HOW OLDER ADULT CAREGIVERS MANAGE WOUND CARE PROCEDURES,
RESOURCES NEEDED, AND PUBLIC POLICY IMPLICATIONS

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DEDICATION

I would like to dedicate this dissertation to a few important people who have supported me. I could not have been successful without the support of my parents, Steve and Diane Clark. Mom and Dad, I am so grateful for your encouragement and all that you have done to allow me time to focus on this work – most notably, loving on Emily, Maggie, and Jack while I typed. I love you both very much.

To my husband, Charlie, I’m not even sure where to begin. Your unwavering support of anything and everything that I am passionate about has allowed me to explore many avenues of the nursing profession until I finally found my place. We didn’t really know what this journey would look like four years ago, but you jumped right in and have been by my side in numerous ways. You are the best computer support guy, the most patient listener, and have kept me grounded and focused on what’s important. I am blessed to be on the same team as you. I love you more and more each day.

And finally, to our children, Emily, Maggie, and Jack. I hope you one day see the time that mom spent writing papers and “doing homework” as an example of setting a goal and doing what it takes to pursue your passions. I pray that each of you develops an interest in something you love and know that your dad and I will do whatever it takes to support and encourage your dreams. I love you.

Finally, to the participants who shared their story with me, thank you. I’d like to dedicate this dissertation to all the caregivers who find themselves doing things they never thought possible for someone they love. It is my hope that you feel supported and empowered by a nurse at some point along your caregiving journey.
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I must start with acknowledging my mentor and dissertation chair, Dr. Janet S. Fulton. At the completion of my master’s thesis manuscript in 2010, I remember you asking me when I was going to enroll in the PhD program. It took me a few years to believe in my ability to the same degree in which you believed in me. I appreciate your guidance and mentorship as I developed my research ideas and found a topic I am passionate about. You have supported me through the program, but also in my personal life, and for that I am forever grateful.

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I would also like to thank the IU School of Nursing for awarding me the William G. Rodie, Jr. and Doris A. Rodie Nursing Scholarship and Michelle A. White Scholarship. I am thankful for the generosity that has made this degree possible.
Kristen Leigh Swartzell

HOW OLDER ADULT CAREGIVERS MANAGE WOUND CARE PROCEDURES, RESOURCES NEEDED, AND PUBLIC POLICY IMPLICATIONS

As healthcare increasingly shifts to home and community-based settings, informal caregiver responsibilities are increasing beyond assistance with activities of daily living to include complex care procedures previously performed by licensed caregivers in clinical settings. With an aging population, increasing numbers of older adults are assuming a caregiving role, a trend that is projected to continue into the foreseeable future. These older caregivers performing complex care procedures such as wound care. The purpose of this dissertation study was to understand how older adult caregivers manage complex wound care procedures. Aims were to 1) develop a theory for how caregivers manage; 2) identify themes related to resources needed, and 3) determine resources available through the existing Medicaid 1915(c) waivers program. Aims 1 and 2 were achieved using qualitative analysis of interviews with 18 older adult caregivers aged 65 and older who were performing wound care in the home for a care recipient. Grounded theory methods were used to develop a theoretical framework describing the process of how the participants managed caregiving. The resultant theory, *Pushing Through*, consisted of five phases: 1) accepting the role, 2) lacking confidence, 3) creating a system, 4) trusting in self, 5) owning the outcomes. Secondary analysis of the interview data used thematic analysis methods to identify resources used or needed for the caregiver role. The resultant themes were (a) connection to a healthcare professional, (b) written instructions, (c) access to wound care supplies, (d) access to durable medical
equipment, (e) financial resources, (f) personal care coverage, and (g) socialization and emotional support. Aim 3 used descriptive analysis of Medicaid 1915(c) home- and community-based services waivers for adults aged 65 and older for all 50 states plus the District of Columbia to identify the frequency and type of waiver services available for supporting caregivers. Results revealed that the number of services offered by state Medicaid waiver programs varied greatly across the country. Respite in varying forms was the most frequently available service. Findings from this dissertation will contribute to the development of evidence-based strategies to sustain older adult caregivers within their caregiving role.

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<th>Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>AARP</td>
<td>American Association of Retired Persons</td>
</tr>
<tr>
<td>ADLs</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>DC</td>
<td>District of Columbia</td>
</tr>
<tr>
<td>HCBS</td>
<td>Home- and Community-Based Services</td>
</tr>
<tr>
<td>IADLs</td>
<td>Instrumental activities of daily living</td>
</tr>
<tr>
<td>ICIM</td>
<td>Informal Caregiving Integrative Model</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>NAC</td>
<td>National Alliance for Caregiving</td>
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</table>
CHAPTER 1

Introduction

This chapter serves as an introduction to the dissertation research. The chapter includes a discussion of the background and significance of the topic, theories relevant to the study, the purpose and specific aims of the study, a description of the study methods, and a summary of chapters 2-5.

Background

Chronic Disease in the United States

In the United States, 60% of adults have been diagnosed with a chronic disease and more than 40% of adults have two or more chronic diseases, defined as conditions lasting one year or more that require ongoing medical care or limit activities of daily living or both (Buttorff et al., 2017; Centers for Disease Control and Prevention, 2022a). Hypertension (27%) is most common followed by lipid disorders (22%), mood disorders (12%), and diabetes (10%) (Buttorff et al., 2017). Of the nation’s $4.1 trillion in annual health care expenditures, 90 percent is spent on chronic health conditions (Centers for Disease Control and Prevention, 2022b). The risk of chronic disease, specifically dementias, heart disease, type 2 diabetes, arthritis, and cancer, increases with aging (Centers for Disease Control and Prevention, 2022c). For adults aged 65 and older, 81% have two or more chronic diseases simultaneously (Buttorff et al., 2017). Individuals with multiple chronic diseases face poorer health outcomes, higher utilization of healthcare services, and worse disease management (De Maria et al., 2021).
Chronic disease self-management is critical for optimal disease control. Self-management is the strategies one undertakes to control disease, promote health, and live well with illness (Audulv, 2013; Sabo & Chin, 2021). Self-management behaviors include, but are not limited to, managing pain, consuming a healthy diet, taking medications as prescribed, self-monitoring, managing persistent symptoms, managing emotions, and navigating the healthcare system (Audulv, 2013; Brady et al., 2018). Self-management can be challenging in the presence of multiple chronic conditions and when chronic disease results in fatigue, pain, functional impairment, and overlap of symptoms (Audulv, 2013; Boehmer et al., 2016; De Maria et al., 2021). Those who are unable to properly manage their chronic disease are at increased risk of disease progression, hospitalization, and mortality (Hardman et al., 2022). However, individuals with chronic diseases are not alone in self-management. All are influenced, positively and negatively, by healthcare providers, society, and their personal social networks, which can serve as both resources and barriers to successful management of chronic disease (Audulv, 2013).

Personal social networks, in the domain of chronic disease self-management, consist of the people, groups or services considered important in relation to managing one’s chronic disease or diseases (Vassilev et al., 2013). Caregivers, most commonly partners, spouses, and adult children, are the most frequently utilized members of the social network that make important contributions to an individual’s self-care behaviors (De Maria et al., 2021; Vassilev et al., 2013). For the purposes of this dissertation, caregiver is defined as someone lacking formal medical or healthcare training who provides direct care and support to someone 18 years or older in the home setting.
Caregiver Support in Chronic Disease

As the population ages, the demand for caregivers will increase, a trend that is projected to continue into the foreseeable future. In 2019, 47.9 million adults, or 19.2% of the population, identified as a caregiver for an adult care recipient (AARP and National Alliance for Caregiving, 2020). This represents a substantial increase of 8 million more caregivers caring for an adult as compared to a similar 2015 report (National Alliance for Caregiving, 2015). The majority of caregivers are female (61%), three in five identify as non-Hispanic White, and 19% of caregivers are aged 65 or older (AARP and National Alliance for Caregiving, 2020).

Caregivers typically assist with activities of daily living (ADLs), such as getting in and out of bed and or a chair, getting dressed, and getting to and from the toilet, and instrumental activities of daily living (IADLs), which can include transportation, grocery or other shopping, and housework (AARP and National Alliance for Caregiving, 2020). In addition, caregivers are assisting with self-management by preparing prescribed diets, administering medications, monitoring the care recipient’s condition, adjusting the treatment regimen, communicating with the health care team, and performing complex care procedures usually performed by licensed clinicians, such as administering tube feedings and performing wound care (AARP and National Alliance for Caregiving, 2020). Caregiver involvement in self-management has produced positive patient outcomes including improved medication adherence, reduction in hospital readmissions and length of stay, decreased depressive symptoms, and improvements in health-related quality of life (De Maria et al., 2021).
Older Adult Caregivers

Nineteen percent of caregivers are aged 65 and older and 60% of older adult caregivers are caring for someone of the same generation, either a spouse or sibling (AARP and National Alliance for Caregiving, 2020; Bern-Klug, 2018; Family Caregiver Alliance, 2016). Older adult caregivers have a unique perspective on the caregiver role as compared to other generations. The difference may be due to cohort effects (older adults’ life experiences are different than younger generations) or lifespan effects (older adults are at a different developmental stage) or both (Hooyman et al., 2018; Reinhard et al., 2019). In addition, normal physiological age-related changes may impact the older adult’s experience of caregiving (Miller, 2023). For example, the loss of muscle mass, fat tissue, and stiffness in joints may impact the older adult caregiver’s mobility and declining cardiac and lung capacity may impair the older adult caregiver’s ability to be physically active for long periods of time and increase their tendency to become fatigued (Hooyman et al., 2018). Aside from normal age-related changes, older adults frequently have one or more chronic diseases requiring on-going self-care in addition to the needs of the care recipient (Miller, 2023). Older adult caregivers may also have financial challenges based on past and current employment, retirement income, and benefits that complicate the caregiving role (Hooyman et al., 2018).

Older adult caregivers experience challenges due to the caregiving role. When compared to non-caregivers, older adult caregivers were found to experience decreased cognitive functioning, poorer mental health, higher levels of emotional strain, increased feelings of loneliness, and increased depressive symptoms (Lavela & Ather, 2010). In addition, older adult caregivers are known to prioritize care recipients’ needs over their
own physical and mental well-being, often foregoing their own healthcare appointments, regular exercise, and eating a healthy diet (LaManna et al., 2020; Sabo & Chin, 2021).

Support for Caregivers

Support for caregivers often involves utilization of resources. Access to and use of resources are associated with lower levels of older adult caregiver stress, decreased perception of burden, and better physical and mental health (Ahn et al., 2012; Chow & Ho, 2012; Hong & Harrington, 2016; Sabo & Chin, 2021). Stress is believed to occur when an individual’s resources are threatened or actually lost, or when individuals are unable to gain sufficient resources after considerable resource investment (Hobfoll, 2001). Evidence suggests that increasingly stressful caregiving circumstances are associated with fewer or declining resources and higher feelings of burden, whereas lower perceptions of stress and burden are associated with greater access to and use of resources (Hong & Harrington, 2016).

One option for providing resources involves implementation of state and federal policies that support caregivers. Such legislation could include initiatives to address flexible workplaces, family and medical leave policies, access to paid family leave, Social Security credits for caregivers, and prevention of family responsibility discrimination (National Academies of Sciences, Engineering, and Medicine, 2016). When caregivers were asked about national policies that would be helpful, 30% responded in favor of being paid for some of the hours of care they provide (National Alliance for Caregiving & AARP Public Policy Institute, 2015). One federal policy that addresses home care needs is the state Medicaid program. Some state Medicaid programs offer home- and community-based services (HCBS) waivers that are designed to support
care recipients in the home or community setting as opposed to institutionalization in a nursing care facility. In some states, these Medicaid HCBS waivers allow the care recipient to direct their own care and hire their own friends or family as caregivers. While these programs are available, they are limited to Medicaid recipients and there is considerable variability in terms of eligibility and services provided.

Little is known about how older adult caregivers manage complex care procedures in the home setting, the resources needed, and public policies that allocate support for caregivers. This research will explore how older adult caregivers manage a complex care procedure using wound care as an exemplar. In addition, the research will explore older adults’ salient thoughts on the resources needed for wound care and examine caregiver resources provided under Medicaid, a federally funded program for health care.

**Significance**

Caregivers report feeling physical, emotional, and financial stress as a result of their caregiving situation, with fewer caregivers rating their own health as excellent or very good in 2019 as compared to 2015 (AARP and National Alliance for Caregiving, 2020). A decline in the health of caregivers, particularly older adult caregivers, is of concern as health care continues to shift to home-based care over more costly inpatient hospital care, rehabilitation, or long-term care facilities (AARP and National Alliance for Caregiving, 2020). Sustaining the health and well-being of caregivers is critical, particularly older caregivers who may be dealing with their own health demands and functional limitations. Continued research is needed to understand how these older adult caregivers manage care demands in the home setting and their access to and use of
resources. This research is significant because it identified how these caregivers manage a complex care regime from the perspective of the caregiver and explored their salient thoughts on access to and use of resources. In addition, this research analyzed the Medicaid waiver program for caregiver supports available on a state-by-state basis. These findings contribute to a body of knowledge about the older adult caregiver experience, which can inform both continued research, clinical care, and public policy advocacy.

**Theoretical Perspective**

Caregivers are known to experience physical and emotional challenges, financial strain, and workplace conflict, often labeled ‘caregiver burden’ (AARP and National Alliance for Caregiving, 2020; Anderson et al., 2013; National Academies of Sciences, Engineering, and Medicine, 2016; Reinhard et al., 2019; Spillman et al., 2014; Wolff et al., 2016). A large body of evidence about caregiving has come from studies using survey methods or fixed choice instruments. Existing models of caregiving include important, central caregiving concepts and delineate the relationships between and among the concepts. While helpful, this body of work is missing the caregiver’s voice. Expanding this body of evidence using qualitative methodology will enlarge our understanding by including the caregivers’ perspective. In addition, caregivers exist across all age cohorts. Older adult caregivers may hold unique perspectives compared to caregivers in other age cohorts. Research that includes the older adult caregiver perspective is needed.
Symbolic Interactionism and Constructivism

Symbolic interactionism is a theoretical perspective that influenced the development of the qualitative components of this research. In symbolic interactionism, people’s actions towards things and other individuals are based on the meanings they have for the actions, spoken and unspoken language, and symbols of other people and self (Charmaz, 2014; Gray et al., 2017; Munhall, 2012). Individuals create meanings based on interactions with other people, which can be altered based on interpretations of the past, present, and future (Munhall, 2012). Interactions with others and one’s view of self also may alter how individuals interpret the past, present, and future and thus life consists of social processes (Charmaz, 2014; Gray et al., 2017). Constructivism expands on symbolic interactionism and purposes that participants and researchers construct their reality. A constructivist researcher acknowledges that their interpretation of the phenomenon of interest is a construction of the truth (Charmaz, 2014). Qualitative research based on these theoretical perspectives allows for exploration and interpretation of how the subjects or participants construct their world.

