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# CONFRONTING BUREAUCRACY: EXAMINING SYSTEMIC CHALLENGES OF CARING FOR CHILDREN WITH MEDICAL COMPLEXITY AT HOME

a dissertation

by

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# Confronting Bureaucracy: Examining Systemic Challenges of Caring for Children with Medical Complexity at Home

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**Background:** The number of children with medical complexity (CMC) cared for by parental caregivers is increasing in the United States. Studies reveal parental caregivers experience significant caregiver burden, often attributed to the disease management required by CMC. However, literature has also identified numerous systemic challenges that arise while caring for CMC at home. The impact of systemic challenges on parental caregiver burden has not been examined, thus, the purpose of this dissertation is to explore the relationship between these systemic challenges and parental caregiver burden.

**Methods:** Three studies were completed to explore this relationship. An integrative review of literature from 2014-2023 was completed to identify systemic challenges within the home care system and whether parental caregivers attribute burden to these challenges. A case-control secondary analysis of the National Survey of Children's Health compared levels of burden between parental caregivers and parents of children without medical complexity as they relate to systemic challenges. Lastly, a qualitative descriptive study was conducted with parental caregivers living in Massachusetts to examine their experiences of caring for CMC.

**Results:** The integrative review of 10 articles revealed a dynamic and interconnected relationship between systemic challenges and parental caregiver burden. The secondary analysis comparing 1,352 parents (n = 676 parental caregivers) revealed significant associations and increased odds of experiencing burden among parental caregivers while navigating systemic challenges. Finally, three themes capturing the experiences of parental caregivers (N=11) emerged from collected qualitative data; *lack of discharge preparedness causes emotional distress, care becomes increasingly complex creating new unanticipated challenges, and the psychological toll of parents assuming provider role.*

**Conclusion:** The findings from this dissertation provide data-driven evidence to support a relationship between systemic challenges of caring for CMC and parental caregiver burden. This greater understanding of parental caregiver experiences highlights the need for a more holistic perspective in evaluating the care of CMC at home such that systemic challenges, and not a child's medical needs, are the focus of future exploratory, intervention, and health policy work.

## Acknowledgements

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Lastly, a heartfelt thank you to the families I have met as a pediatric home care nurse. Your stories, your strength, and your children are at the heart of this work. It will always be a privilege to know and to learn from each of you.

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# Chapter 1

# Introduction

# Dissertation Overview

For the last five years, I have worked as a pediatric home care nurse and primary care nurse practitioner. In this role, I have met children from around the world who are living with severe chronic medical conditions, often requiring complex care at home. These children with medical complexity (CMC) have profound care needs due to developmental delays and decreased bodily functions. Every child and parent has a story about the journey they have taken as a result of their health conditions. Despite the challenges they face, regardless of diagnosis, age, or geographic location, these children continue to experience and engage in everyday childhood events. However, these opportunities to live life in their homes within their communities is a relatively recent phenomenon over the past forty years that is a result of the advocacy efforts led by the parents and families of these children (Hevesi, 2012; Perkins & Agrawal, 2018).

While many advocacy projects relate to state and federal health policy reform, parents of children with medical complexity must also advocate daily for equity and consistency in the everyday care of their children. Often, as parents work tirelessly to provide their children with the highest health-related quality of life, there are systemic barriers that hinder their ability to do so. As a result, parents find solutions and workarounds to these barriers, which may include time intensive phone calls and emails, paperwork, meetings, and physical, emotional, social, and financial sacrifice. Although parents have expressed the burden of managing these barriers, little work has been done to address these difficulties. This is largely in part due to a perspective within the health care system that experiencing burden is unavoidable given the complexity of their children's conditions (Ames et al., 2023).

The following dissertation reflects a body of work that presents a novel perspective on parental burden. As opposed to the relegating of burden onto the child, this work presents burden as a consequence of caring for CMC within a fragmented health care system. By reframing this phenomenon as a result of systemic challenges, it places the blame of parental burden on a complicated care system that lacks a family-focus. The objective of this dissertation is to establish data-driven foundational information to first understand parents' challenges. Ultimately the goal is to develop interventions that address these systemic challenges which will subsequently decrease barriers to care and thus, parental burden.

Chapter 1 will provide an overview of the history of CMC living in the United States, including the transition of their care from acute care settings into the home as well as the establishment of what is known today as the "pediatric home care system". Following this, the concept of "caregiver burden" as it relates to parents of these children will be discussed with a review of commonly used measures of burden in research. This will then be compared to a review of the pediatric home care literature over the last forty years to highlight the current gap in research related to these children and their families. The overarching theoretical framework guiding this dissertation, Ray's (2021) Theory of Bureaucratic Caring, will also be described to demonstrate its relevance to the experiences of parents caring for CMC at home. To conclude, the three manuscripts comprising the core of this dissertation will be introduced. Subsequently, chapters 2-4 will present the individual manuscripts with a description of the authors, the journal chosen, and the reason for its selection. Tables and figures for each manuscript can be found within individual chapters while references are at the end of the dissertation. Lastly, chapter 5 will discuss the implications of these manuscripts through a synthesis of findings, relevance to the overall objective of this dissertation, and proposed next steps.

## Background

Medical advancements continue to decrease mortality rates of congenital and chronic diseases leading to an increase in the number of children living with one or more chronic illnesses (Amirnovin et al., 2018). Recognizing this growing population, the American Academy of Pediatrics introduced the term, "children with special health care needs" in 1998 to represent children who have, or are at increased risk for, chronic physical, behavioral, emotional, or developmental conditions and also utilize health-related services more frequently than children in general (McPherson et al., 1998). In 2001, the National Survey of Children's Health identified approximately 9.3 million children in the United States, 12.8% of the pediatric population, as children with special health care needs (National Center for Health Statistics, 2001). Within twenty years, this number has increased to approximately 14 million and represents almost 20% of the pediatric population (Ghandour et al., 2022).

### Children with Medical Complexity

Within the children with special health care needs population, there is a smaller sub-population referred to as children with medical complexity (CMC). These children have one or more complex chronic conditions that affect multiple body systems and general development, leading to functional limitations, dependence on life-sustaining medical technology, and require high levels of care coordination (Cohen et al., 2011; Rogers et al., 2021). The number of CMC has grown exponentially over the last decade, and quadrupled from 0.4% (Kuo et al., 2011) to 1.6% of the total pediatric population (Yu et al., 2021a). Prior to the 1980s, CMC exclusively resided within hospitals due to their high medical complexity and technological needs (Liptak, 1997). However, in the last forty years the geographic landscape of care for CMC has evolved away from acute care settings to post-acute and community settings, including the child's home (Berry et al., 2016).

## Bringing Children with Medical Complexity Home

Historically, due to a lack of physical and financial access to home care personnel including nurses and medical supplies, families of CMC had few options but to keep their children within medical institutions. This began to change with the landmark legal challenge for change initiated by the parents of Katie Beckett (Tax Equity and Fiscal Responsibility Act [TEFRA] of 1982, 1982). Shortly after her birth in 1978, Katie contracted viral encephalitis and lived her first three years hospitalized due to her partial paralysis and ventilator dependence (Hevesi, 2012). Katie's parents, recognized that their daughter had chronic conditions but did not require the acute level of care provided in hospitals, wanted to bring her home. Although her hospitalization was covered by the federally and state funded Medicaid health insurance program, Medicaid would not provide coverage for Katie's medical needs outside of a hospital. Meanwhile, her parents' private insurance refused to cover the necessary community-based supports she would require at home given their high cost. With no health insurance option available to cover Katie's care at home, she was forced to remain hospitalized (Hevesi, 2012). Katie's parents, however, advocated for systemic policy change, highlighting the inequity their family faced at the hands of health care policies that did not consider CMC. Katie's story was ultimately brought to the attention of President Reagan who recognized the injustice of her situation and introduced legislation in 1982 that has since become known as the Medicaid Katie Beckett Waiver.

The purpose of the Katie Beckett Waiver was to provide a new pathway through which children with disabilities, if their home state enacted the waiver, would become eligible for a

Medicaid plan that provided coverage for care extending beyond the hospital and into the community. Traditionally an income-based insurance plan, in 1982 the Katie Beckett Waiver led to the creation of second set of Medicaid enrollment criteria which determined eligibility based on medical need - as opposed to financial need - and allowed CMC like Katie to qualify for this expanded Medicaid insurance coverage (Perkins & Agrawal, 2018). The federal passage of the Katie Beckett Waiver in 1982 allowed Katie's parents to finally bring her home after three years of living in the hospital and provided Katie an opportunity to go to school, enter the workforce, and continue to advocate for the rights of individuals with disabilities until her death at the age of 34 (Hevesi, 2012).

The Katie Beckett Waiver, along with the enactment of other Medicaid waivers and the Americans with Disabilities Act in 1990, all contributed to development and enforcement of laws surrounding access to community-based health care services (Perkins & Agrawal, 2018). These various services, such as medical equipment suppliers and home care nursing, have been established across the United States and are known today as pediatric home health services (Nageswaran & Golden, 2017; Fratantoni et al., 2019). With access to these supports, families with CMC continue to have the opportunity to take their children out of hospitals and bring them home. No database currently exists to track how many CMC live at home; however, a recent study estimates this number to be 1.2 million children (Yu et al., 2021a).

## Pediatric Home Care System

Though crucial to transitioning CMC home, pediatric home health services are just one important component of a larger pediatric home care (PHC) system. Like many pediatric patients, CMC still utilize primary, secondary, and tertiary health services as well. Most often, these are accessed for scheduled appointments with specialists related to the child's chronic illnesses and during unplanned hospitalizations for acute condition exacerbations, other illnesses, and surgeries (Fratantoni et al., 2019). Health insurance providers beyond Medicaid are another key element of the PHC system as medications, nutritional formulas, and certain medical equipment are not covered by the Katie Beckett Waiver and related legislation (Foster et al., 2019; Raisanen et al., 2021). Additionally, many CMC attend school which requires utilization of additional resources including district level special education programs, transportation services, and in-school health care (Boss et al., 2020).

These various community-based services, primary and acute care teams, insurance providers, and school resources are just some of the major components that comprise the PHC system. As a whole, the purpose of this system is to provide support to parents caring for CMC at home, often referred to as parental caregivers, as they aim to maintain the safety and maximize the quality of life for their children. These parental caregivers are at the center of the PHC system, advocating for and coordinating the specific services and supports their children require (Foster et al., 2019).

Recognizing the intensity of this responsibility, research efforts have focused on examining the experiences of parental caregivers of CMC. Not surprisingly, these studies have identified the frequent challenges and high number of stressors encountered by parents as they attempt to navigate the PHC system and provide their children with consistent, high-quality care (Fratantoni et al., 2019; Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020). These difficulties with care coordination and care provision have also been linked to decreased health-related quality of life and increased caregiver burden among parents of CMC (Caicedo et al., 2014; Prieto et al., 2020; Yu et al., 2020).

## Caregiver Burden

Caregiver burden is defined as a perceived intensity of physical, emotional, mental, and/or financial strain experienced by a caregiver from caring for a loved one over a period of time (Liu et al., 2020). This is not a novel concept to the discipline of nursing nor to the field of health-related research, though caregiver burden is often associated with the experiences of spouses or adult relatives caring for older adults due to the foundational work of Zarit et al. (1980) who began examining caregiver burden among this population. Despite the field's predominate focus on adult caregivers, burden among parental caregivers of CMC has also been examined in a number of studies using various measures (Caicedo et al., 2014; Prieto et al., 2020; McGrane, 2023).

One measure has been the PedsQL$^{TM}$ Family Impact Module asking parental caregivers to reflect on burden they have experienced "…as a result of [their] child's health…" (Varni et al., 2004). Similarly, the Assessment of Caregiver Experience with Neuromuscular Disease (ACEND) asks parental caregivers to self-report their feelings of burden "due to [their] child's health condition…" (Matsumoto et al., 2011). Additional measures that have been used include the Caregiver Burden Inventory (Novak & Guest, 1989), Kingston Caregiver Stress Scale (Kilik & Hopkins, 2005), and the Zarit Caregiver Burden Interview (Zarit et al., 1980). None of these are pediatric specific measures though they reflect a shared perspective that a caregiver's feeling of burden is directly related to the health of the individual for whom they care. In other words, the disease processes and related management required by CMC are considered direct contributors to burden experienced by their parental caregivers. Under this assumption, parental caregiver burden is then deemed an inevitable experience when caring for CMC at home given the defining characteristics of these children including the presence of chronic illnesses that require management of medical technology and care coordination (Cohen et al., 2011; Rogers et al., 2021).

### ***Weaknesses in the Current Caregiver Burden Perspective***

Despite its prevalence in research, the assumption that parental caregivers feel burdened due to the medical complexities of their children is not reflective of what parental caregivers report. As one parent highlighted in her op-ed, “My personal experience is that often the child with complex needs is seen as the burden, not the systems that fail to provide adequate insurance coverage, meaningful mental health services, and easy access to high quality community-based supports” (Comeau, 2019, p. 1). The assumed linear relationship between a child’s health and parental caregiver burden disregards the complex and dynamic PHC system in which parental caregivers care for their children. Furthermore, it neglects findings from numerous studies in which parental caregivers of CMC have expressed the most difficult aspects of caring for their children are not their children’s needs but gaps and weaknesses within the current PHC system that prevent these needs from being met (Fratantoni et al., 2019; Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020). Ultimately, this lack of consideration of systemic challenges as potential drivers of burden has kept research in this field from meaningfully moving forward and improving parental caregiver experiences. Instead, examination of the PHC literature over the last forty years reveals a cyclical pattern of the same questions being asked and many of the same problems being identified.

## Literature Review

The term “pediatric home care” was first introduced into the United States literature by Stein (1978) when describing an ambulatory clinic designed to provide outpatient and community services to children with chronic illnesses. In the wake of Katie Beckett’s story, however, the term evolved and by the late 1980s “pediatric home care” was used to describe the home-based care of children with technology-dependence (Aitken, 1989; Leonard et al., 1989). At this time, the literature examined the initial development of PHC services across the country and the focus was on the various mechanisms, such as hospital-based, community-based, or bureaucratic models, and the potential for each model to be more appropriate in certain states over others (Aitken, 1989). Additionally, Leonard et al. (1989) described the insurance considerations for children referred to PHC services within the state of Minnesota and highlighted the confusing “patchwork system” that had already developed and its negative implications on health care quality and safety.

## Literature of the 1990s

In the 1990s, the PHC literature appeared to diverge in its focus. Some authors continued to examine the logistics of the system’s establishment such as Lantos and Kohrman (1992) who evaluated the ethical considerations of PHC. They argued that health care providers should not push parents of CMC to bring their children home to simply remove them from the institutional setting but also to consider the parental burden and the parental caregiver’s ability to care for these children safely. Other authors began to examine PHC and discuss what elements were needed for its success. This included Bakewell-Sachs and Porth (1994), who analyzed the intricate process of discharge planning of CMC into home care and advocated for a well-developed system to be in place for successful transitions. Meanwhile, Madigan (1997) felt inpatient nurses needed a better understanding of what comprised the PHC system in order to provide better anticipatory guidance to parents bringing their CMC home; therefore, she developed a detailed outline of the key components of the PHC system. These included home care agencies and their affiliated nurses, medical equipment suppliers, acute care hospitals and staff who care for CMC when acutely ill, and the insurance carriers/Medicaid waivers responsible for covering many of these services.

While Madigan (1997) did not highlight how interactions with these various components may positively or negatively affect the health and well-being of parental caregivers, other researchers in the 1990s did. One quantitative study of 52 mothers of CMC revealed nearly 60% of the sample experienced high psychological distress specifically from navigating the home care services reimbursement process (Leonard et al., 1991). Meanwhile a mixed methods study by Patterson et al. (1994) explored factors to positive and negative parental caregiver-home care nurse relationships among 48 mothers and fathers of CMC. The study identified the importance of proper training for home care nurses in order to decrease caregiver strain experienced by parents. Both of these studies, though limited by their small and geographically isolated sample sizes, began to develop a narrative highlighting how components of the PHC system could positively or negatively affect the experiences of parental caregivers of CMC and subsequently contribute or alleviate feelings of caregiver burden.

## Literature of the 2000s

Unfortunately, at the turn of the century, the prevalence of PHC research decreased as did the exploration of the relationship between the system and parental caregiver burden. Instead, published literature within this time focused solely on the gaps within PHC system without regard to how these gaps affected parents. Mentro (2003), for example, explained the numerous inequities in health care access faced by CMC and their parental caregivers due to decreased resources, unjust health care policies, and inconsistent insurance coverage. One particular limited resource, home care nurses, was further emphasized in a call for more nurses to join the Vermont PHC workforce citing a significant shortage despite the great need (McLean, 2003). To address the poor financing of PHC from both federal funders and private investors, the American Academy of Pediatrics released recommendations for policy makers to follow in the hopes of initiating system reform (Committee on Child Health Financing, Section on Home Care, 2006). These recommendations included coverage of home care services by all insurance payers, adequate reimbursement of these services that include consideration for the time intensive care CMC require, and a call for further research on Medicaid reimbursement rates by state.

## Literature of the 2010s and 2020s

In the last decade, a small though notable resurgence in PHC research efforts has been seen. A number of qualitative studies have once more examined the experiences of parental caregivers caring for their CMC at home (Callans et al., 2016; Fratantoni et al., 2019; Boss et al., 2020; Foster et al., 2020). The findings of these studies revealed significant concerns surrounding the lack of education that inpatient, outpatient, and community nurses and other providers receive about PHC (Fratantoni et al., 2019), the high level of caregiver burden experienced by parents (Boss et al., 2020), and the difficulties parental caregivers face interacting with various home care nurses (Foster et al., 2020). These were the exact concerns and findings of PHC literature from approximately 30 years prior (Leonard et al., 1991; Lantos & Kohrman, 1992; Madigan, 1997; Patterson et al., 1994). Moreover, and as highlighted previously, this literature did not consider how difficult experiences encountered with the PHC system may contribute to level of caregiver burden.

