), physical workspace; lighting; noise; temperature; accessibility, mobility
Organization	How work is organized: teamwork, communication, collaboration, working relationships.	Sharing work between parent caregivers; communication with other caregivers
Barriers	Factors that hinder the caregiver's ability to provide care.	patient symptoms, lack of tools, lack of knowledge, lack of support,
Facilitators	Factors that enhance the caregiver's ability to provide care.	

Appendix D. Complete list of unique strategies

Care work category	Care work sub-category	Strategy types	Unique strategies	# of participants (%)
Providing direct care	Providing direct physical care to the child	Provide care in a location that makes it physically easier.	Live on the ground floor to be close to the child and reduce the need to go up and down stairs.	2 (6.7%)
			Provide care on the ground floor of the home to reduce the need to go up and down stairs.	2 (6.7%)
			Provide all the child's care in their bedroom.	3 (10.0%)
			Provide care for the child on the floor because it is easier for the caregiver.	1 (3.3%)
			Move bed and place child on the floor on gymnastics mat to provide care.	1 (3.3%)
			Do the child's trach changes while the child is lying on the changing table which is more ergonomic for the caregiver.	1 (3.3%)
			Dress the child in the bathroom to avoid having to carry the child back and forth between locations.	1 (3.3%)
		Store devices and supplies in the place(s) care is done.	Store supplies, e.g., diapers, in all the locations that the child receives care, e.g., their room, the living room.	4 (13.3%)
			Do not move devices or supplies around the child's room, i.e., keep the room's layout the same.	1 (3.3%)
			Store one suction machine by the child's bed for care and one suction machine charging for use whenever the family leaves the home.	1 (3.3%)
			Keep necessary devices and supplies for the child (who lives in two homes) in both caregiver's homes.	1 (3.3%)
			Keep devices and supplies that the child needs at school, e.g., hospital bed, changing table, diapers, etc.	1 (3.3%)
		Move or modify the child's bed to make care more ergonomic.	Raise the bed to make caring for the child more ergonomic.	2 (6.7%)
			Build bed risers to raise the bed and make caring for the child more ergonomic.	1 (3.3%)
			Move the child's bed off the wall so both sides are open to make lifting and moving the child easier.	1 (3.3%)
		Develop routines for simplifying direct physical care.	Develop a routine for getting the child dressed.	1 (3.3%)
		Buy/implement tools that support direct physical care.	Buy a bench/table that can be adjusted with the child for use walking, sitting, etc.	1 (3.3%)
			Buy a second crib to have access to one on both floors of the home.	1 (3.3%)

			Buy a laundry basket with wheels on it to save the caregiver from additional back strain.	1 (3.3%)
			Use camping tools to assist in bathing the child in bed to avoid them getting too cold.	1 (3.3%)
			Use Q-tips to clean the child's g-tube spot; one side for cleaning and one side for drying.	1 (3.3%)
			Use a bucket for toileting the child because the commode does not fit over the toilet correctly.	1 (3.3%)
			Modify a kitchen cart so that the caregivers can stand on either side of the child while doing trach cares.	1 (3.3%)
			Switch to using anchors that the child cannot pull off as easily to help keep the child's G-tube site protected.	1 (3.3%)
			Use snap-to-close pajamas to dress the child since they are easier to get on them.	1 (3.3%)
	Keeping the child clean, safe, and healthy	Keep the child home to avoid getting the child sick.	Home school the child to avoid catching the cold/flu and having to find and hire a care attendant.	2 (6.7%)
			Keep the child home from school during the winter so they do not catch a cold/flu.	1 (3.3%)
			Avoid leaving the home so they don't have to interact with physical environments that don't meet the child's care needs or standard of cleanliness.	1 (3.3%)
		Use devices or supplies to prevent messes.	Use extra supplies in addition to the child's diaper, e.g., diaper liners or chux pads, to prevent leaking.	3 (10.0%)
			Keep the child catheterized even though sometimes they can urinate on their own to prevent accidents.	1 (3.3%)
			Put a waterproof mattress pad over the child's recliner to make it easier to clean.	1 (3.3%)
			Create homemade sippy cups (out of Gatorade bottles and thin straws) that the child cannot grip too tightly or sip too quickly.	1 (3.3%)
			Use a tomato chair for seating the child because it is easy to clean.	1 (3.3%)
		Use devices or supplies to keep the child safe.	Use a large umbrella to protect the child, who is at a higher risk of burning due to their medications, from the sun.	1 (3.3%)
			Use an alternating pressure mattress to move the child automatically and prevent pressure sores.	1 (3.3%)
			Use a towel warmer, heater, and fan to keep the child warm while showering.	1 (3.3%)
			Use various devices, e.g., heater, electric blanket, to help keep the child warm.	2 (6.7%)
			Use a "safe feeder" to give the child motor stimulation without feeding them orally and risking aspiration.	1 (3.3%)
			Have the child wear a helmet to protect their head while moving around on the floor.	1 (3.3%)