Relevant Theories of Caregiving

Two caregiving theories have informed the development of the dissertation studies, including the Model of Carer Stress and Burden (Sörensen et al., 2006) and the Informal Caregiving Integrative Model (ICIM) (Gérain & Zech, 2019). These theories were not tested during this dissertation. However, the theories provided the principal investigator with a lens through which to view the caregiving phenomenon.
The Model of Carer Stress and Burden (Sörensen et al., 2006) describes the relationship between caregiving and the mental health of a caregiver who is caring for someone with dementia (see Figure 1.1). This model describes the impact of primary stressors, such as patient characteristics, the care situation, and unmet needs of caregiver, and secondary stressors, including work interference, financial strain, and family conflict, on the caregivers’ appraisal of the situation and the resultant caregiver outcomes (Sörensen et al., 2006).

**Figure 1.1**

*Model of Carer Stress and Burden (Sörensen et al., 2006)*

Caregiver outcomes include psychosocial, physiological, health behavior, and general health outcomes (Sörensen et al., 2006). The extent to which primary stressors develop into secondary stressors can be moderated by exacerbating and mitigating
factors. The model is situated in background and contextual factors including age, gender, ethnicity, culture, and socioeconomic status (Sörensen et al., 2006). Thus, the extent to which primary stressors lead to secondary stressors, moderated by exacerbating and mitigating factors, and subsequent appraisal of the situation, which is all situated in background and contextual factors, results in either negative or positive caregiver outcomes.

The Informal Caregiving Integrative Model (ICIM) is a framework explaining the relationship between caregiver burnout and outcomes for both caregivers and care recipients (Gérain & Zech, 2019). This model (see Figure 1.2) identifies demands and resources inclusive of caregiver factors (sociodemographics, psychological factors, and physical state), the caregiving setting (primary and secondary stressors) and the social environment (informal and partner support, professional support, and sociocultural environment) as important determinants within the framework (Gérain & Zech, 2019). Caregiver coping, appraisal, and the relationship quality between caregiver and care recipient are described as mediators between the determinants and the specific outcome of burnout and general outcomes for caregivers and care recipients (Gérain & Zech, 2019).

Both the Model of Carer Stress and Burden and the ICIM identify stressors as key variables influencing outcomes for the caregiver, as well as influencing outcomes for the care recipient for the ICIM. The inclusion of ‘stressors’ within the model assumes that caregiving is a stressful experience. Both models include appraisal, which would allow for the caregiver to appraise the situation as stressful or not, and to what degree. However, the assumption underpinning both models is that caregiving is stressful, and it
can be measured quantitatively, as was the case in a study of caregiver burden using the ICIM wherein caregivers of care recipients with end-stage renal disease completed a questionnaire to measure caregiver burden (Abed et al., 2020). That caregiving is presumed to be stressful or burdensome is a constraint of these theoretical models.

**Figure 1.2**

*Informal Caregiving Integrative Model* (Gérain & Zech, 2019)

These theoretical models are also limited in considering the timing of the caregiving role within the trajectory of the caregiver’s life. The life course perspective on aging suggests that societal and cultural contexts, timing of events, lives being linked to others, and human agency to make choices influence one’s life and development into old age (Barnett, 2015; Fuller-Iglesias et al., 2009; Hooyman et al., 2018). The structure and application of these caregiving theoretical frameworks are limited to a cross-sectional view of the caregiving experience, which fails to incorporate or examine any changes over time or progression through developmental stages during the caregiving experience (Fuller-Iglesias et al., 2009; Hooyman et al., 2018). These models lack the caregiver’s
interpretation of their experience and their interactions with others to construct their reality making these two models inadequate in understanding the caregiving phenomenon.

While providing important insights into the complexity of the caregiving experience, the *Model of Carer Stress and Burden* and the *ICIM* do not explain how a caregiver manages the caregiving role. The relationships among the concepts within the models have been explored in relation to informal caregiver burden (Gérain & Zech, 2019), and evidence has shown that demands and resources influence outcomes. However, it remains that caregivers do persist in the caregiving role despite the influence of stressors, feelings of burden, and limitations of resources as noted in the models. There is a dearth of research exploring the caregiver’s perspective in their own voice and limited understanding of how caregivers manage the caregiving role. A more in-depth understanding is needed of the processes used by caregivers.

**Concepts and Definitions**

The following terms and definitions describe the major concepts within this study. Terms related to the focus of the study are described in Table 1.1. Terms related to the methods used in this study are described in Table 1.2.

**Table 1.1**

Terms and Definitions Related to the Focus of the Study

<table>
<thead>
<tr>
<th>Substantive Term</th>
<th>Definition</th>
</tr>
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<tbody>
<tr>
<td>Care recipient</td>
<td>Individual aged 18 or older who receives help from someone due to an inability to independently complete care procedures for themselves.</td>
</tr>
<tr>
<td>Chronic disease</td>
<td>A health condition lasting one year or more that requires ongoing medical care or limits activities of daily living or both</td>
</tr>
</tbody>
</table>
(Buttorff et al., 2017; Centers for Disease Control and Prevention, 2022a)

<table>
<thead>
<tr>
<th>Complex care procedures</th>
<th>Skilled medical/nursing tasks typically performed by licensed clinicians (AARP and National Alliance for Caregiving, 2020).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older adult caregiver</td>
<td>Individual aged 65 or older, lacking formal medical or healthcare training, who provides direct care and support to someone 18 years in the home setting.</td>
</tr>
<tr>
<td>Resources</td>
<td>The objects, personal characteristics, and conditions that are valued (Hobfoll, 2001)</td>
</tr>
<tr>
<td>Respite care</td>
<td>A service that allows a caregiver to take a break from the caregiving situation temporarily to attend to personal needs (Rose et al., 2015)</td>
</tr>
<tr>
<td>Self-management</td>
<td>The strategies one undertakes to control disease, promote health, and live well with illness (Audulv, 2013; Sabo &amp; Chin, 2021)</td>
</tr>
<tr>
<td>Medicaid 1915(c) HCBS waivers</td>
<td>A healthcare program defined in statute that provides for additional services beyond traditional Medicaid for caregivers/care recipients in the home setting. Cost is shared by federal and state governments.</td>
</tr>
<tr>
<td>Wound care</td>
<td>Services rendered to promote the healing of a wound and/or prevent wound complications</td>
</tr>
</tbody>
</table>

Table 1.2
Terms and Definitions Related to the Methods of the Study

<table>
<thead>
<tr>
<th>Method Term</th>
<th>Definition</th>
</tr>
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<tbody>
<tr>
<td>Axial coding</td>
<td>The process of relating subcategories and specifying the properties and dimensions of a category (Charmaz, 2014)</td>
</tr>
<tr>
<td>Constant comparison method</td>
<td>The process of comparing new data with previous data throughout analysis to explore similarities and differences among codes, patterns, and categories (Charmaz, 2014)</td>
</tr>
<tr>
<td>Constructivism</td>
<td>A social scientific perspective in which participants and researchers construct reality through their interaction with each other and the world (Charmaz, 2014)</td>
</tr>
<tr>
<td>Credibility</td>
<td>The degree to which the data is reflected within the theoretical framework (Charmaz, 2014)</td>
</tr>
<tr>
<td>Focused coding</td>
<td>The process of comparing the most frequently used or most relevant initial codes to identify patterns and potential categories (Charmaz, 2014)</td>
</tr>
<tr>
<td>Grounded Theory</td>
<td>A method of research in which researchers collect and analyze qualitative data to construct conceptual frameworks or theories that are grounded in the data (Charmaz, 2014)</td>
</tr>
<tr>
<td>Initial coding</td>
<td>The process of defining small segments of the data using gerunds to express the meaning as actions (Charmaz, 2014)</td>
</tr>
<tr>
<td>Purposive sampling</td>
<td>Purposive recruitment of certain participants to obtain essential data for the study (Gray et al., 2017)</td>
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<td>--------------------</td>
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<tr>
<td>Descriptive statistics</td>
<td>Summary statistics that describe a sample’s average and uniformity (Gray et al., 2017)</td>
</tr>
<tr>
<td>Secondary analysis</td>
<td>An analysis of data collected and originally analyzed for a prior study (Gray et al., 2017)</td>
</tr>
<tr>
<td>Symbolic interactionism</td>
<td>A theoretical perspective in which people assign meaning based on how people act and how they interact and communicate with others (Charmaz, 2014; Munhall, 2012)</td>
</tr>
<tr>
<td>Thematic analysis</td>
<td>A qualitative research method used to identify, analyze, and report patterns within data (Braun &amp; Clarke, 2006)</td>
</tr>
<tr>
<td>Theoretical coding</td>
<td>The process of identifying the relationships between categories to create a theoretical framework (Charmaz, 2014)</td>
</tr>
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**Purpose and Specific Aims**

The purpose of this research inquiry is to understand how caregivers aged 65 and older manage complex care tasks using wound care as an exemplar. The specific aims are as follows:

1. Develop a grounded theory that describes how caregivers manage the complex care procedure of providing wound care.

2. Identify common themes related to resources needed or utilized by older adults while performing complex wound care.

3. Determine resources available to caregivers through the existing Medicaid 1915(c) Home- and Community-Based Services waivers health policy program.

**Methods**

To address the specific aims of this dissertation study, three research methods were used. Grounded theory methodology as described by Charmaz (2014) was used for
the first study in this dissertation. Grounded theory first emerged with the 1967 publication *The Discovery of Grounded Theory* by Glaser and Strauss (Glaser & Strauss, 1967), which was built on the assumptions of symbolic interactionism and general sociological theory (Benoliel, 1996). The Glaser and Strauss method was a form of qualitative inquiry wherein the purpose was to create practical theories through inductive and abductive data analysis as opposed to deductive testing of a hypotheses (Charmaz, 2014; Giles et al., 2016). Constructivist grounded theory, based on the work of Charmaz, expands the approach of Glaser and Strauss’s method to include the assumption that the human experience includes one’s social reality and acknowledges that the researcher is a co-constructor of the experience and meaning (Charmaz, 2014; Giles et al., 2016). As a co-constructor, the researcher’s interactions with people in the past and the present, the researcher’s personal views and experiences, and their research practices are the lens through which the researcher *interprets* the data as opposed to creating a concrete definition of the data (Charmaz, 2014; Giles et al., 2016; Munhall, 2012). Constructivist grounded theory focuses on social problems over time that people adapt to, understanding social processes people use to manage situations, and explaining how social circumstances account for behaviors and interactions (Benoliel, 1996).

Chapter 2 addresses older adult caregivers who share common problems in the way they manage complex care tasks, which changes over time and is influenced by their social context. As grounded theory methodology seeks to understand a process occurring within a social group utilizing the voice of the participant as the data set, constructivist grounded theory is an appropriate methodology to support this research inquiry (Charmaz, 2014). Participants were recruited using social media by posting a recruitment
flyer on the principal investigator’s Facebook page. Interviews were conducted by telephone or a secure web-conferencing platform using a semi-structured interview guide (see Appendix A). Data analysis was performed using a constant comparative method consistent with grounded theory methods described by Charmaz (2014).

Thematic analysis using secondary analysis of the transcribed interview data from the grounded theory study was used in Chapter 3 to describe resource needs and related concerns for older adult caregivers performing complex care procedures. Thematic analysis is a qualitative method used to identify, analyze, and report patterns within data (Braun & Clarke, 2006). The thematic analysis utilized a realist approach in which a more detailed understanding of a particular topic, resources, according to the participants, was examined (Braun & Clarke, 2006). Decision-making by the research team regarding what counted as a pattern included any codes or themes that captured an important aspect of the caregiver’s thoughts about resources and was not dependent on prevalence of the identified codes.

While Chapter 2 described a theory of how older adult caregivers manage complex wound caregiving and Chapter 3 identified common themes related to resources needed or utilized by older adults performing wound care, Chapter 4 determined resources available to caregivers through the existing Medicaid 1915(c) Home- and Community-Based Services waivers health policy program. A state-by-state analysis was conducted of Medicaid waiver programs and services providing support to caregivers. This analysis used quantitative descriptive statistics to answer questions related to incidence, frequency, and prevalence of various waiver services. Descriptive statistics are appropriate analysis techniques for understanding the frequency distribution of a
variable(s) (Gray et al., 2017). The frequency of and variations in waiver programs and service availability were data elements amenable to descriptive statistical methods.

**Overview of Chapters 2-5**

An overview of the dissertation is outlined here. Chapter 2 is a study of how older adult caregivers manage a complex care procedure, wound care, using grounded theory methodology to produce a theoretical framework of their process. Chapter 3 presents the results of a thematic analysis identifying the resources needed to provide wound care as expressed by older adult caregivers. Chapter 4 is an analysis of Medicaid waiver programs and services providing support to caregivers using quantitative descriptive statistics. Chapter 5 is a synthesis of the findings from chapters 2, 3, and 4. In addition, chapter 5 includes a discussion of the dissertation study’s connection to prior theories, strengths and limitations of the study, and implications for future research, clinical practice, and health policy advocacy.
Chapter 2

Chapter 2 presents the results of a grounded theory study whereby a theoretical framework was constructed to understand how older adult caregivers manage a complex care procedure, wound care.

Introduction

In the United States, 60% of adults have been diagnosed with a chronic disease and more than 40% of adults have two or more chronic diseases, defined as conditions lasting one year or more that require ongoing medical care or limit activities of daily living or both (Buttorff et al., 2017; Centers for Disease Control and Prevention, 2022a). The risk of chronic disease increases with aging (Centers for Disease Control and Prevention, 2022c). For adults aged 65 and older, 81% have two or more chronic diseases simultaneously (Buttorff et al., 2017). Individuals with multiple chronic diseases face poorer health outcomes, higher utilization of healthcare services, and worse disease management (De Maria et al., 2021).

Self-management, strategies undertaken to control disease, promote health, and live well with disease, is critical for optimal disease control. Self-management can be challenging in the presence of multiple chronic conditions and when chronic disease results in fatigue, pain, functional impairment, and overlap of symptoms (Audulv, 2013; Boehmer et al., 2016; De Maria et al., 2021). Those who are unable to properly manage their chronic disease are at increased risk of disease progression, hospitalization, and mortality (Hardman et al., 2022). However, chronic disease self-management can be influenced, positively and negatively, by healthcare providers, society, and an
individual’s personal social networks, which can serve as both resources and barriers (Audulv, 2013). Among personal social networks, partners, spouses, and adult children are most frequently called upon to become caregivers making important contributions to an individual’s self-management behaviors (De Maria et al., 2021; Vassilev et al., 2013).