Some studies have also focused on the financial support parental caregivers of CMC receive. Keim-Malpass et al. (2019) evaluated a specific Medicaid waiver, Section 1915(c), directed toward coverage of services for CMC. Their findings revealed that the variety of services covered, as well as the coverage provided by this waiver varied substantially across states. In an evaluation of posthospitalization PHC availability for privately insured CMC, significant state to state variability was identified in the number of nursing hours approved by insurance (Rasooly et al., 2020). Unsurprisingly, due to inconsistent coverage options across public and private insurance, approximately 85% of families have been forced to utilize a "financial patchwork" to cover the majority of expenses associated with caring for their CMC (Raisanen et al., 2021). Once again, these findings reiterate concerns raised in the PHC literature from the prior thirty years (Aitken, 1989; Leonard et al., 1989; Mentro, 2003; Committee on Child Health Financing, Section on Home Care, 2006). And once again, there is no discussion on the implications these experiences have on the well-being of parental caregivers as they care for their children.

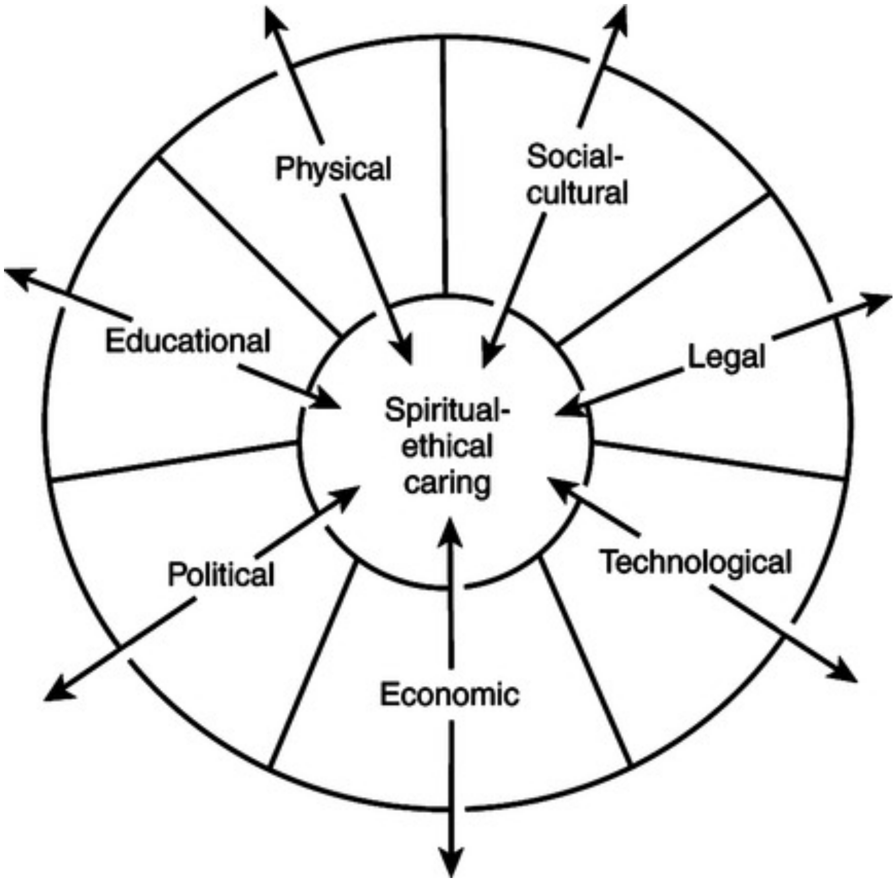
## Implications of Literature to Date

It has been forty years since Katie Beckett's arrival home and though PHC has transformed into a larger and more complex system, the research literature has not evolved alongside it at the same pace. Throughout the decades, two areas of research have developed in parallel with each other. In one area, researchers have identified and explored the burden experienced by parental caregivers. In the other, researchers have recognized and focused on the gaps and weaknesses of the PHC system. Despite parental caregivers highlighting their interconnected nature, these two problems have primarily been treated as separate phenomena without relation to each other (Comeau, 2019). Yet the care parents provide to their children is dependent on the PHC system – meaning failures within the system have direct implications on the care parents can or cannot provide. Given the lack of progress over the last forty years in the literature surrounding parental caregiving experiences as well as lack of advancement in addressing many of the barriers parents encounter, it is important to appreciate the interconnected relationship of systemic challenges and caregiver burden to properly address these complex and interrelated issues. To move the field forward, there must be a shift in how parental caregiver burden is explored, with a closer focus on how the gaps and barriers within the PHC system contribute to experiences of burden. In doing so, systemic challenges that drive parental caregiver burden can be identified and provide a foundation for future interventions and health policy efforts that address these challenges and in turn, decrease burden.

## Theoretical Framework

The theoretical framework guiding my work is the Theory of Bureaucratic Caring (BCT) (Ray, 2021). The foundation of BCT stems from Ray's early work in describing the meaning of caring from the perspectives of various hospital employees, such as nurses, physicians, and mid-level and high-level administrators. This work revealed that healthcare professionals, such as nurses, practiced within a paradox of providing humanistic care to patients while also attending to the bureaucratic needs (e.g., economic, legal, and political requirements) of the hospital system in which they worked (Ray, 2021). Explicating the paradoxical nature of humanistic nursing care within bureaucratic hospital settings, BCT demonstrates their underlying interconnectedness (Figure 1). This theory recognizes that nurses practice within bureaucratic systems. Hospitals need nurses to provide care for patients and paradoxically, without the bureaucratic elements of hospitals, nurses would be unable to provide their care to patients. When this interdependent relationship is appreciated and maintained in harmony, care can be provided most effectively through bureaucratic caring (Ray, 2021).

Figure 1. Ray's Theory of Bureaucratic Caring



The theory presents the concept of spiritual-ethical caring. Surrounding this are seven concepts capturing elements of bureaucracy: technological, economic, legal, political, educational, physical, and social-cultural (see Table 1 for definitions of each concept). Together, these concepts are presented holographically to represent the simultaneous independent and interdependent existence of the concepts, ultimately creating the interconnected whole of bureaucratic caring.

Similarly to nurses caring for patients within a bureaucratic hospital, parental caregivers of CMC must care for their children within the bureaucracy of the PHC system. This parallel, as well as the demonstration that effective human caring can be provided within bureaucratic systems when in harmony, makes BCT a logical and appropriate theoretical framework for PHC research. Additionally, BCT provides a perspective that is lacking in current literature given that the PHC system is situated within a larger sociocultural and political context. This system does not exist within itself but instead, functions in relation to other individual, social, institutional, and cultural systems as noted by the bidirectional arrows of the model that extend beyond the holographic circle (Ray, 2021). Thus, meaningful research related to PHC must also be considerate of these larger systems and likewise, proposed solutions to address gaps must look beyond the superficial layers of the PHC system.

When considering the purpose of my work, exploring the relationship between systemic challenges within the PHC system and parental caregiver burden, BCT provides a strong conceptual foundation from which my proposed studies have been developed. The theory posits effective care can be achieved through bureaucratic caring which occurs when harmony is reached between those providing care and the bureaucratic healthcare system in which the care is being provided (Ray, 2021). In order to achieve this, the relationships between those providing care and each of the seven bureaucratic elements surrounding them must also be in harmony as represented by the bidirectional arrows in Figure 1. As I work to explore the systemic sources of parental caregiver burden, I propose the discordant relationships between parental caregivers of CMC and the bureaucratic elements of the PHC system are preventing parents from engaging in bureaucratic caring and subsequently contributing to their experiences of burden.

**Table 1.**

*Conceptual Definitions Adapted from the Theory of Bureaucratic Caring*

| **BCT Concepts** | **Definitions [a]** | **PHC Examples** |
|---|---|---|
| Social-Cultural | Values and beliefs of bureaucracy related to individual identities and social systems that positively or negatively impact the delivery of services and ability to provide care | • Family<br>• Friends<br>• Societal expectations<br>• Religious beliefs<br>• Cultural traditions and expectations |
| Physical | The components of bureaucracy that promote or inhibit the physical, mental, and emotional health of those within the system | • Direct care of children<br>• Health of parental caregivers<br>• Health of other family members |
| Political | Systems of hierarchy and power within bureaucracy that can facilitate or prevent service delivery and provision of care. Individuals with power include those who provide direct or indirect care to patients | • All health care and social service providers across the health care continuum |

| | | |
|---|---|---|
| Legal | The components of bureaucracy that hold the system accountable for providing professional, equitable, and socially just services and care for all within the system | • Federal, state, and local laws and regulations related to home care and individuals with disabilities |
| Economic | The exchange of financially related items such as money and insurance to promote the stability of the bureaucracy and the services provided to those within the system | • Private and public insurance providers<br>• Non reimbursed out-of-pocket expenses |
| Technological | Nonliving items within the bureaucracy including medical equipment, electronic medical records, and digital media that are vital to services and care of those within the system | • Medical equipment suppliers<br>• Medical equipment belonging to each child<br>• Medical supplies |
| Educational | Programs and mechanisms within the bureaucracy to educate and improve its functionality, the provision of care, and overall health of individuals within the system | • Discharge education<br>• Education of health care providers about PHC<br>• School enrollment<br>• Education of staff and educators |
| Spiritual-Ethical Caring | The act of providing care within the bureaucracy through love and compassion to foster the well-being of others and self within the system | • Parents caring for their CMC at home<br>• Love and compassion of parents and those who support them<br>• Ability to balance their own self care needs as a couple and as individuals |

[a] Definitions adapted from Ray (2021)

## Purpose of Proposed Work and Aims

With the number of CMC living at home steadily increasing, it is imperative that future research focus on how to decrease parental caregiver burden to allow the next generation of CMC an opportunity to be cared for at home. The current perspective on parental caregiving which relegates burden as inevitable, fails to consider the presence of numerous systemic challenges in caring for CMC at home, and leaves little room for intervention work to improve caregiver experiences. In light of these weaknesses, the purpose of my work is to explore the experiences of parents caring for their children with medical complexity at home as they navigate challenges within the pediatric home care system and the ways in which these experiences contribute to caregiver burden. In particular, the nature of this relationship will be examined using BCT to identify how various elements of the PHC system bureaucracy may positively or negatively affect burden among parental caregivers of CMC.

As the use of BCT is novel for this area of research, I will first demonstrate how the PHC system is a bureaucratic system as defined by the theoretical framework. Next, I will determine current levels of burden among parental caregivers of CMC to establish the continuation of this problem. Lastly, I will explore the relationship between challenges within the bureaucratic PHC system and parental caregiver burden among parents caring for their CMC in Massachusetts. This will all be done through exploration of existing literature and data as well as through collection of new data related to parental caregivers of CMC. The specific aims to be addressed through this work are as follows (see Table 2 for associated chapters):

**Aim 1:** To identify elements of the bureaucratic health care system that contribute to burden among parental caregivers of children with medical complexity living at home as presented through existing literature.

**Aim 2:** To identify prevalence/sociodemographic characteristics of children with medical complexity and contemporary levels of parental caregiver burden among a nationally representative sample of parents with children with medical complexity.

**Aim 3:** To qualitatively explore parents' experience of pediatric home care, including the PHC system and parental caregiver burden through the lens of BCT among parents living in Massachusetts.

**Table 2.**

*Specific Aims and Associated Chapters*

| Specific Aim | Chapter |
|---|---|
| **Aim 1:** To identify elements of the bureaucratic health care system that contribute to burden among parental caregivers of children with medical complexity living at home as presented through existing literature. | **Chapter 2:** Caring for children with medical complexity at home: An integrative review |
| **Aim 2:** To identify prevalence/sociodemographic characteristics of children with medical complexity and contemporary levels of parental caregiver burden among a nationally representative sample of parents with children with medical complexity. | **Chapter 3:** Case-control analysis of burden among parental caregivers of children with medical complexity |
| **Aim 3:** To qualitatively explore parents' experience of pediatric home care, including the PHC system and parental caregiver burden through the lens of BCT among parents living in Massachusetts. | **Chapter 4:** A qualitative descriptive study exploring the systemic challenges of caring for children with medical complexity at home |

**Aims of Each Individual Manuscript**

<u>Manuscript #1</u> Caring for children with medical complexity at home: An integrative review

- **I.** Synthesize the existing pediatric home care literature using the Theory of Bureaucratic Caring.
- **II.** Identify which bureaucratic elements are present within the contemporary pediatric home care system.

<u>Manuscript #2</u> Case-control analysis of burden among parental caregivers of children with medical complexity

- **I.** Characterize the prevalence and characteristics of children with medical complexity living in the United States.
- **II.** Evaluate parental caregiver burden associated with caring for a child with medical complexity using the Theory of Bureaucratic Caring.

<u>Manuscript #3</u> A qualitative descriptive study exploring the systemic challenges of caring for children with medical complexity at home

- **I.** Explore the processes involved in caring for children with medical complexity at home as presented by parental caregivers living in Massachusetts.

## Implications of the Research

The following manuscripts contribute individually to this field of research and build upon themselves collectively to move the field of caring for CMC forward meaningfully. Chapter 2 highlights important findings from past PHC research but reframes these findings through a novel systems-level perspective. In doing so, the study establishes preliminary evidence to support a relationship between systemic challenges within the PHC system and parental caregiver burden. Chapter 3 explores this relationship further but through a quantitative lens, and describes the significant, and increasing, burden parental caregivers experience nationally as a result of contemporary systemic challenges. Although meaningful, the first two studies are limited by their post-hoc evaluation of parental caregiver burden and systemic challenges. To address this limitation, Chapter 4 reflects qualitative interviews of parental caregivers living in Massachusetts that explored their experiences with systemic challenges of caring for their CMC at home. Together, these studies work together to inform future work that will begin to address the identified systemic challenges through continued research, clinical initiatives, and health policy reform.

More broadly, the most explicit implication my proposed work has for nursing science (and beyond) is the introduction of two disciplinary perspectives. The first being that of humanization as discussed by Willis et al. (2008). Nurses consistently partake in the facilitation of humanization of patients through intentional and unconditional care. Seeing patients as human beings and interacting through meaningful and relational experiences is key to the humanization process; even if these experiences appear to be opposite in nature as there is an underlying unification within them (Willis et al., 2008). The current perspective on caregiver burden among parental caregivers of CMC does not consider humanization. Explicitly, the notion that caring for children who are experiencing chronic illnesses and disabilities will inevitably contribute to parental burden is dehumanizing and presents CMC as burdensome in nature.

The second disciplinary perspective introduced is Ray's (2021) Theory of Bureaucratic Caring. Prior literature evaluating the experiences of parental caregivers of CMC has primarily been atheoretical and as discussed previously, led to a troubling perspective that attributes caregiver burden to the high needs of the children (Fratantoni et al., 2019; Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020). The introduction of BCT through my proposed work is intended to provide a framework to spark a paradigm shift away from this perspective.

Moving forward, research in this field should reflect the words of Comeau and other parental caregivers of CMC, and bring greater focus to the systemic inequities these families face and the impact these experiences have on parental burden. This includes through the development of measures that allow parents to report their feelings of burden, not in relation to their child's health care needs, but to the challenges they face navigating a fragmented PHC system. The availability of measures specific to parental caregivers of CMC will also provide a foundation for future intervention work that can begin to address these various systemic challenges. Through the explicit exploration of systemic challenges with the PHC system and associated burden among parental caregivers, this dissertation work will introduce data-driven foundational information to help guide this field of home care research toward a more humanistic and holistic perspective.

# Chapter 2

## Caring for Children with Medical Complexity at Home: An Integrative Review

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# Caring for Children with Medical Complexity at Home: An Integrative Review

Approximately 14 million children in the United States, 18.8% of the pediatric population, are reported to have at least one special health care need (Ghandour et al., 2022). A subset of children within this population are referred to as children with medical complexity (CMC). These are children who have at least one complex, chronic condition affecting multiple body systems, experience limitations in their functional abilities, are dependent on life sustaining medical technology, and require extensive care coordination (Cohen et al., 2011; Rogers et al., 2021). With increased technological advancements and subsequent decreases in mortality from complex pediatric diseases, the number of CMC in the United States grows each year (Yu et al., 2021a). Historically, without access to necessary home and community-based services such as skilled home care nurses and medical equipment, parents of CMC were forced to institutionalize their children.

However in the 1980s, new waivers and policies funded by Medicaid, a traditionally income-based federally and state funded public health insurance program in the United States, began to cover these services under newly developed medical-need criteria which provided many parents the opportunity to bring their children with medical complexity home (Perkins & Agrawal, 2018). Unfortunately, state-to-state variation in these medical-need criteria has led to geographic discrepancies in Medicaid enrollment accessibility (Kusma et al., 2022). Enactment of the Patient Protection and Affordable Care Act in 2010 aimed to address these discrepancies by increasing federal funding of Medicaid and expanding eligibility criteria to allow more individuals, regardless of where they live, the ability to enroll into Medicaid programs (Patient Protection and Affordable Care Act, 2010; Crowley & Golden, 2014). This process of Medicaid expansion went into effect on January 1st, 2014, though ten states have yet to adopt this expansion plan at the time of this writing (Kaiser Family Foundation [KFF], 2023). Despite the weaknesses of the Medicaid program, it remains the primary insurance provider for CMC (Yu et al., 2021a).

As parents of CMC, henceforth referred to as parental caregivers, take advantage of their ability to bring their children home, they also assume direct responsibility for the care their children require. To ensure the appropriate care is provided, parental caregivers must interact with various elements of the healthcare system including healthcare providers at all levels of care, durable medical equipment (DME) suppliers, and insurance companies (Allshouse et al., 2018; Foster et al., 2019; Rasooly et al., 2020). Unfortunately, the current healthcare system in the U.S. is failing to properly support parental caregivers in addressing the sophisticated care needs of CMC (Foster et al., 2022). Shortages in available home care nurses with pediatric expertise leaves parental caregivers without home care support and drive hospital discharge delays among CMC, with approximately 92% of additional days in hospital attributed to unavailability of home care nurses (Maynard et al., 2019). These discharge delays contribute to 47.2% of Medicaid spending toward acute care services for CMC, twenty times higher than spending on preventative healthcare services at the outpatient and community levels (Berry et al., 2014). Additionally, despite the enactment of Medicaid expansion, state to state variation among available Medicaid waivers directed toward community-based services for CMC continue to perpetuate geographic inconsistences in the care available to children (Keim-Malpass et al., 2019).