			Use a gait belt to strap the child into the Hoyer lift so that they cannot push and fall out of it.	1 (3.3%)
		Develop routines to prevent negative outcomes.	Only leave the home for short periods of time so that it is possible to return home before the child needs to be changed.	1 (3.3%)
			Wait 30 minutes after giving the child medications to do any other care to avoid upsetting the child's stomach.	1 (3.3%)
			Do not feed the child in the car to prevent challenges with the feeding pump and upsetting the child's stomach.	1 (3.3%)
			Limit the child's use of the eye gaze machine because it is tiring. Use simple choices when not using the eye gaze.	1 (3.3%)
			Develop methods for clothing the child so that they don't play with their trach or G-tube.	1 (3.3%)
			Always have a backup plan, e.g., for the family vehicle, child's equipment, etc.	1 (3.3%)
			Sit with the child while they are in the bath chair to ensure they do not fall out. Use rolled up towels to help position and support them.	1 (3.3%)
			Isolate the child if they get sick, e.g., move them to a different floor of the house, wipe off any shared spaces the child touches.	1 (3.3%)
	Delivering care using medical devices	Modify devices or supplies to fit the child.	Modify the nebulizer mask so that the elastic strap fits the child.	1 (3.3%)
		Modify devices or supplies to fit the home environment.	Modify the wheelchair so that a feeding pole can be attached and easily moved.	1 (3.3%)
			Create a feeding pole that takes up less space than the typical IV pole.	2 (6.7%)
			Build a portable cart to hold the child's medical devices to make it easier to move the child around the home and optimize outlet usage.	3 (10.0%)
			Modify an IV pole for use feeding and venting the child while they are in bed.	1 (3.3%)
			Use the backpack (designed for use on-the-go) versus an IV pole for daily feeding because it is more portable.	1 (3.3%)
			Change parameters on pulse oximeter so that it doesn't alarm constantly.	1 (3.3%)
		Develop methods for using or modifying device use to fit the home environment.	Use oxygen tanks instead of the oxygen concentrator because the oxygen concentrator is loud and annoying.	1 (3.3%)
			Do not move the child from their bedroom for home school activities to avoid having to adjust their eye gaze communication device.	1 (3.3%)
			Hang the feeding bag for longer than is usually advised to avoid waking up in the middle of the night.	1 (3.3%)
			Pair giving the child their Flovent medication (which requires brushing their teeth) with their morning and evening routine of brushing the child's teeth.	1 (3.3%)
			Place the oxygen concentrator in a less-trafficked area because it is loud. String up oxygen tubing throughout the home so the child can access the	1 (3.3%)

			oxygen from anywhere.	
	Communicating and working with or around the child	Develop methods for communicating with the child.	Teach the child to hit the audio monitor to get the caregivers' attention because the child is not always verbal and can be hard to hear from other rooms.	1 (3.3%)
			Narrate to the child what they are doing as they provide care because the child cannot see what is happening.	1 (3.3%)
			Use laminated photos with words, e.g., "pancakes," to give the child a choice of what to eat and support their language development.	1 (3.3%)
		Develop methods for modifying the child's behavior.	Do not keep hard toys to avoid having them thrown by the child.	1 (3.3%)
			Distract the child with TV to keep them still for care, e.g., venting or changing.	2 (6.7%)
			Give the child a makeup mirror to hold while brushing their teeth to keep them engaged.	1 (3.3%)
			Play one of the child's favorite songs to calm them out of an upset.	1 (3.3%)
			Refer to a former caregiver that the child really likes to get the child to behave.	1 (3.3%)
			Show affection to the child, e.g., sing, massage, or kiss the child to calm them down.	1 (3.3%)
		Develop routines that avoid experiences that upset the child.	Stay home to avoid upsetting the child who does not like going out.	1 (3.3%)
			Provide morning care after the child wakes up on their own to avoid upsetting them.	1 (3.3%)
			Take the child's blood pressure reading while they are asleep because the child really does not like the experience.	1 (3.3%)
	Monitoring the child	Use tools to monitor the child.	Use a video camera to monitor the child, e.g., at night or when in another room.	10 (33.3%)
			Use an audio monitor to alert them when to access and look at their video monitoring feed on their phone.	1 (3.3%)
		Modify routines to stay near the child or keep the child nearby to monitor them.	Sleep in the child's room to monitor them overnight.	2 (6.7%)
			Keep the child on the ground floor near the caregiver, e.g., kitchen, front door, etc., where they are easier to monitor.	1 (3.3%)
			Stay in a room other than the "master" bedroom to have better sight lines to the child.	1 (3.3%)
			When packing to leave the house, bring all devices and supplies into one room, put the child in the pack and play, and turn on the TV to distract the child to safely monitor the child while packing.	1 (3.3%)
		Organize the physical environment to support monitoring the child.	Place comfortable living room furniture in the kitchen where it is easiest for the overnight nurse to hear the child.	1 (3.3%)
			Carry supplies, e.g., crib, between floors daily to be able to monitor the child.	1 (3.3%)
		Develop personal methods for	Hold their breath while changing the child's trach to feel how long it is taking.	1 (3.3%)
			Listen for the sound of the child de-cannulating.	1 (3.3%)