As the population ages, the demand for caregivers will increase, a trend that is projected to continue into the foreseeable future. In 2019, 47.9 million adults, or 19.2% of the population, identified as a caregiver for an adult care recipient (American Association for Retired Persons [AARP] and National Alliance for Caregiving, 2020) and among caregivers aged 65 and older (hereafter referred to as older adult caregivers), 60% are caring for someone of the same generation, either a spouse, partner, or sibling (AARP and National Alliance for Caregiving, 2020; Bern-Klug, 2018; Family Caregiver Alliance, 2016).

Older adult caregivers have unique challenges and perspectives on the caregiver role when compared to younger generations. Normal physiological age-related changes, such as musculoskeletal changes compromising mobility and cardiopulmonary changes resulting in fatigue, may impact the older adult’s ability and experience of caregiving (Hooyman et al., 2018; Miller, 2023). In addition, older adult caregivers are likely to have one or more chronic diseases requiring personal self-care in addition to the care demands of a care recipient (Miller, 2023). Further, older adult caregivers are known to experience personal health challenges because of the caregiving role. When compared to non-caregivers, older adult caregivers were found to experience decreased cognitive functioning, poorer mental health, higher levels of emotional strain, increased feelings of loneliness, and increased depressive symptoms (Lavela & Ather, 2010). Older adult
caregivers are known to prioritize care recipients’ needs over their own physical and mental well-being, often foregoing their own self-management needs, such as personal healthcare appointments, regular exercise, and eating a healthy diet (LaManna et al., 2020; Sabo & Chin, 2021).

Typically, caregivers have assisted with activities of daily living (ADLs), such as getting in and out of bed, getting dressed, daily grooming and hygiene, and toileting, along with some instrumental activities of daily living (IADLs), such as transportation, grocery shopping, and housework (AARP and National Alliance for Caregiving, 2020). However, caregiving responsibilities have been expanding and now include performing complex care procedures previously performed by licensed caregivers in a clinical setting. Approximately 40% of older adult caregivers are performing complex care procedures in the home (Reinhard et al., 2019). Wound care, a complex care procedure, is being managed by an estimated 35% of caregivers in the home setting (AARP and National Alliance for Caregiving, 2020). The types of wounds being managed include pressure injury wounds, venous insufficiency and arterial ulcers, diabetes-related foot complications, traumatic injuries, burns, and wounds related to human immuno-deficiency virus (Miller & Kapp, 2015). Treatment regimens include dressing changes with wound cleansing, debridement, and application of prescription topical medications in addition to turning and repositioning the care recipient (Miller & Kapp, 2015). Wound care was reported to be a difficult task by 66% of caregivers due to fear of making mistakes or causing harm and/or pain to the care recipient (Reinhard et al., 2012).

Historically, researchers examining older adult caregivers have focused on the psychological and physical health of the caregiver often described in terms of burden for
the caregiver (AARP and National Alliance for Caregiving, 2020; Anderson et al., 2013; National Academies of Sciences, Engineering, and Medicine, 2016; Reinhard et al., 2019; Spillman et al., 2014; Wolff et al., 2016). Prior research has also focused on the care recipient’s outcomes of care performed in the home setting with limited exploration of how the older adult caregiver manages the care procedures (McDonald et al., 2017; Waite-Jones et al., 2020). As a result, there is a dearth of knowledge about how older adult caregivers manage the performance of complex care procedures on a day-to-day basis. A more complete understanding of how older adult caregivers manage complex care in the home is needed to design supportive caregiver interventions. The purpose of this study was to develop a theoretical framework describing how older adult caregivers manage complex care procedures using wound care as an exemplar complex care problem.

Methods

Study Design

Grounded theory first emerged in the sociological approach of Glaser and Strauss based on the assumptions of symbolic interactionism and general sociological theory (Glaser & Strauss, 1967). This qualitative research approach is based on the defining principles that the human experience includes one’s social reality, the researcher is a co-constructor of the experience and meaning, and truth is a socially constructed and contextually dependent notion through which the researcher interprets the data as opposed to creating a concrete definition of the data (Charmaz, 2014; Giles et al., 2016; Munhall, 2012). Grounded theory methodology seeks to understand a social process
occurring within a group and uses an iterative process of simultaneous data collection and data analysis to develop a theoretical framework (Charmaz, 2014).

For this study, constructivist grounded theory methodology was used to describe the process of managing a complex care procedure and to create a theory of the social phenomenon of being an older adult caregiver providing wound care. Performing wound care is considered a phenomenon shared by older adult caregivers within the social context of the home setting that occurs over time as the wound heals, thus grounded theory was chosen to satisfy the research purpose. The study method was guided by Charmaz’s methodical, yet flexible, procedures for obtaining and analyzing qualitative data to generate a theory grounded in the data (Charmaz, 2014).

**Sample and Setting**

Eligible participants were age 65 or over at the time of being a caregiver, were currently or had previously provided wound care for a person aged 18 or older and spoke English fluently. Exclusion criteria were older adults with any formal healthcare training in providing direct clinical care, including wound care, or had cognitive challenges that would interfere with participating in an interview.

**Recruitment**

Participants were recruited using social media by posting a recruitment flyer on the principal investigator’s Facebook page. The flyer indicated that the principal investigator would like to interview informal caregivers ages 65 and older who were providing, or had previously provided, wound care to an adult care recipient. The flyer defined informal caregiver as someone without formal medical or healthcare training in
wound care and included a phone number and email to contact the investigator. The option of a private Facebook message also was provided. Persons interested in the study contacted the investigator using one of these options. Upon initiating contact, participants were interviewed for eligibility. Appropriate cognitive status for participating in an interview was determined based on the potential participant’s responses to the initial eligibility questions and, if eligible, potential participants were invited to participate. A mutually agreeable time was established for an interview. Initial analysis revealed predominantly female caregivers. To increase recruitment of men, purposive sampling was conducted using a new Facebook post targeted towards recruitment of older adult male caregivers. The Institutional Review Board (IRB) at the investigators’ university approved the study.

Data Collection

Interviews were conducted by telephone or a secure web-conferencing platform using a semi-structured interview guide. See Figure 2.1 for a general outline of the interview guide. Interviews were conducted during the COVID-19 pandemic when in-person interviews were not permitted. Interviews began with general questions related to becoming a caregiver and transitioned to focused questions about the management of wound care and associated caregiver tasks. Participant responses were probed for details and examples illustrating situations. Interviews were audio-recorded and transcribed verbatim by a professional transcription service.
Data Analysis

Data analysis was performed using a constant comparative method consistent with grounded theory methods described by Charmaz (2014). Data analysis for this study was performed by a team of three researchers (KS, JSF, JV). The analysis occurred in four stages: 1) initial coding, 2) focused coding, 3) axial coding, and 4) theoretical coding (Charmaz, 2014). Once initial coding was completed on five interviews, focused coding began whereby the most frequently used or most relevant initial codes were compared for similarities and differences and analyzed for their strength within the data (Charmaz, 2014). Axial coding identified the prominent categories that had strong support from the data. During the final stage of data analysis, theoretical coding, relationships between categories were identified to form the structure of the theoretical framework (Charmaz, 2014). Throughout the process the team met to review findings, reconcile interpretative differences, update coding, and refine coding categories. See Table 2.1 for an example of the coding procedure.

Figure 2.1
General Outline of Interview Guide

1. Tell me about when you first started being a caregiver
2. Tell me about how you learned to perform wound care.
3. Tell me about any support you had for being a caregiver. Who helped you and what did they do?
4. Tell me about resources you needed such as supplies and equipment.
5. Tell me about how and in what way your caregiving experience changed over time.
One investigator (KS) reviewed the transcripts to validate the identified categories and the corresponding relationship between categories and kept notes to document thoughts and characteristics of the emerging codes and categories. These notes, emerging codes, categories, and relationships were discussed among the research team members during team meetings. Research team members provided feedback based on reading of the transcripts. Microsoft Excel™ was used to organize all levels of data analysis.

**Table 2.1**

*Example of Coding Procedure*

<table>
<thead>
<tr>
<th>Quote</th>
<th>Code</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>It was easy because it was my mother and I wanted her to be well.</td>
<td>Finding it easy</td>
<td></td>
</tr>
<tr>
<td>You’re a partner for life, so you just step in. He’d do the same for me.</td>
<td>Relying on strength of marriage</td>
<td></td>
</tr>
<tr>
<td>I have to say, I think I’m better than he is on wound care, because I bandaged a lot of knees back in the day.</td>
<td>Using experience with kids’ injuries</td>
<td></td>
</tr>
<tr>
<td>I had to learn some organizing skills and I did some more labeling that made sense to me.</td>
<td>Creating a labeling system</td>
<td></td>
</tr>
<tr>
<td>I mean, it made sense to the nurses, but it then came into my world, and I had to secure this one first, this one second, this one third, that sort of thing.</td>
<td>Developing own routine</td>
<td></td>
</tr>
<tr>
<td>You’d get all the washcloths, the towel, you’d get all the band-aids, get them out of their little bags and have them all laying there.</td>
<td>Opening all supplies before starting</td>
<td></td>
</tr>
<tr>
<td>Basically, like you do when you’re operating in an operation. You have everything laying there, so once you started it, you didn't have to pause for a while. You just go from one thing to another.</td>
<td>Proceeding systematically</td>
<td></td>
</tr>
</tbody>
</table>

To maintain credibility, the research team met to review and discuss data analysis. Detailed notes were used to document the developing categories, themes, and relationships throughout the study. The team meetings and notes allowed the researchers to review the logical connections between codes, categories, and theoretical relationships.
to ensure the final product was supported by the participants’ data and reflected consensus among the entire research team. In addition, one investigator (KS) validated the emerging categories during interviews with subsequent participants as part of the iterative nature of grounded theory methodology (Charmaz, 2014).

**Results**

Eighteen caregivers participated in the study, 11 (60%) were female and 7 (40%) were male. The mean age of participants was 73.7 years old (SD = 5.5). Most caregivers (88%; n=16) were caring for a spouse with the remaining caregivers caring for a parent (16%; n = 3). One caregiver was caring for both a parent and a spouse, resulting in 19 total care recipients cared for by 18 older adult caregivers. Length of time spent as a caregiver ranged from 1 month to 9 years with some participants being unable to provide an exact answer. See Table 2.2 for demographic information. Interviews averaged 40 minutes in length. Some participants had completed or were completing caregiving responsibilities prior to the COVID-19 lockdown, whereas others had begun or were continuing caring during the lockdown period.

**Overview of the Framework**

Providing wound care for a care recipient was described by participants as going through a process labeled *Pushing Through*. This process consisted of five phases: 1) accepting the role, 2) lacking confidence, 3) creating a system, 4) trusting in self, and 5) owning the outcomes. Participants described a process of becoming an expert caregiver for their care recipient that began by first accepting the caregiving role. The decision to accept the role was grounded in abilities gained from past difficult experiences and/or the
strength of their relationship with the care recipient. Participants expressed an initial lack of confidence characterized by fear arising from limited understanding about providing wound care. They described the importance of being able to access professional healthcare support for skill development and obtaining required supplies. As the wound care became familiar, participants described creating systems to organize and manage the required tasks. Over time, participants acknowledged that they were more trusting of their judgment and began modifying wound care procedures for best results based on their care recipient’s unique needs. Participants also made alterations to the household and changed life priorities to accommodate the complexities of their caregiving role. Eventually these caregivers saw themselves as experts for their care recipient and expressed pride in what they had accomplished. These phases are summarized in a framework, see Figure 2.2.

Table 2.2

Participant Demographic Data

<table>
<thead>
<tr>
<th>Participant characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of participant</td>
<td>18</td>
</tr>
<tr>
<td>Female</td>
<td>11 (61.0)</td>
</tr>
<tr>
<td>Male</td>
<td>7 (39.0)</td>
</tr>
<tr>
<td>Participant &amp; recipient genders</td>
<td>19</td>
</tr>
<tr>
<td>Female caring for a male</td>
<td>9 (47.0)</td>
</tr>
<tr>
<td>Male caring for a male</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Female caring for a female</td>
<td>3 (16.0)</td>
</tr>
<tr>
<td>Male caring for a female</td>
<td>7 (37.0)</td>
</tr>
<tr>
<td>Relationship</td>
<td>19</td>
</tr>
<tr>
<td>Male caring for a spouse</td>
<td>7 (37.0)</td>
</tr>
<tr>
<td>Female caring for a spouse</td>
<td>9 (47.0)</td>
</tr>
<tr>
<td>Male caring for a parent</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Female caring for a parent</td>
<td>3 (16.0)</td>
</tr>
<tr>
<td>Wound Type</td>
<td>23</td>
</tr>
</tbody>
</table>
Surgical wound 12 (52.0)
Pressure injury 2 (9.0)
Infectious wound 3 (13.0)
Venous Insufficiency Ulcer 3 (13.0)
Traumatic Wound 3 (13.0)

Depending on the nature of the wound and difficulty of care procedures, progression across the phases varied in length of time. Some wounds were anticipated, such as those that result from a planned surgical procedure. Participants who cared for planned wounds described an overall smooth and efficient transition through the phases. However, for those participants who were caring for an unexpected wound or one with unanticipated complications like infection or deterioration, the progress through each phase was more difficult and took longer. The remainder of the results section will discuss each phase in more detail.

**Figure 2.2**

*Pushing Through, A Framework Describing How Older Adult Caregivers Manage Wound Care*
Accepting the Role

Participants described a distinct process of coming to accept the caregiving role. Some participants accepted the challenge due to their existing relationship with their care recipient, such as being a spouse or adult child, while others described relying on prior caregiving or parenting experiences. Still others accepted the role by default in that there was no one else to provide care. Some participants stated they were unaware there was an option to refuse.

Acknowledging Traditional Relationships

Participants spoke about the strength of the relationship with their care recipient as a reason for being able to take on the caregiving role. The participants described caring for someone as a component of their marriage vows or as an obligation to a parent in recognition of the parent’s care for them as a child. One participant stated, “I was the stronger of the two of us and I just assumed that I would be taking care of him. I mean, when you get married, isn't that your job? Whatever happens, you do.” Some participants described caregiving as an act of love as one participant stated, “It's a tough thing, I do it out of love, but it isn't like in the movies. It's a bumpy road.”

Considering Similar Experiences

Another factor in deciding to accept this role was the caregiver’s experience in caring for someone else. Participants identified their abilities whether it involved other complex care procedures or parenting experiences providing first aid for minor wounds or ailments. One participant stated, “You just got to, if you raised kids you can deal with that kind of stuff, you know? It's just harder when you're older that's all.” Participants
reflected on these situations as a source of strength to be able to take on new wound care responsibilities.