Navigating these and other barriers to care places tremendous responsibility on the shoulders of parental caregivers. Coupled with the responsibilities of supporting other family members and meeting employment demands, these parents experience negative effects on their physical, emotional, and mental health (Yu et al., 2020). Previous work has examined these effects, often referring to them as “caregiver burden” and attributing this burden to the stressors of disease management (Cousino & Hazen, 2013; Caicedo, 2014; Graham et al., 2016; Prieto et al., 2022). Though widely used, the current operationalization and definition of caregiver burden among parental caregivers of CMC carries a major weakness. As Comeau (2019) describes, there is an inherent stigmatization and danger in placing blame on a child’s needs as the root cause of burden experienced by a parent. It also fails to consider the systemic barriers associated with caring for CMC at home. In other words, there may be factors beyond the diagnosis, such as home care nursing shortages, discharge delays, and variations among insurance coverage, that are root causes of parental caregiver burden.

A greater understanding of how barriers and gaps at the systems-level may be contributing to burden experienced among parental caregivers of CMC is needed. Therefore, the purpose of this integrative review is to address the following question: Which elements of the bureaucratic healthcare system are contributing to burden among parental caregivers of children with medical complexity living at home?

## Theory of Bureaucratic Caring

Guiding this integrative review is Ray’s Theory of Bureaucratic Caring (BCT) (Ray, 2021). Grounded in Hegelian dialectic, BCT represents a synthesis of two contrasting concepts – nurse caring and bureaucracy (Ray, 2021). Embracing the paradox of nurses attempting to provide humanistic care within financially driven and technology dependent hospital systems, Ray’s theory demonstrates their intertwined nature. One cannot exist without the other and through integration of the bureaucratic elements of hospitals, nurse caring can propel forward successfully (Ray, 2021).

Within this theoretical framework exist seven major concepts, each representative of an element of bureaucracy: social-cultural, physical, educational, political, legal, economic, and technological (Figure 1). These concepts surround an additional concept of spiritual-ethical caring which represents the essence of nurse caring. The framework presents these eight concepts as holographic in nature, meaning each individual concept exists independently and collectively to create the interconnected whole referred to as bureaucratic caring (Ray, 2021). The intertwined nature between caring and bureaucracy that underlies the phenomenon of bureaucratic caring posits a bidirectional relationship between them. Meaningful positive occurrences within the bureaucracy can have positive implications on the care process and likewise, negative occurrences can inhibit the process of caring. For parental caregivers caring for their children within the bureaucracy of the healthcare system, barriers within the system may not only prevent effective caring but also contribute to overall feelings of burden.

## Method

As outlined in Whittemore and Knafl's (2005) five stages of an integrative review, problem identification, literature search, data evaluation, data analysis, and presentation were completed.

### Literature Search

The literature search was conducting using CINAHL, PubMed, and Medline electronic databases with assistance from a research librarian. The following search terms were utilized: "Child* or adolescent* or teen* or "emerging adult" with medical complexity" AND "Pediatric home care" OR "Pediatric home health care". An initial search was conducted in October 2022 followed by a second search in October 2023 to capture additional articles that may have been published during data analysis and evaluation. All articles identified by the three databases were uploaded to citation manager Zotero for initial duplicate identification and screening by title and abstract.

### *Inclusion and Exclusion Criteria*

Inclusion criteria included peer-reviewed research articles related to parental caregivers of CMC living in the United States and their experiences caring for their children at home. Additionally, only studies published after 2014 were reviewed to focus on the experiences of parental caregivers after Medicaid expansion was initiated. Exclusion criteria included those articles that focused on parental caregiver experiences caring for CMC in acute care settings or in countries outside of the United States due to the differences in healthcare structures and the complexities of healthcare delivery faced by families of CMC that may be unique to the United States healthcare system. Other exclusion criteria included studies focused solely on CMC and not their parental caregivers as well as healthcare services for nonmedically complex children. Abstracts, protocols, literature reviews, dissertations, and non-English articles were also excluded.

## Data Evaluation

Studies that met inclusion criteria were evaluated for quality using the Johns Hopkins Nursing Evidence-Based Practice, Evidence Level and Quality Guide (Dang et al., 2022). This tool yields a single score for each article, comprised of an evidence level (I-V) and a quality level (A-C). Evidence levels are reflective of study designs, Level I represents experimental studies and randomized controlled trials and Level V represents articles developed from personal experiences and non-research designs. Quality levels evaluate overall scientific quality of an article ranked from high quality (A) to low quality/major flaws (C). Final scores for all articles included in this study can be found in Table 1.

## Data Analysis

Studies were first analyzed for study characteristics including authors, year of publication, study design, and study sample size and characteristics. Subsequently, studies were evaluated for findings related to burden experienced by parental caregivers that were attributed to barriers and challenges within the healthcare system. These findings were then further critiqued using the BCT framework to identify which elements of bureaucracy were contributing to the burden experienced by parental caregivers.

# Results

The literature search yielded a total of 1,967 articles which were screened for appropriateness as outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram (Page et al., 2021) (Figure 2). The most common reason for article exclusion was no relevance to PHC experiences of parental caregivers of CMC. After full text review, ten articles were included in this integrative review. These ten articles were published between 2018 and 2022 and were comprised of qualitative (n = 8), quantitative (n = 1), and mixed methods (n = 1) studies. Six studies recruited from single center clinics from which at least one author of each study was affiliated with (Amar-Dolan et al., 2020; Barton et al., 2021; Black et al., 2022; Foster et al., 2020; Toly et al., 2019; Ware et al., 2020). One study recruited through national patient organizations for families with a loved one diagnosed with a neuromuscular disease (Edwards et al., 2018). The remaining three articles represented findings from a single study that recruited participants via national family advocacy group listservs, allowing for representation of parental caregivers across all ten Human Resources and Services Administration regions (Boss et al., 2020; Fratantoni et al., 2019; Raisanen et al., 2021).

## Demographic Characteristics

### *Parental Caregivers*

Sample sizes across studies varied from 12 to 226 parental caregiver participants. One study (Ware et al., 2020) did not report number of parental caregivers included in the sample as the study was a qualitative analysis of notes written by care coordinators during appointments and no direct interviews with parents were conducted. Overall, parental caregivers in each study were primarily mothers of CMC. Other than Ware et al. (2020) who focused exclusively on experiences of Spanish speaking Latino parental caregivers, the remaining nine studies recruited only English speaking parents. Among the remaining studies, four reported race/ethnicity with White, Non-Hispanic parental caregivers comprising 61-80% of study samples (Barton et al., 2021; Black et al., 2022; Foster et al., 2020; Toly et al., 2019). Additional demographic information relevant to study samples were often limited with five studies not reporting any additional parental caregiver information (Amar-Dolan et al., 2020; Boss et al., 2020; Fratantoni et al., 2019; Raisanen et al., 2021; Ware et al., 2020).

### *Children with Medical Complexity*

Seven studies reported demographic information related to the CMC of parental caregivers (Amar-Dolan et al., 2020; Barton et al., 2021; Black et al., 2022; Edwards et al., 2018; Foster et al., 2020; Toly et al., 2019; Ware et al., 2020). The ages of the children ranged from 6 months old to 18 years old. Their diagnoses were generally related to neuromuscular and/or genetic abnormalities and the most common medical equipment required were gastrostomy tubes and tracheostomies with or without ventilatory support. Most studies had CMC with varying diagnoses and medical needs, however, Edwards et al. (2018) specifically examined the out-of-pocket costs of parental caregivers of children utilizing home mechanical ventilation.

## Parental Caregiver Burden

Parental caregivers across all ten studies reported experiencing physical, mental, emotional, and financial stressors. The most prominent sources of this burden were the shortage of home care nurses (Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020; Fratantoni et al., 2019; Toly et al., 2019), difficulties with attaining and incorporating medical equipment into daily life (Amar-Dolan et al., 2020; Barton et al., 2021; Black et al., 2022; Foster et al., 2020; Toly et al., 2019; Ware et al., 2020), and the high out-of-pocket costs associated with caring for CMC at home (Black et al., 2022; Boss et al., 2020; Edwards et al., 2018; Foster et al., 2020; Raisanen et al., 2021; Toly et al., 2019; Ware et al., 2020). No evidence of parental caregivers identifying their child's chronic illnesses as a source of burden was found in the selected articles.

# Discussion

## Parental Caregiver Burden Using Theory of Bureaucratic Caring

### *Social-Cultural*

The social-cultural element of bureaucracy represents the values and accepted norms within a system that either facilitate or inhibit the provision of care (Ray, 2021). Through exploration of the lived experiences of parental caregivers, Boss et al. (2020) identified attributes of the current culture within the pediatric home healthcare system. Themes from their study included the inextricable nature of home care services within family life, the negative implications gaps in the system have on family health/functioning, the consistency of out-of-pocket spending, and the need for parents to frequently advocate for high quality services. These findings highlight the tumultuous nature of utilizing home care services and the expectations placed on parental caregivers to make sacrifices and navigate these challenges in order to have their children live at home. An additional expectation was identified across several studies (Foster et al., 2020; Toly et al., 2019; Ware et al., 2020) with Fratantoni et al. (2019) and

Raisanen et al. (2021) highlighting that parental caregivers must independently learn the complexities of home care due to limited anticipatory guidance and education from healthcare providers.

### ***Physical***

Health as it relates to the physical, psychological, and emotional conditions of individuals within a bureaucratic system are captured by the physical element (Ray, 2021). Most prominently captured across the articles were the effects a lack of available home care nursing has on the wellbeing of parental caregivers who must assume all aspects of their child's care in the absence of a nurse (Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020; Toly et al., 2019). Two additional studies looked beyond physical self of parental caregivers and evaluated the physical home environments in which CMC are cared. Black et al. (2022) identified accessibility barriers such as staircases and bathroom access within homes that were challenging for parental caregivers to address without costly home renovations or medical equipment that were rarely covered by insurance. Inclement weather was another environmental factor identified as a barrier to accessibility and mobility for CMC. These challenges lead to physical injuries of parental caregivers and their children and were found to become increasingly more difficult to navigate as children grew in size (Black et al., 2022). Separately, Ware et al. (2020) identified concerns parental caregivers had related to food and housing insecurity, often related to loss of income; a direct result of parents having to give up full-time or even part-time employment to be able to care for their child.

### ***Political***

The political element represents systems of power and hierarchy within a bureaucracy that can directly impact the process of caring (Ray, 2021). In the realm of home care, healthcare providers at all levels of care, DME suppliers, and insurance companies all fall under this category. As captured by Fratantoni et al. (2019) a significant knowledge gap among inpatient and outpatient providers related to home care services of CMC negatively effects parental caregivers who must compensate for this lack of understanding and at times, educate providers on their role in facilitating home care services. Inconsistencies in the quality and caliber of home care nursing abilities also lead to burden among parental caregivers as they are unable to find reliable support (Amar-Dolan et al., 2020; Boss et al., 2020; Foster et al., 2020; Fratantoni et al., 2019; Toly et al., 2019). Difficult experiences with DME suppliers were another shared burden, as parents faced delays in the approval and arrival of necessary equipment to the home (Amar-Dolan et al., 2020; Foster et al., 2020; Ware et al., 2020). These delays must then be addressed by parental caregivers either through purchasing the items themselves or by contacting the child's insurance provider for support. Unfortunately, variations in Medicaid waivers across the country as well as limited coverage of equipment by private insurance companies often led to little success in covering most DME, forcing parental caregivers to choose between paying out-of-pocket for necessary equipment or going without (Foster et al., 2020; Raisanen et al., 2021).

### *Legal*

The responsibility of the legal element of bureaucracy is to facilitate and maintain equitable and socially just care of all individuals. This is actualized through large scale regulations such as federal and state healthcare laws to smaller scale policies of healthcare facilities (Ray, 2021). Across five studies, parental caregivers consistently referred back to difficulties they faced in caring for their children due to Medicaid waivers and/or insurance plans that were in place to facilitate care yet often acted as barriers instead (Black et al., 2022; Foster et al., 2020; Raisanen et al., 2021; Toly et al., 2019; Ware et al., 2020). As discussed earlier, Black et al. (2022), Foster et al. (2020), and Toly et al. (2019) all identified the frequent rejections parental caregivers receive when requesting DME be covered by insurance companies leading to delays in necessary equipment being made available at home. Beyond these delays, however, was the general difficulty of enrolling into, as well as maintaining access to, these waivers and insurance plans. Raisanen et al. (2021) described the arduous task of obtaining these services, with parental caregivers having to undergo frequent reevaluations to determine their child's medical necessity for DME and spending hours on the phone with insurance representatives and medical providers to coordinate submission of documentation that supports this eligibility. When a request for services has been denied, parents must then spend even more time on the appeals process, though Raisanen et al. (2021) note that this process is not always accessible to individuals with lower health literacy. This disparity was also noted by Ware et al. (2020) who found Spanish speaking Latino parental caregivers often faced language barriers when attempting to call insurance agencies and DME companies as interpreter services were not consistently available. Furthermore, paperwork needed to maintain access to these services were often printed in English and many of the parental caregivers in the study were unable to complete these forms independently.

### ***Economic***

The economic element encompasses the exchange of money within the bureaucratic system, often through processes involving payment for services and care delivery (Ray, 2021). In exploring these processes, Raisanen et al. (2021) identified 85% of parental caregivers were utilizing a "financial patchwork" of public and private insurance plans coupled with out-of-pocket spending in order to cover the majority of expenses associated with caring for their child with medical complexity. The prevalence and significance of non-reimbursable out-of-pocket expenses were echoed by parental caregivers in multiple studies, often citing the financial sacrifices associated with them (Black et al. 2022; Boss et al., 2020; Edwards et al., 2018; Foster et al., 2020; Toly et al., 2019; Ware et al., 2020). For example, among parental caregivers of CMC requiring home mechanical ventilation, greater than 5-10% of annual household income (approximately $9,000 among this study population [now estimated at $11,200 today]) was directed toward non-reimbursable out-of-pocket costs (Edwards et al., 2018). In order to afford these costs, parents reported reducing expenses directed toward their own self-care. For other families, these out-of-pocket costs also led to difficulties in affording basic household needs such as groceries, utility bills, and rent (Ware et al., 2020).

### ***Technological***

As defined by Ray (2021) the technological element encompasses all nonhuman resources required in the provision of care. Barton et al. (2021) examined how parental caregivers of CMC engaged with and incorporated the medical technology required by their children into daily life. They found that parents faced challenges with the various DME as the devices were not originally designed to be utilized outside of hospital walls, were disruptive in the home environment, and sometimes did not meet the needs of the child and/or parental caregivers. However, given the importance of the equipment in maintaining their children's lives and left with no other options, some parents identified workarounds to increase the conduciveness of the DME within their homes (Barton et al., 2021). These included washing and reusing supplies due to limited quantity being covered by insurance and replacing large medical equipment items (e.g., IV poles) with repurposed household items to make more room in the home. Toly et al. (2019) also identified barriers with medical equipment, particularly related to transportation difficulties, as many pieces of equipment were not designed to be portable and many modes of transportation are not consistently accessible nor have enough space for CMC who require multiple pieces of DME.

### *Educational*

This final bureaucratic element represents programs and processes that promote overall system functioning through education of those within (Ray, 2021). Although none of the selected studies explicitly focused on the ways in which parental caregivers or healthcare providers learn about caring for CMC at home, lack of knowledge and preparation were identified as barriers faced by parental caregivers. This included the lack of anticipatory guidance provided to parental caregivers bringing their CMC home (Amar-Dolan et al., 2020; Barton et al., 2021; Raisanen et al., 2021) and lack of understanding among healthcare providers of the supports these families require and ways to attain them (Fratantoni et al., 2019).

## Interconnectedness Among Systemic Challenges

Guided by Ray's Theory of Bureaucratic Caring, this integrative review of ten studies identified bureaucratic barriers within the healthcare system that challenge parental caregivers as they care for their CMC at home. These barriers subsequently contribute to their experiences of physical, mental, emotional, social and financial burden. Barriers and stressors reported by parental caregivers across all studies were seamlessly captured by at least one of the seven bureaucratic concepts of BCT thus, parental caregiver burden is exacerbated by social-cultural, physical, political, legal, economic, technological, and educational aspects of the healthcare system. Certain stressors reported by parental caregivers appeared within multiple bureaucratic concepts. This was best captured by the variability and gaps in coverage provided by public (Medicaid) and private insurance companies.

By definition, insurance falls under the legal category of BCT though the implications of inconsistent accessibility to necessary coverage contributes to weaknesses across the bureaucracy. Physical burden is exacerbated when parental caregivers are unable to get approval from insurance providers for necessary home equipment that would assist with activities of daily living (Black et al., 2022). Politically, home care nurses are difficult to attain and retain due to the low hourly wage, a direct result of poor Medicaid reimbursement for home nursing services (Foster et al., 2019). This shortage leaves parental caregivers solely responsible for completing direct skilled nursing care for hours, days, or weeks at a time without help (Boss et al., 2020; Foster et al., 2020; Fratantoni et al., 2019). The pressure of having to be available to assume care for their child at any moment subsequently contributes to the high levels of physical, mental, and emotional burden identified by Yu et al. (2020). This responsibility directly affects the financial instability experienced by families as well, with previous literature identifying many CMC as living in single-parent households with unemployed parental caregivers (Yu et al., 2021a; Kuo et al., 2011). At the same time, the inconsistent insurance coverage also leads to high, non-reimbursable, out-of-pocket spending by parental caregivers as they attempt to obtain equipment and resources required by their children (Black et al. 2022; Boss et al., 2020; Edwards et al., 2018; Foster et al., 2020; Toly et al., 2019; Ware et al., 2020). In combination, these financial sacrifices reflect the disarray of the economic component of the bureaucracy.