			monitoring the child.	
	Supporting the child's inclusion and independence	Develop methods for including the child.	Write a checklist of the tasks the caregiver and child will do on a whiteboard and cross them off as they are done so the child can participate more fully.	1 (3.3%)
			Tape paper down to the table so that the child can color on their own.	1 (3.3%)
		Buy/implement tools that support the child's independence.	Buy a special kind of spoon that is easier for the child to hold.	1 (3.3%)
			Buy a device that allows the child to refill their own water.	1 (3.3%)
			Buy a chair that offers the child some support so they can sit independently.	1 (3.3%)
			Modify lap table with PVC pipe to make it more useful for the child.	1 (3.3%)
			Use a tablet to engage the child while other tasks need to be done.	1 (3.3%)
			Use a tool to prop up the child's tablet so the child can interact with it easily.	1 (3.3%)
	Positioning the child	Buy/implement tools that support positioning the child.	Buy the child a special chair that they are comfortable in, e.g., recliner.	3 (10.0%)
			Use a small bath that helps the child stay sitting up while bathing them.	1 (3.3%)
			Buy Tempur-Pedic bed that is comfortable for the child and can be inclined to support respiratory care.	1 (3.3%)
			Create tools to help the child sleep on their side, which better supports their body and breathing.	1 (3.3%)
		Develop methods for positioning the child.	Develop a method for positioning the child with a pillow such that their G-tube vents well.	1 (3.3%)
			Use rolled up receiving blankets to create cushions that support the child's head.	1 (3.3%)
	Moving the child	Develop methods for moving the child.	Develop a specific method for transferring the child into the shower or bathtub.	3 (10.0%)
			Develop specific method for carrying the child, their sibling, and the stroller upstairs.	1 (3.3%)
			If the child is unstable on their feet, move the child by having them sit down on the stairs and move step by step.	1 (3.3%)
			Carry child between locations in the home because it is challenging to navigate the home with the wheelchair.	2 (6.7%)
			Have only the stronger caregiver move the child, e.g., lift the child out of their bed.	1 (3.3%)
Ordering, organizing, and maintaining medications, devices, and supplies	Storing medications, devices, and supplies	Organize medications to support the cognitive work of preparing and administering them.	Organize the child's medications so it is clear what should be given in the morning versus in the evening.	1 (3.3%)
			Store active medications in bins organized by route of administration to make preparation easier.	1 (3.3%)
			Store all liquid medications in the refrigerator to prevent accidentally leaving one out that needs to be refrigerated.	1 (3.3%)
			Store the child's medications in one central location near where they are administered to the child.	1 (3.3%)
			Keep medication, e.g., laxative mix, near where it is used, e.g., kitchen, for	1 (3.3%)

			easy preparation.	
		Organize medications and supplies to make them easy to store, access, and inventory.	Label the child's supplies so any caregiver can easily locate, re-stock, and order supplies.	3 (10.0%)
			Store the child's medications together in one central location, e.g., the kitchen.	3 (10.0%)
			Store the child's supplies based on how frequently they are used, i.e., have a place for the supplies that are used daily and keep other supplies that are used less frequently out of the way.	3 (10.0%)
			Store all the child's supplies in their room so the supplies are accessible and easy to find for the nurses.	1 (3.3%)
			Have nurses check deliveries, e.g., supplies and medications, and put them away.	1 (3.3%)
			Store the child's medications together in a specific location within the refrigerator.	2 (6.7%)
			Keep the child's medications and food stored above the sink in the kitchen so that if anything spills it goes into the sink.	1 (3.3%)
			Store heavy supplies, e.g., water and oxygen tanks, near the door on the ground floor.	2 (6.7%)
			Keep only the supplies that fit in the two storage closets they use, i.e., minimize storage.	1 (3.3%)
		Implement/use tools to organize medications, devices, and supplies.	Create a portable storage cart to organize and label supplies by frequency of use.	1 (3.3%)
			Use laundry storage bins to organize the child's medical supplies.	1 (3.3%)
			Use a shoe organizer to organize and store the care supplies that are kept in the child's room on the back of a door.	1 (3.3%)
			Use storage drawers that are clear so that the supplies they are holding are visible.	1 (3.3%)
	Navigating insurance, DME vendor, pharmacy	Develop methods for communicating with insurance, DME vendor, or pharmacy to get what they need.	Reason with the vendor/pharmacy about being given a few extra supplies each month to avoid running out during a month that has high supply utilization.	2 (6.7%)
			Call and "pull on someone's heart strings" to deal with insurance denials.	1 (3.3%)
			Call and complain or be demanding to get their child the care they need, e.g., an appointment or supplies.	2 (6.7%)
			Ask the pharmacy for specific supplies that make medication administration easier.	1 (3.3%)
			Work only with the one representative who is familiar with their case.	1 (3.3%)
		Work with clinicians to get flexibility from the DME vendor or pharmacy.	Ask for prescriptions to be written vaguely so that the vendor/pharmacy will be more flexible with quantity of supplies provided.	1 (3.3%)
		Take on the work of	Repair the child's wheelchair on their own so that it does not need to be taken	1 (3.3%)