**Being a Caregiver by Default**

Some participants accepted the caregiving role out of default. Default was described as the inability to identify any other available caregivers. As one participant stated, “Well, I mean the other thing is there was nobody else. There's nobody else that could do this for my family.” Still other participants accepted the role without knowing it was possible to refuse. One participant described this situation, stating, “I must’ve accepted it [the role]. I did not know I had a choice.”

**Lacking Confidence**

Once participants decided, for whatever reason, to accept the role of caregiver, they described feelings of uncertainty and a lack of confidence in their ability to perform wound care. Participants acknowledged their lack of formal training in this area and were unsure of their ability to perform the required procedures.

**Lacking Knowledge about Wound Care Procedure**

Participants described their lack of knowledge and skill, recognizing a need for information and training to perform this type of complex care procedure. Participants noted the inadequacy of wound care information from healthcare providers. One participant shared, “You know, nobody said a word to me about caring for it or anything like that.” A lack of knowledge about dealing with an unfamiliar care procedure contributed to participants’ feelings of incompetence and undermined confidence.


**Being Fearful of Causing Harm**

Many participants described being afraid of causing pain for the care recipient. Participants were also afraid of making mistakes and performing wound care incorrectly causing subsequent harm and complications. One participant who had to pack a deep wound shared “I was afraid I was going to hurt her… to just sit there and stuff that stuff inside a hole in your wife's neck is pretty unnerving.”

**Dealing with Supplies**

Participants described the need for proper supplies to support their care recipient. For some participants, wound care supplies were available directly from a healthcare provider, such as a primary care physician or surgeon. However, participants were not always connected to a healthcare provider in the beginning and supplies were a significant challenge. One participant described the issue of obtaining supplies stating,

I go wherever I can get things. I get rubber gloves from [name of store A], of course right now they don't have any [due to the pandemic]. I go to [name of store B] to get gauze pads, which I use to wipe down her legs. And [name of store C], like these foam bandages, they had them. I don't know where you go to get some of this stuff.

In addition, participants shared stories about getting and using the wrong supplies and running out of supplies. One participant described their experience finally getting the correct supplies, stating, “All those months of everything being wrong and once we got on the right path it was like a piece of cake, you know. The right supplies, the right everything.” For fear of not having enough supplies, participants purchased supplies out of pocket through online merchants and at local pharmacies and stockpiled items as assurance of availability.
Creating a System

Participants created their own system for managing care to sustain their efforts. The participants developed a process to engage with healthcare providers, a system to schedule the timing of wound care and other personal care tasks, and a system of various informal support persons.

Garnering Healthcare Provider Support

Participants garnered support from healthcare providers for learning the proper wound care procedure, accessing wound care supplies, and feedback on wound healing progress. The participants initially learned how to properly care for the wound by observing the actions of the healthcare providers prior to performing the wound care independently. One participant shared how they learned, stating, “I watched the hospice nurse the first time. Maybe the first couple of times, I'm not sure but I watched her while she did it and kind of learned from that.”

Connection with healthcare professionals created the avenue for accessing wound care supplies. One participant had the support of home hospice care, stating, “The hospice supplied all [dressings]. They gave me the [gauze] and the Q-tips and gloves and salves and everything I needed.” Participants also relied on the healthcare professionals for reassurance that they were caring for the wound properly and that the wound was healing as expected. One participant sent photographs, stating, “Every once in a while, I might send [the provider] a picture and say, “What do you think of that” and I’d tell her what I’m doing and she’d say, “Yeah, that sounds right. That sounds good.”
**Organizing Care Procedures**

Participants spoke of creating an organizational system, such as a chart, electronic spreadsheet, or written notes. As caregivers, they used these individualized tools to keep track of the timing of wound care tasks, medical appointments, supply orders, and other caregiving duties such as medication administration and personal care needs. One participant described the system, stating,

I made a chart, because in addition to caring for the wound and feeding her, I also had to give her medication several times a day through the feeding tube. So, I had a chart on what time I gave this and what time I gave that and what time I changed the bandages, what time I fed her, basically from the time I got up until the time I went to bed.

In addition to this overall organization, participants described creating a systematic approach to specific tasks, such as how to lay out supplies for the dressing change and how to perform the steps of wound care more proficiently. These systematic approaches included minute details such as where to place a trashcan or table for maximum efficiency.

**Creating a Network for Personal Support**

Participants recognized the need for emotional support and practical help from family, friends, and volunteers. They created a social network of individuals that could be relied on for a variety of support, such as those who would help with household chores, meals, or provide spiritual care. One participant described their network stating, “The kids were bringing food over, helping me with that, which that wasn't any big deal. But I had a good support system.”
The network of personal support also provided respite care, defined as planned or emergency care for the care recipient to relieve the primary caregiver on a short-term basis (Rose et al., 2015). One participant stated, “I’ve got a daughter that lives three blocks away, so she comes over and watches her and her girlfriend comes over and sits with her if I'm gone for a Saturday or something.” Participants relied on their network to provide respite care for running errands, personal healthcare appointments, exercise, or social activities.

Managing a network of personal support sometimes included refusing help or avoiding conversations. To maintain a system that worked for them, the participants shared how they would avoid, or decline offers of support that they considered disruptive or unhelpful. One participant avoiding talking to family members whose advice did not align with the care recipient’s desire to remain in the home setting. That participant stated, “I couldn’t talk to my sisters because their answer is put him in an institution.” Participants were careful to exclude some persons from the hands-on tasks of wound care due to the invasive or unpleasant nature of caring for a wound. Participants also described a desire to protect some persons when the participant judged the offer of support would be burdensome and thus, sometimes avoided asking for help. For example, one participant stated, “I didn’t ask anybody for help because, I mean, I knew I had a complicated situation. I don’t know. I just didn’t ask for help.”

**Trusting in Self**

Participants came to trust their ability to manage the wound procedure over time. They were comfortable making changes to the procedure and began adjusting their lifestyle as needed.
Modifying Care Procedures

Over time, participants used their growing knowledge and skills to modify care procedures. Through observation of the wound and feedback from healthcare providers, participants learned the signs of wound healing and adjusted care, such as altering the frequency of dressing change or modifying procedural steps. One participant who was managing a wound with a high volume of drainage shared a story of deciding to switch from gauze to an ostomy bag to control the drainage, stating, “I had these ostomy bags and put it on there and it did work.” In this phase the participants were able to modify the care procedures to best meet the care recipient’s unique needs.

Altering Household Arrangements

Caregivers also modified their household arrangements or routines to accommodate the caregiving tasks. In some situations, these modifications involved actual alterations to the home, for example, moving furniture to keep the care recipient on the first floor or remodeling to accommodate a wheelchair. One participant adjusted the home to provide the care recipient with a private bedroom with all necessary equipment easily accessible and implemented a communication system to facilitate the separate living spaces, explaining:

We have set up a doorbell system in his room. This bell has two buttons that you push. I put one behind his chair and one by his bed. So, either place he is he could just ring the bell and I can go. I live in the rest of the house.

Changing Life Priorities and Interests

Participants modified their priorities and personal interests, such as cancelling travel plans and avoiding social outings due to the demands of caregiving. For some
participants, the caregiving demands were more complex and of longer duration ultimately limiting priorities and interests indefinitely. One participant described this situation stating, “It has stopped my life… I have had to drop out of sorority, drop out of book club, drop out of church, drop out of – you name it, I don’t do it anymore.” Others described life as “on hold” with hopes that priorities and interests could resume once the wound was resolved. A participant described their cancelled vacation, stating, “I had just retired. We went to Europe, and we had planned another one and then this happened. We had to cancel that. We were going to France on a river cruise. Yeah, life is on hold.”

**Owning the Outcomes**

In the final stage of the process, the participants took ownership of what they had accomplished and the outcomes they had achieved. The participants described how they were the expert for their care recipient and were proud of their ability to contribute to the care recipient’s well-being.

**Becoming an Expert**

Constant presence and attention made the participants the expert for their care recipient. Many participants spoke of how their intimate knowledge of the care recipient’s situation and unique needs made them a vital member of the healthcare team. For example, one participant described their interaction with a provider, stating,

When we would go in every week, he [the doctor] would ask me, what do you think, or how did you do it or, or how's it going type thing. And then sometimes even before he looked at it, he would say, “Well, what do you think? So, we had a good rapport.
The participants noted that healthcare providers came to value their assessment skills, decisions, and opinions as the care recipient’s expert caregiver during subsequent appointments.

**Feeling Proud**

As a result of becoming an expert for their care recipient, participants described feeling proud of having taken on the caregiver role and viewed themselves as responsible for the outcomes of their care. One participant shared this sentiment, stating, “When he was healed… Oh, gosh. That felt so good, I mean I was proud. You know, I felt like I had helped him through this, and maybe it wasn't professionally done, but I felt pretty good about it.” The participants recognized that they made an impact and were central to the progress toward healing despite lacking professional healthcare education or training.

**Discussion**

Healthcare continues to rely on informal caregivers for collaboration in chronic disease self-management. Once limited to activities of daily living, caregivers are performing complex care procedures in the home setting (McDonald et al., 2015). Evidence suggests caregiving impacts the health of both caregivers and care recipients (AARP and National Alliance for Caregiving, 2020; Anderson et al., 2013; Bangerter et al., 2019; Barnett, 2015; Larson, 2023; Rich & Upton, 2018; Rodrigues et al., 2016). Older adult caregivers are more likely to have multiple chronic diseases making them more vulnerable (Hooyman et al., 2018; Larson, 2023). While 19% of today’s caregivers are over age 65 (AARP and National Alliance for Caregiving, 2020), potential caregivers aged 45 to 64 is decreasing due to changing family structures and composition (Redfoot
et al., 2013). The future caregiver shortage in combination with the prevalence of chronic disease in older adults and increasing need for complex care procedures to be managed into the home setting underscores the importance of understanding how to support and sustain older adult caregivers in their role (Hooyman et al., 2018). However, there is a shortage of research on the day-to-day process for older adult caregivers performing complex care. In describing these participants’ process for managing wound care for their care recipient, the aim was to understand how older adult caregivers manage a complex care procedure in the home setting.

Wound care is complex involving highly individualized procedures, specialized supplies, and frequent assessments. Wound healing can proceed along an unpredictable course, requiring numerous changes to the procedure and varying wound care supplies which may be costly and difficult to obtain (Doughty & McNichol, 2016). Caregivers must learn how to distinguish between signs of wound healing and wound complications, such as expected wound drainage versus drainage caused by infection (Doughty & McNichol, 2016). Likewise, the caregiver must determine when it is necessary to notify the healthcare professionals of their concerns. Individuals may require accommodations for activities of daily living like bathing and mobility or a special diet to support wound healing (Doughty & McNichol, 2016). These factors intensify the caregiving situation; yet the participants in this study were successful in their caregiver role. Other older adults with personal health problems and deteriorating health related to the caregiving role, such as fatigue, poor sleep, physical strain, anxiety, depression, or loneliness, may not be able to overcome such complexities. (Greenwood, Pound, Brearley, et al., 2019; Lavela & Ather, 2010)
Relationships with healthcare professionals were an important part of the process. Healthcare professionals provided wound care procedure education for the participants, facilitated supply acquisition, and offered reassurance to the caregivers about their performance. An initial lack of confidence and feelings of fear gave way to eventually seeing themselves as the expert for their care recipient after garnering support from the healthcare professionals. Connection with healthcare professionals for promoting health and well-being as well as preventing and managing chronic disease is a critical component in achieving health equity (National Academies of Sciences, Engineering, and Medicine, 2021). Parents managing technology-dependent children in the home also valued the relationship with healthcare professionals for information, hands-on training, supplies, and reassurance and the healthcare professionals acknowledged the expertise of the parents in caring for their child’s complex needs (Kirk & Glendinning, 2002). Similarly, the role of healthcare professional support leading to eventual caregiver expertise was also noted in interviews of caregivers managing a variety of complex care procedures and the healthcare professionals who supported them (McDonald et al., 2016).

While some participants relied on selected individuals for support, others did not ask for help or declined offers. For older adult caregivers, it is possible their social network is decreasing with age, or their own personal health makes it difficult to maintain relationships. Due to the personal or invasive nature of wound care procedures, caregivers may be protective of the care recipient’s privacy and thus avoid involving other individuals (Larson, 2023). Feelings of guilt should be considered as some older adult caregivers reported avoiding help because they felt guilty going out to enjoy themselves while their care recipient was feeling ill or home-bound (Greenwood, Pound,
Brearley, et al., 2019). Other researchers have also found caregivers do not seek out informal support persons and have hypothesized that caregivers may feel obligated to manage on their own or that asking for help was too burdensome (Greenwood, Pound, Brearley, et al., 2019; Larson, 2023). Given the known benefits of a social support network, especially for respite care, on caregiver stress and burden (Rose et al., 2015), understanding caregivers’ decision-making processes and rationale for avoidance of help is a pressing issue.

Motivation for accepting the caregiving role varies. Participants in our study acknowledged the importance of the relationship with their care recipient and became a caregiver as a natural fulfillment of their marriage vows or familial obligation. Motivation to perform a complex care procedure in the home setting may be influenced by potential benefits to the caregiver, such as less time spent traveling to appointments or being able to address problems immediately instead of waiting for professional assistance. Similar to our findings, other researchers found older adult caregivers accepted the role as an integral part of their long-term relationships (Greenwood, Pound, Brearley, et al., 2019; Larson, 2023). Yet in a study of caregivers managing a variety of complex care procedures in the home, participants were primarily motivated by the expected benefit for the care recipient, such as adequate nutrition due to nasogastric tube feedings (McDonald et al., 2015). Some participants, however, accepted the caregiver role due to a perceived lack of choice. Previous research has identified caregivers lacking choice in the decision as being more likely to report stress as compared to those caregivers with a choice in caregiving (Al-Janabi et al., 2018; Winter et al., 2010). Assessing older adult caregivers’ choice or motivation for becoming a caregiver could be
an early warning signal to providers about potential negative consequences and a need for early interventions to minimize stress and burden.

Taking on the caregiving role resulted in unexpected modifications. Modifications included changes to the physical home, such as wheelchair accessibility and rearranging furniture, which require adequate financial resources. Almost half of all caregivers report negative financial impact as a result of caregiving, such as spending their personal savings, leaving bills unpaid or paying bills late, and borrowing money from others (AARP and National Alliance for Caregiving, 2020). While the participants in our study were able to make modifications to the home setting, this may not be feasible for all older adult caregivers such as those sustained on a fixed income from Social Security benefits (Hooymann et al., 2018; Miller, 2023). Unexpected modifications also adjustments to an anticipated future lifestyle, such as cancelling vacations, leaving a job, or limiting social engagements. Diminishing social circles, restricted lives, and cancelled social engagements were echoed by other older adult caregivers (Greenwood, Pound, Brearley, et al., 2019; Greenwood, Pound, Smith, et al., 2019). Feelings of social isolation and loneliness for caregivers can lead to decreased mental well-being (Larson, 2023). Understanding of the impact of such modifications on the older adult caregiver’s health, ability, and desire to continue in the caregiving role is needed.