These stressors are all a result of inconsistent insurance coverage, a single weakness within one component of the bureaucracy; yet the ripple effect into other bureaucratic elements highlights the underlying interconnectedness of the healthcare system. This reinforces a philosophical underpinning of BCT in which all things within the bureaucratic system are relational, dynamic, and interdependent (Ray, 2021). However, systems do not exist in isolation and therefore, these connections also extend beyond the healthcare system which coexists and interacts with other bureaucratic entities. For example, a lack of home care nurses is exacerbated by a weakness within the academic bureaucracy where emphasis is often placed on preparing nursing students for acute care roles after graduation. Another example is the availability of federally funded Medicaid coverage, which is at the mercy of political agendas of numerous individuals within the United States government.

The central concept of BCT, spiritual-ethical caring, was the only theoretical concept not examined in this study. Although not a bureaucratic concept, spiritual-ethical caring represents the other element that is crucial for bureaucratic caring to exist. Ray (2021) defines spiritual-ethical caring as a unifying experience that supports the interconnectedness of all bureaucratic elements through love and humanistic or spiritual acts, with a goal of promoting the good of all individuals and things within the system. While there may be overlap with this definition and what drives parental caregivers to care for their children (e.g., love) the selected articles did not explore the *meaning* of caring with parental caregivers. It is unclear what would constitute spiritual-ethical caring among parental caregivers of CMC and how this may differ from the definition developed by Ray. What is known, however, is that true spiritual-ethical caring cannot be experienced by parental caregivers until gaps within the bureaucracy are addressed and overarching harmony is achieved.

## Implications for Nursing Practice

Multiple studies identified the large knowledge gap that currently exists among healthcare providers related to the care of CMC at home (Fratantoni et al., 2019; Amar-Dolan et al., 2020; Barton et al., 2021; Raisanen et al., 2021). Lack of understanding leads to insufficient anticipatory guidance or support for parental caregivers of CMC, a direct reflection of the weak educational component of the healthcare bureaucracy. Nurses across the healthcare system are in a position to be able to address these educational weaknesses. Home care nurses should be invited to speak with inpatient and outpatient healthcare providers to increase their awareness of considerations related to caring for CMC at home. Stronger understanding of what home care entails would allow inpatient nurses to work with parental caregivers to develop the skills required to address the nursing needs of their children upon discharge. Meanwhile, outpatient providers can use insight from home care nurses to become familiar with community-based services available for CMC within their region. Pediatric focused APRNs in particular are uniquely qualified to provide the necessary comprehensive and individualized care required by these children and should continue to be included in multidisciplinary clinical teams focused on the care of CMC (Doyle et al., 2021). The experiences of home care nurses should also be utilized to educate the future generation of nurses of workforce opportunities that exist beyond the acute care setting, a particularly pressing issue given the home care nursing workforce shortage that currently exists in the United States (Foster et al., 2019). One proposed educational partnership has been development of a role that allows nurses to work both inpatient and in home care to begin bridging the knowledge gap between inpatient and community based care of CMC (Sobotka et al., 2023).

## Implications for Future Research

The use of BCT in research related to the care of CMC at home has not been done before, therefore additional work should be done to further evaluate the appropriateness of this theory. While the bureaucratic components of BCT were evaluated through this study, the central concept of spiritual-ethical caring was not examined. Future studies should explore how parental caregivers of CMC define caring to identify potential differences from the definition provided by

Ray. Additionally, future studies should work alongside parental caregivers to explore the process of caring for CMC within the healthcare bureaucracy to identify additional elements of bureaucracy that may exist beyond the BCT framework.

The findings of this study also provide evidence to support the need to reevaluate “caregiver burden” as a term to describe the experiences of parental caregivers of CMC. Researchers currently utilize the term to highlight hardships experienced by these parents, though, as previously discussed, these challenges are linked to the complex care needs of a child and not reflective of the systemic challenges these parental caregivers encounter (Comeau, 2019). Moving forward, efforts should be made to utilize terminology in research that better reflects the stories of parental caregivers and holds systemic challenges accountable for the “burden” they experience.

## Limitations

This review has several limitations. First, additional studies that examine the experiences of parental caregivers of CMC may not have been captured through the literature search. Second, the selected articles for appraisal were limited to studies completed in the United States. The experiences of parental caregivers in other countries could provide further insight and comparisons on how a bureaucratic healthcare system may enforce and/or alleviate caregiver burden. Lastly, the included studies each had limitations of their own, such as including only English speaking parental caregivers or recruiting from one geographic region which may have subsequently had an effect on the results of this integrative review.

# Conclusion

Parental caregivers of CMC living at home do not attribute their high physical, mental, emotional, and social burden to the medical complexities of their children. This integrative review revealed a novel perspective on the burden they experience, presenting it as a byproduct of the barriers parental caregivers face as they attempt to care for their children within a bureaucratic healthcare system, composed of social-cultural, physical, political, legal, economic, technological, and educational elements. These barriers arise from weaknesses within these interconnected bureaucratic elements that directly challenge and inhibit the ability for parents to care for their children effectively. Efforts to alleviate parental caregiver burden must address the weaknesses in the healthcare bureaucracy and nurses have the unique ability to direct these efforts through clinical practice and future research.

**Figure 1.**

*Ray's Theory of Bureaucratic Caring (BCT)*

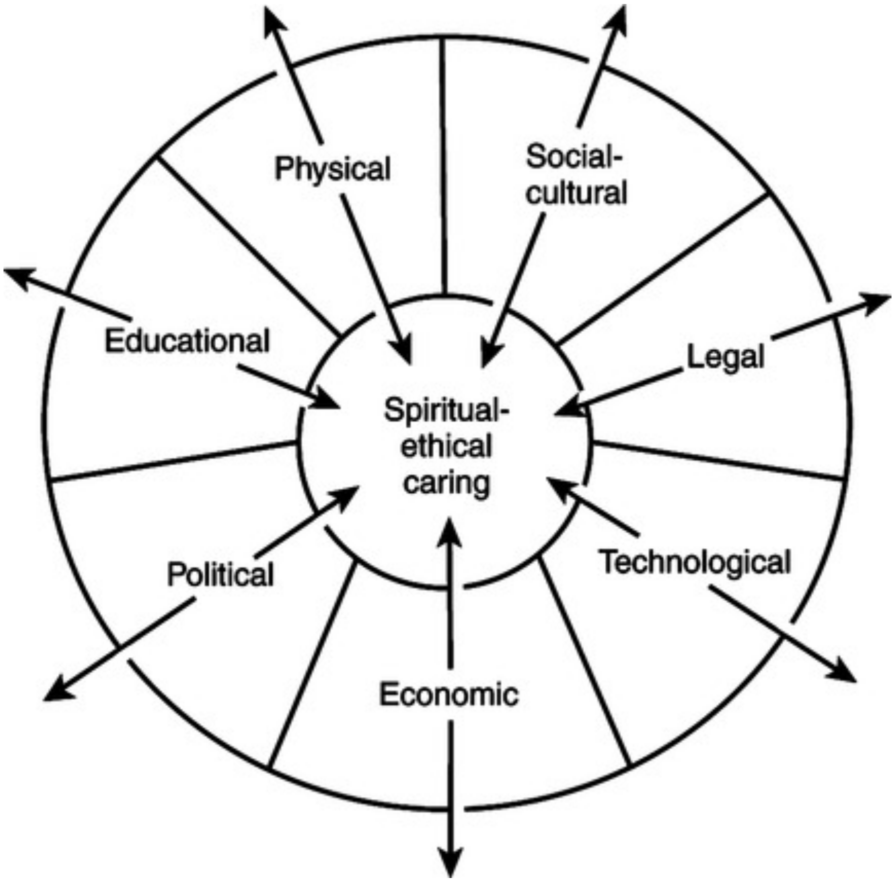

**Figure 2.**

*Preferred Reporting Items of Systematic reviews and Meta-analysis (PRISMA) flow chart*

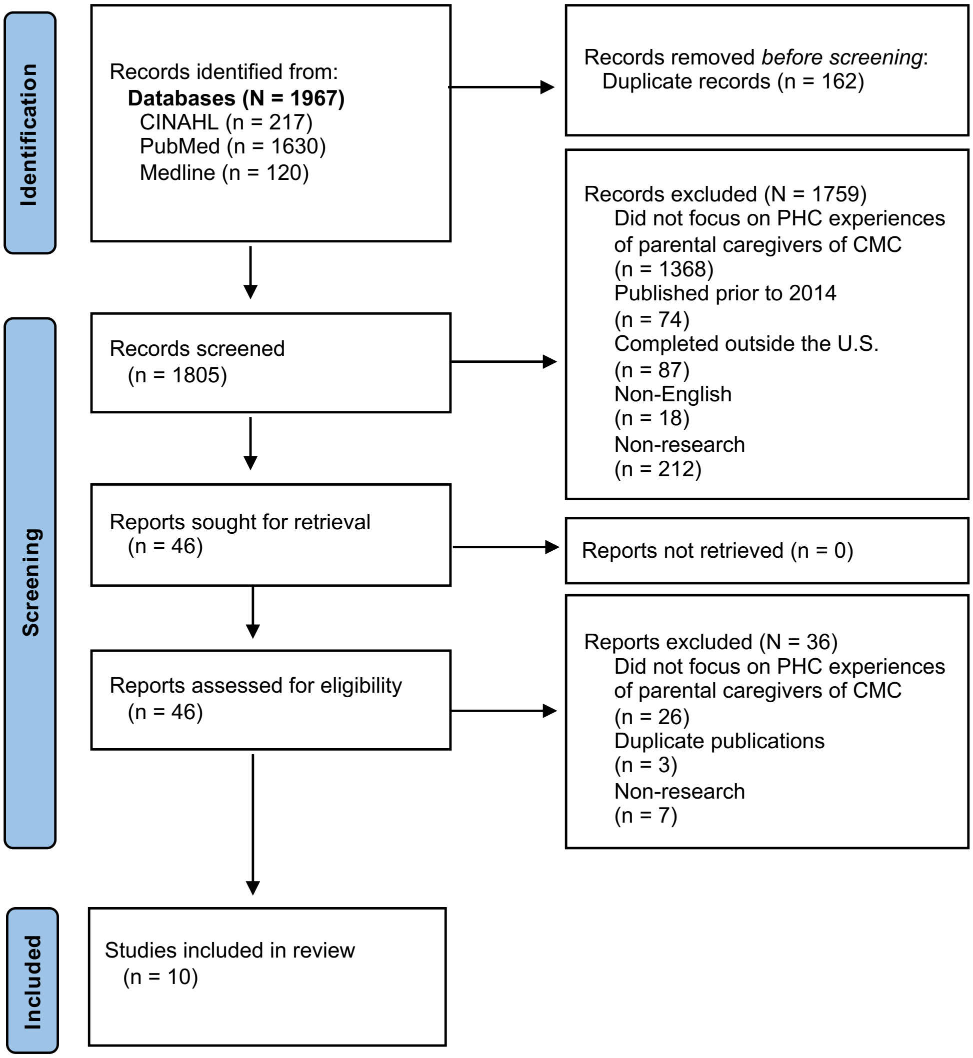

**Table 1.**

*Evidence Table and Description of Included Studies*

| Author and Year | Study Design | Evidence Level and Quality Rating | Demographic Characteristics | Findings Related to Parental Caregiver Burden | Bureaucratic Elements Represented in Findings |
|---|---|---|---|---|---|
| Amar-Dolan et al., 2020 | Qualitative: Non-experimental descriptive | IIIB/C | Parental Caregivers: (N = 12) 11 mothers. All English speaking. All enrolled in a single center home ventilation program.<br>CMC: (N = 12) 9 months to 18 years old. All requiring tracheostomies with or without ventilator support due to various chronic conditions. | Parental caregivers report challenges with home care nursing, coordinating care and medical equipment, managing medical emergencies, setting boundaries, and adjusting to the process of caring for their children, all which could be addressed with improved teaching and anticipatory guidance. | Physical, Political, Technological, Educational |
| Barton et al., 2021 | Qualitative: Non-experimental descriptive | IIIB/C | Parental Caregivers: (N = 30) 24 mothers. All English speaking, 23 White, 23 with urban residence. All enrolled in a single center complex care program.<br>CMC: (N = 30) Average age 7 years old. 26 with gastroenterological, neurologic, and/or respiratory diseases, each with varying medical technology needs. | Parental caregivers must find workarounds to incorporate their children's life sustaining medical technologies designed for hospital use, into the home environment. Not all parental caregivers are able to identify workarounds despite sharing similar difficulties with technology, emphasizing the importance of anticipatory guidance in adapting equipment into the home environment. | Technological, Educational |

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|---|---|---|---|---|---|
| Black et al., 2022 | Qualitative: Non-experimental descriptive | IIIB/C | Parental Caregivers: (N = 18) 16 mothers. All English speaking, 11 White, 10 with suburban residence. Recruited through outpatient clinics of a single center.<br>CMC: (N = 18) Average age 8 years old. 8 with neuromuscular diseases, 5 with some form of ambulation (including wheelchair use). | Parental caregivers face numerous environmental barriers while caring for their children. These lead to increased risk of harm to both parent and child. Contributors to these barriers extend beyond physical space and include delays in receiving necessary equipment (wheelchairs, braces, etc.) due to delays in insurance authorizations, discrepancies in insurance coverage, and out-of-pocket costs. | Physical, Legal, Economic, Technological |
| Boss et al., 2020 | Qualitative: Non-experimental descriptive | IIIB | Parental Caregivers: (N = 48) All English speaking, no further demographics reported. Recruited from all ten Human Resources and Services Administration regions via public listservs.<br>CMC: (N = Not reported) No demographics reported. | The lives of parental caregivers become interwoven with the care needs of their children. The gaps in necessary services (such as lack of home care nursing, insurance difficulties, and variable quality) contribute to difficulties in accomplishing other daily tasks unrelated to the child’s care. Parental caregivers also report high out-of-pocket costs. | Social-Cultural, Physical, Political, Economic |

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|---|---|---|---|---|---|
| Edwards et al., 2018 | Quantitative: Non-experimental, descriptive | IIIA | Parental Caregivers: (N = 226) Median yearly household income, $90,000. 77% of survey respondents were employed full-time. Additional individual demographic information not reported. Recruited via patient organizations.<br>CMC: (N = 226) Median age 7 years old. All with neuromuscular disease and home mechanical ventilation, 152 with invasive ventilation. | Parental caregivers of children with home mechanical ventilation spend greater than 5-10% of household annual income on out-of-pocket costs related to the child's care. Parents must either leave their job or significantly reduce hours to care for their child, further exacerbating financial stress. Sacrifices are also made to decrease spending in other domains of life (including personal care for the parents) to afford out-of-pocket expenses. | Economic |
| Foster et al., 2020 | Qualitative: Non-experimental descriptive | IIIB | Parental Caregivers: (N = 20) 16 mothers. All English speaking. 16 White, Non-Hispanic. 75% not employed outside the home, and 60% living within an urban area. Recruited through single center inpatient and outpatient clinics.<br>CMC: (N = 20) 10 months to 17 years old. All with a neuromuscular or genetic diagnosis, with majority (85%) requiring a feeding tube. | Parental caregivers report difficulties accessing services for their children due to variations in state-based waivers and insurance authorizations. Lack of comprehensive insurance coverage by public and private payers, contributes to delays in equipment delivery, provision of home care nursing services, and home modifications all leading to out-of-pocket spending by caregivers. Inadequate access to services contributes to physical, emotional, financial burden. | Social-Cultural, Physical, Political, Legal, Economic |

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|---|---|---|---|---|---|
| Fratantoni et al., 2019 | Qualitative: Non-experimental descriptive | IIIB | Parental Caregivers: (N = 48) 39 mothers.<br>Recruited via family advocacy group listservs. All English speaking, no further demographics reported. Recruited from all ten Human Resources and Services Administration regions via public listservs.<br>CMC: (N = Not reported) No demographics reported. | Parental caregivers become default care coordinators due to lack of support and experience in care coordination among healthcare providers. Lack of trained home care nurses further contributes to parental caregiver burden. | Social-Cultural, Political, Educational |
| Raisanen et al., 2021 | Qualitative: Non-experimental descriptive | IIIB | Parental Caregivers: (N = 48) 39 mothers.<br>Recruited via family advocacy group listservs. All English speaking, 27 living in suburban regions. Recruited from all ten Human Resources and Services Administration regions via public listservs.<br>CMC: (N = Not reported) No demographics reported. | Parental caregivers report needing a "financial patchwork" of private and public insurance as well as out-of-pocket payments to cover services for their children. Parents must learn about available services for their children through their own research and peer groups due to lack of anticipatory guidance from healthcare providers. Enrolling in services, including Medicaid waivers, is time consuming and drawn out. Gaps in care also occur due to systemic barriers that deny necessary home care related services. | Social-Cultural, Legal, Economic, Educational |

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|---|---|---|---|---|---|
| Toly et al., 2019 | Qualitative: Non-experimental descriptive | IIIB/C | Parental Caregivers: (N = 101) All mothers. All English speaking. 71% married, 73% White, Non-Hispanic, ages 21-66 years old. Half with yearly household income < $60,000. Recruited from specialty clinics of a single, Midwestern children's hospital.<br>CMC: (N = 101) 6.75 months to 16 years. 44% with neuromuscular dysfunction and 87% with gastrostomy tube. | Parental caregivers report facing difficulties related to medical supplies and equipment (particularly related to transportation outside the home due to lack of portable equipment), balancing personal needs with the needs of their children (including maintaining a job), interruptions to family dynamics (such as care for other children), demands with care coordination and provision (due to instability of consistent home care nursing services), and covering the medical expenses of their children (including out-of-pocket expenses leading to financial burden). | Social-Cultural, Physical, Political, Legal, Economic, Technological |
| Ware et al., 2020 | Mixed methods: Non-experimental descriptive | IIIB | Parental Caregivers: Not directly interviewed. Data collected from care coordinator notes summarizing visits with Latino, primarily Spanish speaking, parental caregivers through single center pediatric complex care program.<br>CMC: (N = 70). 51% female. 100% Latino. All 6 months to 18 years old. 80% residing in urban region and 97% on Medicaid. Majority with genetic condition or chromosomal abnormality. | Parental caregivers experience difficulties in addressing basic needs of their households such as rent, utility bills, and groceries. This stems from financial challenges of providing necessary medical care for their children and the loss of full-time employment among one or more parental caregiver within a household. Language barriers made navigating health insurance, medical equipment companies, and the overall healthcare system challenging. This leads to interruption of necessary services for the children. | Social-Cultural, Physical, Legal, Economic |

# Chapter 3

## Case-Control Analysis of Burden Among Parental Caregivers of Children with Medical Complexity

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# Case-Control Analysis of Burden Among Parental Caregivers of Children with Medical Complexity

In an era of medical advancement, the number of children with chronic conditions living in the United States now account for approximately 20% of all children under 18 years old (Health Resources and Services Administration, Maternal Child Health Bureau, 2020). Children with medical complexity (CMC) are a subpopulation of the most medically involved children. CMC have one or more complex, chronic conditions that affect multiple body systems and result in limitations in their functional abilities and increased need for life-sustaining medical technology and care coordination (Cohen et al., 2011; Rogers et al., 2021). Prevalence of CMC has quadrupled in size in the last decade, estimated to represent 1.6% of the total pediatric population (Yu et al., 2021a).