		the DME vendor to avoid interacting with them.	by the DME vendor for multiple days.	
		Schedule medication or supply delivery.	Schedule medications to ship once a month to make it easier to manage incoming orders.	1 (3.3%)
	Obtaining necessary equipment and supplies	Use social media to find necessary equipment and supplies.	Search social media for medical equipment the child needs, e.g., a hospital bed or stander.	2 (6.7%)
			Swap surplus supplies for needed ones with other families through a social media group.	3 (10.0%)
		Buy necessary equipment and supplies.	Buy supplies, e.g., a specific brand of dressings, to supplement those that are provided by insurance.	1 (3.3%)
			Buy a tool that helps keep the child warm (functions similar to a Bair Hugger).	1 (3.3%)
			Buy absorbent pads made by another parent for use around the g-tube site in place of gauze.	1 (3.3%)
		Make, modify, or substitute supplies themselves.	Make (or have another caregiver make) homemade bibs for the child.	3 (10.0%)
			Use tape instead of anchors for G or J tube if they run out.	1 (3.3%)
			Take parts from other trach adaptors, i.e., the piece that connects the child's trach to the ventilator, to modify the trach adaptor that is in use.	1 (3.3%)
		Obtain equipment and supplies before they are needed.	Store supplies, e.g., bath chair or hospital bed, that may be useful in caring for the child in the future.	2 (6.7%)
	Preparing for insufficient supplies or broken devices	Wash and reuse supplies.	Wash and reuse supplies, e.g., syringes and suction catheters, because they are not provided in sufficient quantity.	2 (6.7%)
		Stockpile devices and supplies.	Keep back up medical devices, e.g., an old feeding pump, in case one stops working.	3 (10.0%)
			Keep extra supplies, e.g., syringes or BiPAP supplies, in case they don't have enough.	4 (13.3%)
			Ask to keep the syringes that are used in the hospital because they are not covered by insurance, i.e., family must buy them themselves.	1 (3.3%)
			Order the maximum number of supplies, e.g., suction catheters, to prevent running out of them.	2 (6.7%)
	Cleaning devices and supplies	Implement/use tools to clean supplies.	Use a baby bottle sterilizer to sterilize supplies, e.g., ventilator circuits and trach care supplies.	1 (3.3%)
		Develop routines for maintaining device and supply cleanliness.	Keep syringes in water to keep them clean.	1 (3.3%)
			Put alcohol-based mouth wash into the suction canister to cut down the smell.	1 (3.3%)
			Wash the nebulizer immediately after use and place it in a specific location to find it for the following use.	1 (3.3%)
Preparing and	Preparing medications	Develop methods for preparing medications	Lay out medications and develop a routine for preparing medications and washing syringes.	1 (3.3%)

administering medications and feedings/food		that support their cognitive work.	Lay out all the child's medications and feeding preparation materials and put them away as they are used during preparation.	1 (3.3%)
		Prepare medications ahead of time to simplify medication administration.	Pre-prepare medications for later administration by the caregiver.	2 (6.7%)
			Pre-prepare medications in the morning for the nurses to administer later.	1 (3.3%)
			Prepare the child's morning medications the previous night.	1 (3.3%)
	Administering medications	Develop methods for ensuring safe medication administration.	Have only the primary caregiver(s) administer medications to avoid errors.	2 (6.7%)
			Use a pillbox to organize the child's medications. Double check that the medications that come out of the pillbox are correct before administering them.	1 (3.3%)
			Cross out the dosing instructions on the medication bottles when dosing instructions were recently adjusted.	1 (3.3%)
		Develop method for remembering to administer medication.	Keep track of the medications that need to be given in a notes app on their phone. Set alarms to remind them to give the medications at those times.	1 (3.3%)
			Pair evening medication administration with feeding the child to ensure it gets done.	1 (3.3%)
		Modify medication administration routine to improve the child's symptoms.	Change the timing of medication administration to better address the child's symptoms.	1 (3.3%)
	Preparing food/feedings/formula	Develop methods for preparing food/feedings/formula efficiently.	Pre-mark a container, e.g., bottle or pitcher, at levels that are frequently measured to speed up formula preparation.	3 (10.0%)
			Designate a space for preparing medications and feedings that is easy to clean up.	2 (6.7%)
			Prepare the child's evening feeds in the morning so no food is wasted.	1 (3.3%)
			Pre-cook and freeze portioned amounts of certain ingredients, e.g., vegetables, meat. Blend the following day's two meals each evening.	1 (3.3%)
		Buy/implement tools to support the preparation of food/feedings/formula.	Buy one-cup containers to store pre-prepared feeds more easily.	1 (3.3%)
			Use glass and stainless-steel bottles because the child's feeds will stain other materials and require more work to clean.	1 (3.3%)
			Use a metal blender ball to help mix up the child's formula.	1 (3.3%)
			Use coconut water to increase the calories in the child's food blend.	1 (3.3%)
	Administering feedings/feeding the child	Modify tools to support feeding/administering feeds.	Modify a lunchbox to hold the child's feeding bag to keep it cool.	2 (6.7%)
			Remove flow regulator from the feeding pump to move the blenderized food through easier.	1 (3.3%)
		Modify feeding administration to improve the child's	Switch the child from continuous feeding to bolus feeds to reduce the child's reflux symptoms.	1 (3.3%)
			Water down food blends to get them to go through the feeding tube.	1 (3.3%)