Limitations

With increasing demands on informal caregiving, these findings provide valuable insights into how older adult caregivers managed providing wound care, a complex care procedure. The findings should be considered within the context of the limitations of the study. Recruitment of participants was limited to those willing to be interviewed; persons
declining to discuss their experience may have different perceptions. Additionally, recruitment was completed during the COVID-19 pandemic using social media Facebook posts and data were collected via phone or internet methods, thus excluding individuals without access to the internet. The impact of pandemic public health restrictions on recruitment, participation, and data collection is not known. It is reasonable to assume that since participants had internet access and were to some extent computer literate, they were likely within a higher socioeconomic status. Participants of varying socioeconomic status may have differing processes for managing a complex care procedure. Participants included individuals currently providing care and those who had previously been caregivers. Current caregivers had not completed the experience, whereas the passage of time may have altered other participants’ recollection of their experience. Further, the impact of COVID-19 restrictions may have altered some participants caregiving experience, such as accompanying care recipients to appointments.

Conclusions

This framework captures the process of how older adult caregivers manage wound care as an exemplar complex care procedure. This process takes place in phases over time and is dependent on several factors including the type of wound, such as a planned surgical wound versus an unanticipated wound, development of wound healing complications, health of the care recipient and older adult caregiver, and access to healthcare professionals. An understanding of the older adult caregiver’s process creates opportunities for health care professionals to develop and implement evidence-based interventions. Future research can support increased understanding of how healthcare professionals can support older adult caregivers.
Chapter 3

Chapter 3 presents the results of a thematic analysis identifying the resources needed to provide wound care as expressed by older adult caregivers.

Background

Informal caregivers provide a considerable amount of clinical care in the home and community setting. In the United States, approximately 53 million people are informal caregivers and 19% of those caregivers are aged 65 or older (AARP and National Alliance for Caregiving, 2020). In combination with increased efforts to shift care to the home, increasing numbers of older adults are assuming a caregiving role, a trend that is projected to continue into the foreseeable future (AARP and National Alliance for Caregiving, 2020; Anderson et al., 2013; LaManna et al., 2020). As the population ages, higher levels of assistance are needed. In addition to assisting with activities of daily living, older adult caregivers are performing complex care procedures usually performed by licensed caregivers in a clinical setting (Hooyman et al., 2018). Approximately 48% of caregivers aged 54 and older reported performing complex care procedures, such as injections, tube feedings, catheter, and colostomy care (AARP and National Alliance for Caregiving, 2020; Reinhard et al., 2019; Reinhard et al., 2012). The consequences of caregiving for older adults include increased depressive symptoms, increased feelings of loneliness, higher levels of emotional strain, poorer mental health, and decreased cognitive function when compared to non-caregiver older adults (Anderson et al., 2013; Hooyman et al., 2018; Lavela & Ather, 2010).
Access to and use of resources are associated with lower levels of older adult caregiver stress, decreased perception of burden, and better physical and mental health (Ahn et al., 2012; Chow & Ho, 2012; Hong & Harrington, 2016; Sabo & Chin, 2021). Stress is believed to occur when an individual’s resources are threatened or actually lost, or when individuals are unable to gain sufficient resources after considerable resource investment (Hobfoll, 2001). Evidence suggests that increasingly stressful caregiving circumstances are associated with fewer or declining resources and higher feelings of burden, whereas lower perceptions of stress and burden are associated with greater access to and use of resources (Hong & Harrington, 2016).

While studies have examined resources and the older adult caregiving experience, the focus has been on the effects of resources on physical and mental health (Ahn et al., 2012; Chow & Ho, 2012; Hong & Harrington, 2016) or factors influencing a caregivers’ decision to use resources (Mast, 2013). In addition, prior research about older adult caregivers and utilization of resources included a priori variables, such as income level and satisfaction with transportation (Ahn et al., 2012; Chow & Ho, 2012), as opposed to the older adult caregivers’ salient thoughts on resource needs.

Older adult caregivers have a unique perspective on the caregiver role as compared to other generations. The difference may be due to cohort effects, older adults’ life experiences are different than younger generations, or lifespan effects, older adults are at a different developmental stage, or both (Hooyman et al., 2018; Reinhard et al., 2019). In addition, normal physiological age-related changes may impact the older adult’s experience of caregiving (Miller, 2023). For example, the loss of muscle mass, fat tissue, and stiffness in joints may impact the older adult caregiver’s mobility and
declining cardiac and lung capacity may impair the older adult caregiver’s ability to be physically active for long periods of time and increase their tendency to become fatigued (Hooyman et al., 2018). Aside from normal age-related changes, older adult caregivers frequently have one or more chronic diseases requiring on-going self-care (Miller, 2023). Older adult caregivers may also have financial challenges based on past and current employment and retirement income and benefits that complicate resources needed for the caregiving role (Hooyman et al., 2018). Considering these differences, it is important to understand the distinct issues and perspectives of older adult caregivers.

Little is known about older adults’ thoughts on resources important to caregiving and performing complex care procedures. The purpose of this study, therefore, was to describe older adult caregivers’ thoughts about resources needed or utilized while performing complex care using wound care as an exemplar complex care procedure. A better understanding of resources utilized by older adult caregivers performing complex care procedures will allow for nurses and other health care professionals to advocate for and provide greater support to older adult caregivers.

Methods

Parent Study

The data for the current study is from a qualitative study describing how older adult caregivers manage complex care procedures using wound care as an exemplar complex care problem. Participants in this study were adults aged 65 or older (n=18) who lacked any formal healthcare training related to providing direct clinical care. The participants were currently or had previously provided wound care for a person aged 18
or older in the home setting. Participants were recruited by posting a flyer on the principal investigator’s Facebook page. Individuals were excluded from participating in the study if they did not speak English fluently or had cognitive challenges that would interfere with participating in an interview. Demographic information was collected at the start of the semi-structured interviews driven by an interview guide. All procedures were approved by the IRB at the investigators’ university.

Interviews were conducted in English, lasted approximately 40 minutes, were audio-recorded, and transcribed by a secure professional transcription service. Interviews were conducted by telephone or a secure web-conferencing platform from February 2021 through September 2021, this time frame occurring during the COVID-19 pandemic with accompanying public health restrictions. Interviews began with broad questions related to demographic information and becoming a caregiver then transitioned to focused questions about the management of wound care and associated caregiver tasks. Responses to questions related to resources as well as the discussion of resources at any point during the interview, were used for analysis in the current paper.

**Current Study**

Thematic analysis described by Braun and Clarke (2006) was used to analyze the interview transcripts for patterns related to resources used by the older adult caregivers. Thematic analysis is a qualitative method used to identify, analyze, and report patterns within data. A realistic approach examining a particular topic, resources, was utilized. The research question for this analysis was: What are older adult caregivers’ thoughts about resources needed or utilized when caring for a person with a wound? Analysis identified patterned responses in the data that were related to the research question.
Decision-making by the research team regarding what counted as a pattern included any codes or themes that captured an important aspect of the caregiver’s thoughts about resources and was not dependent on prevalence of the identified codes. This inductive approach to analysis is data-driven and the themes captured important ideas within the entire data set.

Data analysis for this study was performed by a team of three researchers (KS, JF, JV). We followed the 6-stage analysis provided by Braun and Clarke (2006) summarized in Table 3.1.

**Table 3.1**

*Six Stages of Data Analysis Process* (adapted from Braun & Clark, 2006)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarize yourself with the data</td>
<td>Transcribe the interview data. Read transcripts several times and verify transcripts against the original audio recordings for accuracy. Make note of preliminary ideas about the data.</td>
</tr>
<tr>
<td>2. Generate initial codes</td>
<td>Code important sentences and phrases related to research question throughout the complete data set.</td>
</tr>
<tr>
<td>3. Search for themes</td>
<td>Group similar codes together and sort into potential themes. Label overarching themes. Relationships between the codes within the themes and between the themes were discussed among the team.</td>
</tr>
<tr>
<td>4. Review themes</td>
<td>Review themes to identify relevant patterns and relationships. Review themes for internal homogeneity (codes within the themes connect meaningfully) and external heterogeneity (clear distinction between the themes). Reread entire data set to ensure adequate representation among the themes.</td>
</tr>
<tr>
<td>5. Defining and naming themes</td>
<td>Refine each theme and label with an identifying statement to capture the essence of the theme described by the participants. Resolve discrepancies in theme statements until consensus is established.</td>
</tr>
<tr>
<td>6. Producing the report</td>
<td>Prepare a write-up of the report. Utilize compelling extracts of the data that demonstrate the themes and relate back to the research question and relevant literature.</td>
</tr>
</tbody>
</table>
Interviews were professionally transcribed. Transcripts were read several times by the primary investigator (KS) and checked against the original audio recordings for accuracy. Initial coding was performed using a table in Microsoft Word. Similar codes and patterns were grouped together and sorted into potential themes and labeled within the table. See Table 3.2 for examples of the coding procedure. Relationships between the codes within the themes and between the themes were discussed amongst the team. The entire data set was reread by the primary investigator (KS) to ensure adequate representation amongst the themes. Each theme was identified with a statement to capture the nature of the resource and discrepancies in theme statements were resolved by continuing discussion with the team until consensus was reached.

**Table 3.2**

*Examples of Coding Procedure*

<table>
<thead>
<tr>
<th>Quote</th>
<th>Code</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>And [family doctor] said, “you better go to the wound unit somewhere and have them work on that”</td>
<td>Needing expert wound consult</td>
<td>Connection to healthcare professional</td>
</tr>
<tr>
<td>And you couldn't heal it because the edema was so bad. Got a wound care professional and she helped us through this for, I don't know, a period of maybe a month and a half, two months.</td>
<td>Wound care professional</td>
<td></td>
</tr>
<tr>
<td>The home nurse came in and showed me how to set it up and do it and everything.</td>
<td>Home care nurse support</td>
<td></td>
</tr>
<tr>
<td>The hospice supplied all [dressing supplies]. They gave me the alginate and the Q-tips and gloves and salves and everything I needed.</td>
<td>Wound care supplies provided by hospice</td>
<td></td>
</tr>
<tr>
<td>They sent away immediately for bandages, and they came within two or three days, the bandages and all the little felt pads that they use over the bandage.</td>
<td>Receiving bandages in the mail via the wound clinic</td>
<td>Obtaining wound care supplies</td>
</tr>
<tr>
<td>He was really sent home [from the surgeon’s office] with the bandages and resources he needed.</td>
<td>Supplies from surgeon’s office</td>
<td></td>
</tr>
</tbody>
</table>
Trustworthiness of the findings was established through team meetings to validate the themes by reexamination of the data. Themes were reviewed for internal homogeneity and external heterogeneity by the team. The principal investigator (KS) maintained an audit trail to document how decisions were made in identifying patterns and labeling themes. Information was reviewed during team meetings and retained for the audit trail.

**Results**

**Sample description**

Eighteen participant interviews were included for the thematic analysis, 60% (n = 11) female. The mean age of participants was 73.7 years old (SD = 5.5). Most participants (88%; n = 16) were caring for a spouse and the remaining were caring for a parent (16%; n = 3). One participant was caring for both a parent and a spouse, resulting in 19 total care recipients cared for by 18 participants. Length of time spent as a caregiver ranged from 1 month to 9 years with some participants being unable to provide an exact answer. See Table 3.3 for demographic information.

**Themes reflecting older adult caregiver’s thoughts on resources**

Seven themes related to participants’ thoughts about resources needed or utilized while performing wound care were identified. Each theme is described below.

1. **Expert guidance from healthcare professionals on care procedures is an important resource.**
Healthcare professionals were described as an important resource for gaining clinical knowledge and skill. Participants recognized their lack of formal medical or healthcare education and talked about their need for initial training and ongoing expert guidance for managing their care recipient’s wound. One participant stated, “I don’t have that medical background, and I need the help from the medical professionals.”

Table 3.3

Participant Demographic Data

<table>
<thead>
<tr>
<th>Participant characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of participant</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>11 (61.0)</td>
</tr>
<tr>
<td>Male</td>
<td>7 (39.0)</td>
</tr>
<tr>
<td>Participant &amp; recipient genders</td>
<td></td>
</tr>
<tr>
<td>Female caring for a male</td>
<td>9 (47.0)</td>
</tr>
<tr>
<td>Male caring for a male</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Female caring for a female</td>
<td>3 (16.0)</td>
</tr>
<tr>
<td>Male caring for a female</td>
<td>7 (37.0)</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
</tr>
<tr>
<td>Male caring for a spouse</td>
<td>7 (37.0)</td>
</tr>
<tr>
<td>Female caring for a spouse</td>
<td>9 (47.0)</td>
</tr>
<tr>
<td>Male caring for a parent</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Female caring for a parent</td>
<td>3 (16.0)</td>
</tr>
<tr>
<td>Wound Type</td>
<td></td>
</tr>
<tr>
<td>Surgical wound</td>
<td>12 (52.0)</td>
</tr>
<tr>
<td>Pressure injury</td>
<td>2 (9.0)</td>
</tr>
<tr>
<td>Infectious wound</td>
<td>3 (13.0)</td>
</tr>
<tr>
<td>Venous Insufficiency Ulcer</td>
<td>3 (13.0)</td>
</tr>
<tr>
<td>Traumatic Wound</td>
<td>3 (13.0)</td>
</tr>
</tbody>
</table>

Medical professionals that served as a resource included wound care nurses, home health care nurses, home hospice staff, nursing home personnel, primary care providers, and a physician who made house calls. Struggling to manage the wound at home, one participant asked for a wound referral to an outpatient wound clinic, stating “I got back
with the nurse practitioner from the family doctor’s office and said please make that referral for me. I don’t know what to do.” Other participants noted the importance of routine provider appointments to learn about wound care and expectations for wound healing. One participant stated, “I attended all the doctors’ appointments. He pretty much told me what to do. He told me what ointment to use… to soak it in warm soapy water, clean it and over time it just started to heal.”

Some participants were actively serving as caregivers during the COVID-19 pandemic and shared how public health restrictions complicated their ability to interact with healthcare professionals. One participant spoke of needing to get permission to attend appointments with the care recipient at the wound clinic, stating, “It was ‘could I go in with her or not?’ So they okayed me to go in because I was her spouse and I’m kind of a hands-on guy.” Another participant received care instructions over the phone after wound clinic appointments due to being unable to accompany the care recipient inside the clinic. The participant stated, “There was a woman who would call me near the end of the appointment and tell me what had been going on. She’d tell me what was coming home, how he had done that day, what they thought about it.” This participant would have preferred face-to-face communication but deemed interaction with the healthcare professionals over the telephone an important resource considering the COVID-19 pandemic restrictions.