Historically, CMC were institutionalized due to their complex medical needs and lack of available insurance plans to cover their medical care beyond the inpatient setting. However, passage of the Katie Beckett waiver in 1982 expanded Medicaid coverage to include primary care and community based care of children with chronic illness or disabilities, allowing parents of CMC to bring their children home (Perkins & Agrawal, 2018). Consequently, many CMC began to transition to home based care with parents as caregivers. This transition also led to the development of the pediatric home care (PHC) system responsible for facilitating the care of CMC at home. The PHC system is intricate; composed of inpatient, outpatient, and community based healthcare providers, durable medical equipment suppliers, insurance companies, and state/federal policies (Fratantoni et al., 2019). Parental caregivers rely on coordination among the various system elements in order to provide safe and effective care for their CMC. Unfortunately, countless challenges within the PHC system have been identified and prevent CMC from receiving high-quality care (Boss et al., 2020; Foster et al., 2020; Yu et al., 2021b). In turn, these systemic challenges and gaps in care contribute to parental caregiver burden through increased levels of mental, emotional, financial, and physical stress (Geyer & Vessey, 2024).

A secondary analysis of existing national data by Kuo et al. (2011) revealed parental caregivers of CMC experience significantly higher care demands, underemployment and unemployment, and financial difficulties when compared to parental caregivers of children without significant medical complexity. However, this study was completed over ten years ago and the associated data analyzed were collected nearly twenty years ago (Kuo et al., 2011). Since then, the number of children living longer with significant congenital and chronic illnesses has continued to increase (Amirnovin et al., 2018). Additionally, the healthcare system has evolved as changes in federal healthcare policies have aimed to increase breadth and depth of insurance coverage for Medicaid recipients (Patient Protection and Affordable Care Act, 2010). Even more recently, the healthcare system has been impacted by the COVID-19 pandemic which in turn, has had positive and negative implications on parental caregiver experiences (Pitch et al., 2023). The landscape in which parental caregivers are caring for their CMC has changed in the last twenty years, therefore, an updated evaluation of parental caregiver burden is needed to ensure potential impacts of these systemic changes on feelings of burden are captured.

Furthermore, while previous work has highlighted various systemic challenges to high-quality home care, the effect of these challenges on parental caregiver burden has often only been evaluated through an economic lens to evaluate financial burden (Edwards et al., 2018; Belza et al., 2023). Measurement of other factors and types of burden can provide guidance for future legislation, health policy work, and initiatives to improve the system in which parental caregivers care for their children. Accordingly, the purpose of this study was to 1) identify any changes in prevalence of CMC living in the United States and 2) assess caregiver burden of parents caring for CMC as it relates to the PHC system.

### Theoretical Framework

The Theory of Bureaucratic Caring informed this analysis (Ray, 2021). The theory describes the underlying interconnectedness between humanistic nursing care and bureaucratic hospital settings. Without nurses, patient care in hospitals would be interrupted and services compromised. Without the bureaucratic support of hospitals, nurses would be unable to provide care to patients. Through recognition and optimization of this interdependence, patient care can be promoted effectively (Ray, 2021). The theory presents nursing care as the concept of *Spiritual-Ethical Caring*. Surrounding this are the seven concepts of bureaucracy: *Technological, Economic, Legal, Political, Educational, Physical, and Social-Cultural*. Together, these eight concepts are presented within a holographic model to represent the simultaneous existence of the concepts as independent and interdependent, creating the interconnected whole of bureaucratic caring (Ray, 2021).

The challenges faced by nurses as they navigate healthcare bureaucracy also are experienced by parental caregivers of CMC. The transferability of the Theory of Bureaucratic Caring to represent the experiences of these parental caregivers has been analyzed in prior work (Geyer & Vessey, 2024). The caregiver burden documented among parental caregivers is exacerbated by the continuous, and often negative, interactions they have with the bureaucratic elements of the PHC system.

## Methods

A secondary analysis of existing data was conducted using 2021 data from the National Survey of Children's Health (NSCH). The NSCH is an annual survey that collects state-level and national data on the physical, mental, and emotional health of children ages 0 to 17-years-old through parent proxy reporting (U.S. Census Bureau, 2022). The NSCH is comprised of a screener questionnaire to determine the number of children living within a household as well as their demographic information. For households with children present, a topical questionnaire is then administered to inquire about the health of only one of the children. For the 2021 survey, the screener questionnaire was administered nationally to 300,000 households between June 2021 and January 2022 and had a weighted overall response rate of 40.3% (U.S. Census Bureau, 2022). The NSCH questions pertinent to parental caregiver burden were evaluated and categorized using the eight conceptual components of bureaucratic caring. Institutional Review Board approval was obtained by the author team's academic institution.

## Aim I: Identify Prevalence of CMC

To identify the prevalence of CMC within the 2021 data, the CMC identification method developed by Yu et al. (2021a) for the NSCH was used. This method organizes survey questions into five categories, four representing the domains of medical complexity (chronic health conditions, functional limitations, health care use, and health service needs) as identified by Cohen et al. (2011) and a fifth category for all questions non-specific to CMC. Applying this organizational method to the 2021 survey led to identification of 110 pertinent survey items. Compared to questions included by Yu et al., selected questions were identical except for those related to substance abuse as representative of the chronic health conditions domain as no questions related to this were noted in the 2021 survey. Children whose survey responses screen positively within all four domains are then identified as CMC. Positive screening occurs when the minimum number of questions within each domain are endorsed as determined by Yu et al. All children who do not meet inclusion criteria either represent children with less complex special health care needs or children without any special health care needs. For the purposes of this study, these two groups were combined into one to create a dichotomized variable for CMC status – CMC or non-CMC.

## Aim II: Assess Parental Caregiver Burden

To evaluate parental caregiver burden, pertinent NSCH questions were organized into domains using the concepts of Theory of Bureaucratic Caring (Ray, 2021). Using the concepts of Ray's theory, a total of 60 relevant survey questions were identified [Table 1]. Of the eight concepts, *Educational* was the only concept not captured by the questions of the survey. Once organized, one question from each of the conceptual groupings was selected for analysis. Each question was selected either because it was used to measure parental caregiver burden in the previous secondary analysis of this dataset completed by Kuo et al. (2011) or because it was believed to best operationalize the concept it was grouped with. When necessary, reverse coding of response options was completed for consistency among questions such that higher values represented higher levels of parental caregiver burden. Responses for each question were compared between CMC and non-CMC to identify significant differences in parental caregiver burden across various bureaucratic elements of the healthcare system.

Given the low prevalence of CMC in previous work using the NSCH, it was hypothesized that prevalence of CMC within the 2021 dataset would continue to be low (Yu et al., 2021a). In light of this suspected population discrepancy between CMC and non-CMC, a case-control matching approach was conducted prior to completing analyses for Aim II in order to increase statistical rigor. Case-control matching allows for individuals within a dataset to be paired with each other based on shared characteristics. The approach allows for an equal number of individuals to be present in both groups of interest while keeping select variables consistent between them. In doing so, this technique may also decrease the effects of confounding by holding certain variables constant across control and treatment groups (de Graaf et al., 2011; Pearce, 2016). In this study, CMC and non-CMC were matched by demographic characteristics including language spoken at home, age and sex of child, race of family, family structure, insurance type, highest education, and the employment status of both adults at home.

### Statistical Analyses

CMC and non-CMC identified in Aim I were compared using descriptive statistics and Chi-square to identify demographic differences across groups and associations between demographic characteristics and identity of CMC and their families. In Aim II, Chi-square analyses were initially conducted to evaluate statistically significant differences in parental caregiver burden between parents of CMC and parents of non-CMC among the Bureaucratic Caring domains. Subsequently, domains with statistically significant associations were entered into a binomial logistic regression model to evaluate the odds of experiencing the individual domains of burden when a parental caregiver had a child with medical complexity. Certain survey items were recoded to dichotomous variables due to the presence of multiple response options for parental caregivers to select from while taking the survey. Results of these analyses were evaluated with level of significance held at $p \leq 0.05$. All statistical analyses were completed using SPSS Version 28 statistical software.

## Results

### Aim I: Identify Prevalence of CMC

Of the 50,892 children represented in the sample, 2.1% (n=1,063) were identified as CMC. When compared with the demographic characteristics of children without medical complexity, CMC were significantly associated with older age (12-17 years), male sex, racial/ethnic diversity, and enrollment in public insurance ($P < .001$). Additional characteristics can be found in Table 2.

### Aim II: Assess Parental Caregiver Burden

Through case-control matching, a total of 1,352 children were identified from the original sample and composed of 676 CMC, each matched with a single, non-medically complex child who shared identical selected demographic characteristics. The results of the Chi-square analyses for each of the selected parental caregiver burden questions are found in Table 3. Having a child with medical complexity was significantly associated with increased levels of parental caregiver burden among five of the seven Theory of Bureaucratic Caring domains (*Economic, Legal, Political, Physical, and Spiritual-Ethical Caring*) ($P < .001$ for all). Logistic regression of these domain questions identified significant increased odds of experiencing burden among parental caregivers of CMC within each domain [Table 4].

## Discussion

The number of CMC in the United States has increased and caregiver burden among parents of CMC has not only remained persistent but increased in severity. Significant associations and increased odds of experiencing caregiver burden among parents of CMC when interfacing with bureaucratic elements of the PHC system were also identified. The prevalence of CMC in this study, 2.1% (n = 1,063), is similar to findings by Yu et al. (2021a) who identified a prevalence of 1.6% (n = 1,071) among a larger sample population of 71,811 children. These results provide support for the consistency of this CMC identification method and highlights the growing presence this population has within the United States. The demographic characteristics of CMC of this sample also reflect findings by Yu et al. (2021a) with CMC continuing to be primarily older (12-17 years), male, racially/ethnically diverse, and living at home with two unmarried caregivers or single parent caregiver, with lower educational attainment, increased likelihood of unemployment, and enrollment in a public insurance plan.

Comparison of current burden levels with previous findings revealed multiple bureaucratic elements of the PHC system continue to burden parental caregivers and with greater severity. From an *Economic* lens, parental caregivers of CMC were previously three times more likely to pay more than $1,000 in yearly out of pocket healthcare costs for their children (Kuo et al., 2011). This study identified these parents are now 4.3 times more likely to pay more than $1,000 a year and 8.9 times more likely to pay more than $5,000 a year. The increase in odds reflects a growing concern with health insurance programs and whether they are designed to effectively support CMC and their parental caregivers. In particular, it is a reflection of reimbursement plans within medical insurance programs not keeping pace with the development of new equipment and pharmacological therapy options for CMC. Despite 60% of parental caregivers of CMC enrolled in public insurance (i.e. Medicaid), one study found approximately 85% of parental caregivers of CMC report the need of a “financial patchwork” of multiple insurance payer types to ensure coverage of the necessary equipment and supplies to care for their children (Raisanen et al., 2021). Variability in the breadth and depth of services covered by these various payers leads to inconsistencies in care for CMC, often based on geographic location and state-level health policies (Keim-Malpass et al., 2019; Rasooly et al., 2020). For example, despite being a federally funded program, Medicaid allows state governments to determine their eligibility criteria and reimbursement rates, resulting in some states providing more robust coverage than others (Kusma et al., 2022). Further contributing to high out of pocket healthcare spending is the minimal Medicaid spending directed to home-based services for CMC compared to funding directed to their inpatient care, 2.4% and 47.2% respectively (Berry et al., 2011). This small investment by Medicaid into the care of CMC outside the hospital not only places a financial burden on parental caregivers but also decreases accessibility to preventive services that may reduce hospitalizations and inpatient spending overall (Chen et al., 2023).

The responsibility of the PHC system to provide services to CMC and their families is captured by the *Legal* concept of the Theory of Bureaucratic Caring. In this study it was evaluated through parental frustrations in getting necessary services for their child. Kuo et al. (2011) also examined frustrations among parental caregivers and overall, parental caregivers of CMC were 2.4 times more likely to experience frustrations with this process. This study found parental caregivers now 7.5 times more likely to experience frustrations, emphasizing the inability of the PHC system to support these families. One source of frustration, as highlighted by Fratantoni et al. (2019) is the discrepancy in knowledge among inpatient, outpatient, and community based PHC providers in the needs of CMC and their parental caregivers. The lack of understanding subsequently inhibits provision of care coordination and health services as providers are unable to consistently and effectively engage with parental caregivers to facilitate care services. The Theory of Bureaucratic Caring includes relationships and power dynamics within the healthcare system as a *Political* concept (Ray, 2021). When operationalized in this study, parental caregivers of CMC were approximately 3.4 times more likely to experience some level of dissatisfaction with the communication between their child's doctor and other healthcare providers.

Another cause of frustration, linked closely with the *Economic*, *Legal*, and *Political* components of PHC, is the large gap in the availability and quality of the home care nursing workforce. Consequently, parental caregivers often provide skilled nursing and medical care to their children for consecutive hours, days, or even weeks at a time (Foster et al., 2019). Nearly

50% of parental caregivers in this study's sample reported decreasing their work hours to part time or less to have flexibility in caring for their child as they are unable to rely upon a consistent presence of home care nursing support [Table 2]. The lack of home care nursing subsequently impacts the *Physical* domain of bureaucratic caring, as parental caregivers are expected to compensate for the deficiencies of the PHC system by filling in as their child's nurse. In this analysis, parental caregivers of CMC were 31 times more likely to have to provide at least one hour of home care to their child than a parent of a child who is non-medically complex. Because children without medical complexity do not often require home care services, an additional regression model evaluating the odds of a parent having to provide more than 11 hours of home care services revealed parental caregivers were still 21 times more likely to do so. This normalization and expectation of parental caregivers to be able to provide medical care to their children for prolonged periods of time without help subsequently affects their physical, emotional, and mental health (Boss et al., 2020; Yu et al., 2020).

The remaining two bureaucratic concepts that were analyzed in this study, *Technological* and *Social-Cultural*, did not have significant associations with parental caregivers of CMC. A likely reason for this stems from the questions available from the NSCH to measure these concepts. Despite CMC requiring life sustaining medical technology, no questions in the survey ask about parental caregiver experiences with these technologies (Cohen et al., 2011). The only survey item related to technology in any capacity inquired about access to transportation which can be a barrier to receiving health care services but has not been noted in literature related to CMC and barriers or gaps in PHC (Fratantoni et al., 2019; Foster et al., 2020; Boss et al., 2020). To better capture possible sources of parental caregiver burden as it relates to the *Technological* domain, more specific questions related to technologies that support CMC should be asked.

On the other hand, there were a number of questions reflecting the *Social-Cultural* domain which centers around values and relationships within families, communities, and other social structures (Ray et al., 2021). The question analyzed in this study evaluated the parental caregiver's belief that they had someone available to turn to for emotional support in the last 12 months. Parental caregivers of CMC had only a slight difference in response to this question, with 41.2% reporting they did have someone to turn to compared to 42.1% of parents of non-CMC. The similarity in responses indicates that simply having a child with medical complexity does not imply greater or lesser access to emotional support for parental caregivers, and thus, may not be a good indicator of emotional burden. This reflects the importance of looking beyond a child's direct medical needs when evaluating caregiver burden and instead, considering systemic challenges to caring (Comeau, 2019). Future studies using the NSCH should consider the use of a more systems-level oriented survey item to evaluate the *Social-Cultural* domain.

The various elements of bureaucracy such as the *Economic*, *Legal*, *Political*, and *Physical* domains are both independent and interdependent (Ray, 2021). Together, they interact with, as well as on, the *Spiritual-Ethical Caring* provided by those responsible for care provision. Considering the significant association and odds of burden experienced by parental caregivers of CMC, these negative forces negatively impact the overall experience of caring for their child. Parental caregivers analyzed in this study were nearly 11 times more likely to report they felt their child was more difficult to care for than another child. It is important to note, however, that these feelings do not translate to parental caregivers feeling their child is the source of their burden. Instead, the burden stems from the consequences of the fragmented PHC system and the barriers and gap within it (Comeau, 2019). Future work evaluating burden among parental caregivers of CMC should consider the larger bureaucratic system of PHC and the implications of the system's dysfunction on parental caregivers and their experiences caring for their children.