			symptoms.	
Hiring, training, and supporting caregivers	Hiring new caregivers	Recruit caregivers with particular expertise and/or motivation.	Hire caregivers who are interested in pursuing a health degree, e.g., pre-med or physician assistant school, and are looking for care experiences.	1 (3.3%)
			Hire nurses who work in local hospitals to work one day a week.	1 (3.3%)
			Recruit respite caregivers through after-school programs.	1 (3.3%)
		Hire their own caregivers to avoid working with agencies.	Hire caregivers themselves, including paying the child's sister through Medicaid to be a caregiver.	1 (3.3%)
			Staff their own nurses to prevent last minute cancellations and ensure they have coverage for the days they need a nurse.	1 (3.3%)
		Hire respite care because finding qualified caregivers is challenging.	Hire respite care instead of a personal caregiver because it is challenging to find personal care attendants.	1 (3.3%)
		Develop methods for interviewing and hiring caregivers.	Develop methods for interviewing potential caregivers to assess how they will fit in with the family's culture and values.	1 (3.3%)
			Set a competitive caregiving rate using their financial resources. Offer additional pay for watching their other children.	1 (3.3%)
			Place an ad in the paper and on social media, interview candidates in a public place first, then have candidates come to their home to see their interactions with the child.	1 (3.3%)
	Training and supporting caregivers in delivering high-quality care	Create tools for supporting daily care delivery by any/all caregivers.	Create a care schedule that lists the child's daily care needs, e.g., feedings and medication administration times, for reference by caregivers.	5 (16.7%)
			Create a brief document that travels with the child to describe them and their care needs, e.g., their likes and dislikes, contacts for their care team, etc.	3 (10.0%)
			Create a list of house rules for any nurses working in the home, e.g., they must bring their own lunch.	1 (3.3%)
			Take a photo of feeding pump and settings to show other caregivers how it should be set.	1 (3.3%)
			Use a whiteboard to remind caregiver which day the child needs their Scopolamine patch changed.	1 (3.3%)
		Develop methods for training caregivers in care tasks.	Have caregivers demonstrate their ability to change the child's G-tube so they are prepared in case of an emergency.	1 (3.3%)
			Involve other caregivers, e.g., both of the child's parents, their grandmother, etc., in appointments and trainings so they can learn how to provide care first-hand.	2 (6.7%)
	Ensuring caregiver well-being	Use social media to connect with people who understand them.	Participate in online social media groups to connect with other parents and caregivers who also have children with complex care needs.	3 (10.0%)
		Develop routines that	Hire a respite care worker or have the child's grandmother help take a night	1 (3.3%)

		support the caregivers in taking care of themselves.	away from home to get some rest.	
			Hand off the children between caregivers by swapping cars so that the primary caregiver can go to therapy.	1 (3.3%)
			Try to get as much alone time to rest and recharge as they can.	1 (3.3%)
			Workout regularly (5-7 days a week) to stay fit and have time to themselves.	2 (6.7%)
		Make decisions about how to conceptualize time and/or space.	Plan to resume dating once the child and their siblings have grown up.	1 (3.3%)
			Designate one floor of the home as the family's private space.	1 (3.3%)
	Addressing workload	Modify employment status to be able to care for the child themselves.	Select a specific work shift so that they can cover the child's care and not rely on respite care or home nursing.	1 (3.3%)
			Quit their job to stay home to coordinate and provide care for the child.	3 (10.0%)
			Take a leave from work to take care of and work with the child while they are getting stronger.	1 (3.3%)
		Modify standards to be able to accept help from another caregiver.	Accept a lower standard of privacy, i.e., hiring a night nurse, to sleep.	1 (3.3%)
		Develop methods for reducing workload.	Schedule the child's appointments for the days that their sibling goes to preschool because they are already leaving the house.	1 (3.3%)
			Switch off the child's care between caregivers daily.	1 (3.3%)
Coordinating care	Scheduling caregivers	Use digital tools to communicate schedules to caregivers.	Communicate caregivers' schedules via email so that it exists in writing.	1 (3.3%)
			Use texting to resolve scheduling issues between caregivers. Use MyChart to communicate with the child's care team.	1 (3.3%)
			Take a screenshot of the digital calendar to share caregivers' work schedules with them.	1 (3.3%)
		Have one person manage the caregiving schedule.	Have one nurse coordinate all the other caregivers, i.e., call and schedule them.	1 (3.3%)
	Coordinating care delivery among caregivers	Create/use shared tools to track the delivery of the child's care.	Have a paper medication log for nurses to indicate when they have administered the child's medication.	2 (6.7%)
			Create a health log that travels with the child to track the child's status.	2 (6.7%)
			Use a mobile application, e.g., task-manager application, notes, or timer, to remember and track care tasks.	2 (6.7%)
			Create an excel sheet to track care and medication timing and completion to prevent errors.	1 (3.3%)
			Work with the healthcare agency to create documentation for the nurse to use that is not too cumbersome.	1 (3.3%)
		Use physical notes to leave timely messages	If off schedule, leave a note on the care schedule for the next caregiver to communicate where care was left off.	1 (3.3%)