2. Written instructions are a vital source of information in learning new procedures.

Written instructions were a vital resource as participants shared that they were often overwhelmed in the initial phase of their caregiving role. Participants described their reliance on written instructions from the healthcare professionals to guide
performance of hands-on wound care procedures. For example, one participant shared, “I did ask for printed out instructions because it was traumatic for us to see her go through that and I knew I would not remember everything that I needed to do.”

3. Relationships with healthcare professionals are a strategic resource for obtaining wound care supplies.

Wound care supplies were a necessity for participants. Participants shared stories of initially using the wrong supplies causing wound complications and unnecessary frustration for both participant and care recipient. Participants described needing gauze, tape, topical creams and ointments, compression wraps, and specialized medicated dressings. They shared examples of wound care supply needs changing frequently, as often as weekly, due to the condition of the wound bed.

The connection with healthcare professionals was a strategic resource for the acquisition of wound care supplies. Participants spoke of receiving dressing supplies directly from a provider’s office when caring for a planned surgical wound. Other participants purchased wound care supplies out of pocket from the internet or a local pharmacy based on the healthcare professional’s instructions. One participant stated “They [surgeon’s office staff] gave me dressings, gave me gauze and stuff like that. Of course, I bought some at the drugstore too, they never give you enough.” Some participants received supplies directly from a home health care agency, for example one stated “they [home health care company] provided all the special bandages that I needed and the solutions and that kind of stuff that I needed to use on him.” The relationship with healthcare providers was discussed as an important resource for access to wound care supplies.
4. **Caregivers need additional medical equipment to assist their care recipient.**

Caregivers required durable medical equipment in addition to wound care supplies. Participants utilized wheelchairs, shower chairs, lift chairs, bathing supplies to protect the wound, and incontinence products. Once discovering a need for a piece of equipment, the caregivers sought out these items independently by ordering online or purchasing from a local drugstore. One participant stated, “I buy, well I take out of her account, wipes, and liners for her potty. She has a bedside commode that she uses at night... and I bought a transport wheelchair for her.” Another participant stated:

I had to buy something for showering, like a covering…I just went to [name of store] and bought a couple of different ones to try to see what was going to work best for him and for me because there are a lot of contortions involved here, and it worked. I mean, I was able to keep it dry.

These additional pieces of medical equipment were a valued resource allowing the participants to assist their care recipient with activities of daily living, provide comfort, prevent complications, and enhance mobility.

5. **Financial resources are necessary for caregiving.**

Participants described financial resources as necessary to support their care recipient. Some participants relied on the care recipient’s medical insurance to cover the cost of equipment, supplies, and health care appointments. Other participants spoke of paying out of pocket for wound care supplies and durable medical equipment. One participant stated, “We’re fortunate that we’ve had a white-collar job. I had a white-collar job. His retirement was good… His plan… it has provided for us in such a way that I can go up to [name of store] and buy what I need.” Another participant spoke of reliance on Medicare, stating:
We had Medicare and we never paid a bill… He had [16 months] of an open wound. The bandaging is very expensive, and they submitted it and we never got one bill, so that was not an issue for us. We had Medicare and then we had a supplemental insurance, so it covered it. It would have been devastating had it not.

The participants relied on insurance coverage or their ability to pay out of pocket for caregiving expenses and recognized the importance financial resources played in their caregiving situation.

6. **Coverage for caregiver personal time is a needed resource.**

Participants relied on friends and family members for informal respite care. Respite care is a resource that allows a caregiver to take a break from the caregiving situation temporarily to attend to personal needs (Rose et al., 2015). Trusted individuals would stay with the care recipient to allow the participant an opportunity for running errands, personal health care appointments, exercise, or social events. Some participants also hired individuals to provide respite care, such as a retired registered nurse, or enlisted help through volunteer organizations. A participant shared her experience with a volunteer, stating:

I have a senior companion who is a volunteer through Catholic Services… I feel like I can only be gone about two and a half hours before I need to get back because I know mother has to go to the bathroom. That’s my window of opportunity to go to the grocery store, that’s it.

Friends and family served as a resource allowing participants to attend to personal needs as opposed to formal respite care services.

7. **Caregivers sourced select persons as resources for social and emotional support.**

The participants described friends, neighbors, adult children, and church members who provided emotional support and socialization. Some individuals provided help with
household chores or prepared meals for the participant and care recipient. One participant stated, “I just rely on my friends from church. They call and check on me.” Another participant shared a similar situation, stating, “I have good neighbors and I’ve got four kids who are very supportive.” These selected individuals provided the participants with emotional support and socialization outside of the caregiving situation to prevent feelings of social isolation.

Discussion

This study revealed the older adult caregivers’ thoughts on resources needed to perform their wound care caregiving role. Limited research has examined the older adult caregivers’ thoughts on resources. Most research to date has studied the effects of resources on physical and mental health, factors influencing a caregivers’ decision to use resources, or a priori resource variables. By examining this topic using qualitative interview data, we have identified the resources that are important from the participants’ own thoughts. These findings serve as a call to action for healthcare professionals who interact with older adult caregivers performing complex care procedures, such as wound care.

Participants relied heavily on healthcare professionals as a resource for learning how to perform wound care procedures. Access to health care professionals disproportionately affects older adults resulting in an increase burden of illness (National Academies of Sciences, Engineering, and Medicine, 2021). Prior research has shown that most commonly, caregivers learned caregiving skills on their own and one study found only 55% of caregivers learned how to perform wound care from a healthcare professional (Reinhard et al., 2019). Normal age-related changes in sensory, perceptual,
and psychomotor skills as well as education level, verbal ability, and physical health can influence older adults’ ability to learn or perform new processes (Hooyman et al., 2018).

In addition, caregivers face information overload particularly at onset of the care recipient’s initial diagnosis and information overload is associated with caregiver burden (Kim, 2021). The current findings serve to inform healthcare professionals of the importance of advocating for a referral to healthcare professionals with applicable expertise who can appropriately guide older adult caregivers.

Healthcare professionals must recognize the valuable resource they are for older adults and their caregivers and seek out opportunities for providing guidance and education consistent with an older adult learners’ needs, including more exposure to the content, visual instruction, supervised hands-on practice with care procedures, slowing the rate of information flow, breaking lengthy content into smaller units, and a phone number to call with questions (Hooyman et al., 2018; McDonald et al., 2016; Reinhard et al., 2019). Written instructions allow the older adult caregiver to self-moderate information processing and serve as an external cognitive aid to performing a new skill, however health literacy and reading level must be assessed and taken into consideration (Hooyman et al., 2018; Miller, 2023).

Participants identified access to wound care supplies and durable medical equipment as essential resources. Participants relied on the healthcare professionals for information on the specific wound care supplies needed and how to acquire supplies. In contrast, the participants sought out durable medical equipment independently. Participants shared challenges with mobility, transportation, managing incontinence and bathing their care recipient for which appropriate durable medical equipment eased their
struggles. The importance of durable medical equipment for older adult caregivers is not well documented. That participants sought this equipment independently suggests that providers tend to be focused narrowly on treating the wound and underlying etiology. Providers should consider a proactive holistic assessment of the caregiver and the care recipient’s supply and equipment needs. This finding suggests an opportunity for both providers and researchers to consider how to best assess, advocate, and coordinate supply and equipment resource needs.

The financial means to purchase necessary supplies and equipment was identified as a significant resource for participants. Participants spoke of healthcare insurance or paying out-of-pocket when describing financial resources necessary for caregiving expenses. The participants of this study believed they were fortunate in their financial situation, and none spoke of any financial difficulties. Participants in this study were likely of higher socioeconomic status due to recruitment being limited to social media posts during the COVID-19 pandemic. It is likely that potential participants without internet access or experience with using technology would have different thoughts regarding financial resources.

A network of supportive persons willing to provide respite care was identified as a valuable resource for the participants. In this study, participants relied on informal support persons, such as friends, family, and neighbors, to be able to attend to personal needs. Respite has been shown to reduce caregiver stress and burden, improve the quality of life for caregivers and care recipients, and reduce institutionalization of care recipients (Mast, 2013; Rose et al., 2015). Prior research found only 12% of caregivers use formal respite services such as adult day care or services provided in the home by a
health care agency (Mast, 2013) and only one participant in the current study paid for
respite care services. Mast (2013) examined the factors influencing a caregiver’s use of
formal support services and found a wide range of variables, such as availability, quality,
cost, marketing, caregiver perceived need for the service, caregiver level of health,
burden of the caregiving situation, cognitive and physical health of the care recipient,
dynamics of the caregiver’s relationship with the care recipient, family norms and
cultural values. It is unknown why the older adult caregivers in the current study relied
on informal supports for respite care as opposed to formal support services. Some
participants were caregiving during the COVID-19 pandemic, which may have
influenced their willingness to engage with all but the most trusted family members and
friends.

A network of informal supports for socialization and emotional support was the
final resource identified by participants. Participants spoke of friends and family
members calling to “check in” or being “available.” Social isolation of caregivers is
known to be detrimental to the caregiver’s physical and mental health (Ahn et al., 2012;
Mast, 2013). In previous studies, older adult caregivers were noted to cite their own
declining physical and emotional health and strength as challenges to maintaining social
contacts (Greenwood, Pound, Brearley, et al., 2019). Again, it is unknown how public
health restrictions due to the COVID-19 pandemic impacted the participants’ interaction
with their social network. Additional exploration of older adult caregiver’s perceived
barriers to accessing or engaging with others for social and emotional support and
subsequent evidence-based interventions are needed to maintain caregivers’ health and
longevity within the role.
These findings provide valuable insights into the thoughts of older adult caregivers regarding resources needed to provide complex care tasks such as wound care in the home setting. Recruitment of participants was limited to those willing to be interviewed about their experience. Caregivers who were unwilling to discuss their experience may have had a different experience than those who volunteered. Some participants had completed a caregiver role before the pandemic began while others were actively providing wound care during the pandemic. The impact of the COVID-19 pandemic on recruitment and participation is not known. Recruitment for this study was limited to internet Facebook posts due to public health restrictions and data were collected via remote (phone or internet) methods, thus excluding individuals lacking internet access. It can be reasonably assumed that participants were computer literate, had internet access, and were likely within a higher socioeconomic status. Participants of varying socioeconomic status may have differing views on resources.

Conclusions

In conclusion, older adult caregivers need and use a variety of resources when providing wound care including access to healthcare providers, supplies and equipment, finances, and supportive persons for respite and socialization. As increasing numbers of older adults choose to “age in place” as opposed to costly residential nursing facility care, the importance of adequate resources to sustain care recipients and their caregivers in the home setting is critical (Luker et al., 2019). The findings of this study have implications for healthcare professionals by underscoring the importance of the provider’s responsibility for connecting older adult caregivers with healthcare experts, assessing caregiver educational needs and learning styles, evaluating supply and equipment needs,
and advocating for personal support for the caregiver through informal emotional supports, socialization, and respite care.
Chapter 4

Chapter 4 describes the results of a federal policy analysis of all 50 states plus the District of Columbia’s Medicaid 1915(c) home- and community-based services waivers for adults aged 65 and older.

Introduction

Care delivered in the home or community-based setting is more cost-effective than care delivered in a nursing facility; however, it centers on having friends and family members available and able to provide needed care. According to the American Association of Retired Persons (AARP), in 2019 just under 48 million adults, or 19% of the population, had been a caregiver for another adult within the previous 12 months. More than half of all caregivers are over age 50 with approximately 20% being 65 years or older. The majority of caregivers over age 75 years are caring for someone who is also over 75 years (AARP and National Alliance for Caregiving [NAC], 2020).

Caregiving activities include assisting with activities of daily living (ADLs), supporting instrumental activities of daily living (IADLs), ongoing monitoring of health status, providing and adjusting medical treatments and medications, communicating with the health care team, and advocating on behalf of the care recipient with various providers and service agencies (Moorman & Macdonald, 2012; National Academies of Sciences, Engineering, and Medicine, 2016). In addition, more than half of all caregivers are performing complex nursing care procedures such as administering tube feedings, giving injections, maintaining urinary catheters, or providing wound care (Moorman & Macdonald, 2012; Reinhard et al., 2019). When asked to identify which nursing care
procedures were the most difficult, caregivers reported managing continence devices, administering enemas, and providing wound care as the most difficult (Reinhard et al., 2012).

The unintended consequences of caregiving for the caregiver may include emotional distress, worsening personal health, workplace conflict, and financial strain (Moorman & Macdonald, 2012; National Academies of Sciences, Engineering, and Medicine, 2016; National Alliance for Caregiving & AARP Public Policy Institute, 2015). Length of time spent as a caregiver further intensifies negative outcomes (AARP and NAC, 2020; National Academies of Sciences, Engineering, and Medicine, 2016). Employed caregivers find they need to adjust work schedules, reduce work hours, use paid time off, or take unpaid leave (Wang & Wu, 2018). Many caregivers report having received a warning about their work performance or attendance (AARP and NAC, 2020). Reducing hours or leaving the workforce results in additional strain as the caregiver loses benefits, career opportunities, and contributions to retirement funds while often acquiring new debt and using personal savings resulting in increasing reliance on social networks for financial support (National Academies of Sciences, Engineering, and Medicine, 2016; Wang & Wu, 2018). Many caregivers reported working one or more part-time jobs and delaying retirement to address financial strain (AARP and NAC, 2020).

Caregivers consistently reported needing more information about caregiving responsibilities and in-home assistance, yet they experienced difficulties accessing community-based services such as home-delivered meals, transportation assistance, or in-home health services (AARP and NAC, 2020). Very few caregivers reported having an ongoing clinical relationship with a health care professional about the care recipient’s
needs, and even fewer ever discussed receiving support for their personal well-being (AARP and NAC, 2020). Most caregivers reported learning how to do complex nursing care procedures on their own without the involvement of a health care professional (Reinhard et al., 2019).

Government policies and programs are one option for supporting caregivers. State and federal policies supporting caregivers may include flexible workplaces, family and medical leave policies, access to paid family leave, Social Security credits for caregivers, and prevention of family responsibility discrimination (National Academies of Sciences, Engineering, and Medicine, 2016). Policies addressing these supportive options are not universally available at the federal level though some states have initiated some or parts of programs to support care recipients and caregivers. When caregivers were asked about preferences for national policies, 30% indicated they preferred to be paid for at least some of the hours of care they provide (NAC & AARP Public Policy Institute, 2015).