### Limitations

Limitations to this study include those related to the NSCH. While nationally representative, the NSCH prompts participants to answer survey questions about only one child with their home. It is possible that parental caregivers of CMC who completed the survey may have elected to respond to the survey but answer questions about one of their other children. Therefore, prevalence of CMC may be higher than what was captured by the data. Additionally, the NSCH is not specific to CMC, many survey items do not address pertinent aspects of caring for these children at home, preventing a complete understanding of parental caregiver burden. The novel approach of using the Theory of Bureaucratic Caring as a framework for evaluating parental caregiver burden within this population will need further evaluation and explication when used to identify pertinent questions from the NSCH.

### Conclusion

The number of CMC living at home in the United States continues to grow steadily yet the burden experienced by parental caregivers remains largely unaddressed. Although various challenges to caring for CMC at home have been identified, the effects of these systemic challenges on parental caregiver burden have not been well documented. In order to address the needs of parental caregivers, future work must evaluate their experiences in the larger context of the pediatric home care system. Only when the relationship between caring for a child with medical complexity at home and the bureaucratic elements of pediatric home care is understood, can effective interventions be developed to facilitate this process of caring and ultimately decrease parental caregiver burden.

**Table 1.**

*Theory of Bureaucratic Caring Concepts and Pertinent NSCH Questions*

| Concept | Pertinent Survey Questions |
|---|---|
| Technological | Services needed not able to get to do to transportation |
| Economic | Avoid changing jobs because of concerns about maintaining health insurance; How much money spent on healthcare; Services needed not affordable; Problems paying for services/bills; How often costs are reasonable; Job changes because of problems with childcare; Stopped working because of child's health |
| Legal | Problem getting an appointment; Services needed not available in your area; Frustrated in getting services; Lack of insurance coverage due to overdue premiums; due to unaffordable plans, due to inadequate benefits, due to inadequate providers, due to application/renewal problems, other; Health insurance allows for coverage of services; allows for appointments with necessary providers; Needed health care not received; Insurance covers mental health/behavioral services; Services needed child not eligible for; Services needed but office closed |
| Political | Difficulty getting referrals; Communication between providers and other providers; between providers and school; How often did health care providers spend enough time; listen carefully; show sensitivity, provide specific information; feel like a partner; How easy to raise concerns/disagree with providers |

| | |
|---|---|
| Educational | No questions identified |
| Physical | Ability to afford food; Food stamps; General health of child; Days missed of school because of illness; Hours spent coordinating services; Hours spent providing home health care; Cut down on number of hours working; Decisions made regarding health care; How often could use help coordinating care; How often received help coordinating care; Received care from others |
| Social-Cultural | Emotional support from advocacy groups; from family or friends; from healthcare providers; from mental health professional; from other person; from peer support group; from spouse/partner; from place of worship; Someone to turn to for emotional support; Family draws on strength during difficulty; talks about what to do; work together |
| Spiritual-Ethical Caring | Felt child is harder to care for |

**Table 2.**

*Demographics of Children with Medical Complexity, Children without Medical Complexity, and their Families (N = 50,892)*

| Demographic | Overall (N = 50,892) Unweighted % | Non-CMC (n = 49,829) Unweighted % | CMC (n = 1,063) Unweighted % | *P* |
|---|---|---|---|---|
| Age (years) | | | | **<.001** |
| 0-5 | 40.7 | 41.0 | 28.2 | |
| 6-11 | 27.5 | 27.5 | 28.5 | |
| 12-17 | 31.8 | 31.5 | 43.3 | |
| Sex | | | | **<.001** |
| Male | 52.0 | 51.9 | 58.1 | |
| Female | 48.0 | 48.1 | 41.9 | |
| Race | | | | **<.001** |
| White | 76.5 | 76.6 | 73.2 | |
| Black or African American | 7.0 | 7.0 | 9.5 | |
| American Indian or Alaskan Native | 1.0 | 1.0 | 1.4 | |
| Asian | 5.9 | 6.0 | 2.8 | |
| Native Hawaiian/ Other Pacific Island | 0.8 | 0.8 | 1.0 | |
| Two or More Races | 8.8 | 8.7 | 12.0 | |
| Insurance Type | | | | **<.001** |
| Public | 22.5 | 22.0 | 43.9 | |
| Private | 69.0 | 69.7 | 38.4 | |
| Mixed | 4.0 | 3.7 | 15.7 | |
| Uninsured | 4.5 | 4.6 | 2.1 | |
| Family Structure | | | | **<.001** |
| 2 Parents, Married | 70.9 | 71.3 | 55.2 | |
| 2 Parents, Unmarried | 5.9 | 5.9 | 6.5 | |
| Single Parent | 19.4 | 19.2 | 28.5 | |
| Other | 3.7 | 3.6 | 9.8 | |
| Primary Language | | | | **<.001** |
| English | 91.9 | 91.8 | 95.0 | |
| Spanish | 4.1 | 4.1 | 3.3 | |
| Other | 4.0 | 4.1 | 1.7 | |

| | | | | |
|---|---|---|---|---|
| Highest Household Education Level | | | | **<.001** |
| Less Than High School | 2.6 | 2.6 | 3.1 | |
| High School | 13.1 | 13.0 | 14.2 | |
| Some College | 21.1 | 20.9 | 31.0 | |
| College or Higher | 63.2 | 63.4 | 51.6 | |
| Employment Status (Adult 1) | | | | **<.001** |
| Full Time | 67.2 | 67.5 | 52.9 | |
| Part Time | 11.4 | 11.4 | 13.8 | |
| Unemployed | 21.4 | 21.2 | 33.4 | |
| Employment Status (Adult 2) | | | | **<.001** |
| Full Time | 76.9 | 77.0 | 67.7 | |
| Part Time | 7.6 | 7.6 | 7.9 | |
| Unemployed | 15.6 | 15.4 | 24.4 | |

* Bolded *P* value identifies statistical significance

**Table 3.**

*Association of Child's Medical Complexity Status and Parental Caregiver Burden*

| Parental Caregiver Burden Domain | Non-CMC (%) | CMC (%) | *P* |
|---|---|---|---|
| Technological: Difficulties receiving medical care due to transportation difficulties | | | .713 |
| No | 14.1 | 73.4 | |
| Yes | 1.6 | 10.9 | |
| Economic: Dollars spent on medical care in the last year | | | **<.001** |
| 0 | 16.9 | 14.0 | |
| 1-249 | 12.4 | 5.0 | |
| 250-499 | 7.6 | 4.7 | |
| 500-999 | 5.6 | 4.8 | |
| 1,000-5,000 | 6.5 | 13.7 | |
| >5,000 | 1.0 | 7.9 | |
| Legal: Frustrations with getting healthcare services in the last year | | | **<.001** |
| Never | 39.6 | 16.9 | |
| Sometimes | 9.1 | 24.4 | |
| Usually | 1.0 | 5.3 | |
| Always | 0.3 | 3.4 | |
| Political: Satisfaction with communication between providers in the last year | | | **<.001** |
| Very Satisfied | 24.1 | 28.5 | |
| Somewhat Satisfied | 8.5 | 26.7 | |
| Somewhat Dissatisfied | 1.3 | 8.0 | |
| Very Dissatisfied | 0.5 | 2.3 | |
| Physical: Average hours spent providing home care services weekly | | | **<.001** |
| No home care required | 43.5 | 8.9 | |
| <1 | 3.3 | 7.7 | |
| 1-4 | 1.9 | 12.8 | |
| 5-10 | 0.5 | 7.6 | |
| ≥11 | 0.8 | 12.9 | |

| | | | |
|---|---|---|---|
| Social-Cultural: Having someone to turn to for emotional support in the last year | | | .264 |
| Yes | | | |
| No | 42.1 | 41.2 | |
| | 7.8 | 9.0 | |
| Spiritual-Ethical: In the last month, feeling their child is more difficult to care for than children their age | | | **<.001** |
| Never | | | |
| Rarely | 28.9 | 6.4 | |
| Sometimes | 11.1 | 7.4 | |
| Usually | 7.1 | 15.2 | |
| Always | 1.9 | 11.9 | |
| | 0.8 | 9.3 | |

*Bolded *P* value identifies statistical significance

**Table 4.**

*Effects of Having a Child with Medical Complexity on Likelihood to Experience Parental Caregiver Burden*

| Parental Caregiver Burden Domain | Odds Ratio | *P* | Confidence Interval (95%) |
|---|---|---|---|
| Economic: | | | |
| Paying > $1000 out of pocket for healthcare costs in the last 12 months | 4.303 | **<.001** | [3.315, 5.585] |
| Paying > $5000 out of pocket for healthcare costs in the last 12 months | 8.883 | **<.001** | [5.032, 15.680] |
| Legal: | | | |
| Frustrations with getting healthcare services | 7.478 | **<.001** | [5.852, 9.555] |
| Political: | | | |
| Dissatisfaction with communication between doctors and other providers | 3.350 | **<.001** | [1.992, 5.633] |
| Physical: | | | |
| Spending one or more hours providing home care services | 31.096 | **<.001** | [23.050, 41.951] |
| Spending greater than eleven hours providing home care services | 20.943 | **<.001** | [11.263, 38.944] |
| Spiritual-Ethical Caring: | | | |
| Feelings child is more difficult to care for than other children their age | 10.711 | **<.001** | [8.302, 13.819] |

*Bolded *P* value identifies statistical significance

# Chapter 4

## A Qualitative Descriptive Study Exploring the Systemic Challenges of Caring for Children with Medical Complexity at Home

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# A Qualitative Descriptive Study Exploring the Systemic Challenges of Caring for Children with Medical Complexity at Home

In 1982, Katie Beckett made history in the United States as the first child with ventilator-dependence to leave the hospital and live at home. Her discharge was the result of significant advocacy by her parents for federal Medicaid policies to provide insurance coverage of children with medical complexity (CMC) not only during hospitalizations but also in the community (Hevesi, 2012). Her parents' advocacy ultimately led to federal approval of the Katie Beckett waiver to expand Medicaid coverage and provided the opportunity for future CMC to live at home with their families (Tax Equity and Fiscal Responsibility Act of 1982).

CMC are defined as a pediatric population with chronic comorbidities that affect one or more body systems resulting in limitations in functional ability, the use of medical equipment, and high levels of coordinated care (Cohen et al., 2011; Rogers et al., 2021). Advancements in medical interventions have contributed to a steady increase in the prevalence of CMC, currently accounting for approximately 2% of all children living in the United States (Yu et al., 2021a). With continued expansion in state and federal legislation supporting greater community-based care, most CMC are now cared for at home (Berry et al., 2016; Perkins & Agrawal, 2018).

Quantitative studies examining the experiences of parents caring for CMC at home, also known as parental caregivers, have associated this role with high levels of stress and low health-related quality of life (Yu et al., 2020; Prieto et al., 2022). These negative experiences are labeled as "parental caregiver burden" and often attributed to the disease management CMC require (Caicedo, 2014; Edwards et al., 2018; Prieto et al., 2022). Efforts have been made to address these high levels of burden, particularly by identifying ways in which parental efficacy in providing direct care to their child can be strengthened. As parental caregivers learn much of their child’s care during a hospitalization, research often focuses on processes related to the immediate transition of CMC from hospital to home (Callans et al., 2016; Leyenaar et al., 2017; Amar-Dolan et al., 2020; DiFazio et al., 2023). Overwhelmingly, studies have concluded an increase in parental confidence requires overall improvement in discharge teaching quality and availability of post-discharge supports.

However, further exploration of parental caregiver experiences reveals the discharge from the hospital is only one part of the journey to caring for CMC at home (Fratantoni et al., 2019). Parents share the numerous challenges encountered beyond the discharge process including inconsistencies in healthcare provider knowledge related to home care services, a home care nursing shortage, and incomplete financial coverage of services (Boss et al., 2020; Raisanen et al., 2021). These and other challenges ultimately contribute to CMC receiving incomplete access to healthcare services. Compounding these inequities is the significant variability among state funding, legislative support, and implementation of home care services for CMC that has occurred since the initial Katie Beckett waiver, leading to considerable geographic variation in home care accessibility and quality (Keim-Malpass et al., 2019; Kusma et al., 2022). While these inequities have been the focus of national health policy initiatives for nearly twenty years, further improvements are needed (Committee on Child Health Financing, Section on Home Care, 2006).

Unlike discharge challenges which are often temporary, the challenges encountered once home can be unrelenting (Foster et al., 2019). Despite the acknowledgement of these systemic challenges to care, the implications of these challenges on parental caregiver experiences are not well defined. To better understand this relationship, experiences of navigating these challenges must be further investigated directly with parents. However, there is wide variation among home care systems geographically that confound the experience. As such, it is important to fully explore the systemic challenges within one state. Information uncovered can then be used to inform the examination of this relationship nationally.

### Massachusetts Home Care System

Massachusetts was selected as the study's focus as little work has been done to describe parental caregiver experiences in the Commonwealth. Funding for the home care system is robust due to the Commonwealth's adoption of universal health and expanded public insurance program, MassHealth, two decades ago (Chirba-Martin & Torres, 2008). To support CMC, funding from MassHealth maintains a Community Case Management (CCM) program which facilitates home care nursing and other community-based services for an estimated 560 children (Henson et al., 2024). Eligibility criteria for CCM includes enrollment in MassHealth. Unlike most states, CMC in Massachusetts have several enrollment options including whether their family's income meets federal guidelines for public insurance, the child meets medical need-based criteria, or through Medicaid state waivers (Kusma et al., 2022; 130 Code of Massachusetts Regulations 519.000, 2024). Having multiple enrollment options expands accessibility to MassHealth while increasing the number of CMC eligible to receive CCM services which consequently may exacerbate weaknesses within the Commonwealth's home care system. However, due to lack of research, little is known about the systemic challenges that arise in Massachusetts. Therefore, the purpose of this study is to identify and explore the challenges within the Massachusetts home care system encountered by parental caregivers of children with medical complexity.

## Methods

### Study Design

The experiences of parental caregivers were explored through a qualitative descriptive study. This methodological approach was chosen given its use when exploring complex areas where little is known. Participants are able to share their experiences using their own words, which allows for identified themes to reflect language of the participants (Colorafi & Evans, 2016). The study was approved by the Institutional Review Board of Boston College (Protocol no. 24.188.01e).

## Reflexivity

The primary investigator (PI) who completed the qualitative interviews for this study is a white male who has worked with CMC in Massachusetts as a pediatric home care nurse and nurse practitioner for over five years. The PI has witnessed challenges in the CMC system and the frustrations parental caregivers have experienced. To minimize bias in the interpretation of the findings, the PI reviewed the findings with members of the research team as well as a willing parental caregiver. Through discussing the findings, personal biases were called into question. The process allowed for the voices of the parents to be reported without preconceived ideas of the PI influencing findings.

## Participants and Recruitment

Parental caregivers in this study were defined as 1) adult caregivers ($\geq$ 18-years-old) living in Massachusetts, 2) who have full-time custody/guardianship of a child with medical complexity enrolled in CCM, 3) shared residence with their child, 4) had been caring for their child for at least 12 months, and 5) proficient in spoken and written English.

Initially, convenience sampling was employed through the Massachusetts office of a national home health care agency. Snowball sampling occurred as participants notified subsequent parental caregivers of the study opportunity. The PI screened interested parental caregivers for eligibility, answered questions related to the study, and obtained written informed consent.

### Data Collection and Analysis

The PI interviewed each participant via Zoom using its encrypted features. Participants were able to opt in or out of using the Zoom camera feature.  The interview commenced with the collection of brief demographic information. An interview guide developed by the team based on a review of the literature (Geyer and Vessey, 2024) and detailed in (Figure 1) provided prompts for participants as needed. Participants were first invited to share what the experience of bringing their child home for the first time was like. The participant was then asked to share their subsequent experiences caring for their child at home with a focus on the challenges faced. All participants were assured confidentiality. Anonymity was assured through the use of pseudonyms during the interview process.

Throughout each interview, the PI took notes on participant responses, mood, and environment. Additionally, the PI journaled personal reactions to participant experiences. Upon interview completion, demographic information, audio recordings, and associated transcripts were coded and deidentified. All recordings, transcripts, notes, and journal entries were stored on a secured encrypted server.

Transcripts were analyzed individually by the PI and two team members, including an experienced qualitative researcher and a community member with significant experience caring for a child with medical complexity within the Massachusetts home care system. Analysis was completed using conventional content analysis as described by Hsieh and Shannon (2005). The process was iterative and included listening to all recordings, and then re-listening while reading the transcripts. This process allowed the team to check the transcripts for accuracy and also provided an opportunity to note participants' ease of conversation, hesitancies, and emotions. Identified codes and categories were discussed amongst the research team. Themes were reviewed and discussed until consensus was achieved.

## Findings

A total of 11 interviews were conducted between January and April 2024 and each lasted between 60 and 75 minutes. Data saturation was achieved with 11 interviews.

### Participant Demographics

Participants were geographically located across 7 of the 14 counties of Massachusetts and predominately self-identified as female (n = 10). All parental caregivers identified as their child's parent, biologically or through adoption. One participant reported previously caring for their child in another state in addition to Massachusetts (Table 1).

### Systemic Challenges and Related Feelings of Burden

Three themes were derived from the data that captured the experiences of parental caregivers encountering systemic challenges. Each of these is explicated below:

#### ***Lack of discharge preparedness causes emotional distress***

During the initial discharge from the hospital, participants encountered variable discharge teaching quality. Some reported having opportunities to practice skills related to their child's care in a simulation lab (e.g., enteral feeding preparation, tracheostomy care) while others felt they had to advocate for nurses to allow them to practice and demonstrate skills. These participants described feeling anxious, fearful, and terrified knowing they would be responsible for independently completing these nursing interventions once home with their child. Time to practice skills also varied, as some participants expressed the opportunity to practice was only provided once a discharge date was selected for their child. Participant 3 described these concerns in this way:

> This was actually one of my suggestions to the team, is that I don't feel like there was enough education prior to bringing him home. It was like every time I would ask, “Can we learn to do this?”, the response was, “As you get closer to him coming home that's when we start doing the trainings”. And then like two weeks before they were like, “All right, his discharge date is here”. I felt so unprepared. And then, all of a sudden, it's like you have to learn all of these things at once and I didn't want to be there…because if he was medically cleared to come home but we weren't trained properly, I didn't want to be the reason that would stop him from coming home.