			for other caregivers.	Use sticky notes and texting to update caregivers on the status of care tasks.	2 (6.7%)
	Scheduling and managing appointments	Use/implement tools to store and keep track of the child's appointments.		Use a calendar, e.g., paper or digital, to track upcoming appointments.	3 (10.0%)
				Use a monthly planner to facilitate communication between parent caregivers about the child's care.	1 (3.3%)
				Store appointment information in their phone and use reminders to keep track of the child's many appointments.	1 (3.3%)
		Work around another caregiver's method for tracking the child's appointments.		Take a photo of the other caregiver's paper calendar with their phone to stay up to date and prevent surprises.	1 (3.3%)
		Develop methods for avoiding challenges at appointments.		Cancel non-essential appointments if the day is not going well.	1 (3.3%)
				Schedule appointments for when another caregiver is available to attend with them.	1 (3.3%)
	Supporting the care delivered at school	Coordinate with school staff to fit schooling to the child.		Meet with all the staff, e.g., school nurse and aides, before the school year starts to review and introduce any new care routines.	2 (6.7%)
				Work with the school to have the child start later to allow for more space in the morning to provide care without time pressure.	2 (6.7%)
				Work with the school to approve respite caregivers to go to school with the child if the student's usual caregiver is unavailable.	1 (3.3%)
		Use/implement tools to communicate about the child's care.		Send records, e.g., a binder or journal, back and forth between school and home to communicate about the child's care.	4 (13.3%)
		Work with pharmacy to ensure the school can administer the child's medications.		Ask pharmacy to send extra labels (or labeled bottles) for sending medications to school.	1 (3.3%)
Managing information	Understanding the child's conditions and treatments and accessing resources	Use digital tools to ask questions, research the child's conditions and therapies, get advice about care, and find resources.		Use social media groups with other families caring for children with complex care needs to ask questions, get advice about care, find resources, etc.	9 (30.0%)
				Use search engines to search for ideas to improve the child's care, e.g., therapy ideas to improve the child's walking.	3 (10.0%)
				Research alternatives for their child's current feeding method on the internet and social media.	3 (10.0%)
				Use social media groups to figure out what questions to ask the child's care team.	1 (3.3%)
		Develop methods for working with clinicians		Ask clinicians to write down words that they don't know on the whiteboard and communicate in plain language.	1 (3.3%)
				Build a good relationship with clinical staff.	1 (3.3%)
		Seek out resources from experienced		Ask clinicians to share information they have heard from other families, e.g., what school districts are most supportive of children with complex medical	1 (3.3%)

		people.	needs?	
			Ask a neighbor about resources for caring for a child with complex care needs.	1 (3.3%)
		Develop methods for learning from experience.	Be okay with messing up and learning from mistakes.	1 (3.3%)
	Managing the child's care plan	Develop methods for storing/recording decisions around the child's care.	Keep all the child's old medical papers and information in case it is needed in the future.	2 (6.7%)
			Develop a binder system for organizing notes about the child's care, e.g., notes from appointments, resources from Birth to Three, etc.	1 (3.3%)
			Use email or MyChart to send and receive information to ensure there is a paper trail that can be shared with the other caregiver and tracked over time.	1 (3.3%)
			Store information strategically. If it is a change of care, it goes on the daily care schedule. Other notes about appointments and care decisions are saved to a google document.	1 (3.3%)
		Develop methods for updating other caregiver(s) with a recent care plan change.	Call the child's other parent after an appointment to share what was discussed and decided while it is in their head. Follow up with a text.	1 (3.3%)
			Post the child's recent after visit summary on the fridge as a reference for any new care routines or medication dosing instructions.	1 (3.3%)
	Managing important contacts and care team/clinic information	Use digital tools to save, organize, and share important contacts and care team/clinic information.	Store everything on their phone, e.g., phone numbers, calendar events, etc.	2 (6.7%)
			Keep the child's care team on their "Favorite Contacts" list for easy access.	1 (3.3%)
			Store information about the child's care team on a shared google document.	1 (3.3%)
		Use physical tools to record and organize clinic information.	Create a list of the child's clinics in their planner to track the status of care for each, e.g., if an appointment was scheduled.	1 (3.3%)
		Use physical tools to display important contacts and care team/clinic information.	Use a whiteboard to display contacts that would be needed urgently, e.g., the DME vendor, the bus.	1 (3.3%)
	Tracking the child's symptoms	Develop methods for determining when to track the child's symptoms.	Start tracking the child's symptoms when they seem to be occurring more frequently.	1 (3.3%)
		Use/implement tools to track the child's symptoms.	Use a paper calendar to track the child's menstrual cycle.	1 (3.3%)
			Keep a seizure log on the child.	1 (3.3%)