Medicaid is a federal health program created in 1965 under Title XIX of the Social Security Act that offers support for home and community-based care (Centers for Medicare & Medicaid Services [CMS], n.d.-a). Medicaid is housed in the U.S. Department of Health and Human Services and is federally funded primarily through payroll taxes, Congressional authorizations, premiums from select parts of Medicare, income taxes paid on Social Security benefits, and interest earned on trust fund investments (CMS, n.d.-b).

Medicaid provides health care coverage for low-income individuals, qualified pregnant woman and children, and individuals receiving Supplemental Security Income.
Administration of and funding for Medicaid is managed through a partnership between the federal and state governments resulting in variations in services by state. For example, while individual states have the option of expanding coverage for additional groups, such as children in foster care and those receiving home and community-based services, some states choose not to fund these services (CMS, n.d.-c). For low-income adults aged 65 and older, financial eligibility for Medicaid generally is determined using the same standards set for the Social Security Income program and is tied closely to the federal poverty level (CMS, n.d.-c). The bottom line is that for care recipients and their caregivers, no uniform national standard of support exists through Medicaid.

An example of variation in Medicaid services is the 1915(c) Home and Community-Based Services (HCBS) waiver programs, hereafter referred to as waiver programs. The waiver programs allow a state to waive certain Medicaid requirements, such as ensuring uniform eligibility and implementation of a program throughout the state, and instead allowing targeted services to persons with specific needs, such as older adults and those at risk for institutionalization (CMS, n.d.-d). Home and community-based service waiver programs support care recipients who are functionally eligible for the type of care provided in a nursing home yet prefer to remain in the home or community-based setting provided adequate support structures are in place. These waiver programs vary state-to-state with differing types of services offered.

Caregiver outcomes are known to be associated with physical health, emotional stress, and financial strain (Reinhard et al., 2019). The relationships among variables related to caregiving, such as demands of the caregiving situation, affect psychosocial, physiological, health behavior, and general health outcomes for the caregiver, have been
described in a theoretical framework, the *Model of Carer Stress and Burden* (Sørensen et al., 2006). The framework also demonstrates the influence of social, emotional, financial, and other supportive resources as moderators of caregiving stressors and caregiver outcomes. Additional researchers have identified variables impacting caregiver outcomes, such as the multiple family and societal roles of a caregiver (Barnett, 2015) and caregiving trajectory, including duration of the caregiving experience and timing of entry into the caregiving role (National Academies of Sciences, Engineering, and Medicine, 2016). Waiver programs, by providing resources for caregivers, can influence caregiver outcomes. With Medicaid’s individualized state waiver programs, a national picture of Medicaid waiver program services for caregiver support is limited. A more comprehensive understanding of the waiver programs would better prepare nurses to assist care recipients and caregivers with planning and obtaining services at home. To better advocate for home and community-based support for care recipients and their caregivers, and collectively advocate for improved policies, a more complete understanding of the various services available through state waiver programs is needed.

The purpose of this policy analysis is to identify the variability in supportive services available to caregivers through the Medicaid 1915(c) HCBS waiver programs in all 50 U.S states and the District of Columbia.

**Aims**

1. Describe availability of Medicaid 1915(c) HCBS waiver programs for care recipients aged 65 years and older by U.S. state and District of Columbia.

2. Describe available Medicaid 1915(c) HCBS waiver program services providing support for caregivers by U.S. states and District of Columbia.
3. Describe requirements for caregivers covered by Medicaid 1915(c) HCBS waiver programs by U.S. states and District of Columbia.

4. Describe variabilities in supportive services available to caregivers through the Medicaid 1915(c) HCBS waiver programs across U.S. states and District of Columbia.

Methods

Sample and Setting

Data were obtained from approved Medicaid 1915(c) HCBS waiver program applications targeting adults aged 65 and older meeting nursing facility level of care but electing to receive care in the home or community-based setting. Medicaid HCBS 1915(c) waivers for children, individuals with intellectual or developmental disabilities, or those with specific diagnoses such as traumatic brain injury were excluded. Data was collected from the official Medicaid.gov website (CMS, n.d.-e). Approved Medicaid HCBS 1915(c) waiver applications for all 50 states and the District of Columbia were examined between June 2021 and September 2021.

Instrument

An investigator-designed data collection spreadsheet was created for recording specified data elements from the approved waiver program applications. Data elements included the name of the waiver program, eligibility criteria, complete list of services offered, services offered that specifically support caregivers, and eligibility requirements for caregivers to receive financial compensation.
Procedure

The investigator identified each state and the District of Columbia’s approved waiver program applications that targeted older adult care recipients aged 65 and older from the Medicaid.gov website (CMS, n.d.-e). Each data point was located within the application and recorded on the electronic spreadsheet. To record the presence of a waiver program for each state and the inclusion of services that support caregivers, a coding system of 1 = yes and 0 = no was entered into the spreadsheet. To assure accuracy of data extraction, a random sample of 10% of data entries were quality reviewed for accuracy by a second investigator with experience in health policy (SC).

Analysis

The functionality of the computerized spreadsheet allowed for analysis of the number of waiver programs nationwide, frequency data for specific services that support caregivers, and review of similarities and differences amongst states. To facilitate visualization of findings for possible geographic or regional patterns, the investigator transferred data elements to an electronic map of United States to examine geographical trends.

Findings

Results revealed 50 waiver programs across the 50 states and District of Columbia with some states having more than one waiver and some having none. Eight (16%) states do not offer a waiver for care recipients aged 65 and older meaning Medicaid waiver programs are not an option for support in Arizona, Delaware, Hawaii, New Jersey, New Mexico, Rhode Island, Tennessee, and Vermont. See Figure 4.1.
However, seven states (14%; Alabama, California, Massachusetts, New York, Ohio, Utah, and Washington) offer two waiver programs for this population. In states that have two waiver programs for older adults, the eligibility criteria differ for each waiver program and care recipients can only receive services via one waiver program. For example, California offers two waiver programs. The California Home and Community-Based Alternatives waiver is available to care recipients of all ages, including those 65 and older, who are medically fragile and elect to receive services within the home setting with no cost limit for services. The California Multipurpose Senior Services Program waiver is only for care recipients aged 65 and older who also chose to receive services within the home setting, but the cost of services must be equal...
to or less than the cost of care in a nursing facility. Thus, care recipients aged 65 or older in California have two waiver programs to choose from based on their care needs. As in this example, there are two possibilities for accessing the same services for care recipients over age 65. States with two waiver programs do not necessarily offer the most comprehensive caregiver support.

The most common service offered by the waiver programs is at least one form of respite care with 41 (80%) states offering either in-home respite care, out-of-home respite care, adult day care with professional healthcare services, and adult day care for socialization only (no healthcare services). Some states offer only one form of respite care, such as Kansas where only adult day care with professional health care services is offered. However, other states offer multiple respite care services, like Arkansas where all four respite care services are available. These respite care services are for care recipients unable to care for themselves when an informal caregiver needs relief on a short-term basis (CMS, n.d.-e). Alabama, California, Massachusetts, New York, and Utah offer in-home respite care through two separate waiver programs, making 40 total waiver programs available in 35 (67%) states. Adult day health care with professional services provides social and health-related services, such as skilled nursing, physical therapy, and occupational therapy, in a structured, community-based, group setting during daytime hours (CMS, n.d.-e). Alabama, Ohio, and Utah offer adult day health care with professional services in two separate waiver programs, making a total of 38 waiver programs available in 35 (67%) states. Out-of-home respite care is like in-home respite care but is offered outside the care recipient’s primary residence, such as at a skilled nursing facility or acute care hospital. California, Massachusetts, New York, Ohio, and
Utah offer out-of-home respite care in two separate waiver programs, for a total of 37 waiver programs offering out-of-home respite care in 32 (63%) states. Finally, adult day care focusing on care recipient socialization without any healthcare related professional services is offered in only seven states (14%). New York provides adult day care for socialization in two waiver programs. See Figure 4.2 for a chart on the number of states and number of programs that offer each waiver service examined in this analysis.

After respite services, the next most common waiver service is paid relative/legal guardian caregiver allowing relatives or legal guardians, exclusive of spouses, to become a paid caregiver (39 states, 76%). Several states require extreme circumstances before providing financial remuneration to a relative or legal guardian. For example, living in a remote area where no other qualified caregivers are available could be considered an extreme circumstance. In yet other states, the only criteria for remuneration are that the paid relative or legal guardian meets required employment qualifications, such as being at least 18 years old and submitting to a background check. Four states, Alabama, Massachusetts, Ohio, and Utah, offer two waiver programs wherein a relative or legal guardian can receive remuneration for caregiving for a total of 43 waiver programs in 39 states.

Skilled nursing is a service where a licensed registered nurse, or licensed practical nurse under the guidance of a registered nurse, provides nursing care for a care recipient in the home. Skilled nursing care includes complex care procedures such as wound care, administration of intravenous medications, and administration of enteral nutrition. Twenty-eight states (55%) offer skilled nursing services in 30 waiver programs. Ohio and Washington offer this service in two different waiver programs.
When the caregiver is the care recipient’s spouse, 18 states (35%) will provide financial compensation for the spouse. Alabama offers this support in two separate waiver programs, making 19 waiver programs in 18 states.

Caregiver education/training is a distinct waiver service offered in 15 states (29%) and Washington offers caregiver training in two distinct waiver programs. There is no standard or common content related to education and training. Caregiver education varies widely in content and format. For example, in Florida, caregiver training includes instruction about treatment regimens and use of equipment specified in the care recipient’s plan of care whereas Oregon offers caregiver training on personal care assistance, ongoing medical treatments, and medication administration. Table 4.1 offers a complete list of services supporting caregivers available by each state, including services offered in two waiver programs for the state.
Table 4.1

State-by-State Comparison of Services Supporting Caregivers and Number of Waiver Programs per State that Offer the Service

<table>
<thead>
<tr>
<th>State Name</th>
<th>Relative as paid caregiver</th>
<th>In-home Respite</th>
<th>Adult Day Health Care</th>
<th>Out-of-Home Respite</th>
<th>Skilled Nursing</th>
<th>Spouse as paid caregiver</th>
<th>Caregiver Training</th>
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Legend: 1 = 1 waiver program covering the service; 2 = 2 waiver programs covering the service; grey shading = no waiver program for the service; **bold/italics** = state offers most comprehensive caregiver support with 7 of the 8 services

Discussion

The results of this policy analysis demonstrate the national scope of available caregiver support services via the Medicaid 1915(c) HCBS waiver programs. Not all states offer caregiver support services, and the type of services varies across states that do offer services. There is no observable geographic, population, or political pattern to state waiver programs noted in this data.

Medicaid waiver program services are intended to be a source of support for care recipients and their caregivers within the community however, when asked about accessing services within the community, 60% of caregivers reported it was very to moderately difficult (AARP and NAC, 2020). Noted barriers include availability, quality, accessibility in terms of location and schedule, cost, poor coordination of services, not knowing about the service due to poor marketing, and difficulty navigating competing demands between care recipient and caregiver (Mast, 2013; Sabo & Chin, 2021). Additional research is needed to identify opportunities for nurses and health care teams to help caregivers navigate such barriers.
This analysis found that eight states lack a waiver program for older adults leaving care recipients and their caregivers unable to access those services via a Medicaid waiver. A lack of Medicaid waiver programs in some states combined with such a wide variety in available services between states is reveals an existing health inequity, which is a systematic difference in opportunity to achieve optimal health, resulting in unfair and avoidable poor health outcomes (National Academies of Sciences, Engineering, and Medicine, 2021), among Medicaid recipients. Nurses are often the most frequent point of contact for care recipients and caregivers seeking care. Therefore, nurses are uniquely positioned to address the inequity in accessing Medicaid waiver services by assisting care recipients and caregivers to navigate the health care system, providing close monitoring and follow-up care, marketing available assistance programs and services, and through evidence-based health policy reform and advocacy (National Academies of Sciences, Engineering, and Medicine, 2021).

Additionally, the burden of caregiving on the caregiver’s physical health and emotional well-being has been well described, with caregiver self-related health on the decline as compared to the general U.S. population (AARP and NAC, 2020). Respite care services support sustainability of caregiving. Adult day care services, for example, provide a caregiver with the ability to take a break from the caregiving situation temporarily to attend to personal needs such as shopping, haircuts, and dental visits (Rose et al., 2015). Respite care has been shown to reduce caregiver stress and burden, improve the quality of life for caregivers and care recipients, and also reduce institutionalization of care recipients (Rose et al., 2015). With evidence to demonstrate that respite care is beneficial to caregivers, it is unclear why out of the 43 states that offer the Medicaid
waiver examined in this analysis, 2 states, Oregon and West Virginia, have not included
this service within their waiver program. While it is encouraging that most states offer at
least one option, each caregiver’s needs are unique and if only one option is available, it
may not be sufficient. For example, the only service Illinois offers is adult day health
care with professional services, which is only available during daytime hours thus lacking
an option for overnight respite care for the caregiver.

Using wound care as one example of a complex nursing care procedure, the
responsibilities of the caregiver in caring for a wound are numerous and extend beyond
the actual application of topical dressings and treatments, including monitoring for
wound infection or deterioration, managing associated lifestyle modifications, such as
diet and hygiene, and transportation to corresponding medical appointments (Miller &
Kapp, 2015). The support of skilled nursing services via the waiver programs could
eliminate or reduce the burden of such tasks associated with wound care or other complex
care procedures from the caregiver’s list of responsibilities. Nonetheless, this policy
analysis found that skilled nursing services are only available via the Medicaid waiver in
a little over half of the country (28 states, 55%).

Further, caregivers engaged in complex care procedures need education,
information, and training (AARP and NAC, 2020). However, among the waiver
programs within this analysis, only 15 states offer caregiver training as a standalone
service. Caregivers report operating home dialysis equipment, administering test kits
(such as testing for bladder infection), managing catheters, administering edemas, and
performing ostomy care as the most difficult complex care tasks to perform and
explained not understanding what to do and fear of making mistakes as some of the
reasons these procedures were difficult (AARP and National Alliance for Caregiving, 2020; Reinhard et al., 2019). Caregiver training comes from a variety of sources, however most commonly, caregivers report learning on their own how to perform complex care procedures (Reinhard et al., 2019). Caregiver training and education is an opportunity for nurses to make an impact through expanded roles that include developing and delivering educational programs for caregivers that are supported by new and emerging care models such as community nursing and telehealth (National Academies of Sciences, Engineering, and Medicine, 2021).

Additionally, financial strain on caregivers can be significant with caregivers taking unpaid leave, reducing work hours, acquiring new debt, using their personal savings, and delaying retirement (AARP and NAC, 2020). The loss of income over a caregiver’s lifetime for those who have had to leave the workforce or reduce their working hours averages over $300,000 (Dawson et al., 2020). Receiving financial compensation for their caregiver duties can alleviate some of the financial burden on caregivers, however only 18 states offer compensation for spousal caregivers and 39 states offer compensation for other relatives and legal guardians.