Regardless of the quality and time spent on skills practice, all participants recalled feeling unaware and underprepared for the tasks and challenges they would encounter once their child came home. As Participant 7 shared, “There is no manual for kids in general, but there's not even a compass for these kids”. Most participants recalled a social worker or MassHealth liaison introducing CCM services prior to discharge, however, this connection only provided a rudimentary introduction to home care nursing agencies and durable medical equipment suppliers. Participants shared that once home, they still felt underprepared and overwhelmed by the responsibility of caring for their child at home. Participant 2 shared, “I felt relieved to be home, because it was really hard to be away from my other kids…But everything else was completely overwhelming. A lot of it actually just seems like a blur because I remember crying so much”.

In addition, participants began to encounter unexpected challenges in navigating CCM services. These included a lack of available nurses trained to care for CMC to fill approved nursing hours, delays and shortages of necessary medical equipment, and lack of clarity surrounding private and public insurance coverage of medications. No participant was able to recall a discussion with healthcare providers or CCM representatives prior to discharge home about how to manage these common challenges.

### ***Care becomes increasingly complex creating new unanticipated challenges***

As participants shared their stories, it was noted that the medical diagnoses, necessary medications and equipment, and various community-based services quickly evolved after their children came home for the first time. Participant 2 stated, “Every time we went to a doctor’s appointment, it was like we got a new diagnosis. We got more added on”. Another participant described bringing her child home with a feeding tube, tracheostomy, suction machine, pulse oximeter, and being under the care of a CCM case manager and 12 specialists. In the four years since initial discharge, her child continues to require the original equipment as well as supplemental oxygen, a nebulizer machine, and several humidification devices. Furthermore, the child’s care team has expanded to also include three full-time and several per diem home care nurses, the home care nursing agency scheduler and case manager, two durable medical equipment companies, two insurance programs, two pharmacies (commercial and compounding), occupational therapy, two speech therapists, the school district’s special education director, the child’s classroom teachers, and the school nurse.

As additional components and individuals were added to their child’s care, participants described facing new challenges they had not anticipated when first bringing their child home.

One such challenge was the transition from home-based early intervention services to school-based learning. Eight participants had children who were old enough to be enrolled in school programs. When asked about the process of enrolling their child into school, participants either described having a supportive school district with a strong special education program or having to significantly advocate for their child to receive access to an equitable education that met and fulfilled their child's needs. For those needing to advocate, participants described how their child's complex medical needs were used by the school district as pushback to not enroll the child into the local school. Participant 2 detailed as follows:

> He's in school, he's in public preschool, and that was another big battle of mine. They took two looks at his paperwork and kind of, knowing us a little because my other kids [attend the school], wanted to send [son] out of district and I'm like, "You didn't even evaluate him!" so I fought to keep him in district…So we fought. We won. He's doing amazing there, like they didn't take medical kids at that school, that's what multiple people told me.

Once enrollment was achieved, participants then shared a secondary challenge of ensuring their child would be safely cared for during school hours, often by a one-to-one nurse. Depending on the school district, some participants were able to interview and select a home care nurse to accompany their child to school while others shared the school district selected a nurse without parental input. All participants highlighted how a lack of available nurses interested and capable of caring for their children in the community has resulted in inconsistencies in their child's ability to attend school. Participants expressed how their ability to attend work, complete tasks/errands, or address the needs of their family are contingent on whether or not their child is able to attend school each day. Participant 11 described:

> If I’m doing something and the school calls me, now I have to stop what I’m doing and I have to go pick up my child. I can’t have a job; I physically cannot have a job because there’s no other childcare for him. If I’m at a job and my son needs to be picked up from school, who is gonna go get him? I have the vehicle that his chair fits in. I have his car seat that he fits in…I’m not going to be able to do it.

Another participant described the additional layer of care she has navigated since her child turned 18 years old, the loss of access to familiar pediatric services and transition into less robust and supportive adult services. Healthcare providers and teams who participated in her child’s care for over two decades have now been replaced by individuals who are unfamiliar with the child. Due to her child’s increase in age and size, there has been a consistent decrease in the number of home care providers able to work with them. Further, access to community-based services have been disrupted due to her child aging out of waivers that previously qualified them for services. In describing this journey, the participant voiced having never felt more vulnerable in caring for her child:

> Ultimately, these kids are living longer, and they're very complex…I can't imagine what's going to happen in the next 20 years with these kids and these families…there are a percentage of us that are in my shoes, you know? There's not a lot of us, but we're there. And I think we all feel what I'm describing extremely acutely. And we feel less supported as we move forward versus more supported.

### ***Psychological toll of parents assuming provider role***

Participants described having to be the point person for all individuals associated with their child's care. Participants explicitly and implicitly expressed that providers across the home care system often rely on them to inform, coordinate, and direct the care required by their child. Participant 1 noted that her doctor said, "You're going to know [son's] care better than me…better than anyone else' and I remember being like, there's no way, this is so overwhelming and yet, no one knows his care better than me or [husband]". This reliance on parents continued with other entities and individuals within the system.

One example shared by many was the reliance of home care nursing agencies on parents to provide orientation and skills training to nurses joining the child's home care team. Participants felt they were often more confident in their own skills than in the skills of other nurses. While parents reported some level of comfort knowing they were able to teach new nurses, the process of training was noted to be time consuming and frustrating. As Participant 9 stated, "It feels like a daunting task because you could train them, and they could be with you for about a month, and then they're gone".

In another example of this altered parental role, several participants shared how they independently wrote letters of medical necessity or care plans and sent these documents to their child's primary care providers to review and sign in order to expedite the process of getting equipment or access to a program for their child. Although the providers did not explicitly ask for participants to write these documents, there was no recollection of providers telling these parents not to do it again. In fact, Participant 5 recalled positive reinforcement of this act, stating, "My [son]'s pediatrician…he signed six pages of orders I typed, he was like 'I knew you typed them…I read them over fast but I trusted you'. And then he asked me to be on the parent advisory clinic."

Beyond writing letters and care plans, participants also expressed that a lack of access to individuals knowledgeable in the intricacies and complexities of the home care system ultimately places the responsibility of navigating and coordinating services on their shoulders. Many equated the required tasks and responsibilities to that of a full-time job. Participant 4 shared this:

> Coordinating and clerical aspect of this is…it's almost like a whole separate job. And that's how much it is, even with nurse case managers through either any insurance or through, you know, his primary care provider, or whatever…And you're just trying to keep everybody on the same page. And meanwhile you're tackling this problem or this problem and you're trying to remember a list of things that you need…And it's like, there's no time to even do that. It's so busy. Emails, the phone calls, the messages, tracking information down is…Oh, my gosh, it just really is consuming.

Participants reported feelings of isolation, anxiety, and stress as a result of having to lead every aspect of their child’s care. Participant 6 shared, “We have a pile of stuff on our shoulders and around us all the time. So even when it is downtime there's never freedom from the weight of the whole experience”. Several participants used the term “burnout” to describe the effect of this weight, including Participant 7 who stated, “I would probably use the phrase caregiver burnout just because it really is exhausting… lack of sleep, trying to manage stuff completely above my pay grade, you know, and then not having any real resources to navigate it”.

Compounding these feelings are the lack of resources to support parental caregivers address their own wellbeing, noted by Participant 10, “The system isn't designed to be supportive of the caregiver…I think there are people that want to be helpful, but overall, the structures don’t talk to themselves. They're not well integrated to really kind of help”. An example of this included participants who attended therapy sessions but had to stop due to the financial/and or time sacrifice required. Others shared certain extended relatives, friends, and community members have previously offered to help but were unable to provide necessary mental and emotional support due to a lack of understanding of the parental caregiver experience. Participants expressed that in an absence of psychosocial supports, their physical, mental, and emotional health needs remain largely unaddressed.

## Discussion

Findings from this study provide insight into the systemic challenges encountered by parental caregivers and the negative implications these challenges have on caregiver wellbeing. Many challenges encountered by participants were similar to those described by parental caregivers across the nation (Boss et al., 2020). This indicates that increased accessibility to enroll into a home care program, such as CCM, does not equate to a more positive or less demanding parental caregiving experience. Instead, it highlights the need for home care and community-based programs to be redesigned in such a way that parental caregivers receive necessary guidance and support throughout the experience.

### Systemic Challenges

As noted by participants, challenges began even prior to hospital discharge. Consistent with literature in this area, participants who had greater exposure to practice hands-on skills prior to discharge home reported feeling more comfortable with completing these skills (Glick et al., 2023). However, of the participants whose children were initially discharged from a hospital in Massachusetts, none felt they received adequate education related to CCM services or the responsibility they would be expected to take on once home. These findings highlight the importance of providing comprehensive anticipatory guidance related to the home care system when discussing the care of CMC at home.

Focusing on skills development is not enough to prepare parents for the caregiver role. Attention should also be given to accurately describing available home care services and the limitations that currently exist within them. Similar findings were described by Nageswaran et al. (2020) among parental caregivers living in North Carolina, noting the importance of preparing parents for differences in home care versus hospital care of CMC as a means of improving the overall transition process from hospital to home. Facilitating this level of parental education may decrease the initial distress encountered by parents as their expectations of caring for their child at home will be informed by a realistic description of the strengths and weaknesses of the home care system. However, as described by Fratantoni et al. (2019), inpatient providers often carry the least amount of knowledge related to the intricacies of the home care system given their expertise in acute care management of CMC as opposed to their care in the community. Therefore, ensuring access to individuals such as community-based pediatric focused advanced practice nurses or family liaisons who can provide parents with pertinent and detailed information related to the home care system and experiences of parental caregivers is vital.

Several participants shared experiencing pushback from certain school districts to enroll or adequately support CMC. This is both unethical and unlawful given the Individuals with Disabilities Education Act requires public schools to provide all children with disabilities access to education and to promote a learning environment that is least restrictive to their learning (Individuals with Disabilities Education Act, 2004). Limited work focused on school attendance during the COVID-19 pandemic explored the experience of enrolling CMC into school (Coller et al., 2023). More research is needed in this area, particularly best ways in which parental caregivers are informed of their child’s educational rights and what challenges are encountered prior to, as well as after, school enrollment.

Although only one participant in this study was able to speak to the experience of transitioning her child from pediatric to adult services, her experiences reflected the complexity and uncertainty that surrounds this transition process (Li et al., 2020, Teed et al., 2021; Roy et al., 2022). In particular, she described how the lack of transparency surrounding age cutoffs for pediatric programs and alternative services ultimately left her responsible for addressing these gaps. This reveals a significant gap in care as access to MassHealth and related programs once a child turns 18 years old become limited and increasingly nuanced compared to the multiple enrollment options initially provided. Without comparable programs and services in place, parental caregivers are suddenly tasked with continuing the care their child has always required but with less tools and available systemic supports.

## Parental Caregiver Burnout

Participants expressed how the continuous need to navigate systemic challenges in conjunction with the expectation that parents consistently serve as the point person for all aspects of their child’s care makes it difficult to disconnect from the caregiver role. As a result, participants described the negative implications this has had on their personal health and wellbeing, referring to the experience as that of caregiver burnout. Previous studies have attributed caregiver burden and decreased health-related quality of life among parental caregivers to disease management of CMC as opposed to system challenges being the root cause of caregiver burnout (Caicedo, 2014; Prieto et al., 2022). Additionally, the use of the term “caregiver burnout” by participants, as opposed to “caregiver burden” used by healthcare providers suggests parental caregivers hold different perspectives on the caregiving experience and its most disruptive challenges (Comeau, 2019).

Yu and colleagues (2020) found a significant increase in health-related quality of life when parental caregivers had access to informed care coordinators, likely due the opportunity for parents to designate certain responsibilities to these coordinators. However, consistent with the findings of this study, participants shared, that access to knowledgeable individuals who can assist with coordination of services across the home care system was not consistently available. These findings echo the results of a single site qualitative study of parental caregivers living in the Midwest who expressed similar challenges (Foster et al., 2022).

Another gap that emerged from this study was the lack of resources available to support participant mental health. Similar to findings in a national assessment of parental caregiver mental health by Bayer and colleagues (2021), participants had difficulty identifying existing programs or mechanisms within the home care system available to address these feelings of burnout. The lack of access to mental health supports is of great concern given existing evidence that parents of children with chronic illnesses are more likely to experience medical traumatic stress (Carmassi et al., 2021). A study by Dewan and colleagues (2022) identified preliminary evidence to describe how systemic challenges within the Canadian healthcare system facilitate experiences of medical traumatic stress among parental caregivers of CMC. These challenges included the need for parental caregivers to act as their child’s point person for all services, addressing knowledge gaps among healthcare providers, and an inability to access or receive consistent care for their children (Dewan et al., 2022). Participants in this study reported similar, if not identical, effects of systemic challenges on their wellbeing underscoring the importance of making mental health supports available for parental caregivers.

## Clinical Implications

As healthcare at large moves toward a more holistic and family-centered approach to patient care, it is imperative that home care systems within the nation not only focus on addressing medical needs of CMC, but also the psychosocial factors of the environments in which they are cared for – including parental caregiver wellbeing. Across the profession, nurses are uniquely qualified to support the development of more supportive and sustainable systems. DNP-prepared nurses, for example, have the skillset to lead the development of these new models of care through health policy advocacy, incorporation of research findings, and completion of quality improvement projects (American Association of Colleges of Nursing, 2015). Meanwhile, given their ability to provide efficient and high-quality care coordination, pediatric-focused APRNs in practice are well suited to address the paucity of knowledgeable providers who are able to relieve parents of these responsibilities (Doyle et al., 2021). Therefore, it is imperative that APRN students are educated on the care of CMC and the various components of the home care system (i.e., healthcare policies, insurance waivers, and programs) to maximize the quality of services provided to parental caregivers.

## Limitations

Experiences of only white, English-speaking parental caregivers were captured, limiting the exploration of systemic challenges related to race/ethnicity. All participants resided in Massachusetts, limiting the generalizability of this study. Future work should capture experiences of a more diverse sample.

## Conclusions

Parental caregivers encounter numerous systemic challenges while caring for their CMC at home. These challenges begin prior to discharge from the hospital and persist throughout the caring process, often increasing in complexity as children grow older. Parental caregivers attribute many negative feelings and overall impact on their wellbeing to these systemic challenges, referring to the experience as parental caregiver burnout. Worsening their burnout are the lack of available resources for parents to address their psychosocial needs, ultimately reflecting the fragmented and unsupportive nature of the current home care system. Future work should continue to examine the relationship between systemic challenges and parental caregiver burnout to guide efforts in research, advocacy, and system reform to ensure parents are able to care for their CMC within a sustainable and supportive home care system.

**Figure 1.**

*Interview Guide*

## BACKGROUND INFORMATION

Let's start by talking about the first day you brought your child home.

**Questions:**

- *What was that day like?*
- *How did you feel about bringing your child home?*
    - *How did others in the family feel?*
- *Can you think of anything in the process of getting your child home that went well?*
- *Can you think of anything in the process of getting your child home that did not go well?*

It has now been [time since child has come home] since that first day. I imagine you and your child have gone through a lot in this time.

**Question:**

- *How would you describe your overall experience of caring for your child since bringing them home?*

## EXPLORING THE SYSTEM

As I mentioned earlier, I am interested in learning about your experiences with and feelings toward the system in which you have been caring for your child. I will be asking about broad aspects of the system. As we explore each aspect, think about ways in which you have interacted with these aspects while caring for your children and any feelings you have about them.

First is the **Technological** aspect of a system which represents any nonhuman resources or equipment needed to care for someone.

**Questions:**

- *What comes to mind when you hear this description?*
    - *What has been your experience obtaining/using these items?*
- *Who comes to mind when you hear this description?*
    - *What has been your experience interacting with them?*
- *How have these experiences made you feel?*

Next is the **Economic** aspect of a system which represents the exchange of money, either through direct personal spending or via insurance programs/waivers, to provide care for someone.

**Questions:**

- *What has been your experience addressing the financial costs of your child's needs?*
    - *Do particular insurance programs, waivers, or other mechanisms of payment come to mind?*
- *How have these experiences made you feel?*

Next is the **Political** aspect of a system which represents individuals or groups with positions of power who can directly impact the process of caring for someone. These individuals can include nurses, physicians, and other healthcare providers.

**Questions:**

- *Who comes to mind when you hear this description?*
    - *What has been your experience interacting with them?*
- *How have these experiences made you feel?*

Next is the **Legal** aspect of a system which represents ways in which laws, policies, and other regulations ensure the care provided to someone is equitable, accessible, and of high quality.

**Questions:**

- *Who comes to mind when you think about these federal or state healthcare laws/policies?*
- *What federal or state healthcare laws, policies, or regulations are you familiar with that relate to your child's care?*
    - *Can you think of ways in which these have positively or negatively impacted your ability to care for your child?*
    - *How have these experiences made you feel?*

Next is the **Educational** aspect of a system which represents ways in which individuals and programs are taught to promote the caring of someone.

**Questions:**

- *Who comes to mind when you think about who taught you about caring for your child at home?*
- *What were your experiences learning how to care for your child at home?*
    - *Were there any aspects of your child's care that were not taught to you?*
    - *How do these experiences make you feel?*

Next is the **Social-Cultural** aspect of a system which represents values, norms, or social structures that can provide support in the care of someone.

**Questions:**

- *Who or what comes to mind as a support for you?*
- *What have been your experiences accessing these supports?*

Lastly, the **Physical** aspect of a system which represents the physical, mental, and emotional health of individuals within the system.