Managing the physical environment of the home	Ensuring the home environment is safe	Organize the home so it is safe for the child.	Keep the child's food separate from all other food to ensure it has not come into contact with gluten.	1 (3.3%)
			Keep the home open and free of clutter and easy-to-get-into things, e.g., plants.	2 (6.7%)
			Keep care supplies and medications in the child's room and behind a baby gate so that the other child does not get into them.	1 (3.3%)
			Keep bed on the floor to reduce the impact of a potential fall.	1 (3.3%)
		Buy/use/implement tools to make the home safer.	Place soft items on the floor, e.g., a play mat, couch cushions, or foam, on the floor to make it safer for them.	3 (10.0%)
			Use a bed gate and a dresser to keep the child from rolling out of bed or into uncomfortable positions.	1 (3.3%)
			Get a SleepSafe bed that has removable, see-through bedrails.	1 (3.3%)
			Install a humidifier directly onto the home's furnace to regulate the humidity of the home.	1 (3.3%)
			Use kitchen cabinet drawers to build a gate so the child cannot enter the kitchen.	1 (3.3%)
			Create a sensory area with equipment that is safe for the child to play on.	1 (3.3%)
	Supporting the child's inclusion and independence	Design/outfit the child's environment to make it feel like home.	Make the hospital feel like home by keeping routine and bringing familiar items.	1 (3.3%)
			Make the child's bedroom look homey.	1 (3.3%)
			Use lego shaped storage bins to house the child's supplies and make the room less medical.	1 (3.3%)
		Design/outfit the home to make spaces and experiences accessible to the child.	Create a space for the child to do their schoolwork (since they do school at home).	1 (3.3%)
			Store the child's toys in labeled totes in an open closet so any caregiver can help them reach the toys.	1 (3.3%)
			Build an accessible playset that the child can play on.	1 (3.3%)
			Design the child's bedroom to have a wide doorway onto the deck so the child can easily be wheeled outside.	1 (3.3%)
			Use a futon as a couch in the living room because the child can sit on it with the family.	1 (3.3%)
			Keep spaces open for the child to drive their wheelchair around freely.	1 (3.3%)
			Use foam pieces to modify the height of chairs so the child can reach things.	1 (3.3%)
	Ensuring the home environment is navigable	Move to a new home or modify the current home to improve navigability.	Move to a home that has features that better support care, e.g., open floorplan, ranch-style.	5 (16.7%)
			Re-design the bathroom so that it has more space and it is easier to get the child into the shower.	3 (10.0%)
			Design the home with the child's needs in mind, e.g., space for storing all of the child's supplies.	1 (3.3%)

			Use pocket doors in the house design to make wheelchair navigation easier.	1 (3.3%)
			Work with community high schoolers to build a ramp for the entrance to their home.	1 (3.3%)
			Take the door off its hinges to be able to move crib into the room.	1 (3.3%)
		Use/implement tools to make the home more navigable.	Add a not-to-code ramp until the family can make a more permanent renovation to their home.	1 (3.3%)
			Keep a large stone by the door to hold it open.	1 (3.3%)
		Organize the home to make it more navigable.	Select and arrange furniture, e.g., fridge, such that the child's wheelchair can navigate the home.	2 (6.7%)
			Store the dining room table under the child's bed to create more room in the house. Pull the table out when they need to use it.	1 (3.3%)
	Cleaning and maintaining the home	Modify the home to make it easier to clean and maintain.	Install a dishwasher in rental unit so dishes can be washed while other care activities are also happening.	1 (3.3%)
			Remove the carpet and put in flooring that is easier to clean.	1 (3.3%)
Leaving the home care environment	Caring for the child outside of the home	Care for the child in a specific location.	Change the child in a wheelchair that lays back since the child does not fit on a changing table.	1 (3.3%)
			Lay the child down in the van to be changed if the family is out of the house and the child needs to be changed.	1 (3.3%)
		Buy/use/implement tools to support caring for the child outside of the home.	Buy portable ramps that can travel with the family to make other living environments accessible.	1 (3.3%)
			Make sure the child has a blanket when they leave the home because they get cold easily.	2 (6.7%)
			Repurpose car "garbage cans" as storage for items while in the car.	1 (3.3%)
			Modify the child's car seat so that their feeding bag can hang from it and it can also hold the child's medical devices to make traveling with the child easier.	2 (6.7%)
			Buy a smaller pulse oximeter that the child can wear all day at school and keep in their lap.	1 (3.3%)
		Develop routines for avoiding accidents.	Have wipes on hand for when the child coughs up.	1 (3.3%)
			Always change the child before long car rides to prevent accidents.	1 (3.3%)
	Preparing supplies and food for use outside of the home	Create tools to make preparing to leave home with the necessary supplies easy.	Keep a plastic bin with enough supplies to care for the child for a week to make packing easy; Re-pack the bin upon return.	2 (6.7%)
		Develop routines for leaving home that ensure all supplies are packed.	Prepare the child's clothes, diaper bag, medical devices, and batteries the night before going to an appointment.	3 (10.0%)
			Plan extensively in order to travel with their child safely, e.g., bring extra batteries and extension cords, check that the destination has a backup generator.	1 (3.3%)