While some states do allow Medicaid waiver care recipients to hire their spouse, relative or legal guardian to be a paid caregiver, the eligibility requirements vary throughout the country. In some states, this opportunity exists only under specific circumstances, such as the presence of a language barrier or limited worker availability due to remote location, such as in rural Virginia. In Louisiana and Maryland, a relative can be a paid caregiver provided they become an employee of an approved agency. However, in Kentucky and Maine, the care recipient’s spouse is eligible for employment
as a caregiver if their caregiving duties exceed the range of activities that they would normally provide on the individual’s behalf. These nuances exist throughout the states that offer financial remuneration for caregivers making it difficult for care recipients and their caregivers to navigate the complex requirements.

The results of this analysis found that the number of services offered by state waiver programs varies. For example, this policy analysis found that Oregon and West Virginia each only offered one service whereas California, Massachusetts, Minnesota, and Wisconsin all offer seven of the eight services included (see Table 4.1). Ideally state-level caregiver health outcomes would be reviewed to determine if states with more services have better caregiver outcomes. While Medicaid does survey recipients regarding their satisfaction with the services they receive, there is a lack of information regarding the caregivers’ satisfaction with services or caregiver health outcomes (CMS, n.d.-f).

**Policy Implications**

This analysis examined Medicaid 1915(c) HCBS waiver services available to support caregivers. Ideally, evidence on care recipient and caregiver outcomes would inform policy decisions to determine what services each state should offer within their waiver program. While there are data available examining the variations in eligibility requirements, spending, and services offered in regard to Medicaid long-term services and supports (Musemeci et al., 2020; Watts et al., 2021), there is no known analysis that focuses on 1915(c) HCBS waivers offered to care recipients 65 and older. As this data is currently lacking, future research is needed to determine efficacy of existing Medicaid waiver programs in terms of sustainability of the caregiver within the role and perhaps
identify additional areas of need. Future collaboration between researchers, nurses who support care recipients and their caregivers, and policy makers is needed to improve the quality of care for care recipients, provide better supports for caregivers, and eliminate disparities in health care services.
Chapter 5

Introduction

The purpose of this dissertation was to understand how older adult caregivers manage a complex care procedure, the resources needed, and available services through one public policy initiative. The findings of this dissertation will be disseminated through three separate manuscripts. Chapter 2, a grounded theory methods study, developed a theoretical framework for how older adult caregivers managed performing a complex care procedure, wound care, for their care recipient in the home setting. Chapter 3 described the older adult caregivers’ thoughts on resources they used or needed for their role. Chapter 4 examined resources available to support older adult caregivers through an existing federal policy program, Medicaid 1915(c) HCBS waivers. This chapter contains a synthesis of findings of the three manuscripts, connects the findings to previous theories, describes the strengths and limitations of the dissertation, and finally, summarizes the research, clinical, and public policy implications.

Synthesis of Findings

The findings of this dissertation can be synthesized into 3 key findings as follows:

**Key Finding 1: Healthcare professionals impact older adult caregivers experience performing complex care procedures.**

In chapter 2, the grounded theory study revealed that the relationship with healthcare professionals was a key part of the older adult caregivers’ process in managing wound care for their care recipient. These findings were confirmed in chapter 3 where expert guidance from healthcare professionals was a necessary resource identified by the
older adult caregivers. Healthcare professionals were essential for learning the proper wound care procedure, acquiring the correct wound care supplies, and providing feedback on wound healing progress in the theoretical framework *Pushing Through*. Similarly, in chapter 3, expert guidance from healthcare professionals was a standalone resource for the participants. Yet healthcare professionals also supplied written instructions for the wound care procedure and were vital for obtaining wound care supplies, both resources identified by the older adult caregivers in chapter 3. Older adult caregivers sought out connections with healthcare professionals as they recognized their lack of clinical knowledge and skills and required expert guidance to be successful.

**Key Finding 2: Older adult caregivers managing complex care procedures need resources beyond the usual care procedure supplies.**

In chapter 3, the thematic analysis findings demonstrated that older adult caregivers need several different resources to support the caregiver role. Wound care supplies were necessary and an understandable resource. However, older adult caregivers also need additional resources to support their care recipient as noted in Chapter 3. Beyond wound care supplies, caregivers identified a need for written care procedure instructions, durable medical equipment to aid in performance of ADLs and IADLs, financial resources, care coverage for caregiver personal time, and a network of individuals for social and emotional support.

**Key Finding 3: The Medicaid 1915(c) HCBS waiver program, a federal-state funding partnership, provides for caregiver resources; however, these resources vary across states with some states having no services and other states offering several options.**
In Chapter 3, participants identified care coverage for personal time as a necessary resource. The most frequently provided Medicaid waiver program service was a form of respite care, either in-home respite care, out-of-home respite care, adult day care with professional healthcare services or adult day care for socialization. The variety of respite services allows for care coverage for the caregiver to cover personal needs, yet some states offer all four services and some states do not offer any form of respite support.

Expert guidance and support from healthcare professionals were important findings in both chapter 2 and 3. This service is offered by some of the state Medicaid waiver programs through skilled nursing services for nursing support to the caregiver in the home. Some states have adult day care with professional services which also provides access to healthcare professionals. Older adult caregivers in chapters 2 and 3 established the need for education and training to perform a complex care procedure, however caregiver education and training is only available in a small number of states through the Medicaid waiver programs.

**Connection to Previous Theory**

The findings of the current studies are aligned with previous theories described in chapter 1. The *Model of Carer Stress and Burden* includes several moderators that influence the caregivers’ appraisal of primary and secondary stressors which leads to positive or negative caregiver outcomes (Sörensen et al., 2006). Moderators in the Model of Carer Stress and Burden that are consistent with the findings in our studies include lack of knowledge, perceived competency and mastery, social, emotional, and financial support resources, and available of informal assistance. Resources are also a key concept
in the *Informal Caregiving Integrative Model* which describes the relationship between demands and resources on burnout and general caregiver and care recipient outcomes (Gérain & Zech, 2019). This model includes informal support and professional support as demands and resources, which is consistent with the findings from this dissertation.

**Strengths and Innovation**

To my knowledge, this is the first study that examined how older adult caregivers managed a complex care procedure, wound care, on a day-to-day basis. The resultant theoretical framework, *Pushing Through*, demonstrates how older adult caregivers moved through a process of accepting the role while lacking confidence in their ability, to then creating a system to manage the responsibilities, then trusting in self and finally owning the outcomes as an expert caregiver. Data collection through in-depth qualitative interviews and constant comparative data analysis based on constructivist grounded theory methodology produced a theoretical framework explaining how the older adult caregivers pushed through five phases to be successful expert caregivers despite several challenges.

This is also, to my knowledge, the first study that analyzed caregivers’ salient thoughts on the resources they utilized or needed to perform a complex care procedure. Previous studies of caregiver resources have most often included a priori research variables and a quantitative design using survey methodology. Using qualitative thematic analysis to examine interview data allowed the thoughts of the older adult caregiver to be explored.
The analysis of Medicaid 1915(c) HCBS waiver programs’ services and supports for adults aged 65 and older and their caregivers is the first of its kind. Previous reports on Medicaid waivers have focused on services for children but not older adults. In addition, this analysis examined services that would offer support for caregivers as opposed to only examining available services for the Medicaid recipient.

Limitations

Limitations of the manuscripts derived from the qualitative interviews (chapters 2 and 3) include: 1) use of retrospective accounts from some of the participants which may be inadequate due to the passage of time, 2) recruitment via social media thus restricting participants to those with internet access and knowledge, 3) recruitment and data collection occurred during the COVID-19 pandemic which may have impacted participants’ experiences. Data for the Medicaid analysis of services available by state was extracted from official federal websites and is therefore accurate to the extent that the website is accurate and up to date.

Research Implications

To build upon the results of this dissertation, additional research is needed.

Research Implication 1: Further development of the Pushing Through Framework.

Research is needed to refine and test the Pushing Through framework. The next study should include a more diverse sample including participants from across the socioeconomic spectrum. Recruitment from the community, such as community groups and service organizations, would help eliminate any biases engendered from internet-based recruitment. In addition, a follow-up study could further explore the impact of the
COVID-19 pandemic on older adult caregiver’s process of managing wound care by examining the process before and during pandemic public health restrictions.

**Research Implication 2: Examining older adult caregiver’s decision-making processes regarding utilization of a social support network.**

Our findings suggest an opportunity to deepen our understanding of factors influencing older adult caregivers’ rationale for declining or avoiding help from their social support network. A grounded theory methods study exploring how older adult caregivers manage informal support from friends and family for respite care, social, and emotional support would allow for development of supportive interventions.

**Research Implication 3: Developing a proactive resource needs assessment for older adult caregivers performing complex care procedures is needed.**

To understand what resources older adult caregivers performing complex care procedures need, a proactive needs assessment tool is warranted. Development and testing of a needs assessment tool for this population of caregivers would allow for anticipatory guidance and education of older adult caregivers by healthcare professionals to alleviate unnecessary challenges in their process of managing complex care procedures.

**Clinical Implications**

The results of this study provide insight into the perspective of the caregivers as they assume the role of providing complex care. The challenges expressed by the participants present opportunities for healthcare professionals.
Clinical Implication 1: Build systems allowing older adult caregivers to access healthcare professionals as needed.

Older adult caregivers expressed concerns about being able to interact with someone knowledgeable when they have questions and concerns. Healthcare professionals and healthcare organizations should consider implementing systems to allow for access to expert guidance around the clock including weekends. A telephone triage line, on-call nurses, telehealth, and secure online messaging systems are possible options. The ability to send pictures of the wound to the healthcare professionals was also suggested by older adult caregivers.

Clinical Implication 2: Healthcare professionals working with older adult caregivers need to assess willingness and ability to assume the role.

An important step for healthcare professionals working with older adult caregivers is assessing their willingness to perform the caregiving role. Based on the results of these dissertation studies, healthcare providers should explore fears and concerns about the caregiver role and inquire about equipment needs, financial resources and social support networks prior to assuming an older adult caregiver is able to accept the role. Assessing the availability of a personal support network would allow healthcare professionals to advocate for additional supportive services as necessary. Understanding utilization or rationale for avoiding help would prompt a discussion of the caregiver’s concerns and opportunities for formal services. This assessment should coincide with an evaluation of the risk for social isolation and personal health concerns for the older adult caregiver.
Clinical Implication 3: Ensure access to a reliable system and available financial resources for acquiring supplies and equipment.

Ensuring older adult caregivers have access to a reliable system for acquiring wound care supplies that is also able to adapt to the frequently changing needs of the wound, should be prioritized to eliminate unnecessary frustrations. Need for additional durable medical equipment to support ADLs and IADLs should also be addressed by healthcare professionals. Both supply and equipment need must be addressed considering financial resources available to support the older adult caregiver and care recipient.

Public Policy Advocacy Implications

Health care inequity takes many forms. The variability of Medicaid services across states is one example of how health care is determined by where one lives. Nurses should be aware of the Medicaid service options available to caregivers in the state(s) where the practice. Since Medicaid is a federal-state partnership, states are free to create and fund services or not. Nurses should advocate for states to examine their services and create or expand services to meet the needs of the population.

Future research is needed to determine the efficacy of existing Medicaid waiver programs in terms of sustainability of the caregiver within the role as well as the impact on physical and mental health of the caregiver. Partnerships between policy makers, researchers, and nurses who support care recipients and caregivers is needed to provide better supports for caregivers, ensure quality outcomes for caregivers, and eliminate disparities in healthcare services.
Conclusion

Despite obstacles throughout the process, older adult caregivers can push through and manage a complex care procedure, wound care, in the home setting. The findings of this dissertation shed light on the day-to-day process of older adult caregivers performing wound care, the resources they need, and opportunities for public health policy to support caregivers in their role. Healthcare professionals, researchers, and policy makers can utilize these results to develop evidence-based interventions to support older adult caregivers performing complex care procedures.
APPENDIX A

Interview Guide

Thank you for taking the time to talk with me today. The purpose of my study is to learn about how you manage your caregiving responsibility of providing wound care. Wound care includes any activities that are done to promote wound healing and/or prevent wound complications. You can answer only the questions you feel comfortable with, and we can stop the interview at any time. This interview will be recorded. Do you have any questions before we begin?

• Tell me about when you first started being a caregiver for your friend/family member. Was this the same time you started providing wound care? If not, when did you start providing wound care?

• Tell me about how you learned to perform wound care.

• Tell me about any support you have in being a wound care provider. Who helped you and what did they do? What makes the job easier or more doable?

• Tell me about resources you need to provide wound care, such as money or equipment. How did you find or access these resources?

• Tell me about how your experience of managing the care recipient’s wound care needs changed over time.

• Tell me about a specific caregiving event related to providing wound care that was particularly challenging. What made it challenging?
• Tell me about a specific caregiver event that was rewarding. What made it rewarding?

• Some people have shared that they did not expect to be a caregiver at this stage of their life. Is that true for you? Tell me about that.

Thank you for sharing this information with me.
REFERENCES


Caregiving in the United States 2020. American Association of Retired Persons

https://doi.org/10.26419/ppi.00103.001


Functional health literacy and caregiving burden among family caregivers of patients with end-stage renal disease. Research in Nursing & Health, 43(5), 529–537. https://doi.org/10.1002/nur.22060


Self-reported physical and mental health of older adults: The roles of caregiving and resources. Maturitas, 71(1), 62–69.


https://doi.org/10.1111/scs.12441


https://doi.org/10.1186/1471-2458-13-452


https://doi.org/10.1177/0164027514527834


National Center for Chronic Disease Prevention and Health Promotion.
https://www.cdc.gov/chronicdisease/about/index.htm


Centers for Disease Control and Prevention. (2022c, June 6). *Promoting Health for Older Adults.*
https://www.cdc.gov/chronicdisease/resources/publications/factsheets/promoting-health-for-older-adults.htm


https://www.medicare.gov/about-us/how-is-medicare-funded

https://www.medicaid.gov/medicaid/eligibility/index.html


https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html?f%5B0%5D=waiver_authority_facet%3A1571#content


Hardman, R., Begg, S., & Spelten, E. (2022). Exploring the ability of self-report measures to identify risk of high treatment burden in chronic disease patients: A
https://doi.org/10.1186/s12889-022-12579-1


https://doi.org/10.1093/hsw/hlw025


https://doi.org/10.1177/0193945920959086


https://doi.org/10.1016/j.gerinurse.2020.01.015


   Journal of Wound Care, 24(11), 489–497.


https://doi.org/10.1001/jamainternmed.2015.7664
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