**Questions:**

- *How would you describe your health since bringing your child home?*
    - *Can you identify any experiences in caring for your child that have contributed to your current health?*
- *How do you feel about your health?*

## CAREGIVER BURDEN

Many times in research studies, when describing the challenges parents face in caring for their children with medical complexity at home, the term "caregiver burden" is used. We have talked today about challenges you have faced in caring for your child and the way these make you feel.

**Questions:**

- *How do you feel about the term "caregiver burden" being used to describe your feelings and experiences?*
- *Are there any other terms that could be used instead of "burden" to describe your feelings?*

## CONCLUSION

Lastly, I want to give you time to add anything else you think is important for me to know about the system in which you care for your child and/or the ways in which you have felt as you have cared for your child at home.

**Question:**

- *Is there anything else you came here wanting to share but didn't get a chance to say?*

**Table 1.**

*Participant Demographics (N=11)*

| Characteristics | |
|---|---|
| **Relationship to child** | |
| Parent | 11 (100%) |
| **Gender** | |
| Female | 10 (91%) |
| Male | 1 (9%) |
| **Race** | |
| White | 11 (100%) |
| **Hispanic or Latino** | |
| Yes | 2 (18%) |
| No | 9 (82%) |
| **Always cared for child in Massachusetts** | |
| Yes | 10 (91%) |
| No | 1 (9%) |
| **Child's insurance type** | |
| Public | 3 (27%) |
| Private | 0 (0%) |
| Both | 8 (73%) |

# Chapter 5

# Discussion and Summary

# Discussion

The objective of this dissertation was to explore the relationship between systemic challenges encountered by parental caregivers of children with medical complexity (CMC) and caregiver burden. This was addressed through three specific aims: 1) identifying elements of the bureaucratic health care system that contribute to burden among parental caregivers of CMC living at home as presented through existing literature, 2) identifying prevalence and sociodemographic characteristics of CMC and contemporary levels of parental caregiver burden among a nationally representative sample of parents with CMC, and 3) qualitatively exploring parents' experience of pediatric home care, including the pediatric home care system and parental caregiver burden among parents living in Massachusetts. With guidance from professionals in pediatric healthcare, parents and other lay personnel, the literature, and community resources, three original research manuscripts using diverse quantitative and qualitative methodologies were developed to meet these aims.

The first manuscript represents a synthesis of existing pediatric home care literature using Ray's (2021) Theory of Bureaucratic Caring to identify which bureaucratic elements are present within the contemporary pediatric home care system and whether parental caregivers attribute burden to weaknesses within these elements. This integrative review of the literature revealed all seven bureaucratic elements (social-cultural, physical, political, legal, economic, technological, and educational) exist within the current system and that barriers and stressors across these elements contribute to burden among parental caregivers (Geyer & Vessey, 2024). In particular, the findings of this review highlighted the dynamic and interconnected relationship between systemic challenges and burden; with weaknesses in one bureaucratic element directly resulting in weaknesses and creating synergies among the other elements, ultimately compounding overall feelings of burden. This review was the first published study to explore parental caregiver burden as a reflection of systemic challenges as opposed to a reflection of a child's medical needs (Caicedo et al., 2014; Prieto et al., 2020; McGrane, 2023). The identification of preliminary evidence to support the existence of such a link provided a foundation from which the second and third studies of this dissertation, and their related manuscripts, were developed to further explore this relationship.

The second manuscript represents a case-control secondary analysis of the 2021 National Survey of Children's Health data in which national levels of burden among parental caregivers were evaluated for the first time in over a decade (Kuo et al., 2011). This analysis was also guided by BCT, providing a novel aspect to this evaluation of burden. The National Survey of Children's Health collects data from parents of children with and without medical complexity, responses were stratified into two groups, those with CMC and those without. Parental caregiver burden was then evaluated using logistic regression to compare these two groups and measure odds of reporting burden on survey items related to experiences related to each of the theory's bureaucratic domains. Data revealed feelings of burden to be significantly associated with being a parental caregiver of a child with medical complexity and this burden was more likely to occur across several bureaucratic domains (economic, legal, political, and physical). Full findings are located on page 56.

The results of this secondary analysis provided quantitative data to affirm the preliminary evidence that a relationship between systemic challenges and parental caregiver burden exists. However, these findings were limited by the survey used for this study. Survey items selected to measure burden related to the bureaucratic domains were chosen using a combination of a priori knowledge obtained from previous studies and a posteriori knowledge developed through clinical experience. Given the National Survey of Children's Health is not specific to CMC, available survey items did not allow for all elements of parental caregiver experiences to be measured. Nonetheless, this analysis highlighted the need to address parental caregiver burden as it has not only remained persistent but also increased in severity in the last twenty years.

Though findings from the first and second manuscripts provided foundational evidence for a relationship between systemic challenges and parental caregiver burden, these studies relied on post hoc evaluation of existing data. The third manuscript was a qualitative study and addressed this gap by exploring systemic challenges with 11 parental caregivers living in Massachusetts. Analysis of interview transcripts revealed three themes, each capturing ways in which systemic challenges within the Massachusetts home care system contribute to an overall adverse impact on health-related quality of life among parental caregivers.

First, participants described the emotional distress they experienced during the initial transition from hospital to home due to variable discharge teaching that lacked appropriate anticipatory guidance of what caring for CMC at home truly entails. Second, they shared that once home, a child's care often increases in complexity as they age, introducing new challenges that parental caregivers must navigate such as school enrollment and the transition of care into adult services. Once again participants highlighted the lack of support available to address these challenges and the feelings of anxiety and vulnerability they experienced as a result. Lastly, participants underscored the psychological toll of being responsible for all aspects of their child's care and ways in which the home care system facilitates the reliance on parental caregivers to be at the center of all care needs. Participants shared that ultimately, navigating these responsibilities and systemic challenges culminate in experiencing parental caregiver burnout. In the absence of proper psychosocial supports, parental caregivers are unable to address these feelings of burnout, leading to further exacerbation of their negative health-related quality of life.

## Summary and Implications

The results of the three manuscripts provide data-driven foundational evidence to support a relationship between systemic challenges that exist within the pediatric home care system and the negative impact these challenges have on the health and well-being of parental caregivers of CMC living at home. Evidence of this relationship has implications for future research, clinical practice, and policy initiatives related to the care of CMC and their parental caregivers.

### Research Implications

Despite the growing number of CMC living in the United States, the population is often underrepresented in research due to the varying and often unique diagnoses of these children (Yu et al., 2021a). This lack of attention is of concern given evidence by Berry et al. (2014) that CMC account for at least one-third of Medicaid dollars spent ($1.6 billion in 2011) on all children enrolled into Medicaid programs. In light of the increasing prevalence and lifespan of CMC, significant healthcare spending directed to their care, and evidence of numerous systemic challenges encountered by parental caregivers, it is essential that research related to CMC and their care at home continue in order to better our understanding of how to support these children and families in the most efficient and cost effective way. This dissertation contributes three studies exclusively examining the care of CMC at home, helping to grow the small, yet critical, body of literature currently available in this field and the findings provide a roadmap for future intervention work that can begin to address the significant systemic challenges encountered by parental caregivers.

More broadly, findings from this dissertation also suggest the current disease-centered research perspective of caring for CMC does not fully capture the experiences of parental caregivers and consequently limits the breadth and depth of interventions developed to address their needs. This reinforces the words of Comeau (2019) who expressed her concerns of a disconnect between the focus of research related to CMC and the needs and experiences of parental caregivers. To ensure future work lends itself to productive and logical progress of this field of research, a paradigm shift toward a more holistic perspective of parental caregiver experiences is needed; in particular, one that considers the bureaucratic systems in which experiences occur.

The three manuscripts of this dissertation not only provide the basis to support this paradigm shift but also highlight the value of the disciplinary perspective of nursing to inform this transition. All three studies were rooted within the nursing theoretical perspective of BCT (Ray, 2021). A fundamental philosophical underpinning of this theory is that of “caring”. This concept is a central focus of grand nursing theories such as Newman’s Theory of Health as Expanding Consciousness and Watson’s Theory of Transpersonal Caring (Newman et al., 1991; Watson, 1985). Several scholars in nursing have identified the concept of caring as central to the disciplinary focus (Willis et al., 2008; Smith, 2019). The act of nurses caring for patients is not only a socially agreed upon characteristic of the profession but serves as the motivation for why nurses do what they do. These experiences of caring also lend themselves to an appreciation for caring within systems that do not always facilitate this act. These findings supported nursing research guided by BCT aimed at understanding the experiences of parental caregivers of CMC.

Just as the three studies of this dissertation have provided a foundation for future intervention development, continued research under this holistic paradigm can provide further knowledge on interventions to support parental caregivers. Ideally, as more work is done to explore systemic challenges, intervention work will be able to grow beyond addressing challenges that currently exist but also develop upstream solutions to prevent future challenges from arising. Establishing a body of literature centered around proactive interventions may not only address challenges within systems of the United States, but also those existing in other countries. This could ultimately facilitate equitable healthcare of CMC and their parental caregivers on a global scale.

## Clinical Implications

A lack of knowledge among healthcare providers was identified as a consistent challenge encountered by parental caregivers. Across the manuscripts, the inadequate understanding of the home care system was found to not only be a frustration to parental caregivers, but also have negative consequences on their well-being. Providers in all clinical arenas, including acute, primary, and specialty care, are in a position to help alleviate these negative effects through increased awareness of the home care system and parental caregiver experiences. For clinicians currently in practice, this may be attained through completion of continuing education modules and attendance of presentations related to the care of CMC at home. For future clinicians, this understanding can be fostered through coursework and clinical experiences that introduce providers to CMC and the care they receive across the healthcare continuum. Recent work by Lattanza et al. (2024) has shown the positive impact on provider confidence to work with CMC when integrating CMC-focused curriculum into the inpatient experience of pediatric residents and medical students. Expanding CMC-focused curriculum into the coursework of all healthcare providers, including nurses at the undergraduate and graduate level, can foster greater confidence among future providers to care for CMC.

Greater preparation of future clinicians to care for CMC can also encourage a stronger, more robust network of care coordination supports. As highlighted by participants in the third manuscript, the care coordination required to safely care for CMC at home is extensive and grows in complexity as children get older. Additionally, high-quality coordination is required during lateral transitions, such as discharge from hospital to home, as well as longitudinal transitions, such as enrollment into school. Kuo et al. (2016) proposed a “medical neighborhood” as a means of providing this comprehensive care coordination, with providers across the healthcare spectrum working together to ensure CMC and their parental caregivers consistently have access to necessary supports. Unfortunately, implementation of medical neighborhoods has not become standard practice of care for CMC in the United States given the vast array of hospitals, outpatient clinics, home care agencies, insurance options, and other healthcare-affiliated systems that exist across the nation. Necessary mechanisms to promote continuity of care among these services, such as shared medical record systems and available services for CMC, are simply not in place. As a result, parental caregivers must compensate for these systemic weaknesses and facilitate the necessary communication and actions to ensure coordination of care for their child. Introducing the next generation of clinicians to the implications of fragmented healthcare systems as well as ways in which they can address and reform these fragmented services is a crucial step in developing medical neighborhoods for CMC and alleviating a major contributor of burnout among parental caregivers.

## Policy Implications

Highlighted through this dissertation, healthcare policies are significantly interwoven within the home care system and have implications for parental experiences of caring for CMC at home. Findings from this work highlight important considerations to be made when pursing future policy initiatives. Most explicitly, the emerging evidence supporting the relationship between systemic challenges and parental caregiver burnout provides valuable data for legislators and other key stakeholders to understand how weaknesses within the current home care system are not only financially costly but also detrimental to the health of the individuals within the system. These data provide insight on existing weaknesses and can inform changes to current policies. An example may include the expansion of age limits to Medicaid waivers such that CMC older than 18 years do not lose access to necessary home-based services simply due to their age. Though this appears to be a relatively small change, this would allow for greater continuity of care for CMC while also alleviating parental caregivers of some of the stress and uncertainty surrounding the process of transitioning their child into adult care.

Policies that increase available supports for parental caregivers as they care for CMC are also critically important, such as initiatives to increase access to home care nurses. This is one way to ensure support is available as home care nurses are one of the few medical professionals within the home care system who function as healthcare providers *within* the homes of CMC and the only individuals, other than the parental caregivers, who are able to provide all levels of care to these children. Barriers to consistent, high-quality home care nursing availability include low hourly wages, inadequate training, and variability in home care agency support of nurses (Simpser & Hudak, 2017; Noritz, 2019). As noted through this dissertation research, the lack of home nursing support contributes to the overall burden and burnout experienced by parental caregivers.

To improve access to high quality home care nursing for CMC, policy initiatives at the state and federal level should work to increase the Medicaid reimbursement rates for home care services. The current shortage of pediatric home care nurses is driven by poor pay yet home care agencies are unable to address this wage discrepancy as the hourly pay of nurses in each state are determined by Medicaid reimbursement rates, not the agencies who manage the nurses (Foster et al., 2019). Without support from state and federal governments to increase these reimbursement rates, home care agencies are unable to compete with the higher pay offered in other healthcare settings, ultimately driving nurses away from pursing home care roles. Certain states, including Massachusetts, have passed legislation to increase these reimbursement rates (101 Code of Massachusetts Regulations 361.000, 2023). Unfortunately, many states have not facilitated such increases in reimbursement rates, contributing to the variability in care of CMC seen across the nation.

## Strengths and Limitations

There are several strengths and limitations to this dissertation research. One strength is the novel use of BCT to inform each of the three studies and to provide an overarching framework for exploring the relationship of systemic challenges on parental caregiver burden/burnout. The use of three separate methodologies across the studies provides both quantitative and qualitative data to support the presence of this relationship and the importance of its continued exploration. Given the limited research in the care of CMC at home the three manuscripts are also a significant contribution to nursing science given their exclusive focus on parental caregivers' experiences of caring for CMC at home.

Limitations of the individual studies were previously discussed within the respective manuscripts. However, general limitations in conducting research related to CMC must also be acknowledged. First, the paucity of available literature indicates there is still much to be explored and understood about caring for CMC at home. While the focus of this dissertation was on parental caregiver experiences, many CMC live within broader family units and little is known about the experiences of the siblings of these children. Second, the expansive diagnoses and medical needs of CMC can make generalizability of research findings a challenge as each child's journey with medical complexity is unique. Additionally, external factors that influence the care a child receives at home also vary, making it difficult to identify valuable trends in outcomes. Compounding this challenge is the absence of a national database to track the number of CMC living in the United States and their related sociodemographic and healthcare usage data. In turn, this limits the ability to track healthcare spending on CMC or to monitor large scale implications of caring for CMC at home. Another limitation is the significant geographic variability in home care that CMC have given the variation in state-driven Medicaid policies dictating the number and quality of available services. The intricacies and complexities of each state's home care system further limit generalizability of study findings as well as the development of "one size fits all" interventions to address national gaps in care.

## Next Steps

The immediate next step in my program of research will be to continue with the second aim of the National Association of Pediatric Nurse Practitioners Foundation Research grant that provided support for the third study of this dissertation. With systemic challenges of the Massachusetts home care system now identified, future work with participants will include developing a process map that outlines the various steps they must take to provide care for their CMC and the ways in which the identified systemic challenges inhibit this process from occurring seamlessly. The goal of this is to develop a parent-informed visual of the experiences of caring for CMC that can then be presented to MassHealth leadership in tandem with data from this dissertation to identify policy initiatives and system reform that will promote a stronger and more supportive home care system. The work completed in Massachusetts will then be used as pilot data to support the expansion of this work into, regional, national, and international settings.

As the work in Massachusetts continues, auxiliary studies can also be completed that can inform both intervention development and policy reform. For intervention work, there is an opportunity to further explore the concept of “parental caregiver burnout” as a possible replacement for “parental caregiver burden”. This deeper exploration of the terms can be evaluated through a concept analysis as well as through review of instruments currently available to measure these concepts among parental caregivers and beyond. In particular, there is opportunity to explore the literature related to “nurse burnout” as a means of understanding whether “parental caregiver burnout” may be a more appropriate term to reflect the experiences of parents caring for CMC at home. If so, the synthesis of a conceptual definition can then be used to guide the development of a new instrument specific to parental caregivers of CMC that more appropriately measures their health-related quality of life compared to currently available tools. Access to such an instrument can then provide measurable data to help evaluate the effect of various interventions on parental caregiver wellbeing.

As noted previously, a shortage of home care nurses nationally as well as evidence of state variation in access to home care nurses exists (Foster et al., 2019; Keim-Malpass et al., 2019; Rasooly et al., 2020). Though low hourly wages have been identified as a potential source of this shortage, each state has a different state Medicaid policy related to reimbursement rates of home care nursing services. Yet an evaluation of the effect of these state Medicaid reimbursement rates on the availability of home care nurses has not yet been done. This is another auxiliary study that can be completed as findings may provide greater insight on the possible positive or negative implications reimbursement rates have on access to home care nursing services across states. This information can then be used to inform state-level policy changes related to reimbursement rates as a means of addressing existing gaps to consistently available, high-quality home care nurses across the nation.

Finally, this dissertation also revealed that despite the worsening levels of burden/burnout among parental caregivers, little attention is given to evaluate the psychosocial health and well-being of parental caregivers in practice. Currently, no recommendation for universal mental health screening of parental caregivers exists and without clear direction on which providers should undertake this responsibility, the mental health of parents simply remains unaddressed. In turn, parental caregivers remain responsible for self-identifying their mental health needs as well as supports to address these needs. The development and implementation of a standard of care to provide mental health screenings of parental caregivers is imperative in promoting more holistic care of CMC, focusing not only on the child's health but also on the health of their parents.

Ultimately, in light of the findings of this dissertation, I plan to continue developing a program of research that holistically explores the care of CMC at home and investigates the systemic challenges encountered by parental caregivers. The overall objective of my program of research will be to ensure meaningful data, reflective of parental caregiver experiences, are not only collected but then subsequently used to inform the development of necessary clinical interventions and policy initiatives that create a stronger, more supportive home care system for CMC and their families.

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