			Always bring ostomy supplies when leaving home.	1 (3.3%)
			Bring power strips and extension cords when traveling with the child.	1 (3.3%)
		Develop routines for ensuring the child has food they can eat outside of the home.	Bring a meal for the child when going to another house, i.e., the sitter's or grandma's, and keep the food separate to ensure it is allergen-free.	1 (3.3%)
			Bring a cooler of food for the child when traveling to ensure they have meals that the child can eat. Prepare some of the foods by cooking them ahead of time.	1 (3.3%)
			Bring a meal for the child whenever the family goes out to eat to ensure there is something allergen-free the child can eat.	1 (3.3%)
			Send the child to school with special treats that fit their diet requirements so that they can celebrate with the class in a way that is healthy for them.	1 (3.3%)
	Transporting the child	Buy/use/make tools to make transporting the child easier.	Fundraise to purchase a wheelchair van to make transporting the child easier.	2 (6.7%)
			Buy and modify an accessible van so that it is easier to transport the child and their wheelchair.	3 (10.0%)
			Make a portable ramp that can travel with the family and assist in getting the child into the car or camper.	1 (3.3%)
			Buy a special brand of car seats that can fit three in a row (versus two).	1 (3.3%)
			Buy a poncho that covers both the child and their wheelchair.	1 (3.3%)
			Use a mirror in the car to monitor the child.	1 (3.3%)
	Transporting the child's wheelchair, devices, and supplies	Keep devices/supplies in the vehicle.	Always keep an extra tank of oxygen in the car so that they have enough oxygen to get the child home from Madison.	1 (3.3%)
		Keep devices/supplies ready for leaving the home.	Keep the medical device, e.g., feeding and suction machine in a bag so they can be easily transported.	2 (6.7%)
			Keep a suction machine, supplies, and an emergency bag on the child's wheelchair so they have supplies when transporting the child.	1 (3.3%)
			Keep the child's backpack stocked with supplies, e.g., back up g-tube, etc., with the child whenever they leave the house.	1 (3.3%)
		Use alternate wheelchair that is more portable.	Use the old wheelchair that fits the child worse when traveling because it is more portable, e.g., light and collapsible.	2 (6.7%)
	Including the child in activities outside of the home	Buy/use tools to include the child in activities outside of the home.	Buy an electric bike that can assist the caregiver in pulling the child in a bike trailer.	1 (3.3%)
			Use a special umbrella that clamps onto the child's chair and articulates to keep their face out of the sun.	1 (3.3%)
			Buy a beach wheelchair for taking the child to the beach.	1 (3.3%)
		Modify tools to include the child in activities outside of the home.	Modify the family's camper van entrance so that it is easier to get the child inside.	1 (3.3%)

Planning for and responding to emergencies	Responding to emergencies	Work with a clinician to support the child's travel.	Have the doctor and nutritionists write notes to ensure they can bring food that the child can eat through security while traveling via plane.	1 (3.3%)
		Conceptualize oneself as an emergency care provider.	Conceptualize oneself as an emergency care provider and respond during an emergency because EMTs are not trained to work with trachs.	2 (6.7%)
		Develop methods for responding to emergencies while also caring for the family.	Take the whole family to the hospital when the child is sick.	1 (3.3%)
		Modify methods of responding to emergencies if not at home.	Suction trach if it becomes clogged outside of the home (versus replacing the trach, which they would typically do during an emergency at home).	1 (3.3%)
		Keep emergency supplies nearby.	Keep a bag full of the child's medications, hygiene, and medical care supplies and monitor it regularly to ensure it is stocked.	10 (33.3%)
			Keep an ambu bag nearby in case the child desaturates.	2 (6.7%)
			Always keep the phone nearby in case of an emergency.	1 (3.3%)
		Buy/implement backup systems to ensure the family has power.	Have a second energy grid with two generators for use if the power goes out.	1 (3.3%)
			Keep a backup battery for use during a power outage to power the child's medical devices, i.e., ventilator.	1 (3.3%)
			Buy a large jump pack, i.e., battery for jumping a car, to power pulse ox machine when traveling outside of the home.	1 (3.3%)
	Planning for emergencies	Develop packing list for use during emergencies.	Develop a packing list for travel to the ER, ordered by priority.	1 (3.3%)
		Work with clinician to develop an emergency plan.	Work with the complex care program to develop a crisis care plan that highlights the child's unique care needs.	1 (3.3%)